

National Institutes of Health  
National Institute of Neurological Disorders and Stroke

**EVALUATION OF THE NINDS MORRIS  
K. UDALL PARKINSON'S DISEASE  
RESEARCH CENTERS OF  
EXCELLENCE PROGRAM – DATA  
REPORT**

**August 17, 2007**

Prepared by:  
Booz Allen Hamilton  
1101 Wootton Parkway  
8<sup>th</sup> Floor  
Rockville, Maryland 20852

## Table of Contents

<b>1.0 INTRODUCTION &amp; BACKGROUND.....</b>	<b>1</b>
<b>2.0 STUDY METHODOLOGY.....</b>	<b>3</b>
<b>3.0 DATA FINDINGS.....</b>	<b>9</b>
3.1 Response Rates.....	9
3.2 Non-Response Analysis.....	10
3.3 Study Question 1.....	11
3.4 Study Question 2.....	24
3.5 Study Question 3.....	39
3.6 Study Question 4.....	52
3.7 Study Question 5.....	69
3.8 Study Question 6.....	84
3.9 Study Question 7.....	101
3.10 Study Question 8.....	108
3.11 Study Question 9.....	115
3.12 Study Question 10.....	118
<b>4.0 NGO DISCUSSION.....</b>	<b>124</b>
<b>APPENDICES.....</b>	<b>127</b>
Appendix A: Conceptual Framework.....	127
Appendix B: Working Group Members.....	128
Appendix C: Primary Data Collection Flow.....	129
Appendix D: Release Form.....	130
Appendix E: Interview Questions.....	131
Appendix F: Survey Questions.....	134
Appendix G: Research Definitions.....	139
Appendix H: Activity Code Descriptions for Multidisciplinary Research.....	140
Appendix I: Supporting Data for Research Sub-Question 3.4.....	142
Appendix J: Supporting Data for Research Sub-Question 5.2.....	143
Appendix K: Methodology for Question 7.....	146
Appendix L: Supporting Data for Research Question 8.....	150

## Exhibits

Exhibit 1. Initial 11 Udall Centers of Excellence for PD Research.....	1
Exhibit 2. Research Questions for the Evaluation of the Udall Centers Program.....	3
Exhibit 3. Responses/Participants for Interviews and Survey from Center Directors, Project/Core Leads, and Comparison Group Participants.....	9
Exhibit 4. Comparative Analysis of RFA Objectives.....	11
Exhibit 5. Comparative Analysis of the Udall Act to the 1997 RFA and 1998 RFA.....	12

Exhibit 6.	Reviewer Comments on Scored and Unscored Applications from the 1997 and 1998 RFAs .....	14
Exhibit 7.	Reviewer Comments on Funded and Unfunded Applications for the 1997 RFA ....	14
Exhibit 8.	Reviewer Comments on Funded and Unfunded Applications for the 1998 RFA ....	15
Exhibit 9.	Center Directors’ and Project/Core Leads’ Ratings of the Initial RFA.....	17
Exhibit 10.	Center Directors’ and Project/Core Leads’ Ratings of NINDS Pre-Award Assistance .....	18
Exhibit 11.	Center Directors’ and Project/Core Leads’ Ratings of NINDS Assistance During the Application Process .....	19
Exhibit 12.	Center Directors’ and Project/Core Leads’ Ratings of NINDS Assistance During the Post-Award Period.....	20
Exhibit 13.	Funding Sources for which Udall Center Investigators Have Applied .....	22
Exhibit 14.	Comparison of Udall Application Process to Other Program Application Experiences.....	22
Exhibit 15.	Additional Interview Comments Regarding NINDS Application and Review Process .....	23
Exhibit 16.	PD-Related Research Investments by NINDS (FY98 – FY03).....	24
Exhibit 17.	Udall, Udall Supplemental, and PD-Related (Non-Udall) NINDS Research Funding (FY98 – FY03) .....	25
Exhibit 18.	Breakdown of NINDS Funding for Udall, PD-Related, and Non-PD Related Funding (FY98 – FY03) .....	26
Exhibit 19.	NINDS Support to Facilitate Collaboration – Within the Udall Center .....	28
Exhibit 20.	NINDS Support to Facilitate Collaboration – Across Udall Centers .....	28
Exhibit 21.	NINDS Support to Facilitate Collaboration – With Outside Researchers.....	29
Exhibit 22.	Ways NINDS Facilitated Collaboration (Other Than Through the Annual Meeting).....	29
Exhibit 23.	Center Directors’ Survey Results: Priorities Lists and Resource Needs of Udall Centers .....	31
Exhibit 24.	Impact of Formal Program Enhancements, Improvements and Additions on Research Needs.....	32
Exhibit 25.	Improving NINDS Assistance During the Pre-Award Timeframe.....	34
Exhibit 26.	Improving NINDS Assistance During the Application Process.....	35
Exhibit 27.	Improving NINDS Assistance During the Post-Award Period .....	36
Exhibit 28.	Suggestions for Improving the Administration of the Udall Centers Program .....	36
Exhibit 29.	Total NIH Funding, By Institution, Over the Five Fiscal Years Prior To Becoming a Udall Center.....	40
Exhibit 30.	Total NIH Funding, by Center Directors, Over the Five Fiscal Years Prior to Receiving Udall Center Funding .....	41
Exhibit 31.	Average NIH Funding, by Project/Core Leads, Over the Five Fiscal Years Prior to Udall Center Funding .....	41
Exhibit 32.	NIH Funding Received, by Institution, for PD Research Prior to Receiving Udall Center Funding.....	43

Exhibit 33.	NIH Funding, by Center Directors, for PD Research Prior to Receiving Udall Center Funding .....	44
Exhibit 34.	Average Amount of NIH PD Research Funding Received by Project/Core Leads Prior to Receiving Udall Center Funding .....	45
Exhibit 35.	NIH Grant Activity Codes That Contain the Term “Multidisciplinary” .....	46
Exhibit 36.	Number of Multidisciplinary Grants Received by Udall Center Directors .....	47
Exhibit 37.	Total NIH Multidisciplinary Grant Funds Received by Udall Center Directors.....	47
Exhibit 38.	Average Percentage of Research Type for Proposed Projects.....	48
Exhibit 39.	Organizational Structure for Conducting PD Research.....	50
Exhibit 40.	Research Categorization Before and After Becoming a Udall Center .....	51
Exhibit 41.	Degree to Which Research was Multidisciplinary After Becoming a Udall Center.....	51
Exhibit 42.	Requests for and Receipt of Udall Center Training Cores .....	52
Exhibit 43.	Research Trainees Program Development: Major Themes .....	53
Exhibit 44.	Examples of Formal Training Components at Udall Centers.....	54
Exhibit 45.	Total Number of Individual Trainees at Each Udall Center* During the First Five Years of the Program.....	55
Exhibit 46.	Udall Center Individual Trainees Stratified by Degree Status* .....	56
Exhibit 47.	Average FTE Trainees by Udall Center During the First Five Years of Funding* ..	56
Exhibit 48.	Udall Center Trainees: Development and Statistics Summary.....	57
Exhibit 49.	Udall Centers With Training Cores versus Udall Centers Without Training Cores .....	58
Exhibit 50.	Adequacy of Research Support Functions.....	59
Exhibit 51.	Supplemental Grant Awards Received in Response to NINDS Notices by Year ....	60
Exhibit 52.	Usefulness of Udall Annual Meetings and Impact of Udall Annual Meetings on Furthering Research.....	62
Exhibit 53.	Impact of Collaboration (Other than the Annual Meeting) on Achieving Research Goals .....	63
Exhibit 54.	Impact of the Center Structure on Management Practices .....	65
Exhibit 55.	Approaches for Setting Goals and Milestones.....	66
Exhibit 56.	Approaches for Monitoring and Measuring Progress Toward Goals and Milestones.....	67
Exhibit 57.	Use of External and Internal Advisors.....	67
Exhibit 58.	Approaches for Identifying and Planning for Operational Improvements .....	68
Exhibit 59.	Impact of Udall Center Structure on Achieving Research Results.....	71
Exhibit 60.	Increased Focus on Interrelated Scientific Problems in First Five Years.....	72
Exhibit 61.	Survey Results: The Number of Centers that Listed Discoveries/Findings/Results in Six Major Areas.....	74
Exhibit 62.	PD Relevant Publications by Udall Center Investigators From 1998 to 2006 .....	74
Exhibit 63.	Impact Ratings (Percentile Position) for Udall Investigators’ Publications .....	75
Exhibit 64.	Interview Results: Did Becoming a Udall Center Increase Your Collaborative Efforts Within the Udall Center, With Other Udall Centers, and/or With Non-Udall Researchers? .....	76

Exhibit 65.	Interview Results: Sharing Findings and Promoting Collaboration Within the Udall Center .....	76
Exhibit 66.	Interview Results: Sharing Findings and Promoting Collaboration With Other Udall Centers .....	77
Exhibit 67.	Interview Results: Sharing Findings and Promoting Collaboration With Non-Udall PD Researchers .....	77
Exhibit 68.	Survey Results: Junior Trainee Recruitment During the First Five Years of the Udall Centers Program.....	79
Exhibit 69.	Survey Results: Senior Researcher Recruitment During the First Five Years of the Udall Centers Program.....	80
Exhibit 70.	Total NIH PD Funding (Excluding Udall-Related Grants) Received by Udall Center Directors and Project/Core Leads During the First Five Years of the Udall Centers Program.....	82
Exhibit 71.	Total NIH PD Funding Received by Udall Center .....	83
Exhibit 72.	Survey Results: Centers Reported Impact on Prevention, Diagnosis, or Treatment Strategies for PD .....	85
Exhibit 73.	Interview Results: Mechanisms that Centers Used to Share their Animal Models ..	87
Exhibit 74.	Report of Novel Tools During the Initial Five-Year Funding Period of the Udall Centers Program .....	88
Exhibit 75.	Novel Techniques Developed During the First Five Years of Udall Funding .....	89
Exhibit 76.	Novel Research Foci Introduced to the Field of PD .....	89
Exhibit 77.	Project/Core Leads: Number of New Independent Research Scientists.....	91
Exhibit 78.	Project/Core Leads: Total Additional NIH Funding Awarded for PD Research After Joining a Udall Center .....	92
Exhibit 79.	Research Staff: Number of New Independent Research Scientists .....	93
Exhibit 80.	Research Staff: Total Additional NIH Funding Awarded for PD Research After Joining a Udall Center .....	93
Exhibit 81.	Project/Core Leads and Research Staff: Number of New Independent Research Scientists .....	94
Exhibit 82.	Project/Core Leads and Research Staff: Total Additional NIH Funding Awarded for PD Research After Joining a Udall Center .....	95
Exhibit 83.	Publication Collaboration Among Udall Centers .....	97
Exhibit 85.	Number of Centers that Increased Institutional Commitment to PD Research: Additional Research Positions .....	98
Exhibit 86.	Number of Centers that Increased Institutional Commitment to PD Research: Increased Recognition.....	98
Exhibit 87.	Number of Centers that Increased Institutional Commitment to PD Research: Additional/Improved Facilities .....	99
Exhibit 88.	Number of Centers that Increased Institutional Commitment to PD Research: Increased Funding Opportunities.....	99
Exhibit 89.	Differences in Baseline Characteristics of Centers Ranking Highest and Lowest on Goal Attainment.....	104

Exhibit 90.	Differences in Activities of Centers Ranking Highest and Lowest on Goal Attainment .....	107
Exhibit 91.	Data Sources and Questions for Research Question 8.....	108
Exhibit 92.	Survey Results: Percent of Discoveries/Findings/Results in Six Major Areas by Centers and by Comparison Group Participants.....	109
Exhibit 93.	Survey Results: Type of Reported Impact by Percent of Those Who Reported an Impact by Centers and Comparison Group Participants.....	110
Exhibit 94.	Publication Rate per Individual per Year for Udall Center Investigators and Comparison Group Participants.....	111
Exhibit 95.	Mean and Median Percentile Positions of Publications Across All Tiers for Udall Investigators and Comparison Group Participants .....	111
Exhibit 96.	Percentile Position of Udall Investigators versus Comparison Group Participants' Publications .....	112
Exhibit 97.	Udall Center and Comparison Group Participants' Responses on the Generation of Top Five Novel Tools and Techniques, and Top Two Research Foci .....	113
Exhibit 98.	Data Sources and Questions for Research Question 9.....	115
Exhibit 99.	Comparison of Responses: Impact of Collaboration on Achieving Research Goals .....	116
Exhibit 100.	Comparison of Responses: Multidisciplinary PD Publications.....	117
Exhibit 101.	Data Sources and Questions for Research Question 10.....	119
Exhibit 102.	Comparison Group: Research Training Opportunities as a Result of R01 PD Funding .....	120
Exhibit 103.	Research Training Program Developments: Udall Centers and Comparison Group Participants .....	120
Exhibit 104.	Comparison Group: Development of New PD Researchers.....	122

## 1.0 Introduction & Background

Parkinson’s disease (PD) affects at least 500,000 people in the United States, with approximately 50,000 new cases reported annually. PD usually affects people over the age of 50, and the likelihood of developing PD increases with age. PD is a progressive neurological disorder that results from the degeneration of neurons in a region of the midbrain controlling muscle movement. This degeneration causes a loss of dopamine-producing brain cells, resulting in the classic PD symptoms of movement impairment such as tremor, rigidity, bradykinesia, and postural instability. Further, persons living with PD often experience a wide range of other symptoms and complications, including depression, personality changes, dementia, sleep disturbances, speech impairment, or sexual difficulties. PD is a chronic, progressive disease and symptoms tend to worsen over time.

In 1997, the United States Congress passed the Morris K. Udall Parkinson’s Disease Research Act (referred to as the Udall Act) and, on November 13, 1997, the President of the United States signed the Act into law. Prior to the passage of the Act, the National Institute of Neurological Disorders and Stroke (NINDS) realized the need to have centers of excellence for PD research, and established the Morris K. Udall Centers for Excellence in Parkinson’s Disease Research Program (referred to as the Udall Program). In 1997, NINDS issued the first Request for Applications (RFA) and, the following year, established three Udall Centers. In 1998, NINDS issued a second RFA that increased the number of Centers. In total, in 1998 and 1999, NINDS funded 11 Udall Centers to conduct PD research (see Exhibit 1 for a list of the Centers).

Exhibit 1. Initial 11 Udall Centers of Excellence for PD Research

Udall Center of Excellence for PD Research	Funding Year
Brigham and Women’s Hospital (Brigham)	1999
Columbia University of the Health Sciences (Columbia)	1999
Duke University (Duke)	1999
Emory University (Emory)	1998
Johns Hopkins University (Hopkins)	1998
Massachusetts General Hospital with Massachusetts Institute of Technology (MGH)	1998
Mayo Clinic at Jacksonville (Mayo)	1999
McLean Hospital with Harvard University (McLean)	1999
University of California, Los Angeles (UCLA)	1999
University of Kentucky (Kentucky)	1999
University of Virginia (UVA)	1999

The Udall Centers are located in different areas of the United States. Though the number and disciplines of research staff vary by Udall Center, the organization of the Centers is similar. Each Center has a Center Director, listed as the Principal Investigator on the grant application. The Center Director oversees Udall Center operations including administrative functions. The

Director may also lead an individual research project within the Udall Center. The Centers that received funding from the 1997 and 1998 RFAs typically included three to five projects and three to four cores. The Project/Core Directors (referred to as the Project/Core Leads within this report to avoid confusion with the Center Directors) lead the research projects and cores that comprise the Udall Center. The projects may vary in research focus from basic to translational to clinical studies. The cores support the infrastructure of the Center and/or the projects and focus on areas such as training, administration, statistical analysis, or clinical and imaging science.

In late 2003, a subcommittee of the National Advisory Neurological Disorders and Stroke (NANDS) Council<sup>1</sup> expressed interest in receiving information on the progress in PD research and knowledge achieved by the Udall Centers Program. In 2004, the Parkinson's Action Network, a non-governmental advocacy group, expressed their support for a review of the Udall Centers Program (for additional discussion on non-governmental organizations' perspectives of the Udall Program, see the final section of this Data Report). Subsequent to these requests, NINDS commissioned a feasibility study for this evaluation. A contractor external to NINDS conducted the feasibility study to develop a conceptual framework for the evaluation, which included the development of potential research questions and an assessment of possible data sources. The framework (see Appendix A) included the Program's short- and long-term goals, as well as Center characteristics and activities that may have influenced the Centers' progress. In 2005, NINDS issued a Request for Quotation (RFQ) for a comprehensive program evaluation of the Udall Centers Program and subsequently selected Booz Allen Hamilton (Booz Allen)<sup>2</sup> as the independent contractor to conduct this evaluation. In this role, Booz Allen's study team operationalized the plan set forth in the feasibility study, developed data collection instruments, collected and analyzed data, and prepared this Data Report and facilitated the development of the Recommendations Report by the Working Group.

In 2005, the NINDS Director, Dr. Story Landis, appointed individuals to a panel, effectively organizing a Working Group of the NANDS Council (referred to as the Working Group in this report; see Appendix B for a list of Working Group members). The Working Group, whose members were external to Booz Allen, guided and informed the evaluation. The Working Group provided guidance on data collection methods and reviewed the data and science for the purposes of providing specific recommendations on the Udall Centers Program. The recommendations of the Working Group are included in the Recommendations Report, while this Data Report provides the supporting information. No NINDS leadership or staff had access to or reviewed the primary data collected (with the exception of one Working Group member who is also an intramural researcher at NINDS).

---

<sup>1</sup> The NANDS Council's role is to advise NINDS on policy and procedures affecting its extramural research program and to provide a second level of review for all grant and cooperative agreement applications considered by NINDS. The Director of NINDS may also ask the NANDSC members to offer expertise on program planning, review aspects of the intramural program, and provide clearance for special initiatives.

<sup>2</sup> Throughout this report, Booz Allen is also referred to as the study team.

## 2.0 Study Methodology

This evaluation of the Udall Centers Program is a review of both process and outcomes of the Program. As a process evaluation, the study team examined the degree to which the program operated as intended. As an outcome evaluation, the study team examined the degree to which the program met its stated goals, as mandated in the 1997 and 1998 RFAs. Furthermore, the evaluation model (see Appendix A) examined the extent to which the predictor variables (i.e., Center characteristics and Center activities) impacted the short- and long-term goals of the Udall Centers. A set of research questions provided by NINDS (see Exhibit 2) drove the data collection activities.

Exhibit 2. Research Questions for the Evaluation of the Udall Centers Program

<p><b>Study Question 1 – How were the initial 11 Udall Centers selected?</b></p> <ul style="list-style-type: none"><li>• Which components of the Udall PD Research Act of 1997 were included in the 1997 and 1998 RFAs issued by NINDS for specialized Centers of Excellence for PD research (later called Udall Centers)?</li><li>• To what extent were the grant applications received by NINDS (and those that were successful) responsive to the RFA?</li><li>• What role did NINDS program staff play in serving as a resource during the application process?</li><li>• In what ways could the process for selecting Udall Centers be improved?</li></ul>
<p><b>Study Question 2 – How did NINDS administer the Udall Centers Program from FY 1998 – 2003?</b></p> <ul style="list-style-type: none"><li>• What level of NIH resources (funding and staff support) was allocated to the Udall Centers Program?</li><li>• To what extent did NINDS staff facilitate collaboration among Udall Center investigators?</li><li>• To what extent did NINDS staff find ways to meet the evolving scientific and resource needs of the Centers and address emerging priorities relevant to the Centers' research programs?</li><li>• Did all of the Udall Center awardees submit a competing continuation application five years later? If not, why not?</li><li>• In what ways could the administration of the Udall Centers Program be improved in the future?</li></ul>
<p><b>Study Question 3 – What were the baseline characteristics of the individual Udall Centers prior to the start of the program (FY 1996 – 1998) in each of the following areas:</b></p> <ul style="list-style-type: none"><li>• Overall research experience of the institution, Center Director, and Project/Core Directors</li><li>• Previous PD research experience of the institution, Center Director, and Project/Core Directors</li><li>• Center Director's previous experience leading multidisciplinary research teams</li><li>• PD research areas to be pursued</li><li>• Breadth of the Center's organizational structure, and whether it includes basic, translational, or clinical research</li></ul>
<p><b>Study Question 4 – To what extent did the individual Udall Centers implement the activities recommended by NINDS during their first five years?</b></p> <ul style="list-style-type: none"><li>• Offer research training relevant to PD</li><li>• Obtain adequate research support for Udall Center projects</li><li>• Promote multidisciplinary collaborations within and between Udall Centers</li><li>• Ensure effective day-to-day management and communications</li><li>• Emphasize strategic planning, including setting milestones, monitoring progress, and seek advisory committee input</li></ul>

<p><b>Study Question 5 – To what extent did the individual Udall Centers and the Centers as a group achieve the following short-term research goals in the first five years:</b></p> <ul style="list-style-type: none"><li>• Integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research</li><li>• Early results leading to new hypotheses relevant to PD</li><li>• New procedures developed for sharing PD research findings and scientific techniques</li><li>• Recruitment of new faculty and trainees to PD research</li><li>• More multidisciplinary research relevant to PD</li><li>• Broader research and infrastructure support for projects relevant to PD</li></ul>
<p><b>Study Question 6 – To what extent did the individual Udall Centers and the Centers as a group achieve the following long-term research goals during their first five years:</b></p> <ul style="list-style-type: none"><li>• Noteworthy research discoveries involving basic, clinical, and/ or translational research that are likely to advance the prevention, diagnosis, and/or treatment of PD</li><li>• New scientific tools developed and shared with other PD researchers (e.g., new models, technologies, databases, repositories, classification standards, research techniques)</li><li>• Increased number of independent research scientists conducting PD research</li><li>• Increased level of collaboration with other PD researchers and the broader PD community</li><li>• Increased institutional commitment to PD research</li></ul>
<p><b>Study Question 7 – Why were some Udall Centers more successful than others?</b></p> <ul style="list-style-type: none"><li>• To what extent were specific Center characteristics related to their subsequent success in achieving program goals?</li><li>• Comparing more (or less) successful Centers, can “Centers with strong potential” be identified from their baseline characteristics? If so, what are the characteristics?</li><li>• To what extent were specific activities conducted by the Centers related to their subsequent success in achieving program goals?</li><li>• Comparing the approaches used by the more successful (and less successful) Centers during the first five years, can “best practices for Centers” be identified? If so, how was each practice usually implemented?</li></ul>
<p><b>Study Question 8 – Were the Udall Center researchers more (or less) successful than a comparable group of PD researchers advancing PD research in:</b></p> <ul style="list-style-type: none"><li>• Generating new hypotheses relevant to PD</li><li>• Achieving noteworthy research discoveries</li><li>• Developing new scientific tools and sharing these tools with the PD research community</li></ul>
<p><b>Study Question 9 – Were the Udall Center researchers more successful than a comparable group of researchers in collaborating with researchers at other institutions to advance PD research?</b></p>
<p><b>Study Question 10 – Were the Udall Center researchers more successful than a comparable group of researchers in increasing the number of new faculty and trainees (independent research scientists) conducting PD research?</b></p>

For this evaluation, the study team focused on the time period between FY 1998 and FY 2003. This includes the first five years of funding for the initial cohort of 11 Udall Centers, depending on whether NINDS funded the Center under the 1997 or 1998 RFA.

### **Working Group**

The Working Group first convened in 2005 and subsequently participated in several conference calls to discuss the evaluation approach. This group reviewed and made final decisions about the data collection instruments (i.e., the web-based survey and interview protocols). All Working

Group members had access to the identifiable data from the surveys and interviews/focus groups, and signed confidentiality agreements pertaining to their receipt of this identifiable data. In June 2007, the Working Group convened in-person to review the collected data and develop recommendations for the Udall Centers Program.

### **Study Population**

The Udall Center Directors and Project/Core Leads who served during the evaluation period (from FY98 through FY03)<sup>3</sup> and were identified in the initial grant applications submitted to NINDS constituted the study population. These individuals, referred to as participants, provided data via semi-structured telephone interviews (one-on-one or group) and/or a web-based survey.

To provide context on how the Udall Centers Program may have differed in its administration and outcomes from other NINDS-funded research projects, the study team chose researchers with R01 grants<sup>4</sup> for projects related to PD as potential participants for a comparison group, and randomly selected 75 R01 grantees from this pool of NINDS R01 grantees. These grantees had received an R01 grant, with “Parkinson” in the grant description, between FY98 and FY03. The grants included for the comparison group may not have been the first award for that grant (i.e., the grant could be for supplemental funding or for project continuation).

### **Primary Data Collection Sources and Methods**

The study team, with guidance from the Working Group, developed the data collection instruments and provided them to the NINDS for review. Since the study team anticipated that data would be collected from 10 or more individuals, the evaluation required Office of Management and Budget (OMB) clearance per the Paperwork Reduction Act of 1995 (PL 104-13). The clearance ensured that the data collection activities minimized any burden on the public. NINDS submitted the data collection instruments and study design to OMB regular review, allowing up to a three-year clearance for the evaluation. Following approval,<sup>5</sup> the study team contacted the identified Udall Investigators and potential comparison group participants via email to participate in the evaluation. All participation was voluntary. To meet the requirements of the Privacy Act, 5 U.S.C., Section 552(b) participating researchers signed a release form to allow the study team, as well as members of the Working Group, to review their identifiable responses to the web-based survey and interview questions (see Appendix C for primary data collection flow). For the language in the release forms, please see Appendix D.

Trained Booz Allen staff conducted all semi-structured one-on-one interviews with Center Directors and group interviews with Project/Core Leads. The study team piloted the interview questions in a mock interview. Approximately one week prior to the scheduled interview, all participants received a copy of the interview questions. The study team recorded and transcribed and/or documented each interview.

---

<sup>3</sup> The combined study population of Center Directors and Project/Core Leads are referred to as Udall Center Investigators or Udall Investigators throughout this report.

<sup>4</sup> An R01 grant is a Research Project grant that supports a discrete, specified, circumscribed project to be performed by the named investigator(s) in an area representing his specific interest and competencies.

<sup>5</sup> The OMB Approval number is 0925-0565. The Notice of Approval Date is 09/28/2006, and the Expiration Date is 09/30/2009.

The study team also collected primary data via administration of a web-based survey. NINDS staff piloted the survey. In addition to the Udall Investigators, comparison group participants also took the web-based survey. The study team provided a different version of the survey to each group of researchers (Center Directors, Project/Core Leads, and comparison group participants) that was tailored to their role. (See Appendix E and Appendix F for interview and survey questions.)

The study team used a thematic analysis technique to analyze the qualitative data that resulted from the interviews and web-based survey. Thematic analysis involves examining the range of responses to each open-ended question, extracting key themes, and quantifying the frequency with which certain themes are mentioned. The unit of analysis was the individual; therefore, the study team counted the number of individuals who stated a theme (not the number of interviews in which a theme emerged). As appropriate, the qualitative interview and survey data were stratified by group (e.g., Center Directors vs. Project/Core Leads; Udall Investigators vs. comparison group participants). To ensure consistency across the study team, the team first underwent a four-hour training on theme coding processes, including a pilot test to ensure that analysts were coding the qualitative data in a manner similar to one another. After completing the thematic analyses, the study team captured the most pronounced themes in theme tables (presented by frequency, in descending order), which are presented throughout the results section of this report.

## **Secondary Data Sources and Methods**

### *Application Materials*

Grant applications, progress reports<sup>6</sup>, and summary statements<sup>7</sup> also informed this evaluation. The study team examined reviewer comments on grant applications, specifically noting comments on proposed projects, funding requests for projects, proposed Udall Center staff, and reported progress by each Center. While these sources provided an abundance of information, there are limitations to their completeness and/or reliability, as the applicant/grant recipient determines much of the structure and content. As a result, the degree and detail of information varies throughout – and across – applications and reports. Consequently, attempts to generalize findings and make conclusive determinations based solely on data gathered from secondary data sources run the risk of incurring type II errors: the lack of data inclusion does not necessarily imply that the data do not exist. When possible, the study team tried to overcome this limitation by seeking confirmation directly from the grantees on the data collected.

### *Publications*

The study team collected information on the publications from the Udall Center Investigators and the comparison group participants. The study team searched PubMed using the following limits and terms:

---

<sup>6</sup> NIH grantees are required to submit progress reports annually to report research progress.

<sup>7</sup> A summary statement is a combination of the reviewers' written comments and the Scientific Review Administrator's summary of the members' discussion during the study section meeting. It includes the recommendations of the study section, a recommended budget, and administrative notes of special consideration.

1. Author's last name and first initial
2. Timeframe: Notice of Grant Award (NGA) Date – October 31, 2006
3. Keyword: Parkinson\*

For comparison group participants, the initial search date for publications was the earliest NGA date that qualified them to be members of the comparison group. The study team collected publication citations from this NGA date through October 31, 2006.

Participants received their list of publications with a request to verify the information and its applicability to PD. The study team also asked participants to select the research type for each publication, that is, if the published research was related to basic, translational, or clinical research (see Appendix G). For Udall Center Investigators who declined to participate, and for participants who did not respond to the requests, members of the study team with experience in neuroscience, PD, and scientific research assigned the research type for each publication.

As publication generation and subsequent citation of publications is frequently used as a marker of success in research, the study team submitted the list of publications to Thomson Scientific ISI Web of Knowledge (Thomson Scientific) to ascertain the citation reports for Udall Center and comparison group publications.

#### *Grants*

In addition to publications, the study team collected complete NIH grant histories of the participants through the NIH Information for Management, Planning, Analysis and Coordination (IMPAC) II<sup>8</sup> database. The study team asked participants to review their individual grant histories<sup>9</sup> for accuracy and to assign each grant with a basic, translational, or clinical research category. The study team provided the Udall Investigators who received their initial Udall funding in FY 1998 with lists of their awarded grants from FY 1996 through FY 1998; the lists for the Udall Investigators who received Udall funding in FY 1999 included grants awarded from FY 1997 through FY 1999. The comparison group participants received their grant histories dating three fiscal years prior to the NGA date of the R01 grant of interest. In all, 26 Udall Investigators and 11 comparison group participants reviewed and returned their grant histories to the study team.

#### **Working Definitions**

The Working Group established definitions for relevant terms used throughout the evaluation (definitions are also listed in Appendix G). These definitions included:

- |                               |   |
|-------------------------------|---|
| <b>Basic Research</b>         | Pure research, without any constraint of practical application.   |
| <b>Translational Research</b> | Applying ideas, insights, and discoveries generated through basic scientific inquiry to interventions, prevention, understanding mechanisms, and/or |

---

<sup>8</sup> The study team accessed the data in December 2006.

<sup>9</sup> The grants that comprised the grant history were only those grants that listed the individual as the Principal Investigator.

management of human disease.

**Clinical Research**

(a) Patient-oriented research. Research conducted with human subjects (or on material of human origin such as tissues, specimens and cognitive phenomena) for which an investigator (or colleague) directly interacts with human subjects. This area of research includes:

Mechanisms of human disease

Therapeutic interventions

Clinical trials

Development of new technologies

(b) Epidemiologic and behavioral studies

(c) Outcomes research and health service research

**Multidisciplinary**

Research that brings experts from diverse disciplines, for example, clinicians from different specialties (pediatrician, infectious disease specialist, epidemiologist, clinical trialist, and a pharmacologist) to address collectively a common complex problem.

## 3.0 Data Findings

This section summarizes the findings from the data collected. For each research question’s sub-question, the report presents the approach, results, and summary. The *approach* explains the method by which the study team addressed the sub-question and the data sources used. The *results* present the data findings in graphical or narrative format. The *summary* section provides a review of the data collected.

### 3.1 Response Rates

As discussed in Section 2.0, the study team collected primary data via semi-structured interviews and through web-based surveys.

Of the 13 Udall Center Directors solicited, nine participated in the web-based survey and 11 participated in the interview process. For two of the Udall Centers, two Center Directors (each) participated in some, but not all, aspects of the evaluation, as their tenure in that position overlapped within the study timeframe. Twenty-eight of the 49 Project/Core Leads solicited to participate in the evaluation (57 percent) participated in the survey, and 31 participated in the group interviews (63 percent). Finally, 31 comparison group participants took the web-based survey (41 percent). See Exhibit 3 for a graphical representation.

Exhibit 3. Responses/Participants for Interviews and Survey from Center Directors, Project/Core Leads, and Comparison Group Participants

Activity	Status	Center Directors (N=13)	Project/Core Leads (N=49)	Comparison Participants (N=75)	Total
Survey	Completed	9 (representing 8 Centers)	28 (representing 10 Centers)	31	68
	Refused*	1	2	9	12
Interview	Completed	11 (representing 10 Centers)	31 individuals in 12 interviews (representing 11 Centers)	N/A	23
	Refused*	-	11 individuals	N/A	11

\*Refusal is an *active* refusal and may have been indicated via an email or through choosing “no” to the release agreement in the survey. Some participants may not have been responsive to participation requests – these individuals are not included in the refusal numbers.

At least one Project/Core Lead from all 11 Centers participated in the evaluation. Center Directors from 10 of the Centers participated in the evaluation; note that one Center Director did not participate in the interview or in the online survey. This Director was the only representative Director for that Center.

### 3.2 Non-Response Analysis

The study team found that, based on the survey response rate, the final sample size for both Udall Investigators and comparison group participants was below the minimum number required to be able to assert with statistical confidence that the samples were necessarily “representative” of the populations from which they were drawn. To gain additional insight into whether the survey respondents were significantly different than the non-survey respondents, the study team performed a non-response bias analysis for both Udall Investigators and comparison group participants.

- For the Udall Investigators, the study team compared the difference in PD funding (defined as NIH-funded research projects with “Parkinson” in the abstract and for which the individual was listed as the PI) in the five years prior to becoming a Udall Center. The results showed that the difference between survey respondents and non-survey respondents was not statistically significant ( $t(23) = 1.34, ns$ ).
- For the comparison group participants, the study team compared the difference in total R01 funding for PD research between FY98 and FY04. These results also showed that the difference between survey respondents and non-survey respondents was not statistically significant ( $t(73) = -.31, ns$ ).

Based on these results, there is no evidence of non-response bias among either the Udall Investigators or among the comparison group participants in terms of funding (the variable available for the analysis).

### 3.3 Study Question 1

How were the initial 11 Udall Centers selected?

#### 3.3.1 Study Question 1.1 – Which components of the Udall PD Research Act of 1997 were included in the 1997 and 1998 RFAs issued by NINDS for specialized Centers of Excellence for PD research (later called Udall Centers)?

##### 3.3.1.1 Approach

The study team reviewed the 1997 and 1998 RFAs that established the first 11 Udall Centers. The study team compared the various aspects of the RFAs to each other and also to the Udall Act.

Data Sources for Research Question 1.1
<ul style="list-style-type: none"> <li>Udall Act</li> <li>1997 RFA &amp; 1998 RFA</li> </ul>

##### 3.3.1.2 Results

Despite the similar structure of both RFAs, variations exist in content and language, as summarized below (see Exhibit 4). In some cases there are changes in meaning and emphasis, and in other instances the changes represent subtle shifts in language.

Exhibit 4. Comparative Analysis of RFA Objectives

Research Objectives	
1997 RFA	Variation in 1998 RFA
The overall purpose of this RFA is to support and develop outstanding Parkinson's Disease Research Centers of Excellence that will advance the understanding of Parkinson's Disease and related movement disorders.	The 1998 RFA does not include <i>movement</i> disorders but does include <i>neurodegenerative</i> disorders.
It is anticipated that each Center will contain both basic and clinical research in proportions that are appropriate for the research objectives.	The 1998 RFA indicates that each Center may contain either basic <i>or</i> clinical research.
Experimental studies may focus on many significant topics that might include, but are not limited to, diagnostic, anatomical, pathological, biochemical, genetic, physiologic, or pharmacologic approaches to elucidating pathophysiological mechanisms of Parkinson's Disease and related movement disorders.	No mention of <i>diagnostic</i> in the 1998 RFA.
Not mentioned in 1997 RFA.	Clinical studies comparing the efficacy and safety of new surgical therapies and their long term outcome are particularly encouraged.
New research techniques have created extraordinary opportunities for further exploration into the etiology and pathogenesis of Parkinson's Disease and related neurodegenerative disorders.	The 1998 RFA includes <i>diagnosis</i> and <i>treatment</i> in its discussion of new research techniques.

The Udall Act includes 15 components<sup>10</sup> that mandate the Director of the NIH to establish a program to conduct and support research and training in PD. The Udall Act further defines the requirements of this Program, including the type of funding mechanism (i.e., Core Center

<sup>10</sup> Components include specific requirements from the Udall Act as well as other general directives.

Grants) and elements that the Centers should consider (e.g., training, basic and clinical research, and education of health professionals). Approximately 47 percent of the Udall Act components are found in the RFA issued in 1997, and 40 percent of the components are found in the RFA issued in 1998 (see Exhibit 5).

Exhibit 5. Comparative Analysis of the Udall Act to the 1997 RFA and 1998 RFA

Component #	Udall Act Component	1997 RFA	1998 RFA
1	Director of NIH will establish a program for the conduct and support of research and training with respect to PD.	X	X
2	Director of NIH will provide coordination of the program established under subsection (a) among all of the national research institutes conducting PD research.	X	X
3	Coordination and convening of a research planning conference no less frequently than once every 2 years. Each conference shall prepare and submit a report concerning the conference to the Committee on Appropriations and the Committee on Labor and Human Resources of the Senate and the Committee on Appropriations and the Committee on Commerce of the House of Representatives.		
4	Director of NIH authorized to award Core Center Grants to encourage the development of innovative multidisciplinary research and provide training concerning PD. The Director is authorized to award no more than 10 Core Center Grants and designate each Center funded under such grants as a Morris K. Udall Center for Research on PD.	X	X
5	Each Center shall use the facilities of a single institution or a consortium of cooperating institutions, and meet such qualifications as prescribed by the Director of NIH.		
6	Each Center shall conduct basic and clinical research.	X	
7	Each Center may conduct training programs for scientists and health professionals.	X	X
8	Each Center may conduct programs to provide information and continuing education to health professionals.		
9	Each Center may conduct programs for the dissemination of information to the public.		
10	Each Center may separately or in collaboration with other Centers establish a nationwide data system derived from patient populations with PD, and where possible, compare relevant data involving general populations.		
11	Each Center may separately or in collaboration with other Centers establish a national education program that fosters a national focus on PD and the care of those with PD.		
12	A Center may use funds provided to provide stipends for scientists and health professionals enrolled in training programs.		
13	Support of a Center may be for a period not exceeding five years. Such period may be extended by the Director of NIH for one or more additional periods of not more than five years if the operations of such Center have been reviewed by an appropriate technical and scientific peer review group established by the Director and if such group has recommended to the Director that such period should be extended.	X	X
14	Director of NIH is authorized to establish a grant program to support investigators with a proven record of excellence and innovation in PD research and who demonstrate potential for significant future breakthroughs in the understanding of the pathogenesis, diagnosis, and treatment of PD. Grants under this subsection shall be available for a period not exceeding five years.		

Component #	Udall Act Component	1997 RFA	1998 RFA
15	For the purpose of carrying out this section and section 301[42 USCS 241] and title IV of the Public Health Service Act [42 USCS 281 et seq.] with respect to research focused on PD, there are authorized to be appropriated up to \$100,000,000 for fiscal year 1998, and such sums as may be necessary for each of the fiscal years 1999 and 2000.	X	X

### 3.3.1.3 Summary

The 11 institutions selected as Udall Centers responded to either the 1997 RFA or the 1998 RFA. Though similar in their description and purpose of the program, the two RFAs did contain some variation in language. NINDS included some components of the Udall Act in the RFAs, (and later initiated other mechanisms to address components not previously incorporated into the original two RFAs).

## 3.3.2 Study Question 1.2 – To what extent were the grant applications received by NINDS (and those that were successful) responsive to the RFA?

### 3.3.2.1 Approach

To address the issue of application responsiveness, the study team reviewed summary statements and conducted a thematic analysis of the collected data. Summary statements are written by members of a study section, who review the grant applications for scientific and technical merit. The applications considered to have the highest scientific merit receive a priority score. Some of the applications funded in 1998 were originally submitted a year earlier, in response to the 1997 RFA. For the purposes of this analysis, the study team considered each application to be an independent submission, regardless of its status as a resubmission. Note that a summary statement is a compilation of reviewers’ comments, and that the absence of reviewers’ comments on a particular theme does not necessarily imply an absence of the theme in an application.

Data Sources for Research Question 1.2
<ul style="list-style-type: none"> <li>• 1997 RFA &amp; 1998 RFA</li> <li>• Summary Statements</li> </ul>

### 3.3.2.2 Results

The 1997 and 1998 RFAs each contained two sets of review criteria. The first set of criteria focused on five points: significance, approach, innovation, investigator, and environment. The second set of criteria was Center-specific and addressed features such as: unifying theme, program director, components, organizational and administrative structure, and budget. The study team identified several dominant themes when reviewing the summary statements for each grant application. Furthermore, the study team conducted a comparison of the scored versus unscored applications, and funded versus unfunded applications.

Exhibit 6, Exhibit 7, and Exhibit 8 summarize the findings. Of the RFAs’ evaluation criteria, study section reviewers most frequently addressed the unifying theme, investigator, components, approach, and innovation. For scored applications, reviewers commented primarily on the integration of projects (i.e., unifying theme) and the positive Principal Investigator’s track record. Reviewers also seemed to indicate their concerns with the scientific approach to one or

more projects. Likewise, reviewers stated these concerns for the applications that did not receive scores. On unscored applications, reviewers also commented on the lack of information on potential research outcomes or possible project confounders.

Exhibit 6. Reviewer Comments on Scored and Unscored Applications from the 1997 and 1998 RFAs

Theme	% of Scored	% of Unscored
Positive Principal Investigator track record	58%	37%
Projects are integrated – unifying theme	53%	16%
Concerns with one or more projects' scientific approach	32%	63%
Flaws in one or more project(s)	26%	58%
Collaboration within institute or with other organizations/institutes	21%	16%
Projects not integrated	16%	26%
Integration of animal and human-subject project /spans basic and clinical work	16%	0%
Lack of supporting preliminary data for individual projects	11%	32%
Did not address possible project outcomes or confounders	0%	42%

For the applications that received funding in 1998, reviewers primarily commented on the integration of projects and positive Principal Investigator's track record. For those that did not receive funding, reviewers commented on their concerns with the scientific approach, flaws in the project, and lack of integration of projects.

Exhibit 7. Reviewer Comments on Funded and Unfunded Applications for the 1997 RFA

Theme	% of Funded	% of Unfunded
Positive Principal Investigator track record	100%	21%
Projects are integrated – unifying theme	67%	26%
Integration of animal and human-subject project/spans basic and clinical work	33%	0%
Collaboration within institute or with other organizations/institutes	33%	21%
Projects not integrated	0%	32%
Lack of supporting preliminary data for individual projects	0%	11%
Concerns with one or more projects' scientific approach	0%	63%
Flaws in one or more project(s)	0%	74%
Did not address possible project outcomes or confounders	0%	21%

For the applications that received funding in 1999, as in 1998, reviewers commented on the integration of projects and when Principal Investigators had track records that reviewers considered positive. For the applications that did not receive funding, reviewers also commented

when Principal Investigators had positive records, but expressed concerns with scientific approach to one or more projects.

Exhibit 8. Reviewer Comments on Funded and Unfunded Applications for the 1998 RFA

Theme	% of Funded	% of Unfunded
Projects are integrated – unifying theme	75%	0%
Positive Principal Investigator track record	63%	75%
Integration of animal and human-subject project/spans basic and clinical work	25%	0%
Lack of supporting preliminary data for individual projects	25%	50%
Projects not integrated	13%	13%
Concerns with one or more projects' scientific approach	13%	63%
Collaboration within institute or with other organizations/institutes	0%	25%
Flaws in one or more project(s)	0%	25%
Did not address possible project outcomes or confounders	0%	50%

### 3.3.2.3 Summary

In summary, the grant applications received by NINDS were reasonably responsive to the RFA; however, the study team identified some variability across the evaluation criteria. As would be expected, the study team found variability between scored and unscored grant applications, and funded and unfunded grant applications. With respect to scored and unscored applications, scored applications were more likely to present a unifying theme (i.e., integration of projects) and unscored applications were more likely to lack information on potential research outcomes or possible project confounders. A similar distinction emerged with respect to funded and unfunded applications. Those that were funded (in 1998 and 1999) were more likely to address a unifying theme and those that were unfunded tended to have problems with the scientific approach.

### 3.3.3 Study Question 1.3 – *What role did NINDS Program Staff play in serving as a resource during the application process?*

#### 3.3.3.1 Approach

To determine the role NINDS Program Staff played as a resource during the application process, the study team posed a series of questions to Udall Center Investigators during the interviews. The study team first asked Center Directors and Project/Core Leads about their reactions to the original RFA and then about their interactions with NINDS Program Staff during three stages: the pre-award phase, the application review process, and the post-award time period.

#### 3.3.3.2 Results

Most Udall Center Directors and Project/Core Leads indicated a response of “good” or “very good” regarding the clarity in the RFA of the characteristics needed for a successful application (27 out of 29 Investigators). Some Udall Investigators cited that past experiences in applying for NIH grants gave them a solid foundation for what was expected, even if the RFA itself did not spell it out directly. Udall Investigators echoed concerns about the focus of the RFA and, in particular, whether the Centers’ science should emphasize basic, clinical, or translational research. However, the quality of the application review committee and whether or not it truly understood what NINDS envisioned for the focus of the Centers emerged as a new concern. Center Directors and Project/Core Leads from two Centers explained that, while NINDS provided clear guidelines, the reviewers did not follow these as they made their recommendations. Other Udall Investigators more generally noted that this holds true of any application: it has to survive the peer review process of study section, regardless of the clarity of the guidelines.

While the majority of Udall Center Investigators (28 out of 30) rated the clarity of NINDS’ program goals in the initial RFA as either “good” or “very good” (see Exhibit 9), several found aspects of the RFA to be ambiguous.

Data Sources and Questions for Research Question 1.3	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>• On a scale of 1 to 5, how would you rate your impression of the initial RFAs on the clarity of NINDS’ goals for the program and the clarity of characteristics needed for a successful application? If you rated either of these dimensions a 1, 2, or 3, please elaborate.</li> <li>• During the pre-award process, application review process or post-award time frame, did you or your staff contact NINDS for assistance with the application? If so, on a scale of 1 to 5, please rate your experience with NINDS on the following dimensions: <ul style="list-style-type: none"> <li>– Providing Guidance</li> <li>– Responsiveness to Questions/Concerns</li> <li>– Clarity of Information Provided</li> <li>– Adequacy of Information Provided</li> <li>– Overall Quality of Assistance</li> </ul> </li> </ul>

Exhibit 9. Center Directors' and Project/Core Leads' Ratings of the Initial RFA

Clarity of NINDS' goals for the program*	Center Directors	Project/Core Leads	Total	Clarity of the characteristics needed for a successful application.*	Center Directors	Project/Core Leads	Total
1 (Very Poor)	0	0	0	1 (Very Poor)	0	0	0
2 (Poor)	1	0	1	2 (Poor)	0	0	0
3 (Average)	0	1	1	3 (Average)	0	2	2
4 (Good)	1	15	16	4 (Good)	3	16	19
5 (Very Good)	5	7	12	5 (Very Good)	4	4	8
Mean Rating	4.4	4.3	4.3	Mean Rating	4.6	4.1	4.2
Median Rating	5	4	4	Median Rating	5	4	4

\*Interviewees who provided a response of N/A were removed from the analysis.

Investigators from three Centers noted it was unclear whether the RFA focused on basic, translational, or clinical science and, for the latter, how necessary of a component it was for a successful application. Two other Investigators were unclear as to how the Udall Center grant differed from other NIH-center grants and questioned whether it was simply designed to show interest groups that NINDS was focusing on PD research. Overall, however, most found the goals to be quite clear and one Director noted that the goals were well-defined and perhaps better than prior RFAs.

### The Pre-Award Timeframe

When the study team asked Udall Center Investigators about their interactions with NINDS Program Staff during the pre-award period, most responded that they did not contact NINDS during that time (see Exhibit 10). Those who did have interactions with NINDS Staff expressed predominantly positive remarks. Both Udall Center Directors and Project/Core Leads highlighted the helpfulness and the professionalism of the NINDS Program Staff.

Exhibit 10. Center Directors' and Project/Core Leads' Ratings of NINDS Pre-Award Assistance

As you were writing the application, did you or your staff contact NINDS for assistance with the application?*	Center Directors	Project/Core Leads	Total
Yes	6	3	9
No	4	26	30
If yes, please rank NINDS on:	Number	Number	Total
<b>Providing Guidance</b>			
1 (Very Poor)	0	0	0
2 (Poor)	1	0	1
3 (Average)	0	0	0
4 (Good)	1	1	2
5 (Very Good)	2	2	4
Mean Rating	4.0	4.7	4.3
Median Rating	4.5	5.0	5.0
<b>Responsiveness to Questions/Concerns</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	0	0
4 (Good)	2	0	2
5 (Very Good)	2	3	5
Mean Rating	4.5	5.0	4.7
Median Rating	4.5	5.0	5.0
<b>Clarity of Information Provided</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	0	0
4 (Good)	3	2	5
5 (Very Good)	1	1	2
Mean Rating	4.3	4.3	4.3
Median Rating	4.0	4.0	4.0
<b>Overall Quality of Assistance</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	0	0
4 (Good)	2	0	2
5 (Very Good)	2	3	5
Mean Rating	4.5	5.0	4.7
Median Rating	4.5	5.0	5.0

\*Interviewees who provided a response of N/A were removed from the analysis.

### Application Review Process

Most of the Udall Center Investigators did not contact NINDS Program Staff during the application review period (after submission of the grant application and prior to the notification of grant awards). For those who did (five out of 38 Investigators), the nature of the interaction was primarily for procedural clarifications and many believed it was not substantive enough to

provide a rating. The few Investigators who felt they could elaborate indicated that they received “good” or “very good” information (see Exhibit 11). One Director described it as comparable to what the Investigators had experienced with other areas of NIH.

Exhibit 11. Center Directors’ and Project/Core Leads’ Ratings of NINDS Assistance During the Application Process

During the application review process, did you or your staff contact NINDS with questions?*	Center Directors	Project/Core Leads	Total
Yes	3	2	5
No	5	28	33
If yes, please rank NINDS on:	Number	Number	Total
<b>Providing Guidance</b>			
1 (Very Poor)	0	0	0
2 (Poor)	1	0	1
3 (Average)	0	0	0
4 (Good)	0	0	0
5 (Very Good)	1	3	4
Mean Rating	3.5	5.0	4.4
Median Rating	3.5	5.0	5.0
<b>Responsiveness to Questions/Concerns</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	0	0
4 (Good)	1	0	1
5 (Very Good)	1	3	4
Mean Rating	4.5	5.0	4.8
Median Rating	4.5	5.0	5.0
<b>Clarity of Information Provided</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	1	0	1
4 (Good)	0	2	2
5 (Very Good)	2	1	3
Mean Rating	4.3	4.3	4.3
Median Rating	5.0	4.0	4.5
<b>Overall Quality of Assistance</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	1	0	1
4 (Good)	0	0	0
5 (Very Good)	2	3	5
Mean Rating	4.3	5.0	4.7
Median Rating	5.0	5.0	5.0

\*Interviewees who provided a response of N/A were removed from the analysis.

### Post-Award Period

While the majority of Project/Core Leads (24 out of 30) did not contact NINDS during the post-award period, eight of 11 Center Directors did interact with NINDS Program Staff and found them to be very responsive to questions and generally helpful (see Exhibit 12). Two of the Directors contacted NINDS Staff with budgetary questions, and two others contacted NINDS Staff about the availability of supplements. Several of the Directors indicated that they found the Program Staff to be timely and helpful in their responses during this period.

Exhibit 12. Center Directors' and Project/Core Leads' Ratings of NINDS Assistance During the Post-Award Period

During the post-award period, did you or your staff contact NINDS with questions?*	Center Directors	Project/Core Leads	Total
Yes	9	6	15
No	2	24	26
If yes, please rank NINDS on:	Number	Number	Total
<b>Providing Guidance</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	2	2
4 (Good)	3	0	3
5 (Very Good)	5	2	7
Mean Rating	4.6	4.0	4.4
Median Rating	5.0	4.0	5.0
<b>Responsiveness to Questions/Concerns</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	2	2
4 (Good)	4	0	4
5 (Very Good)	4	2	6
Mean Rating	4.5	4.0	4.3
Median Rating	4.5	4.0	4.5
<b>Clarity of Information Provided</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	2	2
4 (Good)	4	0	4
5 (Very Good)	4	2	6
Mean Rating	4.5	4.0	4.3
Median Rating	4.5	4.0	4.5
<b>Adequacy of Information Provided</b>			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	0	2	2
4 (Good)	4	0	4
5 (Very Good)	4	2	6
Mean Rating	4.5	4.0	4.3
Median Rating	4.5	4.0	4.5

Overall Quality of Assistance			
1 (Very Poor)	0	0	0
2 (Poor)	0	0	0
3 (Average)	1	2	3
4 (Good)	2	0	2
5 (Very Good)	5	2	7
Mean Rating	4.5	4.0	4.3
Median Rating	5.0	4.0	5.0

*\*Interviewees who provided a response of N/A were removed from the analysis.*

### 3.3.3.3 Summary

Overall, the Center Directors and Project/Core Leads found the NINDS Program Staff to be an excellent resource during the application process. While most could not elaborate on the quality of their interactions with the staff, due to either a lack of substantive contact or an inability to recall the details of the interaction, those who could praised the NINDS Staff for their helpfulness, responsiveness, and quality of advice.

### 3.3.4 Study Question 1.4 – In what ways could the process for selecting Udall Centers be improved?

#### 3.3.4.1 Approach

To determine how the process for selecting Udall Centers could be improved, the study team asked Udall Investigators about their experiences with submitting the Udall grant application and other program applications. The study team also invited additional comments regarding the NINDS application and review process.

#### 3.3.4.2 Results

Exhibit 13 presents a summary of Udall Center Investigators’ experiences in applying for funding, other than Udall Center funding. Of those who responded to the interview questions, over 86 percent of Udall Investigators reported other experience in applying for funding from NINDS (non-Udall) or NIH (non-NINDS). Almost 46 percent reported experience in applying for other federal non-NIH funding.

Data Sources and Questions for Research Question 1.4	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>• Please describe any experience (regarding application and selection) submitting grant applications to other programs (whether within or outside of NINDS) and how it compares to your experience with Udall programs.</li> <li>• Please indicate the programs to which you submitted these applications: <ul style="list-style-type: none"> <li>– Other NINDS (non-Udall) programs</li> <li>– Other NIH (non-NINDS)</li> <li>– Other federal programs (Non-NIH)</li> </ul> </li> <li>• Do you have any additional comments regarding the application and review process?</li> </ul>

Exhibit 13. Funding Sources for which Udall Center Investigators Have Applied

	Center Directors (#)	Center Directors (%)	Project/ Core Leads (#)	Project/ Core Leads (%)	Total (#)	Total (%)
NINDS Funding (Other than Udall)	9*	81.8%	24†	88.8%	33	86.8%
NIH Funding (Other than NINDS)	9*	81.8%	25'	89.3%	34	87.2%
Federal Funding (Other than NIH)	5°	50.0%	12†	44.4%	17	45.9%

\*Out of 11 respondents

† Out of 27 respondents

°Out of 10 respondents

'Out of 28 respondents

Respondents provided examples of other applications for research funding, including submissions to NINDS (non-Udall), the National Institute on Aging (NIA), the National Institute of Environmental Health Sciences (NIEHS), the National Science Foundation (NSF), and the Department of Defense (DoD). Exhibit 14 summarizes the qualitative comments made by 11 Center Directors and 23 Project/Core Leads regarding their experiences with these application processes.

Exhibit 14. Comparison of Udall Application Process to Other Program Application Experiences

Center Director and Project/Core Leads Comments: Udall Application Process vs. Other Application Experiences
<ul style="list-style-type: none"> <li>• The application experiences were comparable (14)                             <ul style="list-style-type: none"> <li>– No major differences compared to other NIH processes (12)</li> <li>– No major differences compared to other processes (2)</li> </ul> </li> <li>• The Udall Center application process was better than other application experiences (13)                             <ul style="list-style-type: none"> <li>– Non-specific (4)</li> <li>– The quality of the review was much better because the Udall applications were reviewed by special emphasis panels of individuals knowledgeable in PD (2)</li> <li>– It was very clear what was expected (1)</li> <li>– NIH had more responsive program officers than NSF (1)</li> <li>– The communication was better than with other institutes (1)</li> <li>– It was better because it used actual scores instead of percentiles (1)</li> <li>– It was easier than other NIH processes (1)</li> <li>– It was better than DoD, which has unusual forms and from whom it is difficult to get reviews back (1)</li> <li>– It was better, especially considering that NINDS has a small staff administering a large research portfolio (1)</li> </ul> </li> <li>• The Udall Center application process was worse than other application experiences (1)                             <ul style="list-style-type: none"> <li>– The review criteria were less clear than with an R01 – it's unclear what is unique about a Udall Center or what the key issues are (1)</li> </ul> </li> <li>• No experience with application processes (3)</li> </ul>

Ten Center Directors and 23 Project/Core Leads responded to the interview question regarding additional comments on the NINDS Udall Center application and review process (see Exhibit 15). Of the 34 Investigators who provided comments on the application process, 27 (79 percent) said that the Udall application process was comparable to or better than experiences with other application processes.

Exhibit 15. Additional Interview Comments Regarding NINDS Application and Review Process

Center Directors	Project/Core Leads
<ul style="list-style-type: none"> <li>• I appreciated having the opportunity to begin the funding renewal process in the fourth year, in preparation for the fifth year (1)</li> <li>• I saw improvement with the renewal process – I received better advice and guidance (1)</li> <li>• NINDS put together a good group of reviewers who were fair and appropriate (1)</li> <li>• NINDS should have had the reviews go to the in-house study sections rather than the general study sections (1)</li> <li>• NINDS should use site visits as a way to improve the quality of the peer review process, as other NIH grants do (1)</li> <li>• NINDS should evaluate the strength of the thematic relationship across the sub-projects (basic, translational, clinical) and offer upfront guidance on how it will evaluate cohesion across the sub-projects (1)</li> <li>• In the first phase, NINDS should have provided more guidance on the difference between a Center and a program project (1)</li> </ul>	<ul style="list-style-type: none"> <li>• NINDS should require a shorter preparation time (2)</li> <li>• I was glad they used a scoring system rather than percentiles (1)</li> <li>• NINDS should have been more clear in the second round if they wanted more Centers focused on clinical and translational work rather than basic – this led to some negative experiences for other Centers (1)</li> <li>• NINDS should use site visits as a way to improve the quality of the peer review process, as other NIH grants do (1)</li> <li>• It would be good if the cores could also receive a research grant and not just be a service for others (1)</li> </ul>

### 3.3.4.3 Summary

A majority of Udall Investigators had other experience applying to the NIH for funding, which enabled them to comment on how the application process compared to other funding mechanisms and how the Udall Center application process could be improved. Most Investigators found the Udall application process to be better than, or equal to, other funding processes. Investigators made suggestions on how NINDS could provide more guidance to Centers on research focus (basic versus clinical) and what is expected of Centers.

### 3.4 Study Question 2

How did NINDS administer the Udall Centers Program from FY 1998 – 2003?

#### 3.4.1 Study Question 2.1 – *What level of NIH resources (funding and staff support) was allocated to the Udall Centers Program?*

##### 3.4.1.1 Approach

To answer study question 2.1, study team members interviewed key program and grants management NINDS staff who supported the Udall Centers Program between FY98 and FY03. In addition, the team extracted Udall Center funding award records and supplemental grant award records from the NIH IMPAC II QVR system. The results are reported as summary annual financial data, illustrating the relative funding invested in the Udall Centers Program versus overall investments made by NINDS in all PD-related research, and total NINDS funding awarded between FY98 and FY03 (see Exhibit 16). The NINDS Financial Management Branch provided the amounts of annual investment by NINDS for all research and PD research, inclusive of the Udall Centers, between FY98 and FY03. The study team also interviewed members of the NINDS staff, who provided additional information on the level of NINDS resources allocated to the Udall Centers Program.

Data Sources for Research Question 2.1
<ul style="list-style-type: none"> <li>IMPAC II QVR</li> <li>NIH Office of Extramural Research Award Data (<a href="http://grants.nih.gov/grants/award/success/Success_ByIC.cfm">http://grants.nih.gov/grants/award/success/Success_ByIC.cfm</a>)</li> <li>Interviews with NINDS Staff</li> </ul>

##### 3.4.1.2 Results

###### NINDS Funding

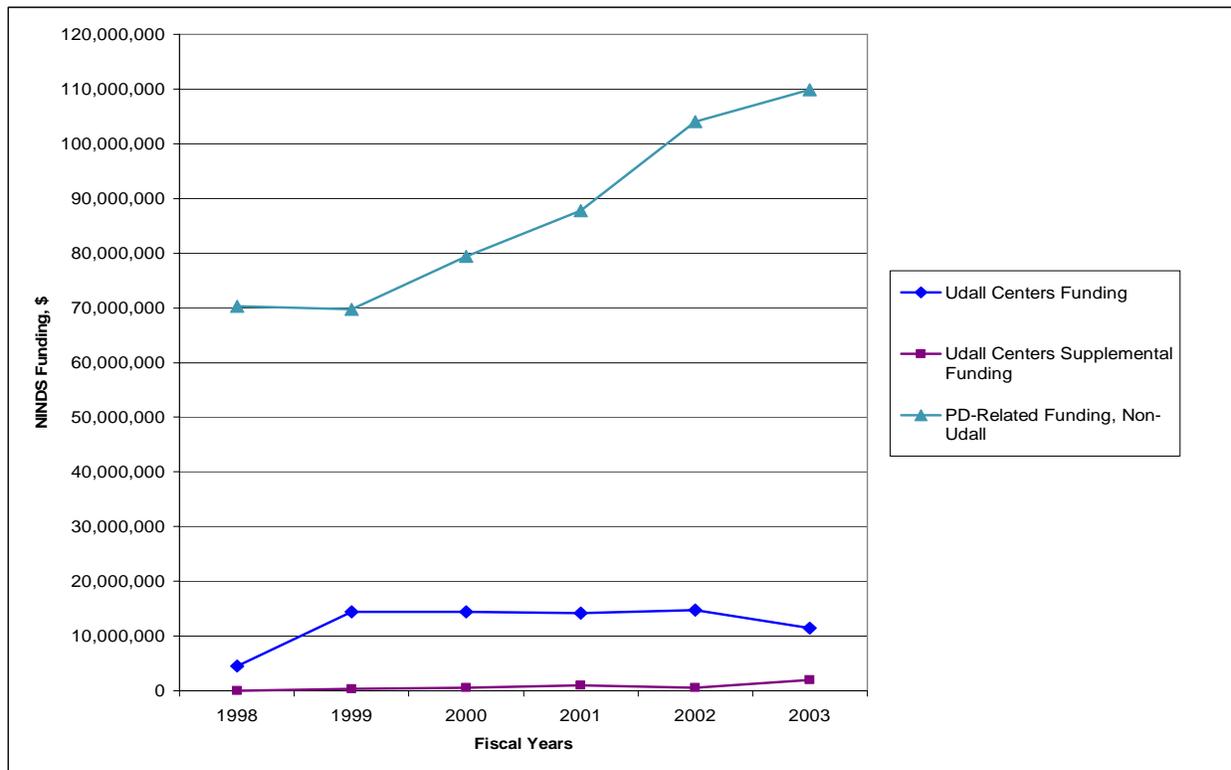
From FY98 through FY03, NINDS invested \$78,044,725 in the Udall Centers Program, based on annual funding to Centers and supplemental grant funding. Exhibit 16 displays the range of annual funding by category of investment, including the annual investment made by NINDS for Udall Center funding (including supplements), PD-related funding, and all research funding.

Exhibit 16. PD-Related Research Investments by NINDS (FY98 – FY03)

Fiscal Year	Udall Centers Initial Funding (\$)	Udall Centers Supplemental Funding (\$)	All PD-Related Funding (\$)	NINDS Funding for All Research (\$)
1998	4,539,249	0	74,858,000	778,432,000
1999	14,383,527	364,450	84,855,000	900,245,000
2000	14,388,530	600,010	95,008,000	1,028,204,000
2001	14,164,883	976,458	103,919,000	1,175,591,000
2002	14,731,674	507,667	119,796,000	1,325,193,000
2003	11,407,720	1,980,557	125,248,000	1,456,426,000
<b>TOTAL</b>	<b>73,615,583</b>	<b>4,429,142</b>	<b>603,684,000</b>	<b>6,664,091,000</b>

Exhibit 17 presents the trend in NINDS funding for Udall, Udall supplemental, and PD-related research from FY98 through FY03.<sup>11</sup> As seen in Exhibit 17, NINDS funding for PD-related research (non-Udall) increased every year between FY98 and FY03, although funding for the Udall Centers Program decreased between FY02 and FY03.

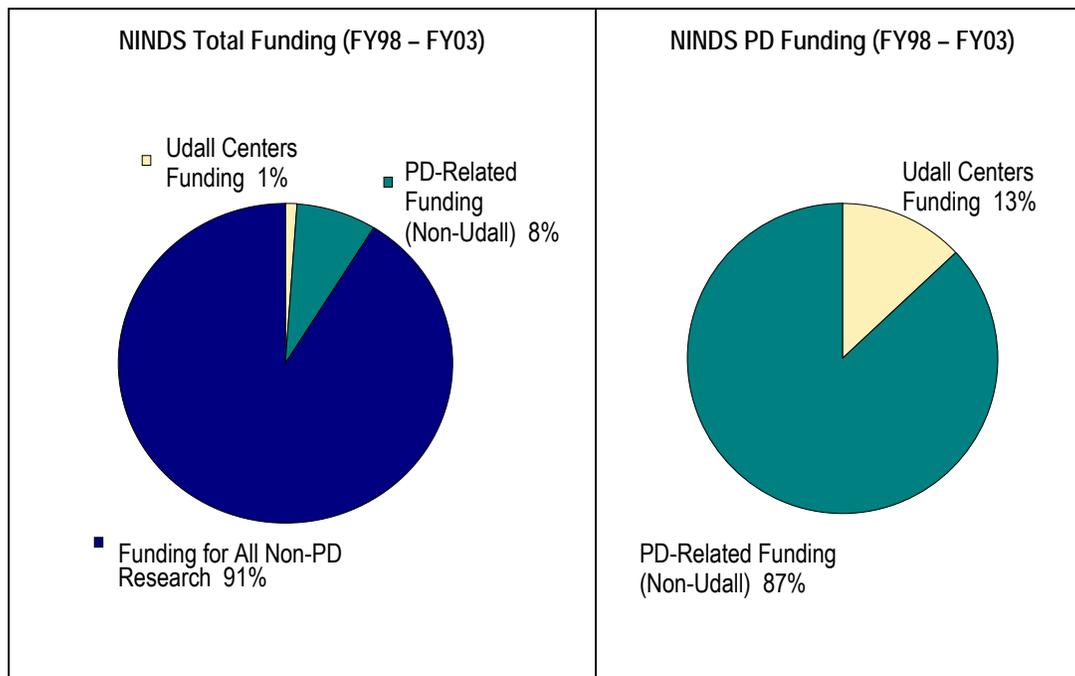
Exhibit 17. Udall, Udall Supplemental, and PD-Related (Non-Udall) NINDS Research Funding (FY98 – FY03)



<sup>11</sup> Note that Udall Center Program funding does have a cap whereas non-Udall PD funding does not.

Between FY98 and FY 2003, NINDS spent eight percent of its funding on PD-related research (non-Udall), and approximately one percent on Udall Center funding, including supplemental funding (see Exhibit 18).

Exhibit 18. Breakdown of NINDS Funding for Udall, PD-Related, and Non-PD Related Funding (FY98 – FY03)



### NINDS Staff Resources Devoted to Udall Centers Program

The study team interviewed six NINDS Program Staff, including the staff responsible for conducting the RFA review processes. They reported that the review process remained the same for the 1997 and 1998 RFAs. According to one staff member, NINDS allocated approximately 1.5 full time equivalents (FTE) to support the Udall Centers. One of the major ways the NINDS staff supported the Udall Centers Program was through the annual meeting planning and facilitation, which involved the Program Manager, two program staff, and contractors for meeting management. Program Managers also worked directly with the Center Directors in encouraging and facilitating collaboration and in promoting the sharing of ideas, resources, and data.

One of the resource issues raised by NINDS staff during the interviews was the tension between the efficiencies of funding a Center (less costly than separate R01s) and the relative inflexibility of a five-year program in an era of changing science. NINDS staff reported that, initially, the Udall Centers had an annual funding cap of \$1 million each, which posed a particular challenge for Centers with a clinical component. In July 2003, NINDS raised the cap to \$1.5 million for Centers with a clinical component. By contrast, R01s do not have a funding cap – although, unlike Center grants funded under an RFA (e.g., the Udall Center Grant), there is no guarantee that funding will be available.

### 3.4.1.3 Summary

From FY98 through FY03, NINDS steadily increased its funding for PD research. With the exception FY02 and FY03, NINDS funding for the Udall Centers Program (including supplements) increased every year as well. This funding included the Udall Center Grants and any supplemental funding available. In addition, NINDS allocated 1.5 FTEs, including a Program Manager, to support the Udall Program. The Program Manager served as a resource for Udall Centers during the application process and after the awards, and also planned and facilitated the annual meetings.

## 3.4.2 Study Question 2.2 – To what extent did NINDS staff facilitate collaboration among Udall Center investigators?

### 3.4.2.1 Approach

To address this question, the study team interviewed NINDS staff regarding their efforts toward fostering collaboration among Udall Center Investigators. In addition, the study team interviewed Center Directors and Project/Core Leads about the degree to which they received communication, networking opportunities, or other forms of support from NINDS; other ways in which NINDS facilitated collaboration; and whether Udall Investigators perceived the Udall Centers Program as a network.

Data Sources and Questions for Research Question 2.2	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>To what extent did NINDS provide communication, networking opportunities, or other forms of support directly to your Center to facilitate collaboration within your Center, with other Centers, and/or with outside researchers? Please rate on a scale of 1 to 3. Please describe the communication or other support they provided and your rating rationale.</li> <li>Do you feel that the NINDS facilitated collaboration (within and among the Centers) in any other ways? If yes, please describe. Do you view the Centers as a network? If not, would it be useful for the Udall Program to move in this direction?</li> </ul>

### 3.4.2.2 Results

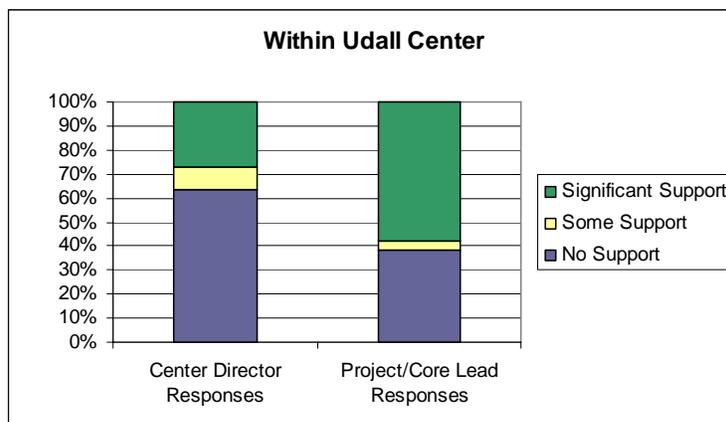
In the study team’s interviews with NINDS staff, the emphasis on fostering collaboration was evident. Interviewees discussed how

collaboration was consistent with the movement toward multidisciplinary research and how it required a fundamental paradigm shift in the minds of some researchers. To promote collaboration, NINDS expressed – in the RFA – that Udall Center applicants should demonstrate an interest in collaboration and idea-sharing. NINDS established annual meetings as an ongoing venue for collaboration, encouraged the sharing of samples, and promoted the benefits of shared databases as additional means through which Centers could collaborate.

To some degree, Center Directors and Project/Core Leads interviewees reported that NINDS provided communication, networking opportunities, or other forms of support to facilitate collaboration within their own Centers, with other Udall Centers, and with outside researchers. Of the three, interviewees indicated that NINDS provided more support in regards to collaborating with other Udall Centers, than within the Center or with outside researchers. In addition, Project/Core Leads were somewhat more favorable about the collaborative support they received from NINDS than were Center Directors.

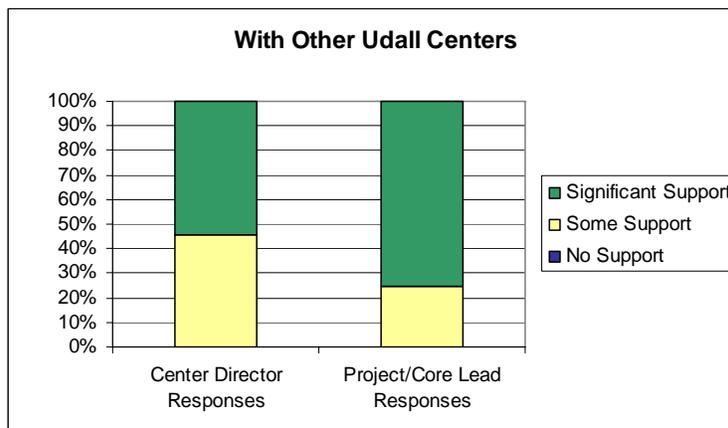
Within their own Centers, Center Directors and Project/Core Leads reported mixed responses; some reported that they received support while others indicated that they did not (see Exhibit 19). This included Investigators who felt that there was no need for NINDS to facilitate collaboration within their Centers – rather, it was incumbent upon the Centers to do so for themselves.

Exhibit 19. NINDS Support to Facilitate Collaboration – Within the Udall Center



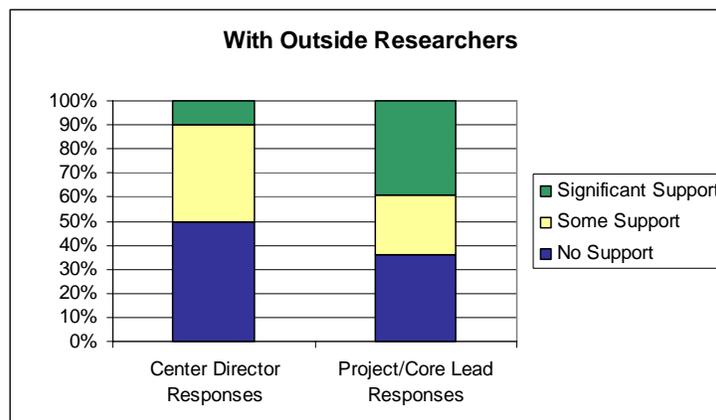
Respondents reported that NINDS was most effective in providing support to facilitate collaboration with other Udall Centers, particularly due to the annual meetings (see Exhibit 20).

Exhibit 20. NINDS Support to Facilitate Collaboration – Across Udall Centers



Some Center Directors and Project/Core Leads reported that they received significant support to connect with outside researchers, while others reported that they did not receive or expect support (see Exhibit 21).

Exhibit 21. NINDS Support to Facilitate Collaboration – With Outside Researchers



While Center Directors and Project/Core Leads recognized the annual meetings as a key means through which NINDS facilitated collaboration, 21 of 35 interviewees acknowledged that NINDS also facilitated collaboration within and across the Udall Centers in other ways. As shown in Exhibit 22, the most common responses from the Udall Investigators focused on funding, data sharing, and communications. For example, interviewees indicated that NINDS provided supplemental funding for collaborative efforts, established the PD Data Organizing Center (PD-DOC) as a central data repository for brain donations, and communicated with Udall Investigators via the website and emails.

Exhibit 22. Ways NINDS Facilitated Collaboration (Other Than Through the Annual Meeting)

Interview Findings: Center Directors and Project/Core Leads
<ul style="list-style-type: none"> <li>• Offered supplemental funding for collaborative projects that involved scientific exchange (7)</li> <li>• Established the PD-DOC to maintain data/facilitate coordination among Centers that have brain donations (6)</li> <li>• Built a website to keep people connected (3)</li> <li>• Sent emails of grant proposals and initiatives (e.g., genetics and brain banking, and clinical operating scales and clinical databases) (3)</li> <li>• Held separate workshops with researchers within and beyond the Udall Centers on topics generated at the annual meetings (e.g., cognitive aspects of PD, non-motor aspects of PD) (3)</li> <li>• Supported and facilitated people talking to each other, but were not directive (best to let collaboration develop organically) (3)</li> <li>• Established a mouse repository (2)</li> <li>• Initiated the Genetic Institute and NET-PD (1)</li> <li>• Shared papers and asked people to comment – got them connected in an informal way (1)</li> <li>• Sent message that we are a community working toward a common goal (1)</li> <li>• Provided funding that allows junior researchers to travel between Centers (1)</li> <li>• Made extra funding available to the Centers (for equipment or collaborative projects) (1)</li> <li>• Phone or e-mailed occasionally to suggest connecting with another researcher (1)</li> <li>• Coordinated discussions with the neuropathology core about tissue banking and DNA banking (1)</li> <li>• Suggestion: offer sabbaticals for investigators or post-doctoral fellows to go to different Centers to learn new techniques, etc. (1)</li> </ul>

Also in the spirit of promoting collaboration, interviewees were asked whether they viewed the Udall Centers as a network and, if not, whether it would be advantageous to move in this direction. Of those who responded, four of nine Center Directors and 13 of 20 Project/Core Leads did view the Udall Centers as a network. They cited the interconnectedness of the Centers, established means of communication, and ability to share information and data as reasons to support this view. Five of nine of the Center Directors and seven of 20 of the Project/Core Leads who responded stating that they did not view the Udall Centers as a network, questioned whether it would be beneficial to move toward becoming a network. A few reported that it would increase the sharing of information while the majority reported concerns that it would not be feasible (due to the diversity of projects that occur in the Centers) or would introduce unnecessary formality.

### 3.4.2.3 Summary

In summary, NINDS staff strived to facilitate collaboration among the Udall Center Investigators. The NINDS staff understood the value of collaboration and took initiative to build it into the structure and administration of the Udall Centers Program. Udall Center Investigators were aware of the emphasis on collaboration, with some collaboration efforts (e.g., the annual meetings) more apparent than others. In addition, Udall Center Investigators took ownership of collaboration, acknowledging that there were certain collaborative efforts for which they should take responsibility and not rely upon NINDS to initiate (e.g., collaboration efforts within their own Centers). NINDS was most effective at supporting and facilitating collaboration among Centers.

### 3.4.3 Study Question 2.3 – To what extent did NINDS staff find ways to meet the evolving scientific and resource needs of the Centers and address emerging priorities relevant to the Centers’ research programs?

#### 3.4.3.1 Approach

To address this question, the study team asked Center Directors – through the web-based survey – if they maintained a list of priorities and resource needs throughout the funding period FY98 through FY03. Additionally, the study team asked the Center Directors if the initial funding of the project met their needs. If the needs were not met, the study team asked the Center Directors if they had made NINDS aware of this. The study team also asked Center Directors and Project/Core Leads about their perception of NINDS supplemental funding, and NINDS’ activities to meet Center resource needs.

Data Sources and Questions for Research Question 2.3	
Data Source	Questions
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>• Did your Center maintain a list of priorities and resource needs throughout the funding period? If so, did you identify time frames for those priorities and resource needs? For both questions, please elaborate on why/why not.</li> <li>• If you found that your needs could not be met through the initial funding of the project, did you convey this to NINDS? Was NINDS able to meet any of these additional needs through supplemental funding or other programmatic tools/mechanisms? If so, in what ways and how adequately? If not, why do you think not?</li> <li>• During the first 5 years, please discuss how NINDS’ formal activities such as program enhancements, improvements/additions, etc., and informal efforts have assisted you in meeting your needs. What impact have the formal activities and informal efforts had on your research?</li> </ul>

### 3.4.3.2 Results

Six of the nine Center Directors who responded to the survey provided responses regarding maintaining a list of priorities and resource needs throughout the funding period (see Exhibit 23). Two of the three Center Directors who did not maintain a list of priorities explained that they did identify needs and were active in institutional committees that addressed these needs, but that they did not establish any formal mechanisms.

Exhibit 23. Center Directors' Survey Results: Priorities Lists and Resource Needs of Udall Centers

Did your Center maintain a list of priorities and resource needs throughout the funding period? If so, did you identify time frames for those priorities and resource needs? For both questions, please elaborate on why/why not.	
Yes/No	Elaboration
Yes: We maintained a list of priorities and resource needs throughout the funding period (3)	<ul style="list-style-type: none"> <li>• We established a master five-year plan</li> <li>• We identified priorities in annual progress reports to the NIH</li> <li>• We maintained a list of priorities/needs for each lab/PI and tried to meet them as new resources became available</li> </ul>
No: We did not maintain a list of priorities and resource needs throughout the funding period (3)	<ul style="list-style-type: none"> <li>• We did not maintain a formal list of resource needs throughout the funding period, but did identify needs on a rolling basis with each meeting of the Executive Committee</li> <li>• The resource needs and priorities were established by the institution; however, Udall Center members were active participants in these institutional committees that set priorities and determined time frames</li> <li>• There was no mechanism for meeting additional needs</li> </ul>

When the study team asked the Center Directors if the initial funding of the project met their resource needs, six of the survey respondents stated that their needs had been met, while two indicated their needs had not been met. Of these two Center Directors, both conveyed their resource needs to NINDS. While one felt that NINDS Staff had been able to meet the Center's needs through supplemental funds or another mechanism, the other Center Director indicated that NINDS Staff was unable to meet the Center's needs. In all, one of the eight surveyed Center Directors felt that the Center's needs went unfulfilled by NINDS.

When asked in an open-ended format about the impact of NINDS' formal and informal mechanisms for helping Udall Centers achieve their research goals, the survey respondents provided a variety of answers. Sixteen Udall Center Investigators indicated that their research benefited from the sharing of information, ideas, and/or reagents at the Udall Center annual meetings. Seven Udall Investigators found the increased funding ceiling and the availability of supplemental funds helpful in establishing – and continuing – clinical research. However, PD-DOC elicited concerns from the Udall Center Investigators; four researchers indicated that PD-DOC had no benefit for their Centers' research (see Exhibit 24 for themes).

Exhibit 24. Impact of Formal Program Enhancements, Improvements and Additions on Research Needs

Center Directors	Project/Core Leads
<b>Annual Udall Meetings</b>	
<ul style="list-style-type: none"> <li>• Our research has benefited from the sharing of information/ideas and/or reagents at the annual Udall meetings as well as from the numerous collaborations that resulted from these meetings (4)</li> <li>• The meetings were very useful in the beginning, as they helped familiarize researchers with what was happening at other Centers (in the first 2-3 years, flexible and open approach to discussing data). (2)</li> <li>• The meetings provided positive interaction with members of the PD support community (1)</li> <li>• The quality of the meetings has decreased recently (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Our research has benefited from the sharing of information/ideas and/or reagents at the annual Udall meetings as well as from the numerous collaborations that resulted from these meetings (12)</li> <li>• The meetings were very useful in the beginning, as they helped familiarize researchers with what was happening at other Centers (in the first 2-3 years, flexible and open approach to discussing data) (1)</li> <li>• The meetings provided positive interaction with members of the PD support community (2)</li> <li>• The quality of the meetings has decreased recently (1)</li> </ul>
<b>Increased Funding Ceiling and Supplemental Funding</b>	
<ul style="list-style-type: none"> <li>• The funding has helped with establishing/maintaining clinical research and/or a clinical core (4)</li> </ul>	<ul style="list-style-type: none"> <li>• The funding has helped with establishing/maintaining clinical research and/or a clinical core (3)</li> <li>• The funding has encouraged collaboration and maintained acceptable levels of research (3)</li> <li>• The increase has funded mouse model and microarray equipment (3)</li> <li>• The nature of a Center is systems, so there is no direct impact from funding (1)</li> <li>• Core Leads have not been affected since the core is only a service; funding for cores is decreasing (1)</li> </ul>
<b>PD-DOC</b>	
<ul style="list-style-type: none"> <li>• The PD-DOC has had no benefit for the Center's research (no further explanation provided) (3)</li> <li>• There are concerns regarding cost-effectiveness (1)</li> </ul>	<ul style="list-style-type: none"> <li>• The PD-DOC has no benefit for the Center's research (no further explanation provided) (1)</li> </ul>
<b>General Comments</b>	
<ul style="list-style-type: none"> <li>• NINDS did a great job initially, although the program seems to have lost its way more recently (1)</li> </ul>	<ul style="list-style-type: none"> <li>• No impact (no further explanation provided) (2)</li> <li>• The needs of our program were generally addressed through informal efforts to share our methods and findings with other PD investigators (1)</li> <li>• Support for the cores of the Udall Center was very good and instrumental for moving forward (1)</li> <li>• External labs did not benefit from additional programs/measures (1)</li> <li>• The Udall Program developed a network of projects and raised awareness of the direction of PD research (1)</li> </ul>

### 3.4.3.3 Summary

Center Directors and Project/Core Leads generally expressed satisfaction with the ways in which the NINDS Program Staff met their resource needs. The majority of respondents stated that their resource needs were met, either initially or upon request. And generally, the respondents reacted positively to the formal and informal mechanisms that NINDS employed to promote the achievement of Centers’ research goals. Respondents provided positive feedback in regards to the Udall Center meetings, funding, and the availability of supplementary funds. Center Directors and Project/Core Leads offered varied opinions regarding the benefits of PD-DOC.

### 3.4.4 Study Question 2.4/2.5 – Did all of the Udall Center awardees submit a competing continuation application five years later? If not, why not?

#### 3.4.4.1 Approach

To answer Study Questions 2.4 and 2.5, the study team collected data from both the Udall Center applications and the interviews with Udall Center Directors.

#### 3.4.4.2 Results

Only one Center decided not to continue as a Udall Center of Excellence. The Center Director felt that there were better funding mechanisms to support PD research than the Udall Centers Program and that more research funding could be obtained by moving outside of the Udall funding mechanism. The Center Director believed it would be easier to fund the research through individual R01s, particularly when the Udall Center grants changed to a PAR.<sup>12</sup> The Center Director noted that this created major concerns about the availability of funding.

Data Sources and Questions for Research Question 2.4/2.5	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>What factors influenced your decision not to reapply for Udall Center funding?</li> </ul>

#### 3.4.4.3 Summary

While 10 of the 11 Udall Centers of Excellence submitted a competing renewal after the first funding cycle, one Center decided not to apply after the initial funding period. The biggest concern cited by the Center Directors was the change in the funding of the Udall Centers Program from an RFA to a PAR.

<sup>12</sup> A PAR is a Program Announcement with special receipt, referral and/or review considerations.

### 3.4.5 Study Question 2.6 – In what ways could the administration of the Udall Centers Program be improved for the future?

#### 3.4.5.1 Approach

In exploring how NINDS could improve the administration of the Udall Centers for the future, the study team relied on interview responses from Center Directors and Project/Core Leads. Similar to study question 1.3, the study team posed a series of questions to the Investigators about their interactions with NINDS program staff during three stages – the pre-award phase, the application review process, and the post-award time period. The study team also asked Center Directors and Project/Core Leads to recommend how the NINDS Program Staff could improve the assistance it provides to applicants. Finally, the study team interviewed NINDS Staff to further elucidate past concerns and ways in which they would like to see the program continue to develop.

Data Sources and Questions for Research Question 2.6	
Data Source	Questions
NINDS Staff	<ul style="list-style-type: none"> <li>Discussions with staff</li> </ul>
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>Could NINDS staff improve the assistance it provides to applicants during the pre-award period? If so, in what ways?</li> <li>Could NINDS staff improve the assistance it provides to applicants during the application review process? If so, in what ways?</li> <li>Could any of the post-award assistance from NINDS listed above be improved? If so, which and in what ways?</li> </ul>

#### 3.4.5.2 Results

##### The Pre-Award Timeframe

Only four of 24 Udall Center Investigators reported that NINDS Program Staff could improve the assistance it provides to applicants during the pre-award timeframe (see Exhibit 25).

Exhibit 25. Improving NINDS Assistance During the Pre-Award Timeframe

Could NINDS staff improve the assistance it provides to applicants during the pre-award period?	Center Directors	Project/Core Leads	Total
Yes	1	3	4
No	5	15	20

*\*Interviewees who provided a response of "not applicable" were removed from the analysis.*

Of the Udall Center Directors and Project/Core Leads who felt they had sufficient interaction with NINDS Staff during the pre-award timeframe to comment further, Investigators from four Centers all spoke to the helpfulness and professionalism of the NINDS Staff and had no recommendations for improvement.

For those who responded that NINDS Staff could improve the assistance it provides to applicants during the pre-award period, their advice centered on how to help researchers who are new to the process. The respondents indicated that the more experienced researchers have a good

understanding of what the reviewers are looking for, but proposed having a pre-application meeting and offering more discussion for the newer researchers. One Center Director suggested it would be beneficial to list the necessary components for a successful application.

### Application Review Process

While most of the Udall Investigators did not contact NINDS Staff during the application period, and therefore could not comment on how assistance during this time period could be improved, those Investigators who did felt they received good advice. One theme emerged from the Center Directors and Project/Core Leads who felt the NINDS Program Staff could improve the assistance it provides to applicants during the application process (see Exhibit 26). The most frequent suggestion involved how to improve the interaction between reviewers and applicants. The Udall Center Investigators believed that NINDS could facilitate this in a number of ways:

- Resolve the discrepancy between what the guidelines in the RFA state and what the reviewers rank as important by:
  1. Making more information available to the applicants about how the review will be conducted
  2. Offering the same guidance to applicants and reviewers so that they approach the Center Grant from the same perspective.
- Establish means of communication, both before and during the review process, for applicants to answer reviewers’ questions. Suggestions included:
  1. Utilizing site visits or reverse site visits
  2. Creating an opportunity for reviewers and applicants to meet in person to talk through issues.

Exhibit 26. Improving NINDS Assistance During the Application Process

Could NINDS staff improve the assistance it provides to applicants during the application process?	Center Directors	Project/Core Leads	Total
Yes	1	3	4
No	5	24	29

*\*Interviewees who provided a response of “not applicable” were removed from the analysis.*

While some Udall Investigators indicated that the feedback they received from NINDS Staff during the application process was excellent, those who spoke to the issue of the review process felt strongly that NINDS needed to address the quality and balance of the reviewers. As one Project/Core Lead commented, having an opportunity to communicate with reviewers – before and during the review process – is essential to avoid misunderstandings.

Several interviewees from a single Center responded that the review process during the renewal phase of the Udall Center grants seemed to have more problems and that, during this second competitive cycle, the peer reviewers themselves did not seem as collectively balanced (in terms of range of expertise) as in the initial review in 1998/1999.

### Post-Award Period

As to whether or not NINDS Staff could improve the assistance it provides to applicants during the post-award period, only two out of 24 Udall Center Investigators believed that opportunities for improvement exist (see Exhibit 27). Again, most comments highlighted NINDS Staff’s helpfulness and responsiveness during the post-award time period. However, two suggestions emerged from the Center Directors and Project/Core Leads: 1) that NINDS provide earlier notice for the annual meeting dates to avoid scheduling conflicts so that more researchers can attend; 2) that NINDS change the administration of the Udall Center grants so that the Center Directors have expanded authority to administer the funds throughout the five years of the grant. As one Center Director noted, without expanded authority, this meant that all of the Center’s money had to be spent by end of the year – which posed a difficulty. With expanded authority, the Center Director explained, there would be less trouble in the context of the program on a yearly basis.

Exhibit 27. Improving NINDS Assistance During the Post-Award Period

Could NINDS staff improve the assistance it provides to applicants during the post-award period?	Center Directors	Project/Core Leads	Total
Yes	2	0	2
No	5	17	22

*\*Interviewees who provided a response of “not applicable” were removed from the analysis.*

In addition, two Center Directors suggested that NINDS create either a full-time or part-time Udall Center manager, within the NINDS Program Staff, who would be responsible for staying current with the Udall Centers’ research. This staff member would be a proactive participant in the administration of the Udall Centers Program, suggesting collaborations between Centers, recognizing opportunities for supplemental funding, and maintaining constant interaction with Center Directors and Project/Core Leads.

### Summary: Suggestions for Improvement

Most Center Directors and Project/Core Leads felt that the NINDS Staff had done an excellent job administering the Udall Centers Program. However, they provided a few suggestions for improvement (see Exhibit 28).

Exhibit 28. Suggestions for Improving the Administration of the Udall Centers Program

Interview Results: Center Directors and Project/Core Leads
<ul style="list-style-type: none"> <li>• Offer more guidance to new investigators (e.g., develop a pre-application meeting) (4)</li> <li>• Create a list of what criteria are absolutely necessary and share this with the reviewers for guidance (2)</li> <li>• Increase interaction between reviewers and applicants prior to the award of grants (2)</li> <li>• Establish review committees that are better balanced in terms of expertise and understanding (2)</li> <li>• Provide earlier notice for the date of the annual meeting (2)</li> <li>• Create a position within NINDS staff for a full-time Udall Center manager (2)</li> <li>• Change the administration of the grants so that Center Directors have expanded authority. (1)</li> </ul>

## **NINDS Staff**

The pressure to meet the needs of all interested parties, including Congress, advocacy groups, and PD research scientists, emerged as the most common theme from the interviews with NINDS Program Staff. One staff member remarked that managing these different expectations is sometimes more challenging than the science itself. But, understanding that the program operates under these conditions, most Staff members felt that the Udall Centers are a success and are the “feather in the cap” of both the research scientists and the PD community alike. That said, the staff members did see areas for improvement.

### *Review Committees*

As with the Center Directors and Project/Core Leads, several NINDS Staff members indicated that the review process could be improved. According to NINDS Staff, the reviewers looked for the applications to meet the criteria presented in the RFA, while simultaneously emphasizing collaboration methods, communications, and the quality of the science, laboratories, and Investigators. But one NINDS staff member felt as though the reviewers did not understand the overall vision of the program – a sentiment echoed by Center Directors and Project/Core Leads.

One of the major challenges to NINDS Program Staff has been establishing a review committee that has the necessary expertise and understanding of PD research and the Udall Centers’ mission to accurately understand and review the applications. Conflicts of interest have arisen from including Udall Center researchers on the review panels. But as one staff member pointed out, the small size of the PD community makes it difficult to avoid such situations. However, in an effort to minimize this, NINDS staff turned to members of the Alzheimer’s disease community to serve on the review panels. Several of the NINDS staff members recognized the need for continuing to improve the quality of the review committees and the Program Staff’s role in educating the reviewers on the Udall Centers Program’s purpose and goals, however they did not provide any specific recommendations.

### *Changing from an RFA to a PAR*

The recent change from an RFA to a PAR (outside the scope of the evaluation) and the resulting impact on the Udall Centers’ research efforts posed another major challenge to NINDS Program Staff. According to one Staff member, the decision to change to a PAR in 2003 meant new flexibility in terms of the administration of the programs, but less certainty for the already established Udall Centers applying for renewal. Because a PAR does not guarantee that any applications will be funded (whereas with an RFA, the funding has already been set aside and thus a certain number can be awarded), one NINDS Staff member believed the PD community saw this as a sign that NINDS was no longer as strongly committed to PD research. This, coupled with a change in research focus, led Center Directors to see the renewal period as highly unsettling, according to one staff member.

Several NINDS Staff members commented that the key to continuing to strengthen PD research lies in a steady dedication of funds to the Udall Centers. One Staff member commented that, if funding was not limited, he/she would provide further support for data sharing, student exchange programs, and developing young Investigators.

### **3.4.5.3 Summary**

In summary, while Center Directors, Project/Core Leads, and NINDS Program Staff generally expressed satisfaction with the application, review, and award phase processes, they also offered suggestions for improving the administration of the Udall Centers. Some suggestions centered on developing greater communication and information sharing so as to provide the Center Directors and Project/Core Leads with a clearer understanding of the expectations, including the selection criteria. Investigators also raised concerns about the balance, in terms of expertise and understanding, of the review panel and, from the NINDS Staff perspective, the challenge of including the right reviewers. Overall, the feedback was reasonably consistent between the Investigators and the NINDS Program Staff, suggesting that concerns were vocalized and heard.

### 3.5 Study Question 3

What were the baseline characteristics of the individual Udall Centers prior to the start of the program (FY 1996 – 1997) in each of the following areas:

- Overall research experience of the institution, Center Director, and Project/Core Directors
- Previous PD research experience of the institution, Center Director, and Project/Core Directors
- Center Director's previous experience leading multidisciplinary research teams
- PD research areas to be pursued
- Breadth of the Center's organizational structure, and whether it includes basic, translational, or clinical research

#### 3.5.1 Study Question 3.1 – Overall research experience of the institution, Center Director, and Project/Core Directors

##### 3.5.1.1 Approach

The study team used awarded NIH grants (e.g., funding received) as the measure by which to determine the overall research experience for the institution, Center Directors, and Project/Core Leads. Using the NIH IMPAC II database<sup>13</sup>, the study team retrieved grant information for the Udall Investigators (i.e., the individual listed as the Principal Investigator on the grant) by reviewing person histories. The Center Directors and Project/Core Leads who participated in the web-based survey and/or interview received a copy of their individual grant histories so that they could make any necessary corrections or additions. Though the study team only asked Udall Investigators to review three fiscal years of their grant histories, the team later determined a need to include two additional fiscal years of grant history to achieve a more robust analysis. For institution funding, the study team used public data provided by the NIH.<sup>14</sup> Funding received for research grants, training grants, fellowships, research and development contracts, and other activities was included in the total amount. The data presented for this study question are available to the public; therefore, the institution name is not concealed.

##### Data Sources for Research Question 3.1

- IMPAC II
- NIH Office of Extramural Research award data (<http://grants1.nih.gov/grants/award/awardtr.htm>)

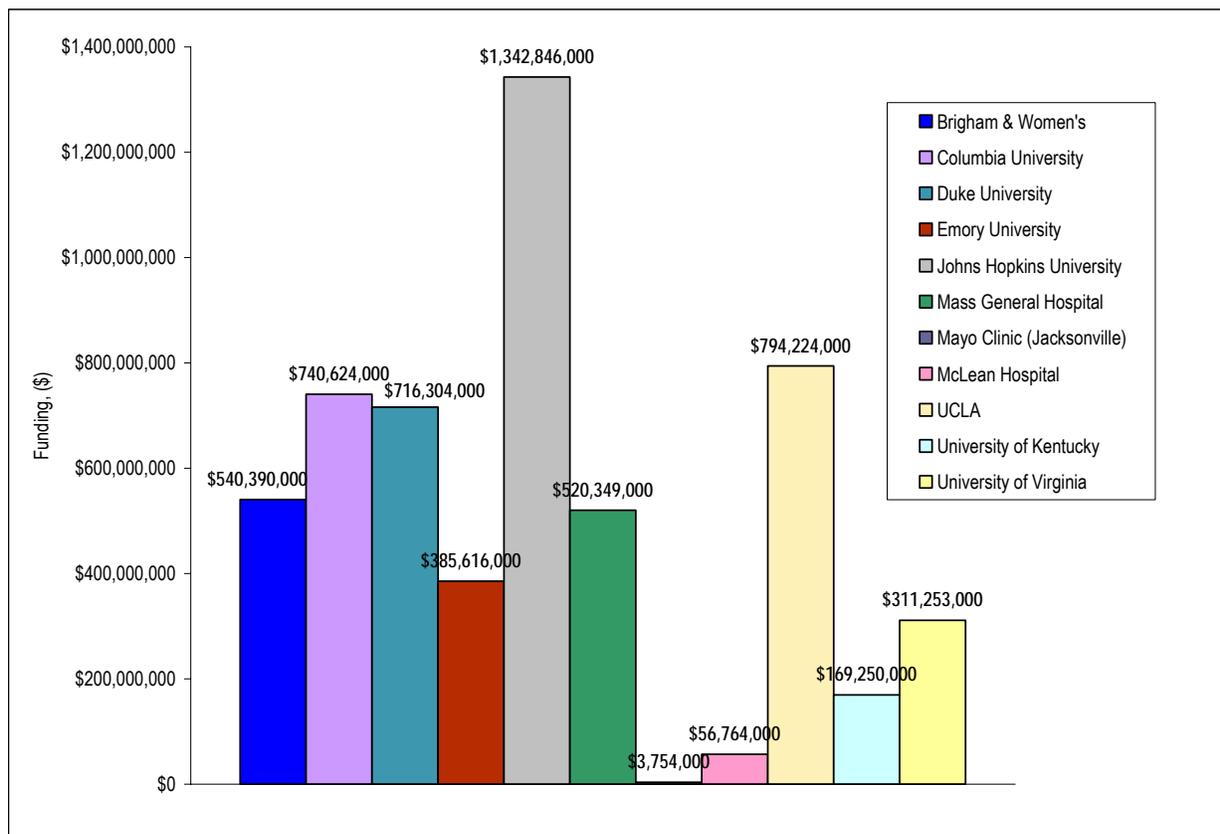
##### 3.5.1.2 Results

The study team collected NIH funding data for each institution for the five fiscal years prior to the institution becoming a Udall Center (see Exhibit 29). For three of the Centers, the data collected were from FY93 through FY97, while the remaining eight Centers' data were collected from FY94 through FY98. The institutions received, on average, \$507 million over the five fiscal years prior to becoming Udall Centers. The median amount was \$520 million. These funding totals include both direct and indirect costs.

<sup>13</sup> IMPAC II database accessed in December 2006 for the data presented in this study question

<sup>14</sup> <http://grants1.nih.gov/grants/award/awardtr.htm> accessed March and April 2007.

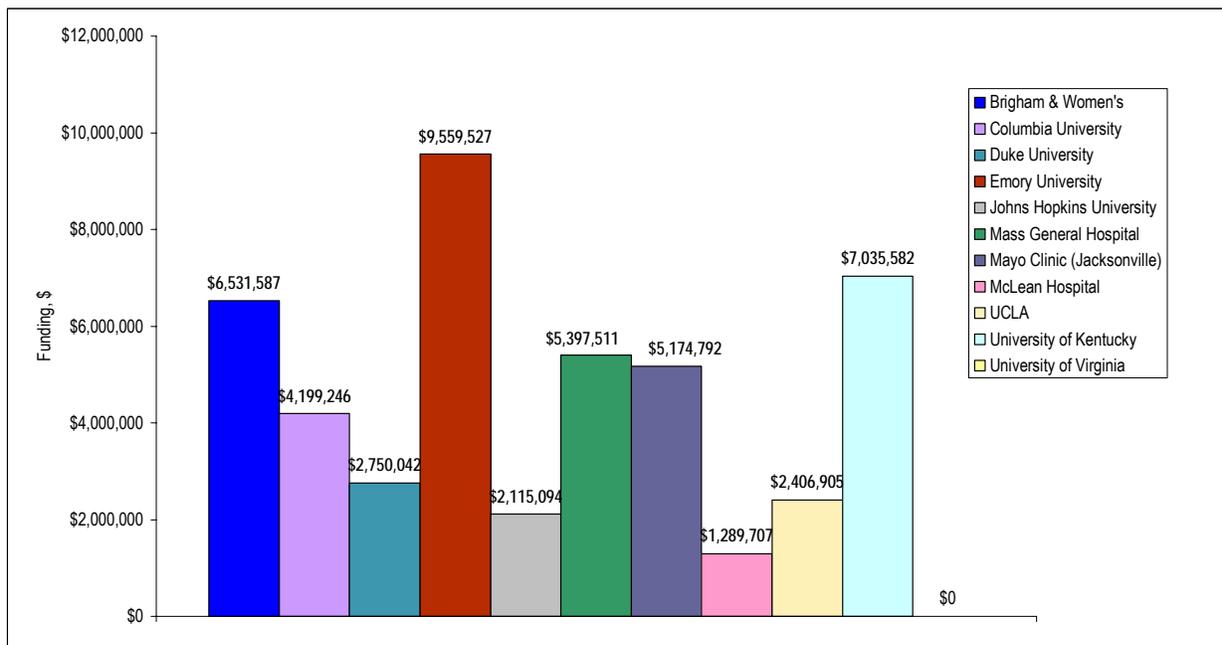
Exhibit 29. Total NIH Funding, By Institution,<sup>15</sup> Over the Five Fiscal Years Prior To Becoming a Udall Center



On average, the Center Directors received \$4.2 million over the five fiscal years prior to becoming Udall Center Directors (see Exhibit 30). The median amount was also \$4.2 million. Again, these amounts include direct and indirect costs. Note that Center Directors may not have been part of the Udall Center Institution when they received prior NIH funding; therefore it cannot be assumed that the Center Director's funding is part of the Udall Centers' Institutions' funding.

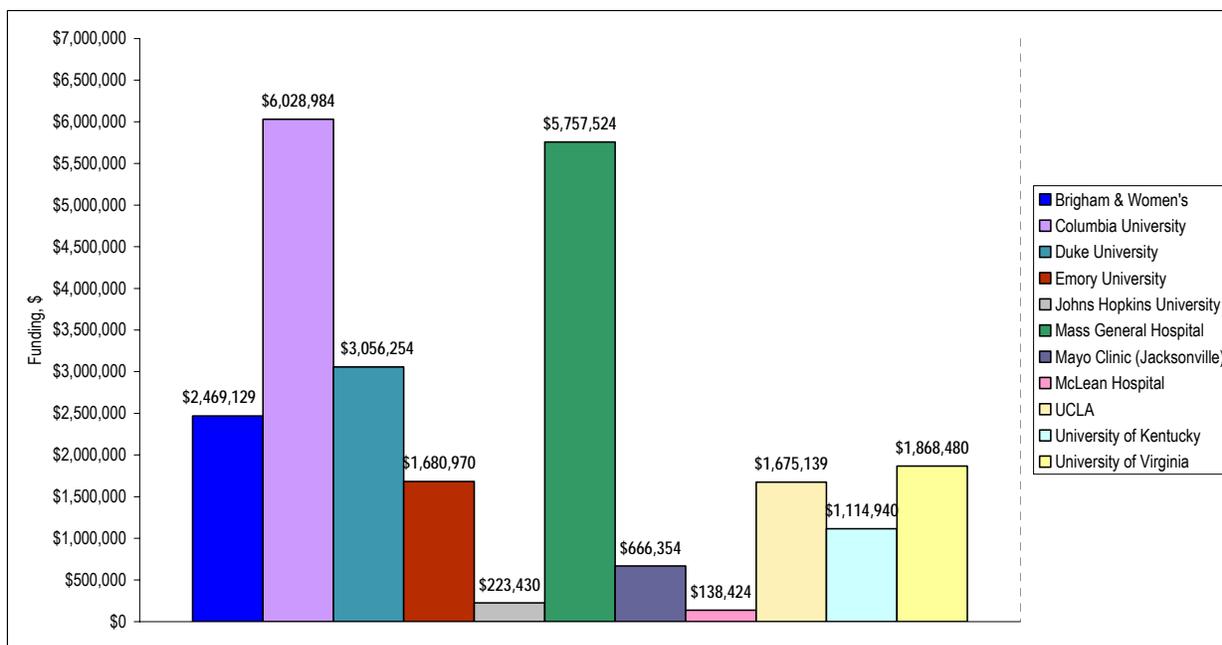
<sup>15</sup> For Mass General Hospital (MGH) only funding for this institution was included – MIT was not included. For McLean Hospital, only funding for this institution was included – Harvard was not included.

Exhibit 30. Total NIH Funding, by Center Directors, Over the Five Fiscal Years Prior to Receiving Udall Center Funding



Since the number of Project/Core Leads varies by Center, the study team calculated a research funding average for these investigators by Center (see Exhibit 31). The average funding received by Project/Core Leads for all Centers is \$2.2 million, and the median amount was \$1.7 million. These funding totals include direct and indirect costs.

Exhibit 31. Average NIH Funding, by Project/Core Leads, Over the Five Fiscal Years Prior to Udall Center Funding



### 3.5.1.3 Summary

In the five years prior to receiving Udall Center funding, institutions varied in their NIH grant experiences. Johns Hopkins University received the most NIH funding, almost \$1.4 billion, for the five years prior to becoming a Udall Center, while McLean Hospital received \$3.7 million. One Center Director was not listed as a Principal Investigator for any NIH funding for the five years prior to becoming the Director of the Udall Center, whereas the Director from Emory University was the Principal Investigator for grants totaling over \$9.5 million in NIH funding. The Project/Core Leads from Columbia University and Mass General Hospital averaged over \$5.7 million in NIH funding during the five years prior to their roles in the Udall Centers. These Centers had the most NIH funding of all 11 Centers.

## 3.5.2 Study Question 3.2 – Previous PD research experience of the institution, Center Director, and Project/Core Directors

### 3.5.2.1 Approach

To measure overall PD research experience of the institution, Center Directors, and Project/Core Leads, the study team analyzed awarded NIH grants (e.g., funding received) containing the key term “Parkinson” in the grant abstract.<sup>16</sup> Each Center Director and Project/Core Lead who participated in the web-based survey and/or interview received a copy of his or her grant history to review. The study team asked the participants to indicate the grants that were related to PD research. Again, though the study team only asked Udall Investigators to review three fiscal years of their grant histories, the team later determined a need to include two additional fiscal years of grant history to achieve a more robust analysis. Note that, due to omissions in the NIH IMPAC II<sup>17</sup> database, data for 1996 were not available. Therefore, this analysis only includes four fiscal years of data.<sup>18</sup>

Data Sources for  
Research Question 3.2

- IMPAC II QVR

### 3.5.2.2 Results

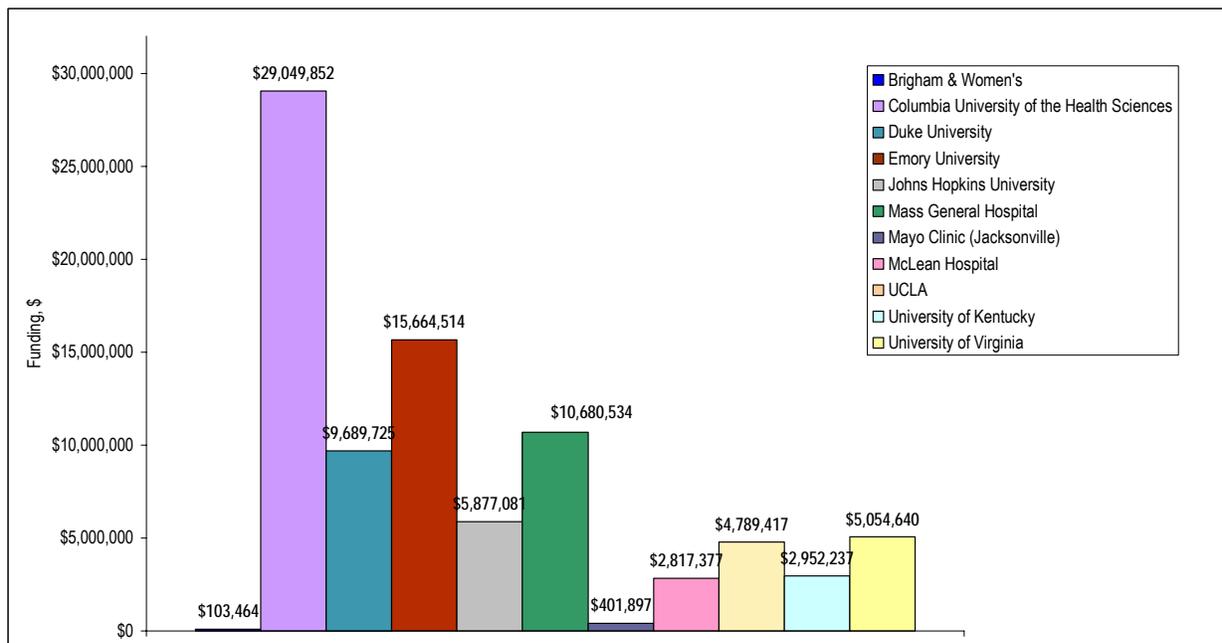
Over the four fiscal years prior to the receipt of Udall Center grant funding, the institutions on average received \$7.9 million in NIH funding for PD research (Exhibit 32). The median amount was \$5.1 million. These funding totals include direct and indirect costs.

<sup>16</sup> For Center Directors and Project/Core Leads, the individuals were the Principal Investigators for the grants analyzed.

<sup>17</sup> IMPAC II database accessed in December 2006 for the data presented in this study question.

<sup>18</sup> For the institutions funded by the 1997 RFA, FY 1993, 1994, 1995, and 1997 were included; for the institutions funded by the 1998 RFA, FY 1994, 1995, 1997 and 1998 were included.

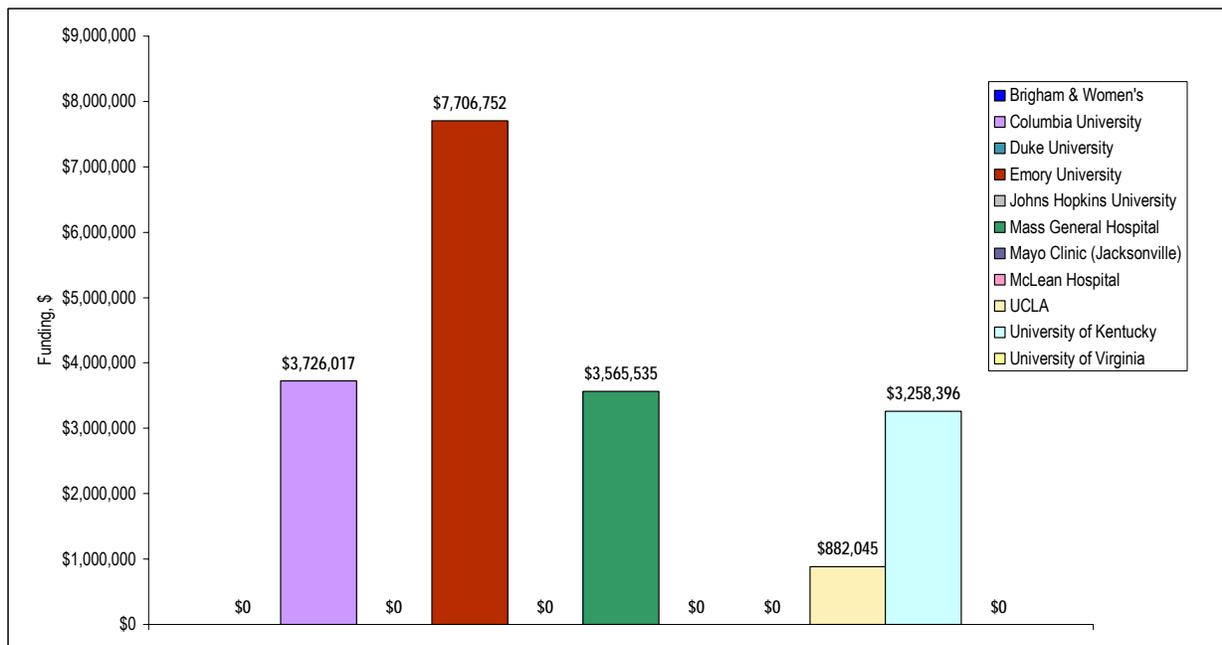
Exhibit 32. NIH Funding Received, by Institution<sup>19</sup>, for PD Research Prior to Receiving Udall Center Funding



On average, Center Directors received \$1.7 million in NIH funding for PD research in the four fiscal years prior to assuming their positions as Udall Center Directors (Exhibit 33). These amounts included direct and indirect costs. If the six Center Directors with no prior PD research experience (i.e., \$0 in funding) are removed from the calculation, the average PD research funding received increases to \$3.9 million. While the six Center Directors with no prior PD funding were not listed as Principal Investigators on NIH grants during the four fiscal years prior to their position as Center Director, this does not imply that the Center Directors did not otherwise engage in research relevant to PD or other neurodegenerative disorders. Furthermore, the scope of this analysis is limited to four fiscal years prior to Udall Center funding; Udall Center Directors may have received funding for PD research, and established themselves in the field, in earlier years as well.

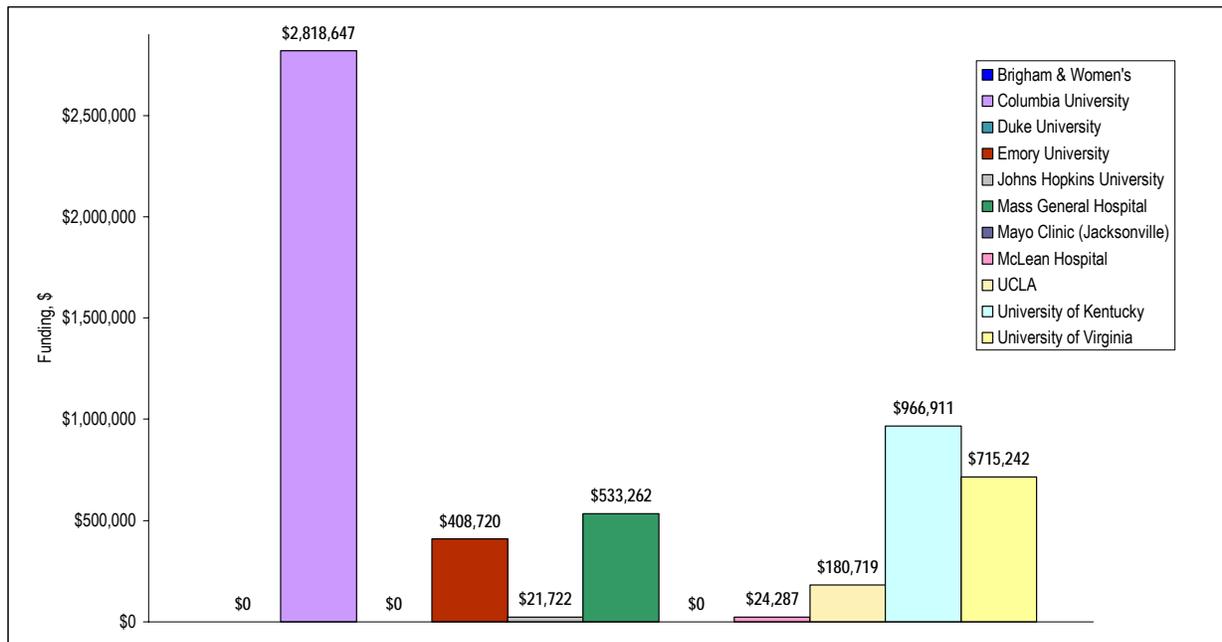
<sup>19</sup> Note that for institute PD research funding, the amount listed is the amount received by Columbia University of the Health Sciences (noted as the awarded institution in IMPAC II) – not all of Columbia University.

Exhibit 33. NIH Funding, by Center Directors, for PD Research Prior to Receiving Udall Center Funding



The study team averaged the amount of funding received by Project/Core Leads for each Center to account for the variability in the number of Project/Core Leads from Center to Center. For the four fiscal years prior to being part of a Udall Center, the Project/Core Leads received an average of approximately \$515,000 in NIH PD research funding (Exhibit 34). These amounts include direct and indirect costs. Note that three Centers' Project/Core Leads with no prior PD research funding were not listed as Principal Investigators on NIH grants for PD research for the years specified. By removing these three Centers from the average calculation, the average NIH PD research funding for Project/Core Leads increases to approximately \$709,000.

Exhibit 34. Average Amount of NIH PD Research Funding Received by Project/Core Leads Prior to Receiving Udall Center Funding



### 3.5.2.3 Summary

In the four fiscal years prior to receiving Udall Center funding, institutions varied in their NIH-grant experiences in PD research. Columbia University of the Health Sciences received the most NIH funding for PD research, at over \$29 million, while Brigham and Women’s Hospital received \$103,464. Six Center Directors were not listed as Principal Investigators for NIH funding in PD research for the four years prior to becoming the Director of the Udall Center, whereas the Director from Emory University received over \$7.7 million in NIH funding. The Project/Core Leads from Columbia University averaged over \$2.8 million in NIH funding for PD research during the four years prior to their roles in the Udall Centers. They had the most NIH funding for PD research of all Project/Core Leads at the 11 Centers.

### 3.5.3 Study Question 3.3 – Center Director’s previous experience leading multidisciplinary teams?

#### 3.5.3.1 Approach

To measure whether the Udall Center Directors had experience leading multidisciplinary research teams, the study team searched the grant histories of the original Center Directors for grants with activity codes that pertained to multidisciplinary research (see Appendix G for the definition of multidisciplinary). Three Centers experienced a change in directorship during the first five years of the program, but the study team included only the original directors in the analysis. The study team generated the list of relevant activity codes from a June 2004 IMPAC publication, *Activity Codes, Organization Codes, and Definitions Used in Extramural*

*Programs*,<sup>20</sup> and a keyword search for the term “multidisciplinary.” Exhibit 35 details the activity codes that contained the term multidisciplinary in their description.<sup>21</sup>

Exhibit 35. NIH Grant Activity Codes That Contain the Term “Multidisciplinary”

Activity Code	Name*
K 07	Academic/Teacher Award (ATA)
P 01	Research Program Project
P 30	Center Core Grant
P 50	Specialized Center
P 51	Primate Research Center Grant (NCRR)
T 90	Interdisciplinary Research Training Award
U 19	Research Program – Cooperative Agreement
U 54	Specialized Center – Cooperative Agreement

\*An official description of each activity can be found in Appendix H.

To establish the Center Directors’ previous experience with multidisciplinary teams, the study team limited each Director’s grant history to the five fiscal years prior to the Director’s receipt of the Udall Center grant. Each funded year of the same grant number was counted as an individual grant. In this section, data are presented by Center for both the number of grants received from NIH and the total amount of funding received, stratified by activity codes. The data presented for this study question are available to the public; therefore, the institution name is not concealed.

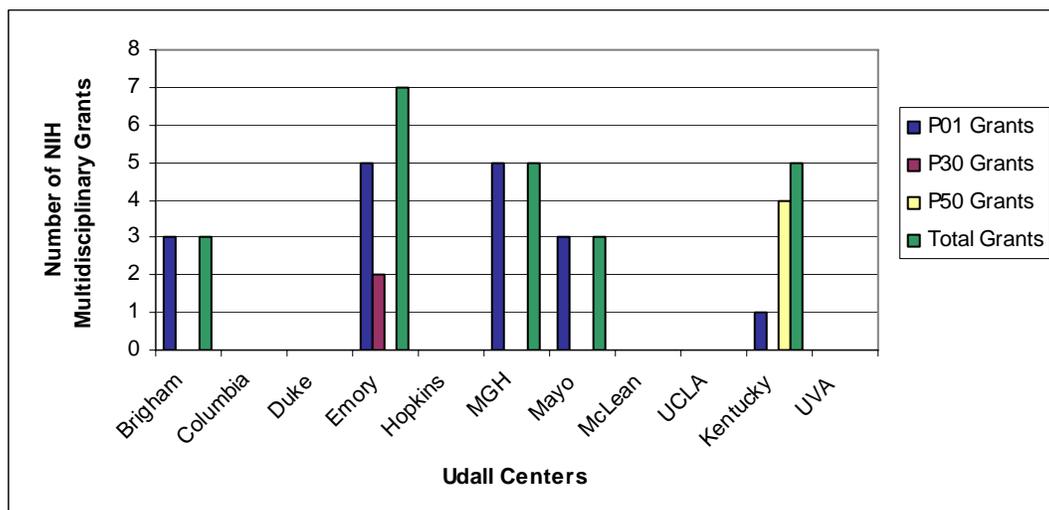
### 3.5.3.2 Results

Five of the 11 original Center Directors (46 percent) had experience leading a multidisciplinary team in the five years prior to receiving the Udall Center grant (see Exhibit 36). These five Center Directors had all received at least one P01 grant. Additionally, one Center Director had received two P30 grants and another Center Director had obtained four P50 grants before the award of the Udall Center grant. The Director of the Emory Udall Center had the most grants for multidisciplinary research, with seven grants between FY93 and FY98.

<sup>20</sup> Activity Codes, Organization Codes, and Definitions Used in Extramural Programs. IMPAC. Planning, Communications & Outreach Branch, Division of Extramural Information Systems, Office of Policy for Extramural Research Administration, Office of Extramural Research, Office of the Director, National Institutes of Health. June 2004.

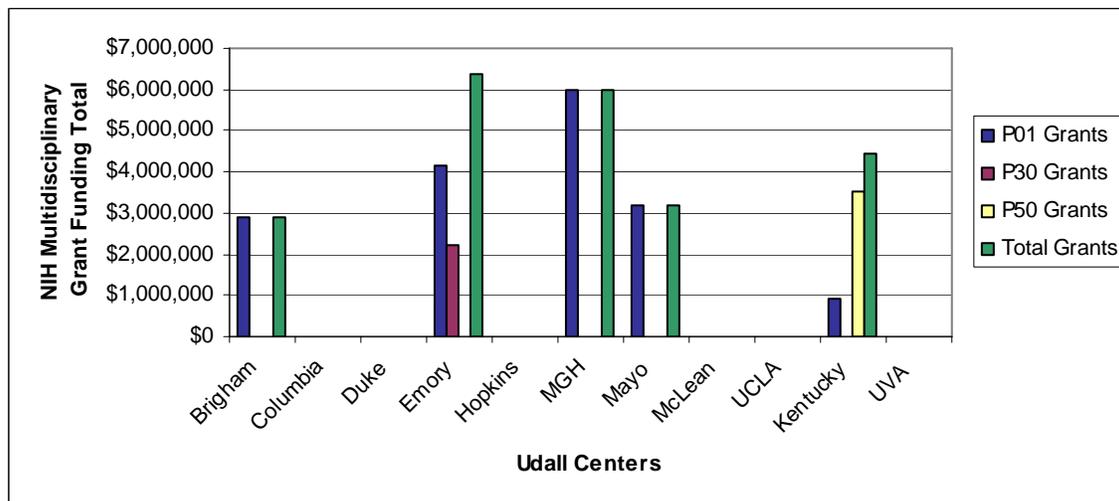
<sup>21</sup> Note that even though “multidisciplinary” is listed in the activity code description, does not imply that individual grant awards were automatically multidisciplinary, and grants awarded under other activity codes not listed in the exhibit may have been multidisciplinary.

Exhibit 36. Number of Multidisciplinary Grants Received by Udall Center Directors



The total multidisciplinary grant funding the Center Directors obtained in the five fiscal years prior to the start of the their individual Udall Centers mirrors the number of grants each Center Director received during that same time period (see Exhibit 37). The Director of the Emory Udall Center – who had the highest number of grants – was awarded \$6,393,360 in multidisciplinary grant funds between FY93 and FY98. Among the five Center Directors with previous multidisciplinary grant funding from the NIH, \$22.9 million was obtained for these research efforts.

Exhibit 37. Total NIH Multidisciplinary Grant Funds Received by Udall Center Directors



### 3.5.3.3 Summary

Using the activity codes that state multidisciplinary as the criteria, the study found that the majority of Udall Center Directors did not have experience leading a multidisciplinary research

team during the five years prior to the Udall Center grant award. However, five Udall Center Directors did have strong histories of involvement in this type of research.

### 3.5.4 Study Question 3.4 – PD research areas to be pursued

#### 3.5.4.1 Approach

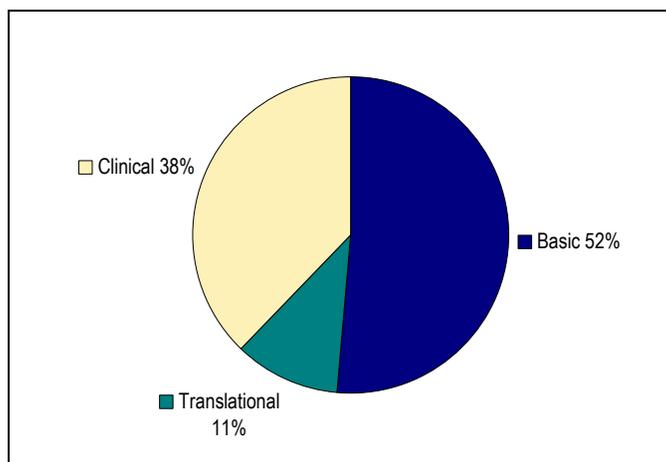
By examining the summary statements from the original Udall Center grant applications, the study team assigned each sub-project on the Center grant with either a basic, translational, or clinical research classification (see Appendix G for definitions). When sub-projects had several objectives, the study team assigned each objective with a basic, translational, or clinical classification, depending on its focus. The analysis included individual cores identified in the Center applications, unless the core was dedicated entirely to administrative purposes.

Data Sources for Research Question 3.4	
•	Summary Statements

#### 3.5.4.2 Results

The study team designated each Udall Center sub-project as basic, translational, or clinical, based on the nature of the research proposed in the grant. An examination of the distribution of project types at each Center revealed that the majority of the work conducted across Centers addressed basic science, with an average of three projects per Center (see Exhibit 38). The remaining projects were either translational (one per Center) or clinical (two per Center). For a complete breakdown of the distribution per Center, see Appendix I.

Exhibit 38. Average Percentage of Research Type for Proposed Projects



The Udall Center grant applications covered a range of PD research that represented all phases of Parkinson’s disease progression, including studies on:

- Likely causes of PD ( $\alpha$ -synuclein, parkin, genetic mapping and linkage, and PD gene expression)
- Contributions to neural degeneration (mechanisms, novel models of PD, and neuropathology)

- Dopamine and other neurotransmitter dysfunction (basal ganglia receptor studies, dopamine, glutamate, and GABA studies)
- Clinical studies (functional imaging, stimulation studies, and behavioral analysis)
- Potential preventative therapies for PD (degeneration prevention and oxidative stress reduction).

An examination of the proposed sub-projects revealed that the projects most frequently focused on the study of  $\alpha$ -synuclein, with 10 sub-projects across the Udall Centers (16 percent) (see Appendix I). This included the generation of novel animal models and cell lines to study  $\alpha$ -synuclein-induced dysfunction and neural degeneration, as well as protein-protein interactions. The remainder of the sub-projects dealt with mechanisms of neurodegeneration (7 projects, 11 percent), genetic linkage studies (7 projects, 11 percent), novel models of PD (6 projects, 10 percent), and neuropathology (5 projects, 8 percent).

### 3.5.4.3 Summary

The most common proposed research area pursued by the Udall Centers' sub-projects was the study of basic mechanisms of PD, with the emphasis on the role of  $\alpha$ -synuclein in PD. A small portion (less than one project per Center) of research focused on translational research. Clinical research emerged as the second largest area of focus, with the majority of sub-projects addressing human genetic linkage studies and the neuropathology of PD brains.

## 3.5.5 Study Question 3.5 – Breadth of the Center's organizational structure, and whether it includes basic, translational, or clinical research

### 3.5.5.1 Approach

To evaluate the organizational structure of the Investigators' institutions prior to becoming Udall Centers, the study team interviewed Center Directors about their prior team, group, or center structure for conducting PD research. In addition, the study team inquired about whether the organizational structure changed after becoming a Udall Center, and, if so, how the Center changed.

Data Sources and Questions for Research Question 3.5	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>• Prior to becoming a Udall Center, did you have an established structure (e.g., team, group, Center) for conducting: <ul style="list-style-type: none"> <li>– PD research?</li> <li>– Other research?</li> <li>– Both PD and other research?</li> </ul> </li> <li>• Please estimate the number and type as related to basic, translational, and clinical research. Did any of this research involve multidisciplinary research teams?</li> </ul>

### 3.5.5.2 Results

Center Directors indicated that, prior to becoming Udall Centers, their groups' structure for conducting PD research was established in a variety of ways. Some groups had a defined structure, with PD researchers working toward common objectives and with sharing mechanisms in place (e.g., journal clubs). Some groups formed a loose structure as a collection of labs, but without integration mechanisms. Other groups did not organize around PD, in particular, but rather were part of a broader neurological disease center. After becoming Udall Centers, a

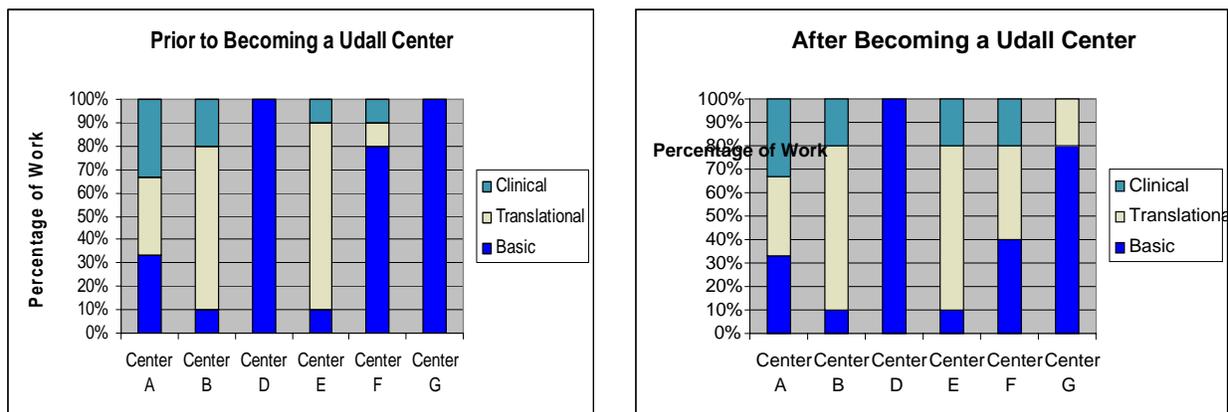
number of the groups formalized and/or expanded their organizational structures and established more formal mechanisms for coordination, such as internal meetings (see Exhibit 39).

Exhibit 39. Organizational Structure for Conducting PD Research

Interview Results: Center Directors	
Before Becoming a Udall Center	After Becoming a Udall Center
<ul style="list-style-type: none"> <li>• Had structured, collaborative working relationship with researchers of similar interest (5)</li> <li>• Had an informal structure; existed as loose “water cooler” discussions of science (4)</li> <li>• Existed as another type of neurological disease Center (4)</li> <li>• Held Journal Clubs on neurological disease (3)</li> <li>• Maintained a collection of individual labs (3)</li> <li>• Maintained a geographically localized network for close lab-to-lab communication (2)</li> <li>• Had clinics, clinical research, and basic research labs (1)</li> <li>• Operated independently without any real collaboration (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Became more structured: for example, implemented internal meetings with data presentations (4)</li> <li>• Expanded structure to become broader (4)</li> <li>• Solidified the existing structure (3)</li> <li>• Brought together PD researchers at the institution (3)</li> <li>• Brought us into the PD arena (3)</li> <li>• Established a formal structure for PD research (2)</li> <li>• Did not define our structure in terms of the Udall Center; did not want to be exclusionary to researchers outside the Udall Center (1)</li> <li>• Expanded established structure to include PD research (1)</li> <li>• Implemented data presentation meetings with non-Udall researchers (1)</li> </ul>

In interviews, the study team asked Center Directors to estimate the percentage of their Centers’ research that was basic, translational, and clinical before and after becoming a Udall Center. As shown in Exhibit 40, both before and after becoming a Udall Center, the Investigators dedicated the greatest percentage of effort to basic research, followed by translational, and lastly, clinical. Three out of six of the Centers reported no change in the distribution of their research from before to after they became a Udall Center. For the three Centers that did experience a change, two reported an increase in the percentage of their translational work, and one reported a decrease in their translational work but an increase in their clinical research.

Exhibit 40. Research Categorization Before and After Becoming a Udall Center



Note: Data are presented for those Centers for which both before and after data were available.

Ten of the 11 interviewed Center Directors reported that at least some of their group’s research, prior to becoming a Udall Center, involved multidisciplinary research teams. As displayed in Exhibit 41, after becoming a Udall Center, the majority of Center Directors reported maintaining the same levels or achieving greater levels of multidisciplinary research.

Exhibit 41. Degree to Which Research was Multidisciplinary After Becoming a Udall Center

INTERVIEW RESULTS: Center Directors
<ul style="list-style-type: none"> <li>• Increased our multidisciplinary teams (3)</li> <li>• Maintained same level as before (2)</li> <li>• Became less multidisciplinary due to funding cap (1)</li> <li>• Adopted a broader approach now focused on PD therapy (1)</li> <li>• Became more [cohesive] (1)</li> <li>• Improved collaboration with outside researchers (1)</li> </ul>

### 3.5.5.3 Summary

While a number of the Udall Centers had a variety of organizational structures in place prior to becoming Udall Centers, most established more formal structures after becoming Udall Centers. Regarding the type of work, Centers either experienced no change or an increase in the percentage of their translational or clinical work. Nearly all Centers maintained the same high levels, or higher, of multidisciplinary research. These findings show that some fundamental shifts did occur by virtue of becoming Udall Centers.

### 3.6 Study Question 4

To what extent did the individual Udall Centers implement the activities recommended by NINDS during their first five years?

#### 3.6.1 Study Question 4.1 – Offering research training relevant to PD

##### 3.6.1.1 Approach

To gauge the PD research training opportunities the Udall Centers offered, the study team relied on the Centers’ annual progress reports and questions from the interview process. From the progress reports, the study team gathered evidence on the development of training cores and the numbers and types of research trainees.<sup>22</sup> Additionally, the progress reports for several of the Centers highlighted efforts to reach out and involve the trainees in PD research. The interviews with the Center Directors and the Project/Core Leads provided

Data Sources and Questions for Research Question 4.1	
Data Source	Questions
Progress Reports	N/A
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>Did the Udall infrastructure have an impact on the number/types of research training opportunities (e.g., courses, workshops, seminars, journal clubs, mentoring) your Center was able to offer during its first 5 years? Please describe.</li> </ul>

opportunities to learn more about the nature of their engagement with the trainees at each Center. Areas of emphasis included journal clubs, mentoring activities, seminars, workshops, and relevant courses. The study team also encouraged Center Directors and Project/Core Leads to provide their own examples during the interview.

##### 3.6.1.2 Results

Six of the 11 Udall Centers developed a training core as part of their original application for the Udall Centers Program grant (see Exhibit 42). Of these six, four received funding for the cores and two did not. While the presence of a training core demonstrates a level of dedication to attracting younger scientists to PD-relevant research, it does not necessarily correlate with the strength or breadth of the training opportunities at the Udall Center.

Exhibit 42. Requests for and Receipt of Udall Center Training Cores

Did the researchers request a training core to be part of the Center?	# of Centers
Requested training core in original application and received funding for the core	4
Requested training core in original application but did not receive funding for the core	2
Did not request training core in original application	5

<sup>22</sup> Research trainees include fellows, post-doctoral trainees, graduate students, undergraduate students, and other students as relevant.

### Udall Center Research Trainees: Center Program Development

During the interviews, the study team asked Udall Center Directors and Project/Core Leads to comment on the numbers and types of training opportunities their Centers were able to offer during the first five years of the program. The study team encouraged interview participants to elaborate on courses, workshops, seminars, journal clubs, and mentoring opportunities developed as a result of the Udall Center infrastructure.

Exhibit 43. Research Trainees Program Development: Major Themes

What program developments did the Udall Center structure allow your Center to create for research trainees?	# of Centers
Increased the number of seminars, journal clubs, and brainstorming workshops	10
Increased the number of post-doctoral trainees for basic and clinical research	8
Increased mentoring opportunities	7
Increased training opportunities for students	7
Enabled young scientists to start and develop their careers in PD research	4
Increased overall collaboration	3
Enabled young scientists to participate in PD meetings	2

With the exception of two Project/Core Leads – one from Center C and one from Center K – all interview participants felt that the Udall Center structure had enhanced the opportunities for research trainees at their respective Centers. The Center Directors from Centers D and G both indicated that the recognition that came from being a Udall Center improved recruitment. Center Directors and Project/Core Leads from 10 of the 11 Centers remarked on an increase in the number of post-doctoral trainees (interviewees from Center B did not comment on this topic). Five of the ten indicated an increase in trainees with MDs and MD/PhDs who focused on clinical research (Centers A, E, F, H and I). Nine of the ten Centers commented on an increase in PhD trainees who focused on basic research (Center D did not indicate a change). In addition, interviewees from Center H observed that the Udall Center structure enabled international fellows to work on PD research.

In terms of programmatic developments, Center Directors and Project/Core Leads from all 11 Centers commented on an increase in the number of journal clubs, seminars, workshops, and mentoring opportunities, and on an increase in training opportunities for students in general (see Exhibit 44 for examples). In some instances, Centers put formal structures in place, as exemplified by the Center Director and a Project/Core Lead from one Center, who explained that their Center established a scholars program to provide training opportunities. Furthermore, Center Directors and Project/Core Leads from Centers A, I, and K explained that the Udall Center structure enabled young scientists to travel and attend meetings on PD research. As a result of these new opportunities for trainees, Project/Core Leads from Centers B, C, and D all felt that there was an overall increase in collaboration, and the Center Director and Project/Core Leads from Center H stated that it allowed young scientists to develop into PD researchers and establish their own labs.

Exhibit 44. Examples of Formal Training Components at Udall Centers

Program Development and Training Opportunities for Udall Center Trainees	
Regular Programs	Description
Movement Disorder Rounds	Staff from the Departments of Neurology and Psychiatry attend this conference for discussions of patient videotapes, case presentations, and journal club reviews.
Neuropsychiatry Conference	Faculty, house staff, nurses, and research staff, primarily from the Department of Psychiatry and its Medical Psychology Division, take part in a series of lectures on specific clinical topics, discussions of research assessment instruments for neuropsychiatric conditions, and case conferences.
Clinical Neuroscience Seminar	Faculty, house staff, research staff, graduate students, and postdoctoral fellows, primarily from the Departments of Neurology and Neuroscience, take part in a series of lectures on the Neurobiology of Disease.
Bi-monthly Meeting with AD Center	Invited speaker seminar series, including presentations directly relevant to PD research
Course Offerings	Course Participants
Neurobehavioral Course	Neurology Residents and Clinical and Research Fellows
Neurodegenerative Disease	Graduate School Students
Community Outreach	Description
Website Development	Serves as a means of information transfer to both professionals and the public. Serves as a means for recruitment and makes available cloning resources.
Community Outreach	
Parkinson's Disease Support Group Meetings	

### Udall Center Research Trainees: The First Five Years

In this section, the study team presents training activity as described in the Center progress reports. Unless otherwise noted, the number of trainees reported indicates distinct individuals, not Full-Time Equivalent (FTE)<sup>23</sup> trainees. Centers B and J did not list relevant information in these reports, so this section does not describe their training activity. However, during the interview process, Udall Center Investigators from Centers B and J described the details and the success of their trainee programs. Exhibit 43<sup>24</sup> included these Centers in its discussion.

#### *Total Number of Individual Trainees*

In total, 112 individual trainees received support from the Udall Centers during the first five years of the program.<sup>25</sup> Exhibit 45 presents the number of trainees – as reported in the progress

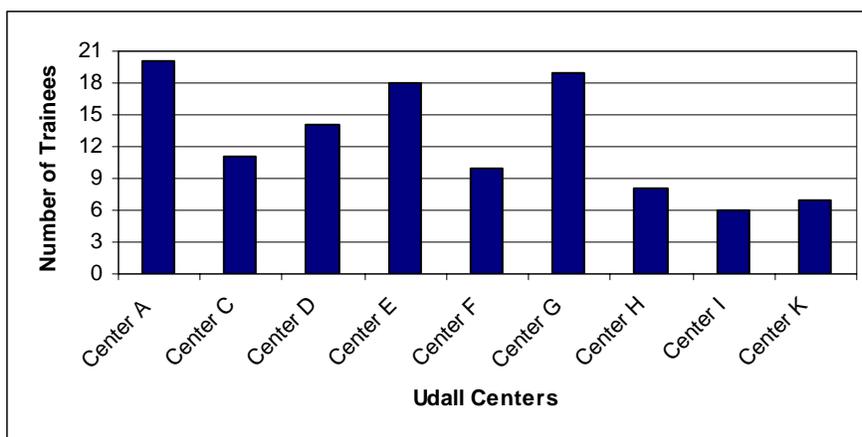
<sup>23</sup> Full-Time Equivalent (FTE) is used to measure the involvement of a researcher with a specific project. An FTE of 1.0 indicates that the researcher is equivalent to one full-time worker. For the purposes of this evaluation, the study team presented FTE trainees as a sum value for each Center (as data permitted).

<sup>24</sup> Trainee data from progress reports and interview questions could not be consolidated because data were not presented in a similar fashion.

<sup>25</sup> While it appears that there were 113 individual trainees who received support from the Udall Centers during the first five years of the program, Centers A and G both supported the same trainee. Therefore, the total number of trainees is 112 individuals.

reports and grant continuations – by Udall Center.<sup>26</sup> Information from the progress reports suggested that over the first five years of the Udall Centers Program, Center A supported the most trainees, with 20 in total. Of the Centers that included information on trainees in their progress reports, Center I listed the fewest number, with six. The Centers with training cores all supported at least ten different trainees during the first five years, with an average of 15 trainees during that time. The Centers without training cores had an average of 11 trainees during the first five years of the Udall Centers Program, more than 25 percent less than the average number of the Centers with training cores.

Exhibit 45. Total Number of Individual Trainees at Each Udall Center\* During the First Five Years of the Program



\*No data available for Center B or Center J

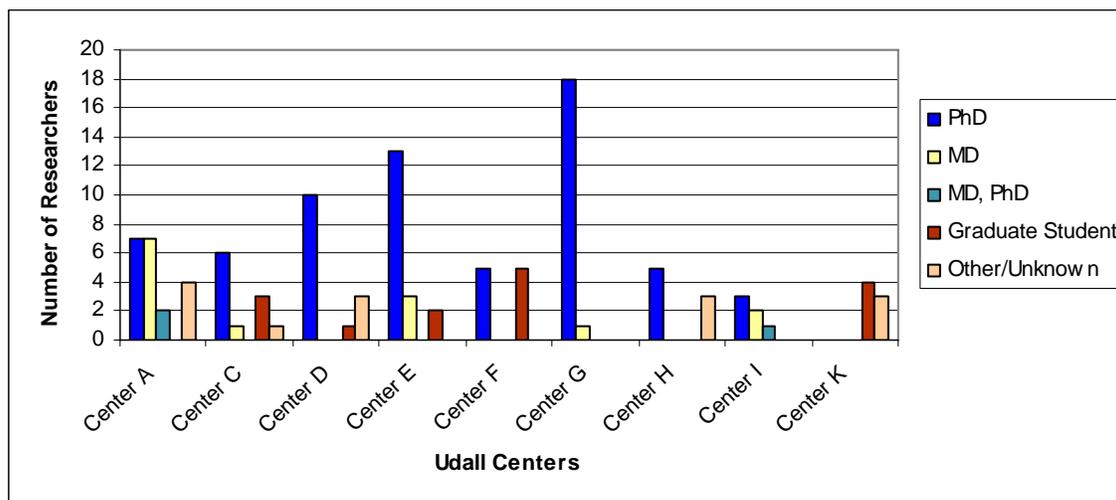
#### Composition of Individual Trainees

As shown in Exhibit 46, the majority of trainees at the Udall Centers during the first five years of the program were post-doctoral trainees<sup>27</sup> (60 percent). Center G supported the greatest number of post-doctoral fellows (18 individuals), who made up almost 95 percent of the Center’s total trainees during the first five years. Center A, the Center with the most trainees during the first five years, supported an equal number of post-doctoral and MD trainees (seven of each) and also supported the highest percentage of MD trainees throughout the Udall Centers (54 percent). Graduate students made up the second largest group of trainees at the Udall Centers with 15 individuals (13 percent); the greatest concentration of graduate students was at Center F, where five individuals received support during the first five years. Overall, only three trainees with MD/PhDs were part of the Udall Centers between FY98 and FY04, and they were all part of Centers A and I.

<sup>26</sup> While many of the Centers listed additional students and fellows as being connected to the Udall Center, if the Centers did not provide specific names and/or the Center did not assign the individual to a specific project or core, the analysis did not include that person. Center E and Center H were the only Centers that listed in their progress reports specific trainees as part of either the training core or the Center in general – even though they did not support a specific project. Center E had 11 of these trainees and Center H had three throughout the first five years of the Udall Centers Program.

<sup>27</sup> Post-doctoral trainees include trainees with PhDs only. This report analyzed trainees with MDs separately.

Exhibit 46. Udall Center Individual Trainees Stratified by Degree Status\*

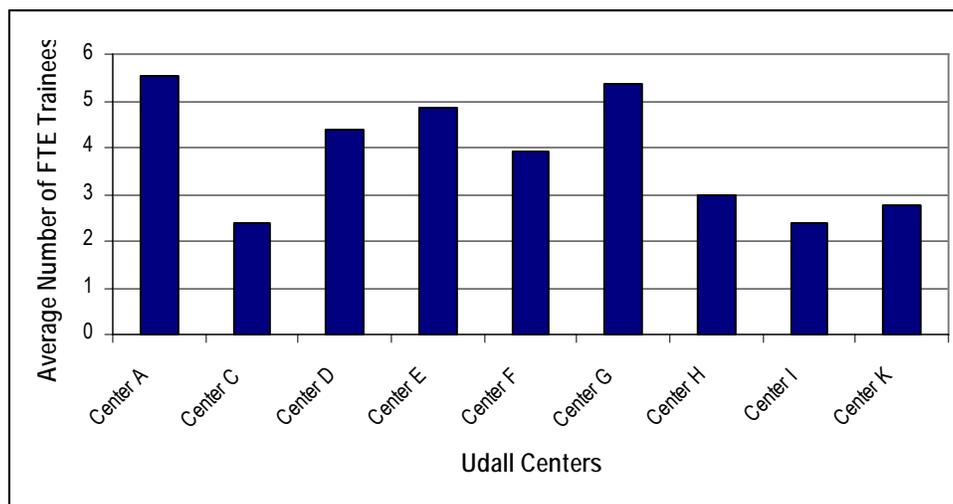


\*No data available for Center B or Center J

**FTE<sup>28</sup> Trainees During the First Five Years of Funding**

Overall, the nine Udall Centers in the analysis averaged 3.8 FTE trainees during the first five years of Udall Center funding. Center A averaged the greatest number of FTE trainees throughout the first five years of the Udall Centers Program, with 5.5 FTE trainees (Center G averaged slightly less with 5.4 FTE trainees). Center I averaged the fewest number of FTE trainees during the first five years, with 2.4 FTE trainees (see Exhibit 47).

Exhibit 47. Average FTE Trainees by Udall Center During the First Five Years of Funding\*



\*No data available for Center B or Center J

<sup>28</sup> Full-Time Equivalent (FTE) is used to measure the involvement of a researcher with a specific project. An FTE of 1.0 indicates that the researcher is equivalent to one full-time worker. For the purposes of this evaluation, the study team presented FTE trainees as a sum value for each Center (as data permitted).

While the majority of Udall Centers experienced relative stability in the number of FTE trainees throughout the first five years of Udall Center funding, Centers A and G both experienced a spike in FTE trainees during a single year of the Centers’ grant funding. Center G experienced a spike during the Center’s third year of funding, when it supported 10.3 FTE trainees – the most of any Center throughout the first five years of the Udall Centers Program.

**3.6.1.3 Summary**

Overall, the Udall Centers were successful in developing research training opportunities for the trainees during the first five years of the Udall Centers Program. The Centers incorporated over 110 individual post-doctoral fellows, trainees, and graduate and undergraduate students into their Centers. As seen in Exhibit 48, Center A trained the largest number of individuals (20) and the highest average number of FTE trainees (5.5). Center I, however, had the least number of total trainees (6) and the lowest average number of FTE trainees (2.4) during the first five years of Udall Center funding. The Centers with training cores surpassed the Centers without training cores in two areas: average of total number of trainees (14.8 compared to 10.8) and average number of FTE trainees (4.3 versus 3.6 each year). However, when comparing the trainees as a percentage of total research staff, Centers with training cores and Centers without training cores both averaged 22 percent over the first five years of funding (see Exhibit 49).

Exhibit 48. Udall Center Trainees: Development and Statistics Summary

<b>Udall Center Research Trainees: Development and Statistics From the First Five Years</b>				
	<b>Training Core</b>	<b>Total Number of Trainees</b>	<b>Average Number of FTE Trainees</b>	<b>Average Percentage of Total Researchers</b>
Center A	Yes	20	5.5	26%
Center B	No	N/A	N/A	N/A
Center C	Yes	11	2.8	17%
Center D	No	14	4.4	28%
Center E	Yes	18	4.9	21%
Center F	Yes	10	3.9	25%
Center G	No	19	5.4	33%
Center H	No	8	3.0	21%
Center I	No	6	2.4	11%
Center J	No	N/A	N/A	N/A
Center K	No	7	2.8	17%

Exhibit 49. Udall Centers With Training Cores versus Udall Centers Without Training Cores

Do Training Cores Make a Difference?*			
	Average Total Number of Trainees	Average Number of FTE Trainees	Average Percentage of Total Researchers
Centers With a Training Core	14.8	4.3	22%
Centers Without a Training Core	10.8	3.6	22%

\*Centers B and J not included in the analysis because of lack of relevant information

Of the 35 Udall Center Directors and Project/Core Leads who commented on the impact of the Udall Center structure on trainee programs, 33 researchers (94 percent) felt that the Udall Centers Program helped them attract more trainees, create more seminars, workshops, and journal clubs, expose more young scientists to PD research, and develop more independent investigators in the field. Only two of 35 respondents (6 percent) believed that it had no impact.

Note: While Center B and Center J did not make any training-related data available in their progress reports, it was evident from the interviews that they do have active and robust training programs. If their progress reports had contained training-related data, the results likely would have varied to some degree.

### 3.6.2 Study Question 4.2 – Obtaining adequate research support for Udall Center projects

#### 3.6.2.1 Approach

To determine if the Udall Center Investigators obtained adequate research support for their projects, the study team examined the funding histories of the Udall Centers and surveyed Center Directors and Project/Core Leads. The study team extracted Notice of Grant Awards (NGAs) from the NIH database – IMPAC II – for two categories: annual funding support and supplemental funding support. The study team also surveyed the Udall Center Investigators to obtain their perspectives on the adequacy of NINDS funding for research support functions.

Data Sources and Questions for Research Question 4.2	
Data Source	Questions
IMPAC II	N/A
Supplemental Grant Awards	N/A
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>On a scale of 1 to 3, please rate the extent to which the research support functions provided by Udall funding were sufficient to meet your needs during the 1998-2004 timeframe:                             <ul style="list-style-type: none"> <li>Facilities</li> <li>Cores</li> <li>Equipment and supplies</li> <li>Personnel</li> <li>Services such as bio-statistical, data management, IT, grants assistance</li> <li>Other needs (please list)</li> </ul> </li> <li>If you rated any of these functions as 1, please elaborate</li> </ul>

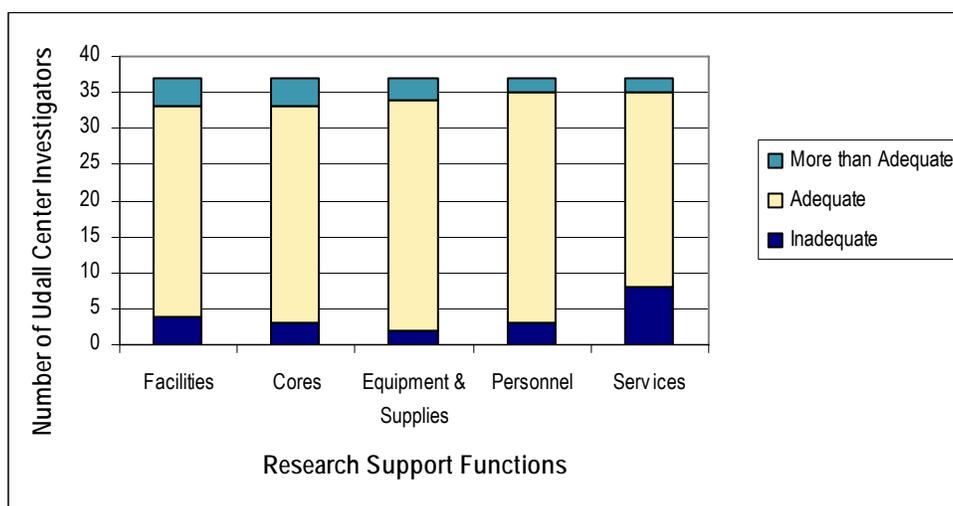
### 3.6.2.2 Results

During the first five years of the Udall Centers Program, NINDS distributed over \$73 million in annual funding across the 11 Centers (see Exhibit 16). During that same time period, NINDS awarded over \$4 million to the Udall Centers in supplemental funding. This section presents further information on the supplemental funding, including reasons, requests, and amounts.

#### Adequacy of NINDS Funding Support: Survey Data

As shown in Exhibit 50, nine Center Directors and 28 Project/Core Leads provided insight into the adequacy of Udall Center funding in supporting the needs and research functions of the Investigators. Of the nine Center Directors who responded, seven (78 percent) indicated that the support they received was “adequate” or “more than adequate” across all five measures (facilities, cores, equipment and supplies, personnel and services). Of the 28 Project/Core Leads who responded, 21 (75 percent) also indicated that the support they received was “adequate” or “more than adequate” across all five measures.

Exhibit 50. Adequacy of Research Support Functions



Respondents who rated the funding support as “inadequate” had an opportunity to elaborate on their opinions. Of the six Center Directors who provided explanations for “inadequate” ratings –

- Two reported a lack of sufficient personnel (e.g., chemists, physicists, and animal technicians for imaging studies)
- Two reported inadequate funding for physical facilities
- One reported insufficient funds for personnel in grant support, IT services, and participation in a Brain Bank
- One would have liked funding for future pilot projects.

In addition, two Center Directors stated that they had compensated for the inadequate funding support by successfully obtaining funding from other sources.

The study team also asked Center Directors if the initial funding of the projects met their resource needs. If it did not meet their needs, the study team asked the Center Directors if they had conveyed their requests to NINDS and, in turn, if NINDS had met those needs (Study Question 2.3 addresses these findings). Overall, only one of the eight Center Directors who responded to the survey question felt that NINDS did not fulfill the Center’s needs.

Seven Project/Core Leads from six Udall Centers provided explanatory comments regarding insufficient funding. Of these –

- Two reported a lack of sufficient personnel for genetic and neuropathology cores and full-time staff dedicated to the clinical core and administrative support
- Two reported a lack of funding for physical facilities
- Two reported inadequate funding for IT and data management services
- Two reported a lack of funding for equipment, including multi-photon microscopes
- One reported inadequate funding for sequencing genes within the genetic core.

### Supplemental Grant Awards

Of the 11 Udall Centers, 10 received supplemental grant support from NINDS during the first five years of the Udall Centers Program. From 1998 through 2004, the Udall Center Investigators, along with other researchers, responded to four Notices of Supplemental funding published by NINDS: NOT-NS-01-002, Administrative Support for Research on PD; NOT-NS-02-013, Administrative Supplements for Sharing and Distributing Mouse Genetic Models and Mouse Lines; NOT-NS-00-007, Administrative Supplements for DNA Microarray Analysis and Work on Human Embryonic Stem Cells; and NOT-NS-03-003, Administrative Supplements for a program that identifies treatments for neurodegenerative disorders by evaluating promising drugs identified or evaluated in ongoing peer-reviewed projects. Exhibit 51 summarizes the supplemental funding awards provided to the Udall Centers under these notices.

Exhibit 51. Supplemental Grant Awards Received in Response to NINDS Notices by Year<sup>29</sup>

Notice	Center	Amount (\$)*	Year
NS-00-007	Brigham & Women’s Hospital	\$75,000	2000
NS-00-007	Duke University	\$50,000	2000
NS-01-002	McLean Hospital w/Harvard University	\$100,000	2001
NS-01-002	University of California, Los Angeles	\$100,000	2001
NS-02-013	University of California, Los Angeles	\$100,000	2001
NS-01-002	Johns Hopkins University	\$100,000	2001
NS-01-002	Brigham & Women’s Hospital	\$100,000	2001
NS-01-002	Duke University	\$100,000	2001
NS-00-007	McLean Hospital w/Harvard University	\$100,000	2002
NS-01-002	Duke University	\$100,000	2002
NS-03-003	Emory University	\$76,000	2003
NS-03-003	Johns Hopkins University	\$81,750	2003

\*Full amount of the grant

<sup>29</sup> NINDS verified the funding amounts listed in the table.

Beyond the Notices of Supplemental Funding, Udall Center Investigators requested additional supplemental funding from NINDS for a variety of needs, including support for infrastructure, administration of the Center, and specific projects.

### 3.6.2.3 Summary

Overall, Udall Center Investigators indicated that they were able to obtain the funding support they needed to conduct their research. In addition to the more than \$73 million NINDS provided to the Udall Centers in annual funding during the first five years of the Udall Centers Program, the 11 Centers received over \$4 million in supplemental funding during that time period. While the majority of Center Directors and Project/Core Leads found the research support adequate or more than adequate, a few Udall Center Investigators expressed their dissatisfaction with the level of research support they received.

## 3.6.3 Study Question 4.3 – Promoting multidisciplinary collaborations within and between Udall Centers

### 3.6.3.1 Approach

Another NINDS-recommended activity was to promote multidisciplinary collaborations within and between Udall Centers. To examine this issue, the study team interviewed Center Directors and Project/Core Leads about the usefulness of the annual meetings, how the annual meetings have advanced their research, and the impact of collaboration on their research goals.

Data Sources and Questions for Research Question 4.3	
Data Source	Questions
Interviews Udall Investigators)	<ul style="list-style-type: none"> <li>How useful were the annual meetings during the initial period (e.g., meetings held prior to 2005)? How have you used the annual meetings to further your research (e.g., making connections, learning alternate strategies/techniques, identifying other ways to collaborate with other Centers)?</li> <li>How has collaboration had an impact on your Center's ability to achieve your research goals?</li> </ul>

### 3.6.3.2 Results

The majority of the interviewed Center Directors and Project/Core Leads indicated that the annual meetings held during the initial period (e.g., meetings held through 2004) were useful (33 of 39 respondents) (see Exhibit 52). According to the Udall Investigators, these meetings provided a venue for initiating collaborations, as Investigators met one another and discussed the range of their research. As a result of the meetings, Udall Investigators felt a greater sense of community, identified opportunities for collaborating and sharing, and increased their involvement with the broader PD community (e.g., volunteer organizations). Furthermore, Investigators indicated that the meetings generated collaborations that ultimately impacted their abilities to meet research goals.

Exhibit 52. Usefulness of Udall Annual Meetings and Impact of Udall Annual Meetings on Furthering Research

INTERVIEW RESULTS: Center Directors and Project/Core Leads	
How Useful were the Annual Udall Center Meetings?	Elaborations and Impact of the Annual Udall Center Meeting on Research
Useful (33)	<ul style="list-style-type: none"> <li>• Allowed us to build relationships with others in the PD field, create a PD research community, and facilitate collaboration (25)</li> <li>• Provided a venue for sharing techniques and methods, including student-post-doctoral exchanges (9)</li> <li>• Provided a venue for discussing ideas, research discoveries, and new areas of research (8)</li> <li>• Provided a venue for sharing reagents, materials, animals, and antibodies (8)</li> <li>• Provided an incentive to prepare because they acted as deadlines (5)</li> <li>• Increased involvement with PD community- volunteer organizations (clinical trial recruitment, understanding different perspectives, and understanding the disease) (4)</li> <li>• Provided an opportunity to learn about the structure, research activities, and progress of the other Udall Centers and the diversity of the portfolio (4)</li> <li>• Exposed us to colleagues in different disciplines (3)</li> <li>• Provided a venue for discussing multi-institutional resource issues (e.g., brain banking, PD-DOC) (2)</li> <li>• The meeting was useful but it did not help in furthering my research (1)</li> </ul>
Not Useful (6)	<ul style="list-style-type: none"> <li>• It was difficult to meet people since they were often presenting or in subgroups; at the later meetings, there was more opportunity for interaction (2)</li> <li>• They were too structured around the presentations by each Center and would have preferred to hear about the data results of pre-published work (1)</li> <li>• They seemed to be opportunities for the Centers to posture among each other (1)</li> <li>• The presentations were not all high-quality (1)</li> <li>• They needed more structure for collaboration (1)</li> </ul>

Six Center Directors and Project/Core Leads also provided suggestions for improving the annual Udall Center meetings. Their comments and recommendations included –

- Provide more depth; for example, rather than hearing everything the Center did at a high level, have the scientists present their greatest accomplishments (3)
- Include more participation by non-Udall PD researchers (2)
- Introduce more frequent or longer meetings to be able to focus on certain topics (e.g., neuropathology or gene expression within the brain) (2)
- Include more students and post-doctoral trainees because they are the ones doing the experiments and it would help for them to talk to each other (1)
- Focus more on basic science (and less on the bureaucratic discussions) (1)

In addition, in interviews, the study team asked Center Directors and Project/Core Leads to comment more broadly on the impact of collaboration on achieving research goals. The majority of Center Directors and Project/Core Leads responded positively. They acknowledged that

collaboration set a new course for their work, promoted sharing of materials and scientific discoveries with peers, and expanded their knowledge base. Some interviewees were less affected by collaboration; they reported that it did not impact research goals or that the impact would have occurred in the absence of the Udall Center structure.

Exhibit 53. Impact of Collaboration (Other than the Annual Meeting) on Achieving Research Goals

Interview Results: Center Directors and Project/Core Leads	
Collaboration had a positive impact on research (21)	<ul style="list-style-type: none"> <li>• Collaboration allowed us to make faster progress on our research, helped to unify our approach and re-directed our research (7)</li> <li>• Collaboration occurred: we received and/or shared materials, tissues, reagents, animal models, and discoveries (7)</li> <li>• Collaboration helped our knowledge base and technical resources; we exchanged protocols, had access to unpublished information, exchanged personnel, exchanged techniques, shared methods, and compared data results (5)</li> <li>• Collaboration outside of the Center was much more than it otherwise would have been without the Udall Center structure (2)</li> </ul>
Collaboration had little impact on research (7)	<ul style="list-style-type: none"> <li>• Collaboration hasn't helped research goals; wasn't relevant for the cores (5)</li> <li>• Collaboration helped us move toward our goals but the impact wasn't huge; would have happened absent of the Udall structure (2)</li> </ul>
Collaboration had some impact on research (2)	<ul style="list-style-type: none"> <li>• Collaboration occurred, but it was not on efforts toward primary research goals – it was outside of the initial goals (2)</li> </ul>

### 3.6.3.3 Summary

One of the activities NINDS recommends is multidisciplinary collaboration within and between the Udall Centers and one of the primary ways in which Centers engaged in collaboration was the annual meeting. The majority of the Center Directors and Project/Core Leads found the annual meetings beneficial and effective in helping them to meet their research goals. Some provided suggestions for improving the meetings, including having a more targeted focus and broader participation from students, post-doctoral trainees, and non-Udall researchers. Beyond the annual meetings, the majority of Investigators also reported that collaboration, in general, contributed to their ability to meet their research goals. These results suggest that the Udall Center Investigators engaged in collaborative activities and understood the value of collaboration for their research.

### 3.6.4 Study Question 4.4 – Ensuring effective day-to-day management and communications

#### 3.6.4.1 Approach

To determine the extent of the Udall Centers’ activities in ensuring effective day-to-day management and communications within the Centers, the study team reviewed grant applications and progress reports and analyzed survey data. The Center Directors responded to the web-based survey about the types of management structures they employed once they became Udall Centers. The grant applications provided information on the structure of the Udall Centers at their inception, and the progress reports outlined management and communications activities that Centers reported to NINDS over the first five years of funding.

Data Sources and Questions for Research Question 4.4	
Data Source	Questions
Progress Reports	N/A
Grant Applications	N/A
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>How the did the Center structure change your management practices (for example, more formal research planning, improved organization of labor/resources, etc.)?</li> </ul>

#### 3.6.4.2 Results

In reviewing the grant applications, the study team found that all Udall Centers proposed an administrative core for their Centers. All administrative cores listed the Udall Center Director as the principal investigator (PI), and one core also included a Project/Core Lead as a co-PI. One Center combined its administrative and training core. Most administrative cores’ descriptions included functions such as fiscal management, meeting coordination – both internally (between projects within the Udall Center) and externally (with advisory or scientific boards) – and generation of progress reports. Two Centers also included data management and statistical analysis as tasks in their administrative cores.

In response to the survey question, Center Directors indicated that they employed a range of practices in managing their Centers’ operations (Exhibit 54). Most commonly, respondents indicated that they established regular meetings as a mechanism for monitoring activities and communicating within the Center. In addition, a few Centers engaged in formal planning activities.

Exhibit 54. Impact of the Center Structure on Management Practices

SURVEY RESULTS: Center Directors
<ul style="list-style-type: none"><li>• Established regular internal meetings due to the increased scope of PD research and need for collaboration (3)</li><li>• Enacted more formal internal meetings (which also provided an opportunity for post-doctoral trainees to present their research to a Review Committee) (1)</li><li>• Enacted tighter and more integrated research planning among laboratories due to the regular reporting requirements and renewal planning (1)</li><li>• Used structured forums for collaboration, including videoconferences and seminars (1)</li><li>• Improved fiscal management of PD studies by having the Center coordinator assist with planning (1)</li><li>• Established an administrative and management structure (1)</li><li>• Did not change management practices (1)</li></ul>

### Day-to-Day Management and Communication

Most of the Udall Centers discussed some aspects of day-to-day management and communications in their progress reports, but the discussions were generally limited in scope. The study team found that Centers reported on the use of regular meetings with Udall Investigators and other Udall Center personnel from the Udall Centers to facilitate frequent interactions between different members of the Project teams and Core teams. These meetings usually occurred monthly or bi-weekly. Most Centers used these meetings for administrative, management, and communication purposes, but some Centers also used them as forums to present research findings. Most Centers identified the administrative core as responsible for overseeing the day-to-day operations of the Center.

The study team also found information on communication mechanisms in the progress reports. These other mechanisms of communication included the establishment of regular educational seminars and conferences by many Udall Centers, as well as the development of journal clubs. Udall Centers located in the same geographic region also held meetings across the different Centers. Additionally, several Centers discussed the roles of individual personnel assigned to administrative and management tasks. Of those, the PIs of the administrative cores (usually the Center Directors) usually contributed about five percent of their time to this role, and an administrative assistant and other personnel supported them. One Center developed a Udall Center website, and another Center developed and coordinated databases across different projects.

#### 3.6.4.3 Summary

The existence of an administrative core seems to have provided a structural base in which the Udall Centers could share information. To ensure effective day-to-day management and communications, most Udall Centers conducted periodic meetings with Udall Center Investigators and with external advisors.<sup>30</sup> In addition to meetings, other communication mechanisms included seminars, journal clubs, and a website.

<sup>30</sup> Study question 4.5 includes further information on external advisors.

### 3.6.5 Study Question 4.5 – Emphasizing strategic planning, including setting milestones, monitoring progress, and seeking advisory committee input

#### 3.6.5.1 Approach

Another NINDS-recommended activity was to engage in strategic planning, including setting milestones, monitoring progress, and seeking advisory committee input. To address this issue, the study team surveyed Center Directors about their approaches to:

- Setting goals and milestones;
- Measuring progress toward these goals and milestones;
- Using advisors to influence their work; and
- Identifying and planning for operational improvements.

#### 3.6.5.2 Results

As displayed in Exhibit 55, four out of nine Center Directors who responded to the web-based survey indicated that they developed project goals aligned with the specific aims for each project, and that they documented these goals in the application. In regard to the initial goals and milestones, respondents reported a number of approaches, including allowing Project/Core Leads to set their own goals, seeking input from advisors, using common models, and establishing milestones following their typical procedures.

Exhibit 55. Approaches for Setting Goals and Milestones

Data Sources and Questions for Research Question 4.5	
Data Source	Questions
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>• How did your Center set goals and establish milestones? Were there any particular approaches or techniques that you utilized?</li> <li>• How did your Center monitor, and measure its progress towards reaching goals and achieving milestones? Were there any particular approaches or techniques that you utilized?</li> <li>• Did your Center use advisors? If so, in what ways, and how were they related to your Center (i.e., from within your institution or from outside your institution, etc.)?</li> <li>• How did your Center identify and plan for operational improvements (e.g., acquisition of equipment, improving processes, etc.)? Were there any particular approaches or techniques that you used that assisted you in that planning process? Please elaborate.</li> </ul>

SURVEY RESULTS: Center Directors
<ul style="list-style-type: none"> <li>• Determined project goals that aligned with the Specific Aims documented in the application (4)</li> <li>• Set own goals for projects and reviewed progress quarterly with the other investigators and trainees (1)</li> <li>• Set milestones based on input from internal and external center advisory boards and other PD professionals (1)</li> <li>• Used common models across laboratories to help drive the goals and milestones (1)</li> <li>• Established milestones, for each method, following our institutional/center grant procedures (1)</li> <li>• Established goals in the beginning but remained flexible to respond to new discoveries (1)</li> </ul>

When asked to comment on approaches used to monitor and measure progress toward goals and milestones, Center Director survey respondents cited a number of established review processes, including reviews by external and internal advisors and regular progress reporting sessions. In

addition, respondents identified a number of more opportunistic methods of assessing progress, such as when preparing annual reports or presentations.

Exhibit 56. Approaches for Monitoring and Measuring Progress Toward Goals and Milestones

SURVEY RESULTS: Center Directors	
<ul style="list-style-type: none"> <li>• Reviewed by External Advisory Committee who provided input (4)</li> <li>• Reviewed progress at weekly meetings or biweekly meetings (3)</li> <li>• Reviewed by Internal Advisory Committee/Internal Review Committee who provided input (2)</li> <li>• Reviewed progress in annual reports (1)</li> <li>• Reviewed progress when preparing presentations for the annual Udall meeting (1)</li> <li>• Involved multiple Center investigators on student theses committees (1)</li> <li>• Assessed by scientific productivity (publications and presentations) (1)</li> <li>• Conducted annual symposium of PD researchers (1)</li> <li>• Communicated progress across group (1)</li> </ul>	

When asked about their use of advisory committee input, the majority of survey respondents indicated that they used both internal and external advisors and/or advisory boards. As shown in Exhibit 57, Udall Centers used external and internal advisors for an objective perspective and for commenting on research activities, preparing for renewal applications, and/or for refocusing their research direction.

Exhibit 57. Use of External and Internal Advisors

SURVEY RESULTS: Center Directors	
Did Your Center Use Advisors?	If so, in what ways, and how were they related to your Center (i.e., from within your institution or from outside your institution)?
Yes, External Advisors	<ul style="list-style-type: none"> <li>• Found them more useful and constructive than internal advisors (2)</li> <li>• Recruited colleagues working on PD or other neurodegenerative diseases at other institutions and who are experts in the Center's approaches to be part of the Advisory Group (1)</li> <li>• Convened an External Advisory Committee comprised of independent and objective outside investigators with expertise in the various facets of our research for criticism and suggestions (1)</li> <li>• Convened an External Advisory Board to conduct an all-day review of our Udall Center prior to formulating our goals for our competitive renewal in 2003; the review results led to new and modified research directions (1)</li> <li>• Convened a Scientific Advisory Board to comment on a site visit and PI presentations; the results helped the Center Director to manage and administer suggestions (1)</li> <li>• Consulted the advisors primarily at the time of the renewal application and now meet annually (1)</li> </ul>
Yes, Internal Advisors	<ul style="list-style-type: none"> <li>• Comprised of leaders in neuroscience research, heads of other NIH-funded Centers, and leading neurologists from our institution (1)</li> <li>• Consulted primarily at the time of the renewal application (1)</li> <li>• Relied on internal advisors, with experience in directing our NIA-funded Alzheimer Research Center, to provide advice and criticism during our first year of funding (1)</li> <li>• Relied on an Internal Advisory Committee to monitor our progress (1)</li> </ul>

As shown in Exhibit 58, some Center Directors sought approval for operational improvements through a group decision-making body. Center Director survey respondents also stated a variety of sources for funding operational improvements, including their own institutions, collaborations with other Centers, philanthropic and other funding agencies, and private organizations.

Exhibit 58. Approaches for Identifying and Planning for Operational Improvements

SURVEY RESULTS: Center Directors
<ul style="list-style-type: none"><li>• Held ad-hoc discussions among Center PIs (1)</li><li>• Made decisions at the regular Executive Committee meetings (1)</li><li>• Made decisions by committees that include representation from members of the Udall Center staff and are based on institutional priorities (1)</li><li>• Made decisions with the support of advisory committees (internal and external) (1)</li><li>• Discussed common needs at regular meetings (1)</li><li>• Obtained institutional support for major equipment acquisitions (1)</li><li>• Made acquisitions for operational improvements by collaborating with other Centers (funding for operational improvements was not available through the Udall Center) (1)</li><li>• Approached both philanthropic and other funding agencies for help with purchasing equipment (1)</li><li>• Increased private fundraising by having incremental federal support from Udall (1)</li></ul>

### 3.6.5.3 Summary

NINDS emphasized strategic planning, including setting milestones, monitoring progress, and seeking advisory committee input, as recommended activities for the Centers and the Udall Centers made some effort to this end. Some Centers set goals and milestones, monitored and measured progress through review processes, used decision-making bodies to approve operational improvements, and used internal and external advisors and/or advisory boards. The wide range of responses suggests that Udall Centers are enacting these processes in different ways and to varying degrees.

### 3.7 Study Question 5

To what extent did the individual Udall Centers and the Centers as a group achieve the following short-term research goals in the first five years?

- Integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research
- Early results leading to new hypotheses relevant to PD
- New procedures developed for sharing PD research findings and scientific techniques
- Recruitment of new faculty and trainees to PD research
- More multidisciplinary research relevant to PD
- Broader research and infrastructure support for projects relevant to PD

#### 3.7.1 Study Question 5.1 – *To what extent did the Udall Centers function as an integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research?*

##### 3.7.1.1 Approach

The study team analyzed progress reports, survey results, and interview results to measure whether the Udall Centers Program met the short-term goal of establishing an integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research. The study team examined this issue from several perspectives, including evidence in progress reports that the Centers employed an integrated, multidisciplinary approach to their research, and perspectives voiced in surveys and interviews that indicated how the program structure helped the Centers achieve results and focus on interrelated scientific programs.

##### 3.7.1.2 Results

Based on a review of the progress reports and other supplemental information provided by each Udall Center, the study team found that all of the Centers had projects involving multiple disciplines. Some Centers directly discussed the multidisciplinary nature of their projects in their reports; others did not comment directly on this issue, but other information in the reports made evident the existence of multiple disciplines.

Data Sources and Questions for Research Question 5.1	
Data Source	Questions
Progress Reports	N/A
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>• Please discuss the role, if any, the Center structure has played in your Center's results. What do you feel you have accomplished that you could not have without the structure of the Udall Centers Program?</li> <li>• Would you describe your Center within the first 5 years as becoming more focused on interrelated scientific problems? If yes, in what ways, if not, please elaborate.</li> </ul>
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>• Prior to becoming a Udall Center, did you have an organizational structure (e.g., team, group, Center) for conducting: <ul style="list-style-type: none"> <li>– PD research?</li> <li>– Other research?</li> <li>– Both PD and other research?</li> </ul> </li> <li>• Please estimate the number and type as related to basic, translational, and clinical research. Did any of this research involve multidisciplinary research teams?</li> </ul>

The research teams assembled for each project and core are the main evidence of the Udall Centers' multidisciplinary nature. All Centers had personnel with a wide range of knowledge, skills, and expertise. Teams and projects involved many disciplines, including –

- Clinical neurology
- Neuropathology
- Neurophysiology
- Neurosurgery
- Stereotactic procedures
- Imaging
- Animal models and studies
- Cell and molecular biology
- Cell transplantation
- Histology
- Behavioral science
- Neuroengineering
- Cell and system neuroscience
- Neuropsychology
- Neuropsychiatry
- Geriatrics
- Nursing
- Mendelian genetics
- Molecular genetics
- Population genetics
- Chemical genetics
- Genomics
- Biostatistics
- Epidemiology
- Biophysics
- Electrophysiology
- Signal and image processing
- Data management
- Computer science
- Environmental risk assessment

The study team observed a pattern of multidisciplinary collaborations between researchers working on different projects. Collaborations were also common between clinicians and basic researchers. For example, in many Centers, patients from the movement disorders clinic participated in a variety of research projects funded by the Udall Center grant. One Center specifically stated that a major aim was to integrate the activities of the various disciplines so that multidisciplinary interrelationships would result in greater scientific contributions. Examples of the multidisciplinary nature of these collaborations from the Centers included:

- A Clinical Core worked closely with the Division of Neuroimaging, Neuropsychiatry, and the Memory Group Clinic to study the relationships between motor, cognitive, and psychiatric phenomena
- A multidisciplinary team worked with the PD clinic to establish a DNA repository
- The Cores provided multidisciplinary support to each other and to the individual projects
- Individual Projects included –
  1. Multidisciplinary animal studies, involving morphological, behavioral, and neurochemical studies
  2. Behavioral, functional imaging, and surgical studies
  3. Basic molecular studies, stereotactic procedures, and functional imaging.

In addition, survey respondents' perspectives on the degree to which the Udall Center structure affected their ability to achieve results provided insight on the goal of establishing an integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research. In this regard, as shown in Exhibit 59, nearly all respondents expressed

positive comments. The most pronounced themes focused on enhanced collaboration on research efforts, greater coordination and sharing, and research advancements as a result of the ability to perform focused, complex studies. The one point of criticism voiced by a small minority (two Investigators) was that, absent of the Udall Center structure, the Centers would have achieved the same results.

Exhibit 59. Impact of Udall Center Structure on Achieving Research Results

Please discuss the role, if any, the Center structure has played in your Center's results. What do you feel you have accomplished that you could not have accomplished without the structure of the Udall Centers Program?
<b>The Udall Center Structure had a positive impact on helping us to achieve our research results</b>
<ul style="list-style-type: none"> <li>• Facilitated collaboration with other Udall Centers and beyond (17)</li> <li>• Facilitated coordination and sharing (11)                             <ul style="list-style-type: none"> <li>– Allowed easier access to information, resources, and ideas</li> <li>– Allowed access to comprehensive perspective on PD</li> </ul> </li> <li>• Helped to advance the field (10)                             <ul style="list-style-type: none"> <li>– Helped perform more complex studies, which led to deeper insight into PD</li> <li>– Increased productivity led to wide-ranging publications</li> <li>– Allowed the researchers to pursue and carry out promising/better research and to focus their efforts</li> </ul> </li> <li>• Enhanced clinical perspective (6)                             <ul style="list-style-type: none"> <li>– Allowed the development of a clinical program</li> <li>– Allowed researchers to integrate clinical protocols in PD patients</li> <li>– Enabled researchers to collect more families/cases</li> </ul> </li> <li>• Improved access to researchers (5)                             <ul style="list-style-type: none"> <li>– Enabled the recruitment of strong new investigators to the Center</li> <li>– Channeled researchers (especially basic researchers) into PD research</li> <li>– Provided training opportunities to clinicians and PhDs, who have in turn developed careers in movement disorders</li> </ul> </li> <li>• Allowed us to achieve results and make new discoveries (6)</li> <li>• Allowed us to achieve accomplishments faster (3)</li> <li>• Provided focus for seeing interrelated interests across several neurodegenerative diseases (2)</li> </ul>
<b>The Udall Center Structure had no impact on helping us to achieve our research results</b>
<ul style="list-style-type: none"> <li>• Did not make a difference; results would have occurred anyway (2)</li> </ul>

Survey respondents also offered their perspectives on the degree to which their Centers focused on interrelated scientific problems in the first five years. As shown in Exhibit 60, the vast majority of Center Directors and Project/Core Leads reported that the focus on interrelated scientific problems increased after becoming Udall Centers. In support of this, the Investigators provided specific examples about the nature of their research (e.g., more complex studies, the ability to move potential therapies from the lab to the clinic, increased collaboration across

genetic studies) and the supporting mechanisms, such as an infrastructure that promotes collaboration and coordination.

Exhibit 60. Increased Focus on Interrelated Scientific Problems in First Five Years

SURVEY RESULTS (Center Directors and Project/Core Leads): Did your Center become more focused on interrelated scientific problems within the first five years?	
	If yes, in what ways? If not, please elaborate.
Yes (33)	<ul style="list-style-type: none"> <li>• Engaged in more complex and/or joint experimental efforts (10)</li> <li>• Established infrastructure as a result of meetings/seminars, site visits, publications, constructive criticism, and sharing of data, technology, resources, and reagents (both in and outside Center) (8)</li> <li>• Provided an incentive for other PD researchers to work with Center investigators (6)</li> <li>• Encouraged focus that would not have happened without the Udall Center designation (4)</li> <li>• Found causal/risk factors that led to therapeutic interventions (moving potential therapies from the lab to the clinic via multi-disciplinary teams) (4)</li> <li>• Increased collaboration across genetic studies (4)</li> <li>• Focused work on improving understanding of how abnormal mitochondrial genomes and mitochondrial function are involved in PD pathogenesis (3)</li> <li>• Encouraged approaching scientific problems from both a basic science and clinical perspective (3)</li> <li>• Allowed an integration of activities that resulted in a greater scientific contribution than could be achieved if each project were pursued individually (2)</li> <li>• Increased interaction among researchers working on basic science projects (1)</li> <li>• Increased understanding and focus on clinical applications, systems physiology, and basal ganglia anatomy (1)</li> <li>• Catalyzed work in inflammation (1)</li> <li>• Moved the neuroprotection and cell regeneration field forward in a goal-oriented manner (1)</li> <li>• Allowed us to focus on the development of genetic mouse models (1)</li> <li>• Increased focus via PD pathogenic pathways (1)</li> </ul>
Somewhat (4)	<ul style="list-style-type: none"> <li>• Was collaborative before the Udall Centers but stable Udall funding advanced this (3)</li> <li>• Some areas expanded in focus while others became less focused (1)</li> </ul>
No (1)	<i>No further explanation available*</i>

\*More detailed comments would reveal the identity of the responding Center and, therefore, are not included

Finally, the study team examined organizational structure, research emphasis, and degree of emphasis on multidisciplinary research within the Udall Centers. As discussed in more detail in response to Study Question 3.5, the study team found that, after becoming Udall Centers, most Centers established more formal organizational structures. The study team also found that after becoming a Udall Center, the greatest percentage of most Centers' effort was on basic research, followed by translational research and, lastly, clinical research (the area of greatest effort before the Investigators became part of the Udall Centers). And, finally, after becoming Udall Centers, nearly all Centers maintained the same high levels, or even higher levels, of multidisciplinary research.

### 3.7.1.3 Summary

The results showed that the Udall Centers Program encouraged operating in ways consistent with the goal of functioning as integrated multidisciplinary programs focused on a set of interrelated scientific problems. The Centers clearly emphasized using a multidisciplinary approach, collaborating with others, and approaching research challenges as interrelated scientific problems. Center Directors and Project/Core Leads reported that having these types of emphases led to positive research results. While many researchers had used a multidisciplinary approach, they acknowledged that the Udall Centers Program’s encouragement and support of this approach was valuable and enhanced their abilities to accomplish their research goals.

### 3.7.2 Study Question 5.2 – To what extent did the Udall Centers demonstrate early results leading to new hypotheses relevant to PD?

#### 3.7.2.1 Approach

The study team examined the degree to which the Udall Centers Program met the goal of achieving early results leading to new hypotheses relevant to PD. The study team analyzed survey data on respondents’

perspectives on their top discoveries, findings, and results during the five-year time period as well as the impact of these discoveries, findings, and results on the development of new research techniques, therapies, and prevention strategies.

The study team also compiled a publication list for each Udall Center Investigator and examined these publications as a method for determining hypothesis generation and its relevance to PD. Because research publications take time to produce, the study team allowed for publications beyond the end of the study period (through October 31, 2006). The study team then submitted the lists to Thomson Scientific, which provided an evaluation of each publication.

Data Sources and Questions for Research Question 5.2	
Data Source	Questions
Thomson Scientific	N/A
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>• Please discuss your Center's findings in terms of basic, translational and clinical research from the first 5 years. Please discuss:                             <ul style="list-style-type: none"> <li>– Your Center's top five (5) key discoveries/findings/results</li> <li>– The impact these discoveries/findings/results have had on the development of new research techniques</li> <li>– The impact these discoveries/findings/results have had on the development of new therapies, prevention strategies, etc.</li> </ul> </li> </ul>

#### 3.7.2.2 Results

The study team categorized each of the Udall Center discoveries into one of six major areas: (1) PD pathophysiology, (2) clinical investigations of PD (i.e., developing methods for better diagnosis of PD), (3) technological developments in PD, (4) treatment options (includes discovery of new therapeutic mechanisms for PD treatment), (5) dopamine signaling, and (6) basal ganglia function. The most prevalent theme for all Udall Centers was investigation into the pathophysiology of PD (Exhibit 61). This included investigations into the role of alpha-

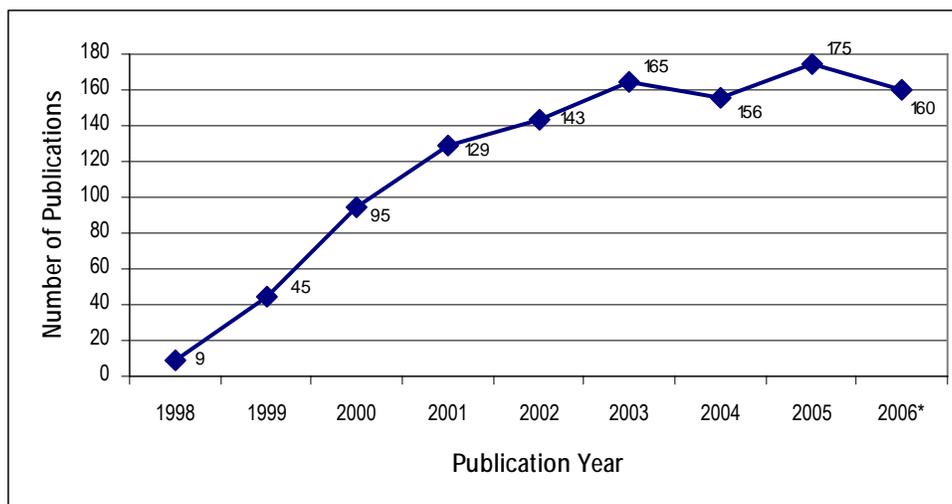
synuclein, Parkin, novel mechanisms involved in PD pathogenesis, and trophic factors in PD. See Appendix J for a complete list of themes.

Exhibit 61. Survey Results: The Number of Centers that Listed Discoveries/Findings/Results in Six Major Areas

Please discuss your Center's findings in terms of basic, translational, and clinical research from the first 5 years. Please discuss your Center's top five (5) key discoveries/findings/results.	
• PD Pathophysiology (9)	• Technological Developments (6)
• Clinical Investigations (8)	• Basal Ganglia Function (5)
• Treatment Options (7)	• Dopamine Signaling (4)

The study team also computed the total number of publications produced by the Udall Investigators each year, from the time the Centers were established until October 2006. Udall Center Investigators authored 1,077 articles related to PD between September 1998 and October 2006. The study team found a steady increase in Udall Investigator publications over time, albeit with one slight decline in year six (see Exhibit 62).

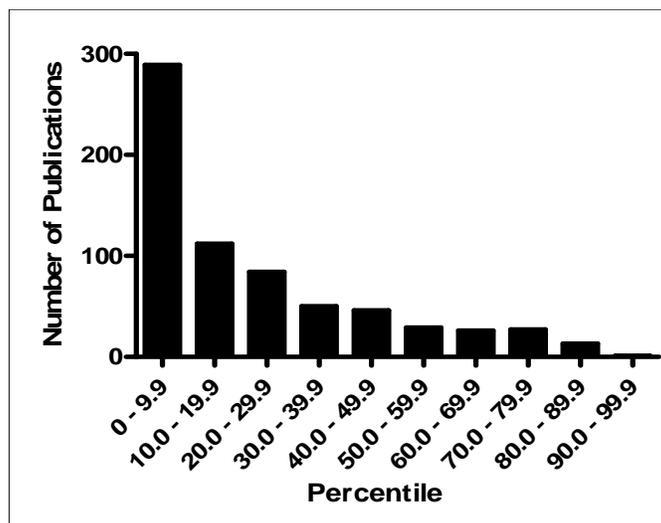
Exhibit 62. PD Relevant Publications by Udall Center Investigators From 1998 to 2006



*\*The study team retrieved the publication data at the beginning of November 2006. Therefore, the number of publications for 2006 only includes those articles published by October 31, 2006.*

Additionally, the study team used the results from Thomson Scientific to evaluate the publications generated by the Udall Investigators. Thomson Scientific relies on a metric called “percentile position,” which is based on a formula that includes the number of times the publication has been cited, the type of publication (e.g., article, review, editorial) in which it has been cited, and other factors. Based on this metric – and including only original Udall Investigator articles (i.e. articles that were not review or editorial articles) (of which there were 693) – the study team found that a large number of the Udall Center publications were in the top percentile (in the tenth percentile or less) in the PD field during the time period of interest.

Exhibit 63. Percentile Position for Udall Investigators' Publications



**3.7.2.3 Summary**

The most common research area of focus of the Udall Centers was investigation into the pathophysiology of PD. An increasing rate of publication and positive metrics on the value of the published research papers shows the effect of the Udall Investigators' work during the first five years of the Udall Centers Program. The discoveries, findings, and results of the Udall Centers demonstrate the focus of the Udall Centers Program on PD research.

**3.7.3 Study Question 5.3 – To what extent did the Udall Centers develop new procedures for sharing PD research findings and scientific techniques?**

**3.7.3.1 Approach**

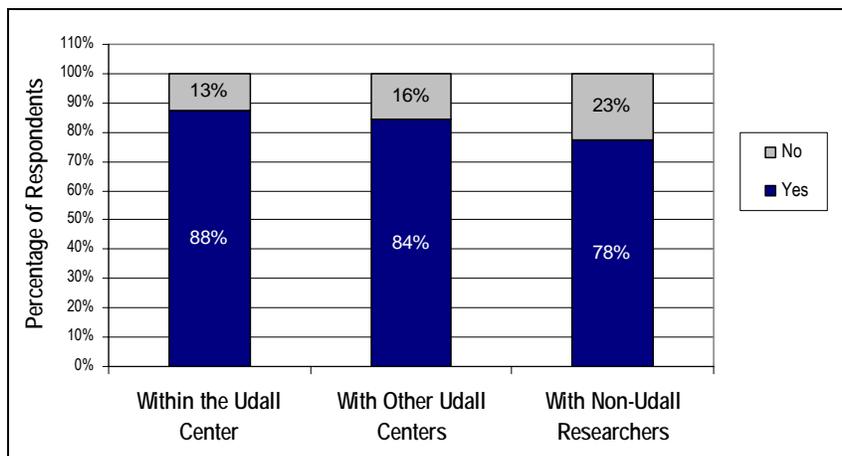
To answer this question, the study team asked Udall Center Directors and Project/Core Leads to discuss new methods they had developed for sharing research findings and scientific techniques in three different areas: within the Center, with other Udall Centers, and with non-Udall researchers. The study team also asked how these methods impacted the Udall Center Investigators' collaborative efforts at these three levels.

Data Sources and Questions for Research Question 5.3	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>Did the act of becoming a Udall Center increase collaborative efforts (e.g., increased communication and joint research efforts including sharing of tools, techniques, concepts, and research findings) within your Center? With other Udall Centers? With non-Udall researchers?</li> </ul>

**Within the Udall Center**

Of the interviewed Center Directors and Project/Core Leads, 35 out of 40 (87 percent) reported that becoming a Udall Center increased collaboration within their Center (see Exhibit 64). Similarly, they reported high levels of increased collaboration with other Udall Centers and with non-Udall researchers.

Exhibit 64. Interview Results: Did Becoming a Udall Center Increase Your Collaborative Efforts Within the Udall Center, With Other Udall Centers, and/or With Non-Udall Researchers?



When asked to describe the increase in collaboration they observed within their Centers, Udall Center Investigators provided a variety of examples (see Exhibit 65), highlighting the means and methods that led to the collaborations. While some respondents addressed specific techniques, such as sharing reagents and animal models, others referred to more general changes, such as increased visibility within the PD field, which in turn led to new collaborations.

Exhibit 65. Interview Results: Sharing Findings and Promoting Collaboration Within the Udall Center

Did the act of becoming a Udall Center increase your collaborative efforts within your Center?	
Yes	<ul style="list-style-type: none"> <li>No further explanation provided (9)</li> <li>Facilitated the sharing of reagents, antibodies, tools, techniques, animal models, clinical and pathological materials, and cores (9)</li> <li>Made us attractive to top talent (including top junior researchers), because they could see they were joining a network of experts – which meant access to their research and discoveries (5)</li> <li>Added formality, even though we were already working together (e.g., more working together, more meetings, and more focused on specific research questions) (4)</li> <li>Allowed us to do more science and to do research we otherwise could not do (3)</li> <li>Increased our credibility and visibility within our institution, which led to more collaboration (3)</li> <li>Facilitated interaction with others in related fields (e.g., Alzheimer’s) within the institution (2)</li> <li>Allowed the Center to expand its clinical side (e.g., psychiatric and cognitive aspects; infrastructure to develop clinical trials) (2)</li> </ul>
No	<ul style="list-style-type: none"> <li>It didn’t change: we have always shared tools and collaborated (2)</li> <li>No further explanation provided (2)</li> </ul>

**With Other Udall Centers**

Thirty-two of 38 (84 percent) Udall Center Investigators indicated that collaboration with other Udall Centers increased. The study team asked Center Directors and Project/Core Leads how their collaboration with other Udall Centers had changed since becoming a Udall Center.

Similar to the previous response on collaboration within their Centers, many Udall Investigators highlighted a variety of examples (see Exhibit 66). Again, respondents mentioned more formal collaborations – such as sharing reagents, databases, and cores – along with less tangible items, such as the expectation to collaborate with other Centers.

Exhibit 66. Interview Results: Sharing Findings and Promoting Collaboration With Other Udall Centers

Did the act of becoming a Udall Center increase your collaborative efforts with other Udall Centers?	
Yes	<ul style="list-style-type: none"> <li>No further explanation provided (14)</li> <li>Facilitated the sharing of ideas, reagents, tools, pathological material, animal models, techniques, cores, and setting up of common databases (5)</li> <li>Expected collaboration because the structure of the Udall Centers is around collaboration (3)</li> <li>Allowed us to do more science and to do research we otherwise could not do (2)</li> <li>Provided access, through other Udall Centers, to many families studied by other clinicians (1)</li> <li>Supported tissue banking, which meant the Center could collect, track, and distribute tissue (1)</li> <li>Promoted collaboration through the Annual Udall Center Meetings (1)</li> </ul>
No	<ul style="list-style-type: none"> <li>No further explanation provided (3)</li> <li>Not yet but may develop with time (2)</li> <li>Not much is different (1)</li> </ul>

**With Non-Udall PD Researchers**

Of the 40 Udall Center Directors and Project/Core Leads who responded to the interview question, 31 (77 percent) reported an increase in collaboration with PD researchers not affiliated with a Udall Center. Once again, the Udall Center Investigators provided a variety of reasons for the expanded collaboration. Some of the respondents cited the sharing of reagents and animal models; however, of those who elaborated on why the Udall Center designation increased collaboration, the most frequent response was a marked increase in credibility and visibility within the scientific community (see Exhibit 67).

Exhibit 67. Interview Results: Sharing Findings and Promoting Collaboration With Non-Udall PD Researchers

Did the act of becoming a Udall Center increase your collaborative efforts with Non-Udall PD Researchers?	
Yes	<ul style="list-style-type: none"> <li>No further explanation provided (10)</li> <li>Increased our credibility and visibility within the scientific community (7)</li> <li>Facilitated sharing of tools, reagents, and animal models (4)</li> <li>Allowed Udall Center investigators to work with researchers from other labs (2)</li> <li>Allowed us to do more science, which led to more interactions and collaborations (2)</li> <li>Made clinical collaborations more successful because of development of the genetics core (1)</li> <li>Provided access beyond the Udall Centers to many families studied by other clinicians (1)</li> <li>Supported tissue banking, which meant the Center could collect, track, and distribute tissue (1)</li> </ul>
No	<ul style="list-style-type: none"> <li>No further explanation provided (4)</li> <li>Udall Center status was not critical for increasing collaboration with Non-Udall Researchers (3)</li> </ul>

### 3.7.3.2 Summary

Overall, the majority of Udall Center Investigators who responded to the interview questions indicated an increase in collaboration and the sharing of scientific techniques and research findings at all three levels of interest: within their Udall Center, with other Udall Centers, and with non-Udall PD researchers. When asked to provide examples, Udall Center Investigators highlighted formal methods, such as the sharing of animal models, tools, and reagents, in addition to more general observations, such as an increase in recognition and visibility throughout the PD research field and the scientific community at large.

### 3.7.4 Study Question 5.4 – To what extent did the Udall Centers recruit new faculty and trainees to PD research?

#### 3.7.4.1 Approach

To measure whether the Udall Centers were able to recruit new faculty and researchers to PD research, the study team relied on the survey data from the Center Directors and Project/Core Leads. The study team was interested in the full range of researchers at the Centers and asked the Udall Center Investigators to comment on their levels of engagement with the research and the degree to which they had joined the PD research community. The responses provided by the Udall Center researchers fell into four categories: junior trainee<sup>31</sup> recruitment, senior researcher<sup>32</sup> recruitment, organizational features, and progress made.

Data Sources and Questions for Research Question 5.4	
Data Source	Questions
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>What effect did your Center have on building the future leaders of PD research (e.g., did funding stimulate others to get involved in PD research) during the first 5 years? Have the new PD researchers (whether junior trainees or more senior researchers joining the PD community) been fully engaged in the research, and have they made progress? If so, in what ways?</li> </ul>

#### 3.7.4.2 Results

##### Junior Trainee Recruitment

Of the 36 Center Directors and Project/Core Leads who responded to this survey question, 24 commented on the number of trainees and/or the number of trainees who continued to participate in the PD community or other relevant areas of neurodegenerative disorders. The Director of one Center stated that his/her Center supported over 40 trainees in PD-related science and clinical discovery research. A Project/Core Lead at another Center recalled over a dozen new researchers becoming part of his Center. Specific examples of junior trainee recruitment hires appear in Exhibit 68.

<sup>31</sup> Udall Investigators often indicated when they were reporting on junior trainees on the web-based survey. In the absence of any indication, however, the study team included junior scientists, fellows, post-doctoral trainees, graduate students and undergraduate students within the junior trainee category.

<sup>32</sup> Udall Investigators often indicated when they were reporting on senior researchers on the web-based survey. In the absence of any indication, however, the study team included established researchers, assistant professors, associate professors and faculty members within the senior researcher category.

Exhibit 68. Survey Results: Junior Trainee Recruitment During the First Five Years of the Udall Centers Program

Hiring and Recruitment of Junior Faculty
<ul style="list-style-type: none"><li>• Three junior faculty: one clinical scientist, one cell biologist, and one animal model expert (1)</li><li>• Two junior scientists and three fellows in clinical methodology (1)</li><li>• Four post-doctoral fellows (1)</li><li>• Two junior faculty in neurodegenerative/PD research, two post-docs, and one graduate student (1)</li></ul>

Additionally, many Udall Center Investigators detailed the ways in which these junior trainees progressed and established themselves within the PD community. A Project/Core Lead from one Center indicated that one junior faculty and several post-docs at the Center had committed themselves to careers in PD research. At two other Centers, two Project/Core Leads explained that some of the Centers' trainees had already moved onto PI positions and/or academic research professorships. Finally, the Director of another Center commented on how his/her Center had developed seven junior faculty during the first five years of the Udall program – two of whom were promoted to Assistant Professor level at the home institution and five of whom were promoted to positions elsewhere.

**Senior Researcher Recruitment**

While junior trainees were a major part of the Udall Center recruitment program, senior researchers were also sought out as potential contributors to the PD research field. One Center Director explained that the Udall Center designation played a major role in stimulating basic scientists – scientists who had not previously engaged in PD research – to become involved. Two Project/Core Leads, one from each of two Centers, indicated that their participation in the Udall Centers Program had a major impact on the direction of their future research: both scientists credited the program with bringing them and their trainees into the PD field. Another Project/Core Lead explained the Udall Center was an important mechanism in allowing his/her career to develop. Although the Project/Core lead started with the Center as a junior faculty member, he/she was promoted to a tenure-track Associate Professor position – a development the Project/Core Lead attributes to the research productivity enabled by the Udall Center.

Exhibit 69 shows more examples of senior researcher recruitment to PD-related work. Overall, 16 of the 36 Udall Center researchers (44 percent) responded that the Udall Centers Program helped bring senior researchers into the PD field. Only 2 of 36 respondents (6 percent) thought the Udall Centers had no effect on recruiting new faculty and trainees to PD research.

Exhibit 69. Survey Results: Senior Researcher Recruitment During the First Five Years of the Udall Centers Program

Hiring, Recruiting, and Developing Senior Researchers
<ul style="list-style-type: none"><li>• Faculty and senior members of the Udall Center group have made a long-term commitment to PD research (5)</li><li>• New investigators were included in the renewal application/supplements at the end of the first 5 years (3)</li><li>• New investigators to PD research were proactively recruited, due to the funding of pilot projects (2)</li><li>• Four researchers developed into world leaders in PD genetics and cell biology (1)</li><li>• One senior researcher now runs a Center at another institution, while another runs a program elsewhere (1)</li><li>• Several international fellows, who are leaders in PD research in their countries, were trained/co-trained by the Center (1)</li></ul>

### Organizational Features

As part of the organizational structure of the Udall Centers Program, many Centers established regular meetings and conferences. These meetings served as ways to attract new scientists for potential collaborations and exposed Udall Investigators to the various paths of research within the PD field. The Center Director and Project/Core Leads from one Center provided specific details on this area of development, and they highlighted two main features of their program:

1. Weekly meetings (including all trainees): Presentations of research-in-progress made by the trainees on a rotating basis
2. Biannual half-day symposium: Included all PIs and trainees working on PD research within or outside the Udall Center.

While this Center was the only one to provide details about its organizational structure and support of trainees and senior researchers, other Centers had similar programs in place during the first five years of the Udall Centers Program. See Study Questions 4.1 and 10 for further information.

### Progress Made

Finally, several Project/Core Leads shared specific items of research progress resulting from the Udall Centers' emphasis on developing new and junior scientists. An Investigator from one Center explained that this support had a significant impact on influencing the initiation of drug discovery efforts. An Investigator from another Center indicated that the Udall Center encouraged two successful grant applications: one on functional neuroimaging of depressive symptoms in PD and the other on neuroimaging in a non-human primate model of the disease. Finally, a Project/Core Lead from a third Center reported that the development of both established researchers and junior trainees into PD investigators significantly affected PD clinical research.

#### 3.7.4.3 Summary

Overall, Udall Center Directors and Project/Core Leads felt the Udall Centers Program had a large impact on developing junior trainees and senior researchers into significant contributors to the field of PD research and, in some cases, prominent members of the PD research community. As one Project/Core Lead explained, the Udall Centers Program provides clear evidence that the

NIH is committed to PD research, which strongly affects how potential researchers view opportunities in the field.

### **3.7.5 Study Question 5.5 – To what extent did the Udall Centers produce more multidisciplinary research relevant to PD?**

#### **3.7.5.1 Approach**

To determine whether the Udall Centers produced more multidisciplinary research relevant to PD, the study team compared a random sample of publications by Udall Center Investigators at three points in time: 1999, 2002, and 2005.

The study team selected 1999 for its baseline data because only three of the Udall Centers received funding in 1998, with the remainder funded in September 1999. Therefore, it is highly unlikely that articles published in 1999 were the result of research activities supported by the Udall Centers Program. To ensure that the three Centers funded in 1998 did not publish any articles resulting from Udall Center funding, the study team cross-checked the publications with those listed in IMPAC II as associated with the Udall Center grant number. This cross-check revealed three publications associated with Udall Center funding, and the study team eliminated them from the analysis.

#### **Data Sources and Questions for Research Question 5.5**

- Publications accessed via the National Library of Medicine (<http://www.nlm.nih.gov/>)
- IMPAC II

The study team selected 2002 and 2005 because the two different comparison points helped ensure that the findings were not simply the result of a particular year being an outlier. In addition, 2002 represents an approximate midpoint in the funding period between 1998 and 2006, while 2005 represents the last year for which the study team had complete (i.e., full year) publication data.

The study team then selected a random sample of 25 publications from each year (1999, 2002, and 2005) and reviewed the author affiliations to determine if the research involved multidisciplinary collaboration. The study team defined multidisciplinary collaboration as collaboration with investigators in other departments and fields.

#### **3.7.5.2 Results**

In terms of multidisciplinary research that resulted in scholarly publications, the study team evaluated the 25 sample articles from 1999, 2002, and 2005. The study team found that –

- In 1999, 22 of the 25 publications (88 percent) involved multidisciplinary research.
- In 2002, 23 of the 25 publications (92 percent) involved multidisciplinary research.
- In 2005, 21 of the 25 publications (84 percent) involved multidisciplinary research.

#### **3.7.5.3 Summary**

As seen in Study Question 5.2, the number of publications increased markedly throughout the duration of the Udall Centers Program. However, the study team found no evidence of a significant difference in the number of publications involving multidisciplinary research as a

result of Udall Center funding. These results are consistent with information presented earlier that most Investigators reported use of a multidisciplinary approach in their research before the Udall Centers' formation.

**3.7.6 Study Question 5.6 – To what extent did the individual Udall Centers and the Centers as a group achieve broader research and infrastructure support for projects relevant to PD?**

**3.7.6.1 Approach**

To determine whether the Udall Centers achieved broader research and infrastructure support for projects relevant to PD, the study team obtained and analyzed grant histories for Center Directors and Project/Core Leads at each Center. To develop a comprehensive view of the research and infrastructure support the Investigators received during the first five years of the Udall Centers Program, the study team collected and aggregated NIH grant totals received by the Udall Investigators for PD research.

Data Sources for  
Research Question 5.6

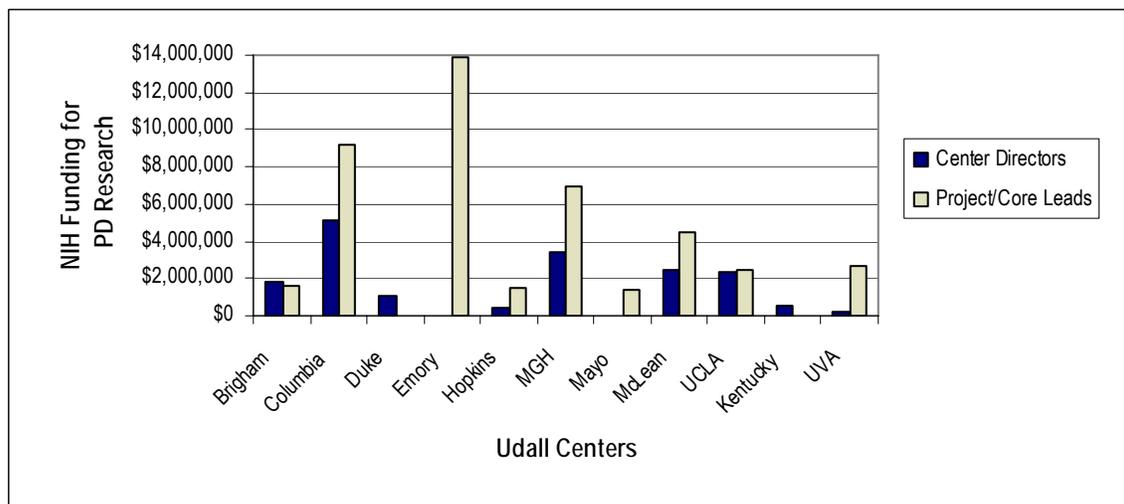
- IMPAC II

**3.7.6.2 Results**

**Udall Center Directors**

As a group, the Center Directors received approximately \$17.5 million in additional funding from the NIH for PD research between FY99 and FY04. The largest amount of NIH funding for PD research (excluding Udall-related grants) Udall Center Directors received was \$5,149,604 (see Exhibit 70), and one Center did not receive any funding for PD research beyond the Udall Center grant. The average amount of NIH funding awarded to Udall Center Directors for PD research during the first five years of the Udall Program was \$1,586,056, even with five of the Center Directors receiving less than \$515,000. At three Centers, the Directors obtained more NIH funding for projects relevant to PD than did the Project/Core Leads.

Exhibit 70. Total NIH PD Funding (Excluding Udall-Related Grants) Received by Udall Center Directors and Project/Core Leads During the First Five Years of the Udall Centers Program



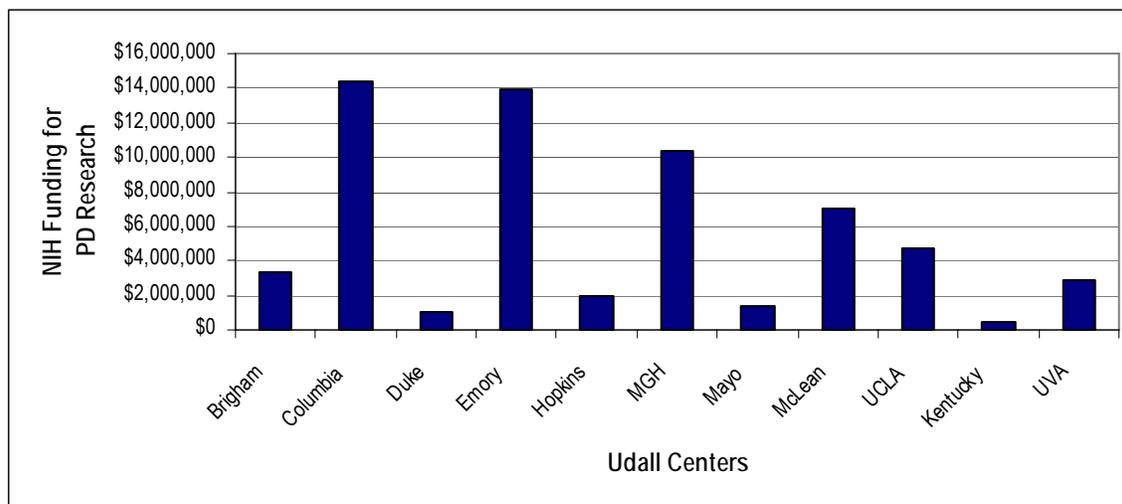
### Project/Core Leads

In total, the Project/Core Leads at all of the Udall Centers received \$44,146,686 in additional research and infrastructure support for PD research from the NIH. The Project/Core Leads who received the greatest amount of NIH funding for PD research totaled \$13,841,356 between FY99 and FY04, while two Centers received no extramural funding support from the NIH for PD research (see Exhibit 70). On average, Project/Core Leads received over \$4 million in NIH funding for PD research between FY99 and FY04. At most of the Udall Centers, the NIH funding for PD research that the Project/Core Leads obtained exceeded the funding the Center Directors received. While the number of Project/Core Leads at each Center varied – with a range of three to five Investigators – the number did not appear to impact the funding totals for each Center.

#### 3.7.6.3 Summary

Overall, the Udall Center Directors and Project/Core Leads successfully obtained additional funding support from the NIH for their PD research efforts. Between FY99 and FY04, in addition to the Udall Center grants, the Udall Center Directors and Project/Core Leads obtained more than \$65.1 million in funding for PD research from the NIH (see Exhibit 71). The Center with the largest amount of additional funding received a total of \$14,344,879, while the Center with the smallest amount received \$498,599. The average amount of funding the Udall Centers received from the NIH for PD research, outside of the Udall Center grant, was slightly less than \$6 million.

Exhibit 71. Total NIH PD Funding Received by Udall Center



While the analysis did not include non-NIH funding, several Investigators indicated that Centers received private funding as a result of their Udall Center status. Center Directors and Project/Core Leads from four Centers indicated that their Centers received private donations during the first five years of the Udall Centers Program, but none specified an amount.

### 3.8 Study Question 6

To what extent did the individual Udall Centers and the Centers as a group achieve the following long-term research goals during their first five years:

- Noteworthy research discoveries involving basic, clinical, and/ or translational research that are likely to advance the prevention, diagnosis and/or treatment of PD
- New scientific tools developed and shared with other PD researchers (e.g., new models, technologies, databases, repositories, classification standards, research techniques)
- Increased number of independent research scientists conducting PD research
- Increased level of collaboration with other PD researchers and the broader PD community
- Increased institutional commitment to PD research

#### 3.8.1 Study Question 6.1 – *Noteworthy research discoveries involving basic, clinical, and/or translational research that are likely to advance the prevention, diagnosis and/or treatment of PD*

##### 3.8.1.1 Approach

The study team collected and themed survey data from the Center Directors and Project/Core Leads to determine the most important advances made during the initial Udall Center funding period. The study team recorded negative responses when survey responses listed a top five research accomplishment but either put *none* or *N/A* for the impact this discovery on the development of novel therapeutics or prevention strategies.

Data Sources and Questions for Research Question 6.1	
Data Source	Questions
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>• Please discuss your Center's findings in terms of basic, translational and clinical research from the first 5 years. Please discuss:                             <ul style="list-style-type: none"> <li>– Your Center's top five (5) key discoveries/findings/results</li> <li>– The impact these discoveries/findings/results have had on the development of new research techniques</li> <li>– The impact these discoveries/findings/results have had on the development of new therapies, prevention strategies, etc.</li> </ul> </li> </ul>

##### 3.8.1.2 Results

Udall Investigators reported on the expected impact of their top five research discoveries made during the first five years of Udall Center funding (see Appendix J for Udall discoveries). The study team analyzed the responses received from Center Directors and Project/Core Leads and grouped the responses by category. Nine of the 10 Centers that participated in the survey reported that their discoveries had an impact on the prevention, diagnosis, and treatment of PD. The top three areas of impact (on prevention, diagnosis, and treatment of PD) noted by the nine Centers were: 1) development of a novel screening method; 2) development of a potentially novel treatment for PD; and 3) work that formed the basis for clinical trials (see Exhibit 72).

Exhibit 72. Survey Results: Centers Reported Impact on Prevention, Diagnosis, or Treatment Strategies for PD

Please discuss the impact these discoveries/findings/results have had on the development of new therapies, diagnosis, or prevention strategies, etc.
<ul style="list-style-type: none"><li>• Developed a novel system or target for screening drug libraries (stable cell lines, mouse models, protein degradation pathways, mGluR4 activation, GDNF/trophic factor delivery, SK channel, PARP-1 inhibitors, cPLA2, computer based pharmacology) (8)</li><li>• Developed a potential treatment for PD which is still under investigation (low energy laser, new deep brain stimulation procedures, embryonic stem cell<sup>33</sup> derived dopamine neurons, p75<sup>ICD</sup>, nicotine, neural transplantation of dopamine cells, AKT viral transduction method, drug delivery pump, transcranial stimulation, small molecules, TrkA agonists, mGluR5) (6)</li><li>• Formed the basis for new clinical trials aimed at the treatment of PD (GDNF, Co-enzyme Q10, antioxidants, creatine, anti-inflammatory agents, RNAi, STAZN, Tempol, improved dopamine cell implantation methods, BDNF) (6)</li><li>• Developed biomarkers or other techniques for early diagnosis (5)</li><li>• Identified novel genetic marker to screen individuals for PD (Lrrk2, Mitochondrial gene ND5) (3)</li><li>• Identified novel candidate genes for PD research (2)</li><li>• Helped to determine changes during PD treatment (1)</li><li>• Enabled genetic testing to screen for PD genes (1)</li><li>• Grouped PD patients better based on genetic cohorts (1)</li></ul>

**3.8.1.3 Summary**

Of the Centers that responded to the survey, nine Centers (90 percent) reported that the discoveries made during the first five years of funding had an impact on the prevention, diagnosis, or treatment strategies for PD. Of those responses that specified the impact, development of potential treatment for PD, development of a novel screening method, and providing the basis for new clinical trials were the top three impacts reported.

---

<sup>33</sup> Udall Centers used only human embryonic stem cell (HESC) lines that were federally approved. This applies to all HESC references in this report.

**3.8.2 Study Question 6.2 – New scientific tools developed and shared with other PD researchers (e.g., new models, technologies, databases, repositories, classification standards, research techniques)**

**3.8.2.1 Approach**

The study team collected and evaluated interview and survey responses from Center Directors and Project/Core Leads to determine to what extent they developed any new research techniques or novel animal models during the initial five-year funding period. The study team counted a non-response when the individual reported a finding but indicated *N/A* or *none* when reporting that finding’s impact in terms of new technique. Upon review of the Udall Investigators responses on whether their discoveries had an impact on development of new research techniques, the study team realized that the responses could be segmented into three groups: tools, methods, and research foci.

Data Sources and Questions for Research Question 6.2	
Data Source	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>If applicable to your work, did you develop any new animal models in the first five years of your Udall funding? If yes, have you shared these models with other researchers, and by what mechanisms?</li> </ul>
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>Please discuss your Center’s findings in terms of basic, translational and clinical research from the first 5 years. Please discuss:                             <ul style="list-style-type: none"> <li>Your Center’s top five (5) key discoveries/findings/results</li> <li>The impact these discoveries/findings/results have had on the development of new research techniques</li> <li>The impact these discoveries/findings/results have had on the development of new therapies, prevention strategies, etc.</li> </ul> </li> <li>Did you establish novel strategies to promote collaboration (e.g., increased communication and joint research efforts including sharing of tools, techniques and concepts) within your Center, with other Udall Centers, and/or with non-Udall researchers during the initial funding period? Please describe.</li> </ul>

**3.8.2.2 Results**

The study team asked both Center Directors and Project/Core Leads to list any novel animal models generated during their initial funding period and to discuss their top five research discoveries.

**Development of Animal Models**

The study team asked both Udall Center Directors and Project/Core Leads whether their Centers developed any new animal models. The study team collated the responses by Center and found that, of the eleven Centers that responded to this interview question, Investigators from eight Centers (73 percent) reported that their Center had developed a new animal model within the first five years of funding as a Udall Center.

The study team also analyzed the individual responses by Center Director and Project/Core Leads. Ninety percent of the Center Directors interviewed (which represented eight Centers) reported that their Center had developed a new animal model within the first five years of being a Udall Center. Of the Project/Core Leads interviewed, eight out of 29 (which represented seven Centers) reported developing a new animal model within the first funding period.

When the study team asked the Udall Investigators if and how they shared their animal models, eight Centers responded that they had done so. Four of the eight Centers (50 percent) shared their animal model protocols with other groups, three of the Centers (38 percent) described their model or methods in meetings, and two of the Centers (25 percent) shared their model by sending it to other labs with a material transfer agreement (see Exhibit 73).

Exhibit 73. Interview Results: Mechanisms that Centers Used to Share their Animal Models

If applicable to your work, did you develop any new animal models in the first five years of your Udall funding? If yes, have you shared these models with other researchers, and by what mechanisms?
<ul style="list-style-type: none"><li>• Shared protocols with other groups (4)</li><li>• Used meetings to describe the methods/discuss model (3)</li><li>• Sent the model to other labs (UPS/FedEx) including a Material Transfer Agreement (2)</li><li>• Provided to other labs when contacted (2)</li><li>• Transferred mice to Jackson Labs (1)</li><li>• Included in the Mutant Mouse Regional Resource Center (1)</li><li>• Shared models with the Parkinson's Institute (1)</li><li>• Shared with other Udall Centers for their repositories (1)</li><li>• Shared via publication (1)</li></ul>

### Development of New Research Techniques

The study team analyzed Udall Investigators' survey responses on their discoveries from the first five years of funding. The study also analyzed the Udall Investigators' responses to the survey question that asked whether these discoveries had any impact on new research techniques. Upon review of the responses, the study team found that the responses could be grouped into three categories: tools, methods, and research focus. The study team defined *tools* as any novel research item (e.g. antibody, peptides, agonists, antagonists), or physical item used for PD research.<sup>34</sup> The study team defined *methods* as how existing tools could be used in a novel way to aid PD research; examples include new microscopy methods or cell culture methods. When Investigators responded that their work generated insights into new areas for PD research, the study team grouped the responses into the *research focus* category.

#### *Tools*

Nine of the ten Centers that responded to the survey reported their discoveries had an impact on the development of tools for PD research, where tools is defined as any novel research item or physical item used for PD research. The most frequently reported tool, cited by 44 percent of the Centers, was the development of new diagnostic tools for PD. A complete list of these tools can be seen in Exhibit 74.

<sup>34</sup> Note that although the Udall Investigators' answered a survey question specifically on their development of new animal models, many Investigators also included animal models in their response to the survey question on whether their discoveries led to new research techniques. The study team placed animal models into the category of research tools.

Exhibit 74. Report of Novel Tools During the Initial Five-Year Funding Period of the Udall Centers Program

Please discuss your Center's findings in terms of the impact these discoveries/findings/results have had on the development of <i>new research tools</i> .
<ul style="list-style-type: none"><li>• Developed new diagnostic tools for PD (GAT1, new PET method, Girk2, live cell imaging) (4)</li><li>• Identified new protein for study in PD research (PARP-1, mGluR4, TrkA, DJ1, ubiquitin ligase, synphilin-1, dyt-1) (3)</li><li>• Developed novel reagents (antibodies, NGF mutant, in vivo biosensors, microarray) (3)</li><li>• Developed novel animal models (non-human primate, tau mouse, alpha synuclein mouse, Lrrk2 mouse) (3)</li><li>• Developed novel cell lines (cybrids, inducible synuclein overexpression, ts-p53 line) (3)</li><li>• Determined novel therapeutic delivery systems (microfluidics, viral vectors) (1)</li><li>• Developed novel genetic models to examine gene interactions (1)</li><li>• Developed virtual reality environment for PD sensory/motor testing (1)</li><li>• Developed novel imaging ligands (1)</li><li>• Developed new screening tool (1)</li><li>• Developed or was involved in commercial genomic tests (1)</li><li>• Developed HTS for assessing synuclein aggregation (1)</li><li>• Identified new biomarkers for PD (1)</li><li>• Developed novel statistical methods (gene association X-linked, neuronal synchrony) (1)</li></ul>

*Methods*

Udall Investigators reported on novel research methods developed during the first five years of the Udall Centers Program, where methods is defined as how existing tools could be used in a novel way to aid PD research. Investigators from nine of the 10 Centers responded that their discoveries had an impact on the development of new research methods. Leading methods were those related to neuronal activity recordings, novel imaging, genetic testing, and genomic convergence. For a complete list of novel methods developed during the first five years of the Udall Centers Program, see Exhibit 75.

Exhibit 75. Novel Methods Developed During the First Five Years of Udall Funding

Please discuss your Center's findings in terms of the impact these findings/results have had on the development of <i>new research methods</i> .
<ul style="list-style-type: none"><li>• Established novel methods for neuronal activity recordings (tetrodes for mice, single unit recordings in basal ganglia, cortical surface electrodes, drug effects in vivo) (2)</li><li>• Developed novel imaging methods (PET, tissue culture, fMRI) (2)</li><li>• Developed better genetic testing methods (2)</li><li>• Solidified the idea that genomic convergence could rapidly narrow a set of candidate genes (2)</li><li>• Enabled more sensitive methods for behavioral testing (in mice) (1)</li><li>• Developed novel methods for investigating drug effects to individual neurons in vivo (1)</li><li>• Developed novel methods for fetal/stem cells in the treatment of PD (1)</li><li>• Identified a new target and small molecules for activating this target to treat PD (1)</li><li>• Determined functional imaging data can be used to validate new biomarkers of disease progression (1)</li><li>• Validated that postmortem mitochondria could be used for functional analysis (1)</li><li>• Developed an intracellular patch electrochemistry technique (1)</li><li>• Developed new sequencing methods (1)</li><li>• Combined behavior tests with in vivo imaging (1)</li><li>• Determined novel high-performance liquid chromatography method to identify DA modified proteins (1)</li><li>• Resulted in "sharpening our analytical tools for choosing candidate molecules" (1)</li></ul>

*Research Focus*

Investigators from six of the nine responding Centers (67 percent) responded that their discoveries introduced new areas of research focus for PD research. The top three novel research fields included the role of inflammation (two of the six Centers), and the study of mtDNA, interneurons and protein folding (two of the six Centers) in PD. A complete list of novel research areas can be found in Exhibit 76.

Exhibit 76. Novel Research Foci Introduced to the Field of PD

Please discuss your Center's findings in terms of the impact these discoveries/findings/results have had on the development of <i>new research foci</i> .
<ul style="list-style-type: none"><li>• Focused PD researchers on the role of inflammation during neurotoxicity (2)</li><li>• Generated a new field of study for PD research (mtDNA, interneurons, protein folding) (2)</li><li>• Brought the field of autophagy into the view of neuroscientists (1)</li><li>• Focused the neuroscience field to examine trafficking mechanisms and protein folding (1)</li><li>• Found that identification of novel mitochondrial gene mutation will prompt investigation of this phenomenon in other sporadic diseases (1)</li><li>• Spurred the investigation of gene/environment interactions (1)</li></ul>

**Collaboration**

Investigators from one Center reported that the impact of their discoveries included an increased interest in sharing models with other PD researchers, which suggests collaboration on the part of this Center. As discussed in Study Question 5.3, when Udall Investigators described an increase in collaboration within their Centers, the most common form of collaboration reported was the sharing of reagents, tools, methods, animal models, clinical and pathological materials, and

cores. When the study team interviewed both Center Directors and Project/Core Leads, 35 of the 40 respondents (87 percent) reported that becoming a Udall Center increased collaboration within their Center. In addition, 32 of the 38 respondents (84 percent) reported an increase in collaboration with other Udall Centers and 31 of the 40 respondents (77 percent) reported an increase in collaboration with other PD researchers who were not affiliated with Udall Centers.

### 3.8.2.3 Summary

Udall Centers developed novel animal models and other tools, methods and research foci during their first five years of Udall funding. In response to the survey question on the impact of Center discoveries, only three Centers reported the development of an animal model; however, when the study team interviewed Center Directors and Project/Core Leads, nine Centers said they developed animal models. Also, as a result of the Centers' discoveries, new diagnostic tools for PD were the most frequently developed novel research tool. The study team learned that Centers primarily shared their models by sharing their protocols with other groups.

## 3.8.3 Study Question 6.3 – To what extent did the individual Udall Centers and the Centers as a group achieve an increased number of independent research scientists conducting PD research?

### 3.8.3.1 Approach

To determine whether individual Udall Centers and the Centers as a group increased the number of independent research scientists conducting PD research during the first five years of the program, the study team conducted a detailed analysis of the grant histories of all Project/Core Leads and research staff.<sup>35</sup> The study considered a researcher to be a new independent PD research scientist if:

Data Sources for  
Research Question 6.3

- IMPAC II

1. He/She did not receive funding for PD-related research *prior* to their participation with the Udall Center, *and*
2. He/She received NIH funding for a PD-related research project *after joining* a Udall Center (the researcher must be named as the Principal Investigator on the research grant).

If a scientist was involved in PD research prior to his/her participation with a Udall Center, he/she was determined to already be part of the PD field and, was not considered to be an “eligible researcher” for the analysis of this question. The findings are presented below for both Project/Core Leads and research staff by Udall Center.

### 3.8.3.2 Results

#### Project/Core Leads

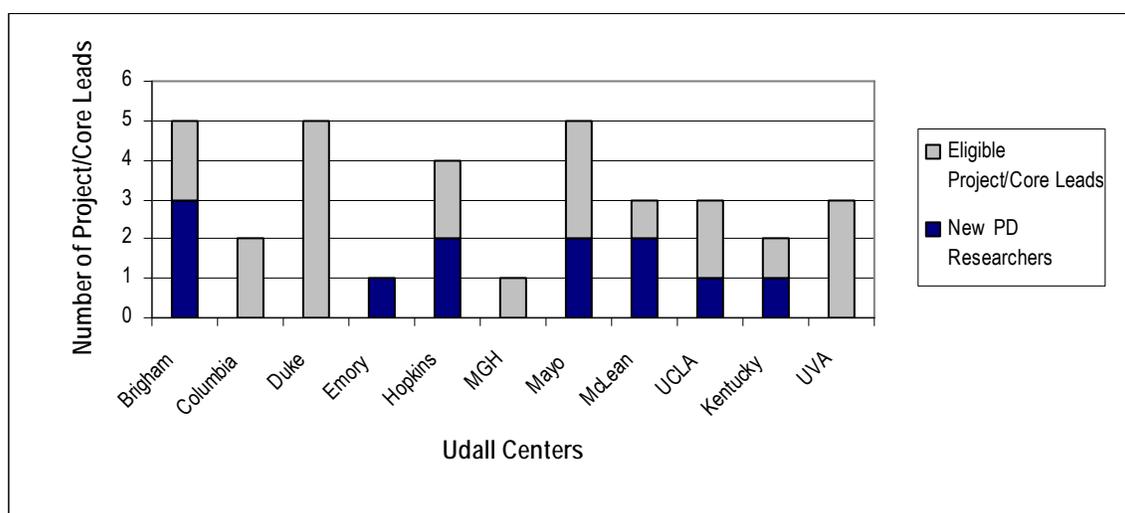
All Udall Centers had at least one Project/Core Lead who had no previous funding for PD research from the NIH, and some had as many as five (see Exhibit 77). As a result, the number of “eligible” Project/Core Leads, who could potentially be counted as new independent research scientists in the PD field, was limited. While the Project/Core Leads remained fairly stable

<sup>35</sup> Research staff includes co-investigators, senior researchers, post-doctoral fellows and research trainees. Exact counts of the research staff were limited by the completeness of the names on the Udall progress reports.

throughout the first five years of the Udall Centers Program, new researchers occasionally assumed these roles within a Center. These scientists were included in the analysis.

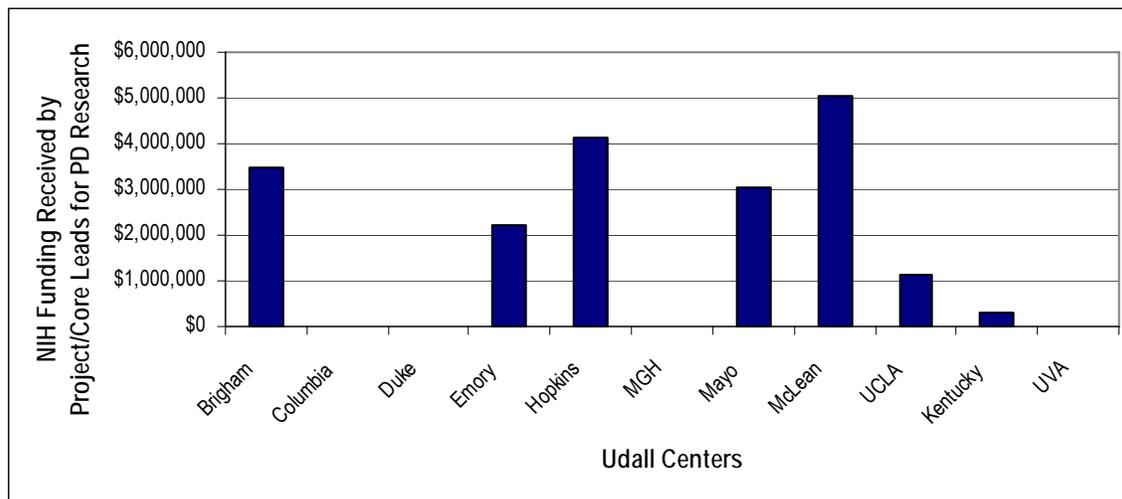
Overall, 12 of the 34 eligible Project/Core Leads (35 percent) at all Udall Centers went on to become PIs on independent NIH grants for PD research. While Brigham and Women’s Hospital had the most Project/Core Leads who became independent research scientists in the PD field (three researchers), Emory University had the highest percentage of Project/Core Leads who proceeded to obtain independent NIH funding for PD research (1 researcher). Of the 11 Centers, four had Project/Core Leads who, although they were eligible for status as new independent researchers in PD, did not receive NIH funding for PD.

Exhibit 77. Project/Core Leads: Number of New Independent Research Scientists



Because no new independent PD researchers developed from the Project/Core Leads at four of the Centers, the NIH funding totals at all four Centers was \$0 (see Exhibit 78). The Project/Core Leads from McLean Hospital obtained the most independent NIH PD funding, which totaled \$5,057,020. With the exception of one Center, as more Project/Core Leads became independent PD researchers, they obtained more independent NIH funding for their Centers.

Exhibit 78. Project/Core Leads: Total Additional NIH Funding Awarded for Newly Independent PD Researchers After Joining a Udall Center

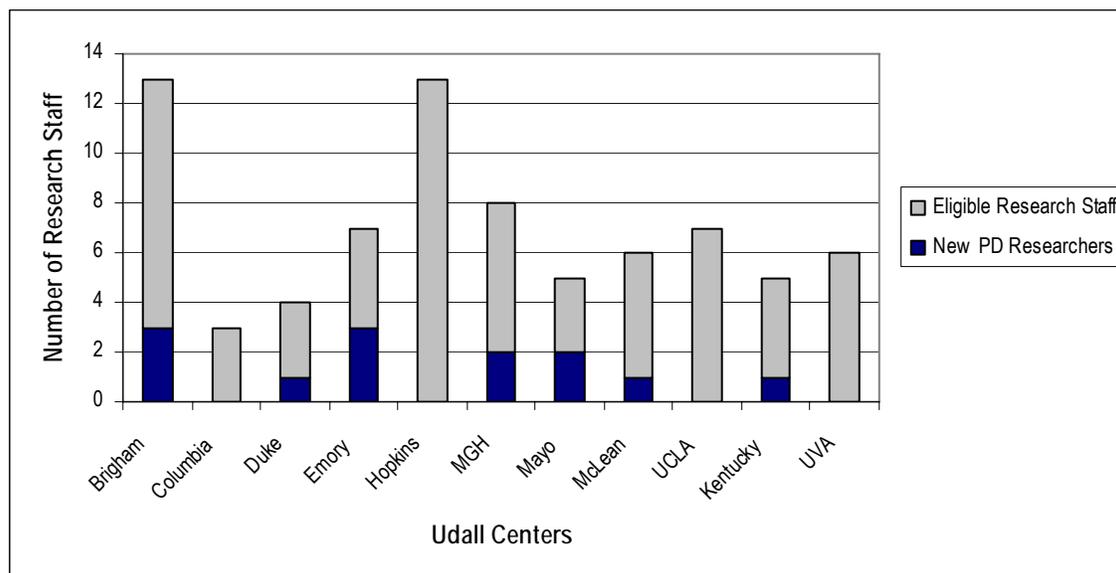


### Research Staff

The number of research staff at each Udall Center was larger than the number of Project/Core Leads. While this is mostly due to the multi-person effort dedicated to each project and core, the research staff also experienced higher turnover rates, particularly among the junior researchers.

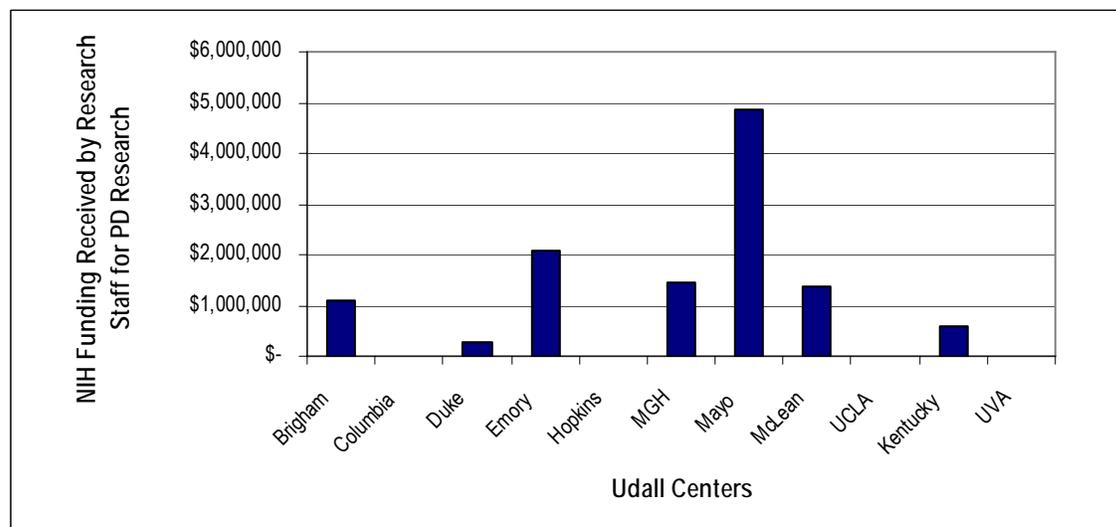
Overall, 13 of the 64 research staff (20 percent) at all Udall Centers went on to become PIs on NIH grants for PD research. Three research staff, from two Centers (Brigham and Women’s Hospital and Emory University), each developed into independent research scientists in the PD field – the most of all the Udall Centers. Of the 11 Centers, seven had at least one member of the research staff become an independent PD researcher in the years following his/her involvement with a Udall Center. Exhibit 79 below illustrates these findings.

Exhibit 79. Research Staff: Number of New Independent Research Scientists



The research staff at the Mayo Clinic obtained the most additional NIH funding for PD research, which totaled \$4,868,152 (see Exhibit 80). Because four Centers had no research staff become independent PD researchers, the funding total for each of these Centers was \$0. Of the Centers with at least one research staff member who became an independent researcher in PD, Duke University had the smallest amount of additional NIH funding for PD research, which totaled \$278,232.

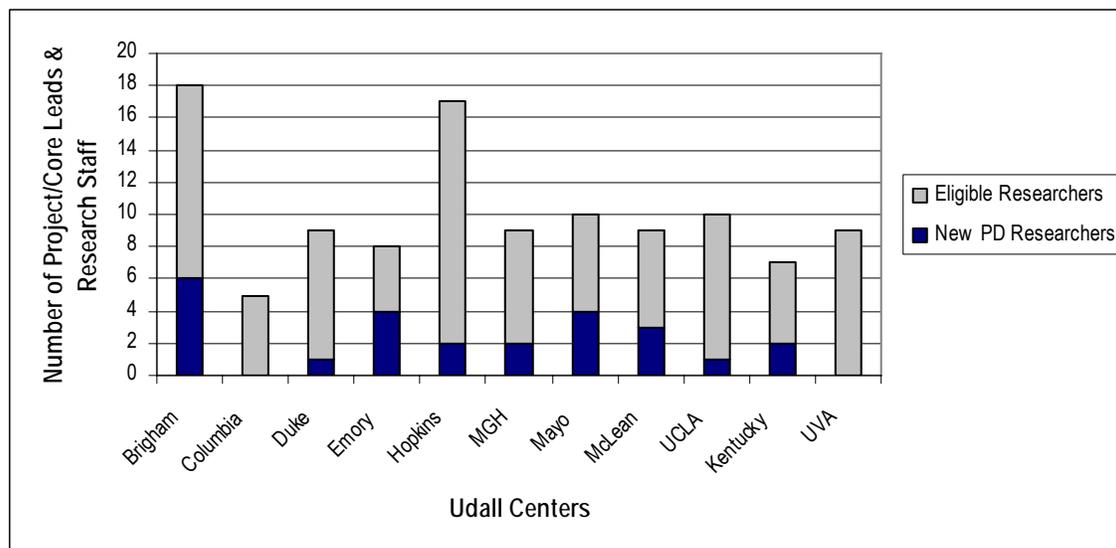
Exhibit 80. Research Staff: Total Additional NIH Funding Awarded for Newly Independent PD Researchers After Joining a Udall Center



### Project/Core Leads & Research Staff

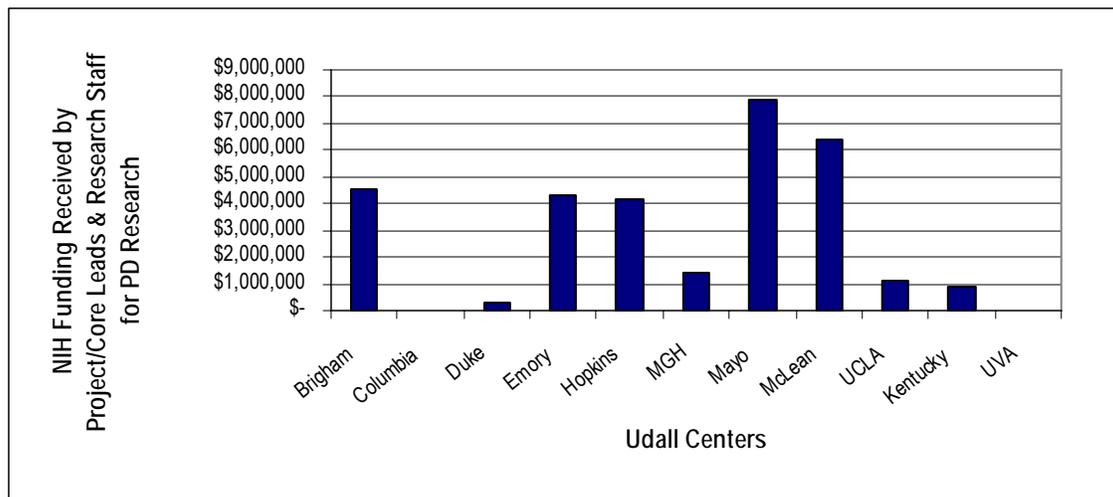
Overall, 25 of the 86 Project/Core Leads and research staff at all of the Udall Centers became independent PD researchers (29 percent). The study team found that Brigham and Women’s Hospital had both the greatest number of eligible scientists (18) and the greatest number of new independent PD researchers (six). At two of the 11 Centers, no Project/Core Leads or research staff developed into independent researchers in the PD. Exhibit 81 illustrates these findings below.

Exhibit 81. Project/Core Leads and Research Staff: Number of New Independent Research Scientists



The 25 new independent PD researchers that developed out of the Project/Core Leads and research staff at the Udall Centers obtained over \$31 million in additional NIH funding for PD research. As expected, Columbia University and the University of Virginia both had NIH funding totals of \$0 since neither Center had a Project/Core Lead or research staff develop into an independent PD researcher (see Exhibit 82). The Mayo Clinic had the largest NIH PD funding total of \$7,909,509, which resulted from four individually-funded independent researchers. Of the Centers with at least one independent PD researcher, the Project/Core Leads and research staff at Duke University obtained the lowest funding total with \$278,232.

Exhibit 82. Project/Core Leads and Research Staff: Total Additional NIH Funding Awarded for Newly Independent PD Researchers After Joining a Udall Center



### 3.8.3.3 Summary

While 31 Project/Core Leads and research staff had obtained PD research funding before their involvement with the Udall Centers, 25 individuals without such prior experience became independent PD researchers after joining the Udall Centers – representing almost one-third of all eligible Project/Core Leads and research staff.

It is worth noting that the method used to determine whether or not the Project/Core Leads and research staff became independent PD researchers after joining the Udall Centers is not all-inclusive. Because the standard of measurement was whether or not the researcher received funding from the NIH as a PI on a PD-related research grant, the analysis did not account for researchers who may have received funding outside of the NIH, through a different government organization or through private funding sources. Additionally, these results do not necessarily indicate that these researchers did not continue to engage in PD-related research. Instead, it can only be asserted that these researchers were not PIs on any PD-related grants awarded by the NIH after they joined the Udall Centers through FY 2006. This does not preclude them from being project or core leads on other NIH grants or from contributing to other PD-related research as co-PIs, co-investigators, or other research staff.

**3.8.4 Study Question 6.4 – Increased level of collaboration with other PD researchers and the broader PD community**

**3.8.4.1 Approach**

The study team used both publication information and interview data to address this question. During structured telephone interviews, the study team asked Center Directors and Project/Core Leads how they had used the annual Udall Center meetings to further their research (e.g., making connections, learning alternate strategies/techniques, identifying ways to collaborate with other Centers). The study team also asked both groups how collaboration had an impact on the Center's ability to achieve its research goals.

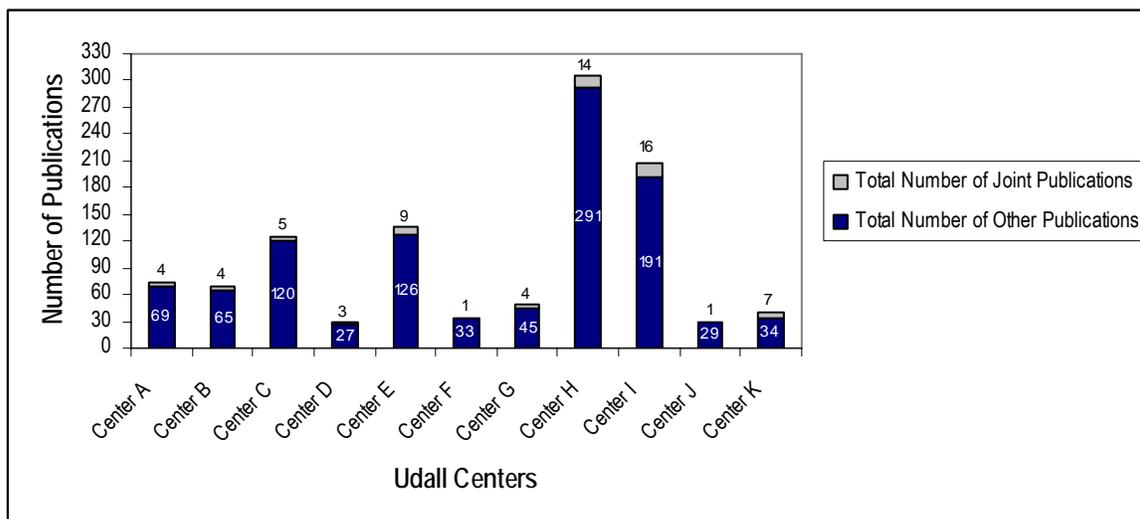
Data Sources and Questions for Research Question 6.4	
Data Source	Questions
Publications	N/A
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>• How useful were the annual meetings during the initial period (e.g., meetings held prior to 2005)? How have you used the annual meetings to further your research (e.g., making connections, learning alternate strategies/techniques, identifying other ways to collaborate with other Centers)?</li> <li>• How has collaboration had an impact on your Center's ability to achieve your research goals?</li> </ul>

**3.8.4.2 Results**

The Center Directors and Project/Core Leads' responses to the interview question on collaboration resulting from the NINDS annual Udall Center meetings are discussed in detail in Study Question 4.3. In response to the two interview questions listed above, the study team found that 33 Udall Investigators thought the annual meetings were "useful" and six Udall Investigators thought the meetings were "not useful." Further explanation of these perspectives – and examples of how the annual meetings helped Udall Investigators collaborate – is presented in Exhibit 52.

Objective evidence of collaboration is shown in publications reporting the Udall Investigators' research findings. All 11 Udall Centers published at least one scientific paper in collaboration with authors from another Udall Center or with non-Udall authors who formed this evaluation's comparison group. There were 48 instances of joint publications; 47 of them involved Investigators from two Udall Centers or one Udall Investigator and one non-Udall researcher. The other instance was a publication involving three Udall Centers. Joint authorship in scientific publications is summarized in Exhibit 83.

Exhibit 83. Publication Collaboration Among Udall Centers\*



Joint publications are defined as authorship by more than one Center, and Other publications are defined as authorship by one Center only.

### 3.8.4.3 Summary

Udall Center Investigators responded that the annual Udall Center meetings provided an opportunity for collaboration in that they were able to build relationships, share reagents, models and techniques, and exchange ideas. Further evidence of collaboration is shown in the number of publications that resulted from collaboration between Udall Centers and between Udall Investigators and non-Udall researchers in this study’s comparison group.

## 3.8.5 Study Question 6.5 – Increased institutional commitment to PD research

### 3.8.5.1 Approach

To measure increased institutional commitment to PD research, the study team surveyed Udall Center Directors and Project/Core Leads and asked them to describe how this was reflected in a variety of ways. The study team mentioned changes in facilities, recognition, additional research positions and/or changes in recruitment policies as possible areas in which an increased institutional commitment to PD could be assessed. The study team invited Udall Center Investigators to add their own examples as well.

Data Sources and Questions for Research Question 6.5	
Data Source	Questions
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>To what extent, if at all, did your institution's commitment to PD research increase as a result of becoming a Udall Center? Please describe facilities, recognition, research positions added, changes in recruitment policies, etc.</li> </ul>

### 3.8.5.2 Results

Across many measures, Udall Investigators believed that their Udall Center award spurred a greater commitment to PD research from their institutions. However, the only Investigator from one Center who answered this question indicated that his/her institution’s commitment did not increase, but no further comments were provided. Another Center provided no response to this

question. The four areas in which Udall Center Investigators saw an increase in commitment were development of additional research positions, increased recognition, provision of additional/improved facilities, and greater funding opportunities.

### Additional Research Positions

Of the four major areas listed by the Udall Center Directors and Project/Core Leads as evidence of increased institutional commitment to PD research, the most frequently cited area was in the creation of additional research positions (see Exhibit 84). Of the 10 Centers from which an Investigator responded to the survey question, eight indicated that their institutions had increased their commitment to PD research in this manner. These additional research positions ranged from general research staff (one Center) to the hiring of one to three new scientists, clinicians and/or PIs (three Centers). The Directors of two Centers reported that they were able to hire former trainees and post-doctoral fellows of their Centers for faculty positions, allowing them to maintain their affiliation with the Udall Centers at each institution.

Exhibit 84. Number of Centers that Increased Institutional Commitment to PD Research: Additional Research Positions

In what ways did your institution increase its commitment to PD research through the development of additional research positions?
<ul style="list-style-type: none"><li>• Added research staff &amp; post-doctoral fellows (3)</li><li>• Hired new scientists and/or clinicians (3)</li><li>• Promoted post-doctoral fellows &amp; trainees to faculty positions (2)</li><li>• Hired new junior faculty (1)</li></ul>

### Increased Recognition

Researchers from six Centers indicated that, through greater recognition, their institutions had increased their commitment to PD research (see Exhibit 85). Several Project/Core Leads from four Centers explained that the Udall Center award increased the prominence of PD research within the institution, which in turn led to greater recognition for them and their work. Another Project/Core Lead explained that his/her pre-clinical Udall-funded research laid the foundation for conducting clinical trials – which led to local as well as international recognition.

Exhibit 85. Number of Centers that Increased Institutional Commitment to PD Research: Increased Recognition

In what ways did your institution increase its commitment to PD research through increased recognition?
<ul style="list-style-type: none"><li>• Received general recognition from the Institution (4)</li><li>• Received recognition from the PD community (3)</li><li>• Received a promotion (1)</li><li>• Received local and international recognition (1)</li></ul>

### Provision of Additional/Improved Facilities

Another way in which Udall Investigators perceived an increase in institutional commitment to PD research was by improvements and changes to the facilities where the Udall Investigators studied and worked (see Exhibit 86). Project/Core Leads from two Centers reported acquiring new laboratory space; one Center received approximately 35,000 square-feet of newly renovated lab space and the other Center obtained two labs in the same building to work on PD models. Investigators at another Center indicated that their institution contributed funds to support the purchase of a confocal microscope and two DNA sequencers. The Director of another Center reported that the receipt of the Udall Center award helped to convince his/her institution that it should renovate their 14,000 square-feet of laboratory space. Additionally, Investigators from three other Centers reported that their institutions either had built, or are planning to build, a new research building to house the institution's PD research and related scientific endeavors.

Exhibit 86. Number of Centers that Increased Institutional Commitment to PD Research: Additional/Improved Facilities

In what ways did your institution increase its commitment to PD research through improving and/or changing facilities?
<ul style="list-style-type: none"><li>• Built or planning to build new laboratory space (3)</li><li>• Acquire laboratory space (2)</li><li>• Upgraded and purchased equipment (1)</li><li>• Renovated laboratory space (1)</li></ul>

### Greater Funding Opportunities

While Investigators from only two Centers indicated they received additional funding from their institutions for PD research, those Investigators – along with researchers from four others Centers – also described the funding they were able to procure beyond the institution as a result of the Udall Center awards (see Exhibit 87). Investigators at four Centers indicated that their Udall Center status led to funding from private donors and one Project/Core Lead from a fifth Center responded that he/she had been able to procure funding from the Mathers Foundation and the Dana Foundation. These comments reveal that the additional support the Center Directors and Project/Core Leads received as a result of their Udall Center status extended beyond the border of their institution; they felt supported by a broader community.

Exhibit 87. Number of Centers that Increased Institutional Commitment to PD Research: Increased Funding Opportunities

In what ways did your institution increase its commitment to PD research through increased funding opportunities?
<ul style="list-style-type: none"><li>• Led to private donations (4)</li><li>• Received funding from non-NIH organizations (2)</li><li>• Received funding support from the community (2)</li><li>• Received funding outside of the department (1)</li><li>• Strengthened the Institution's commitment to relevant basic science (1)</li></ul>

### **3.8.5.3 Summary**

Overall, Udall Center Investigators reported that their institutions significantly increased their commitment to PD research as a result of the Udall Centers Program. They cited four main areas in which they saw an increase in commitment by their institutions: development of additional research positions, increased recognition, provision of additional/improved facilities, and greater funding opportunities. Of these four, the most frequently cited mechanism of institutional support was the creation of additional research positions.

### 3.9 Study Question 7

#### Why were some Udall Centers more successful than others?

- To what extent were specific Center characteristics related to their subsequent success in achieving program goals
- Comparing more or less successful Centers, can “Centers with strong potential” be identified from their baseline characteristics? If so, what are the characteristics.
- To what extent were specific activities conducted by the Centers related to their subsequent success in achieving program goals?
- Comparing the approaches used by the more successful and less successful Centers during the first five years, can “best practices for Centers” be identified? If so, how was each practice usually implemented?

Study Question 7 examines whether a relationship exists between: 1) the baseline characteristics and success in meeting the Udall Centers Program goals; and 2) Center activities and success in meeting the Udall Centers Program goals. Ideally, the study team would conduct a regression analysis to examine these relationships by determining if the characteristics and activities *predict* goal attainment. However, the small number of Centers involved in this study preclude conducting this type of statistical analysis. Instead, for each of Study Question 7’s sub-questions, the study team sought alternative methods for examining the relationship between baseline characteristics and Udall Center activities *and* goal attainment, as is reported in each of the Approach sections.

To prepare for sub-question examination, the study team used one or more of the measures of each characteristic, activity, and/or goal from data in Study Questions 3-6. The study team entered the quantitative data measures (e.g., funding amounts) into a database. For the measures based on qualitative data (e.g., an open-ended survey question on increased institutional commitment to PD research), the study team first transformed the data into quantitative data (e.g., by determining the percentage of respondents from each Center who provided an affirmative response), and then entered the measures into the database. In instances where there were multiple measures for a given characteristic, activity, and/or goal that logically belonged together, the study team created and used composite scores. (Appendix K provides more detail on the methodology.)

#### **3.9.1 Study Question 7.a – To what extent were specific Center characteristics related to their subsequent success in achieving program goals?**

##### **3.9.1.1 Approach**

To determine the extent to which specific baseline characteristics of the Centers were associated with success in meeting the Udall Centers Program goals, the study team performed a series of statistical analyses. The study team entered the following measures into a statistical software database: 1) measures used to examine Study Questions 3.1 through 3.4<sup>36</sup> (Center

<sup>36</sup> Sub-question 3.4 was excluded because it was based on qualitative data that could not be quantified.

characteristics); 2) measures used to examine Study Questions 5.1 through 5.6 (short-term goals); and 3) measures used in Study Questions 6.2<sup>37</sup> through 6.5 (long-term goals). The study team performed correlation analyses to examine what relationships exist, if any, between the baseline characteristics of each Center and Center Program goals. The reader should note that correlation analyses show whether two measures are related but they do not show causality; that is, it cannot be concluded – when there is a statistically significant finding – that the characteristic *led to* goal attainment.

### 3.9.1.2 Results

The study team found that few of the characteristics could be statistically shown to be associated with goal attainment.<sup>38</sup> The study team found that of the 110 possible relationships statistically examined, only two were statistically significant<sup>39</sup>:

- The PD research experience of the institution (as measured by the institution’s NIH PD grant funding for the five years prior to becoming part of the Udall Centers Program) was *positively associated* ( $r = .79$ ) with the goal of obtaining broader research and infrastructure support for projects relevant to PD (as measured by additional NIH funding for PD research beyond the Udall funding)
- The PD research experience of the Center Director (as measured by the Center Director’s NIH PD grant funding for the five years prior to becoming part of the Udall Centers Program) was *positively associated* ( $r = .74$ ) with the goal of obtaining broader research and infrastructure support for projects relevant to PD (as measured by additional NIH funding for PD research beyond the Udall funding)

### 3.9.1.3 Summary

The two significant results seem intuitive: institutions and Center Directors with more extensive PD research experience (as measured by funding) prior to becoming Udall Centers experienced greater support (in the form of funding) while in the Udall Centers Program. Conversely, those institutions and Center Directors with less extensive PD research experience prior to becoming part of Udall Centers continued to experience less support while in the Udall Centers Program.

## 3.9.2 Study Question 7.b – Comparing more or less successful Centers, can “Centers with strong potential” be identified from their baseline characteristics? If so, what are the characteristics?

### 3.9.2.1 Approach

The study team examined whether more or less successful Centers differed on their baseline characteristics. The study team first developed a process to score goal attainment success, which

---

<sup>37</sup> Sub-question 6.1 was excluded because it was based on qualitative data that could not be quantified.

<sup>38</sup> This does *not* imply that the characteristics are not related to the goals; it simply shows that they cannot be *statistically shown* to be related. This may reflect the challenges associated with performing statistical tests on a small sample (e.g., a small number Centers).

<sup>39</sup> Statistical significance was based on  $p \leq .05$ .

relied on rank ordering to account for the fact that the measures were on varying scales (e.g., 30-305 publications, 0-6 new researchers). The study team converted each measure of a short- and long-term goal into a rank ordering of the Centers. Then, the study team calculated an overall ranking for each Center by averaging all of the Center's rankings. By examining natural cut points, the study team created three groupings based on the overall rankings – the highest ranking Centers, the middle ranking Centers, and the lowest ranking Centers (the study team removed one Center from the analysis as data on five of the measures were missing). The study team calculated averages, by group, of the data for each measure. Presented below are the results for the highest and lowest ranking. (Appendix K provides more detail on the methodology.)

### **3.9.2.2 Results**

As shown in Exhibit 88, the highest and lowest ranking Centers on goal attainment differed on nearly every baseline characteristic and in the expected direction. The Centers that ranked the highest on goal attainment had greater overall research experience prior to entering the Udall Centers Program, greater PD research experience prior to entering the Udall Centers Program, and the Center Directors had more experience leading multi-disciplinary research compared to the Centers that ranked the lowest on goal attainment. The study team also found that the focus of projected projects differed where the highest-ranking Centers proposed more basic research projects and the lowest-ranking Centers proposed more clinical projects. (These differences were not testable for statistical significance given the small number of Centers involved in the study.)

Exhibit 88. Differences in Baseline Characteristics of Centers Ranking Highest and Lowest on Goal Attainment

Characteristic	AVERAGE of the Highest Ranking Centers on Goal Attainment	AVERAGE of the Lowest Ranking Centers on Goal Attainment
Overall research experience of the institution — as measured by: Institution's overall grant funding (via NIH grants) for the five years prior to becoming part of the Udall Centers Program	\$651,893,250	\$398,935,667
Overall research experience of the Center Director — as measured by: Center Director's overall grant funding (via NIH grants) for the five years prior to becoming part of the Udall Centers Program	\$4,221,661	\$3,261,875
Overall research experience of the Project/Core Leads — as measured by: Project/Core Lead's overall grant funding (via NIH grants) for the five years prior to becoming part of the Udall Centers Program	\$3,169,073	\$2,013,225
Previous PD research experience of the institution — as measured by: Institution's PD grant funding (via NIH grants) for the five years prior to becoming part of the Udall Centers Program	\$11,502,341	\$5,898,867
Previous PD research experience of the Center Director — as measured by: Center Director's PD grant funding (via NIH grants) for the five years prior to becoming part of the Udall Centers Program	\$1,822,888	\$1,086,132
Previous PD research experience of the Project/Core Leads — as measured by: Project/Core Lead's PD grant funding (via NIH grants) for the five years prior to becoming part of the Udall Centers Program	\$843,408	\$560,718
Center Director's previous experience leading multidisciplinary research teams — as measured by: Total multidisciplinary grants funding the Center Directors obtained in the five fiscal years prior to the start of the their individual Udall Centers	\$2,291,630	\$1,480,990
PD research areas to be pursued — as measured by: Percentage of proposed projects that were Basic Research	55%	33%
PD research areas to be pursued — as measured by: Percentage of proposed projects that were Translational Research	0%	13%
PD research areas to be pursued — as measured by: Percentage of proposed projects that were Clinical Research	45%	53%

### 3.9.2.3 Summary

Based on the results, it appears that non-statistically significant differences exist in the baseline characteristics of more or less successful Centers. “Centers with strong potential” brought greater experience in both overall research experience and PD-specific research experience to the Udall Centers Program. These differences were also evident at multiple levels including the overall institution, the Center Director, and the Project/Core Leads.

### **3.9.3 Study Question 7.c – To what extent were specific activities conducted by the Centers related to their subsequent success in achieving program goals?**

#### **3.9.3.1 Approach**

To determine the extent to which specific Center activities were associated with success with meeting the Udall Centers Program goals, the study team performed a series of statistical analyses. The team entered the measures used to examine Study Questions 4.1 through 4.5 (Center activities) along with the measures used to examine Study Questions 5.1 through 5.6 (short-term goals) and Study Questions 6.2<sup>40</sup> through 6.5 (long-term goals) into a statistical software database (SPSS). The study team performed correlation analyses to examine what relationships exist, if any, between the Center activity and each Udall Centers Program goal. The reader should note that correlation analyses show whether two measures are related but they do not show causality; that is, it cannot be concluded – when there is a statistically significant finding – that the activity *led to* goal attainment. (Appendix K provides more detail on the methodology.)

#### **3.9.3.2 Results**

Few of the Center activities were statistically significantly associated with goal attainment.<sup>41</sup> Of the 121 possible relationships that were statistically examined, only two were statistically significant<sup>42</sup>:

- Obtaining adequate research support for Udall Center projects (as measured by perceptions of the adequacy of facilities made available with Udall Center funding) was *positively associated* ( $r = .69$ ) with developing and sharing new scientific tools with other PD researchers (as measured by a composite measure that included positive perceptions of the development of animal models, novel tools, novel techniques, and/or introduction of a new focus to the field of PD research)
- Promoting multidisciplinary collaborations within and between Udall Centers (as measured by perceptions of whether collaboration had an impact on the Center's ability to achieve research goals in terms of pre-publication collaboration) was *negatively associated* ( $r = -.62$ ) with developing and sharing new scientific tools with other PD researchers (as measured by a composite measure that included positive perceptions of the development of animal models, novel tools, novel techniques, and/or introduction of a new focus to the field of PD research).

#### **3.9.3.3 Summary**

The first of the two significant findings suggests that Centers with more positive perceptions of research support for their facilities were more likely to develop and share new scientific tools. It may be that having sufficient facilities assists in developing and sharing tools. The second of the

---

<sup>40</sup> Sub-question 6.1 was excluded because it was based on qualitative data that could not be quantified.

<sup>41</sup> This does *not* imply that the activities are not related to the goals; it simply shows that they cannot be *statistically shown* to be related. This may reflect the challenges associated with performing statistical tests on a small sample (i.e., a small number Centers).

<sup>42</sup> Statistical significance was based on  $p \leq .05$ .

two significant findings showed that Centers with positive perceptions of collaboration's impact of achieving research goals were less likely to report that they develop and share new scientific tools. This finding is counter-intuitive; one would expect that collaboration would be positively associated with sharing models, tools, techniques, and new fields. It is possible that this is a spurious finding, resulting from the small number of Centers in the analysis.

**3.9.4 Study Question 7.d – Comparing the approaches used by the more successful and less successful Centers during the first five years, can “best practices for Centers” be identified? If so, how was each practice usually implemented?**

**3.9.4.1 Approach**

This study question sought to determine whether certain best practices can be identified based on the results of the first five years of the Udall Centers Program. To examine this issue, the study team examined the Center activities in the same manner in which the study examined the Center baseline characteristics in Study Question 7.b. The study team used this approach because Center activities, and their association with goal attainment, could be considered an indicator of practices that were more or less successful.

**3.9.4.2 Results**

As shown in Exhibit 89, the highest and lowest ranking Centers on goal attainment differed on some, but not all, of the Center activities. The highest ranking Centers were more likely to have a training core, had a greater number of trainees, obtained more supplemental grant support from NINDS, and were somewhat more apt to report that collaboration had an impact on their ability to achieve research goals compared to the lowest ranking Centers. However, there was no difference between the highest and lowest ranking Centers on the adequacy of research support, perceptions of management practices, or perceptions of strategic planning. (These differences were not testable for statistical significance given the small number of Centers involved in the study.)

Exhibit 89. Differences in Activities of Centers Ranking Highest and Lowest on Goal Attainment

Activity	AVERAGE of the Highest Ranking Centers on Goal Attainment	AVERAGE of the Lowest Ranking Centers on Goal Attainment
Offering research training relevant to PD – as measured by: Presence of a training core	Majority have a training core	Majority do not have a training core
Offering research training relevant to PD – as measured by: Number of trainees during the first five years	13	9
Obtaining adequate research support for Udall Center projects – as measured by: Perceptions of the adequacy of research support functions (Facilities; Cores; Equipment and Supplies; Personnel; and Services such as biostatistical, data management, IT & grants assistance) provided by Udall funding	Adequate	Adequate
Obtaining adequate research support for Udall Center projects – as measured by: supplemental grant support from NINDS	\$828,107	\$113,328
Promoting multidisciplinary collaborations within and between Udall Centers – as measured by: Perceptions of whether collaboration had an impact on the Center's ability to achieve research goals in terms of pre-publication collaboration	Positive impact	Some positive impact
Ensuring effective day-to-day management and communications – as measured by: Perceptions of whether the Center structure changed management practices	Yes, management practices changed	Yes, management practices changed
Emphasizing strategic planning, including setting milestones, monitoring progress, and seeking advisory committee input – as measured by: Perceptions of whether the Center set goals and establish milestones; monitored and measured its progress towards reaching goals and achieving milestones; used advisors; and/or identified and planned for operational improvements	Yes, engaged in these activities	Yes, engaged in these activities

### 3.9.4.3 Summary

The results of this study can provide early indicators of possible best practices; however, further study is warranted to elucidate a more comprehensive, defensible list of best practices. Based on these results, some best practices may include having a training core, engaging trainees, and pursuing supplemental grant support.

### 3.10 Study Question 8

Were the Udall Center researchers more (or less) successful than a comparable group of PD researchers advancing PD research in:

- Generating new hypotheses relevant to PD
- Achieving noteworthy research discoveries
- Developing new scientific tools, and sharing these tools with the PD research community

#### 3.10.1.1 Approach

Udall Investigators and comparison group participants listed their top five research discoveries/findings/results in response to a web-based survey question. The study team analyzed and compared the Udall Investigator responses to the responses from the comparison group participants. The study team also analyzed responses from the survey question that requested information on novel strategies and sharing of tools. The data sources for this question are presented in Exhibit 90.

Exhibit 90. Data Sources and Questions for Research Question 8

Data Source	Questions
Study Questions 5.2, 6.1 & 6.2	See analyzed data from Study Questions 5.2, 6.1, and 6.2
Web-Based Survey (Comparison group)	<p>Please discuss the top five key discoveries/findings/results in terms of basic, translational and clinical research based on the NINDS RO1 grant(s) you held during the years of 1998 through 2004.</p> <ul style="list-style-type: none"> <li>• What is one of the top discoveries/findings/results from your research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>
Web-Based Survey (Comparison group)	<p>During 1998-2004, did you establish novel strategies to promote collaboration (e.g., increased communication and joint research efforts including sharing of tools, techniques and concepts) within your group, or with other researchers both at your institution and outside of your institution? Please describe.</p>

#### 3.10.1.2 Results

To address the question of noteworthy discoveries and generation of new hypotheses, the study team analyzed and compared the data from the web-based survey question that asked all participants (Udall Investigators and comparison group participants) to list their top five discoveries and the impact of these discoveries. As discussed in Study Question 5.2, the study team grouped the responses on the top discoveries into six major areas: (1) PD pathophysiology, (2) clinical investigations of PD (i.e., developing methods for better diagnosis of PD), (3) technological developments in PD, (4) treatment options (includes discovery of new therapeutic mechanisms for PD treatment), (5) dopamine signaling, and (6) basal ganglia function.

Investigators from 10 Centers and 29 comparison group participants responded to the question regarding their top five discoveries. The most prevalent area for both groups was investigation into the pathophysiology of PD (Exhibit 91). This included investigations into the role of alpha-synuclein, Parkin, novel mechanisms involved in PD pathogenesis, and trophic factors in PD. The next most prevalent area of top discoveries differed for Udall Center Investigators and comparison group participants; Udall Investigators highlighted clinical investigations, while comparison group participants indicated that treatment options were the next most frequent area of research findings. See Appendix J for a complete list of responses.

Exhibit 91. Survey Results: Percent of Discoveries/Findings/Results in Six Major Areas by Centers and by Comparison Group Participants

Please discuss your findings in terms of basic, translational, and clinical research from the first 5 years. Please discuss your top five (5) key discoveries/findings/results.	
Udall Centers	Comparison Group
<ul style="list-style-type: none"> <li>• PD Pathophysiology (90%)</li> <li>• Clinical Investigations (89%)</li> <li>• Treatment Options (78%)</li> <li>• Technological Developments (67%)</li> <li>• Basal Ganglia Function (56%)</li> <li>• Dopamine Signaling (45%)</li> </ul>	<ul style="list-style-type: none"> <li>• PD Pathophysiology (66%)</li> <li>• Treatment Options (45%)</li> <li>• Clinical Investigations (34%)</li> <li>• Dopamine Signaling (31%)</li> <li>• Technological Developments (24%)</li> <li>• Basal Ganglia Function (21%)</li> </ul>

Udall Investigators and comparison group participants reported on the expected impact of their top five research discoveries. The study team analyzed the responses received to the survey question that asked what impact of the research discoveries had on the development of new therapies, diagnosis and prevention strategies. The study team grouped each response exclusively into the category that seemed most relevant to the type of impact (see Exhibit 92). Study Question 6.1 contains the analysis for the Udall Center data.

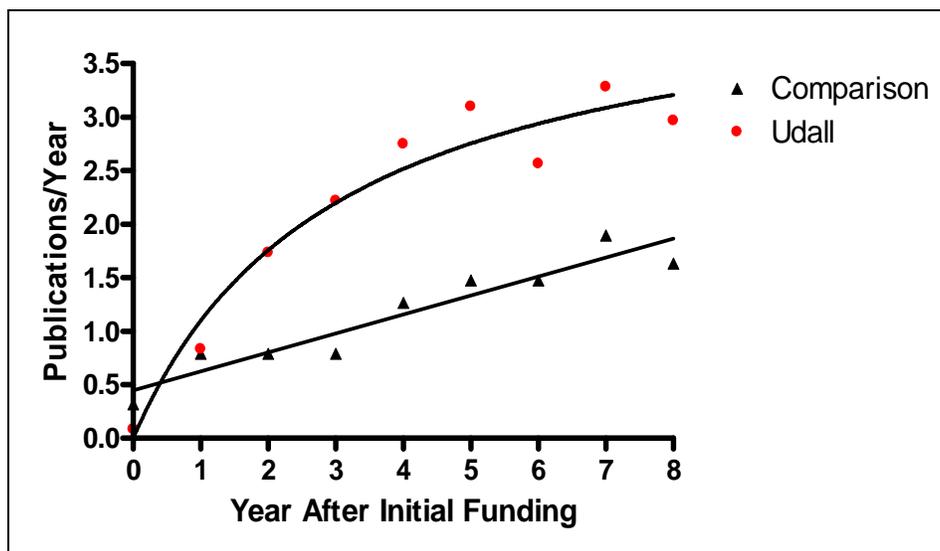
Investigators from nine of the 10 Centers (90 percent) that responded to this survey question reported that their discoveries had an impact on the prevention, diagnosis, and treatment of PD. Fifteen of the 27 (56 percent) comparison group participants reported that their discoveries had an impact on the prevention, diagnosis and/or treatment strategies for PD. The top area of impact, noted by Investigators from eight Udall Centers (89 percent) was that their discoveries led to the development of a novel screening method. However, only one comparison group participant (seven percent) reported this impact. The top area of impact noted by six comparison group participants (40 percent) was that their discovery/result/finding led to the development of a potentially novel treatment for PD (see Appendix L). This same impact was reported by Investigators from six of the Udall Centers (67 percent). The second highest area of impact for comparison group participants was that their discoveries formed the basis for new clinical trials aimed at the treatment of PD.

Exhibit 92. Survey Results: Type of Reported Impact by Percent of Those Who Reported an Impact by Centers and Comparison Group Participants

Please discuss the impact these discoveries/findings/results have had on the development of new therapies, prevention strategies, etc.	
Udall Centers	Comparison Group Participants
<ul style="list-style-type: none"> <li>Developed a novel method for screening drug libraries (cell culture, mouse models, protein degradation pathways, mGluR4 activation, GDNF/trophic factor delivery, SK channel, PARP-1 inhibitors, cPLA2, computer based pharmacology) (89%)</li> <li>Developed a potential treatment for PD which is still under investigation (low energy laser, new deep brain stimulation procedures, embryonic stem cell derived dopamine neurons, p75ICD, nicotine, neural transplantation of dopamine cells, AKT viral transduction method, drug delivery pump, transcranial stimulation, small molecules, TrkA agonists, mGluR5) (67%)</li> <li>Formed the basis for new clinical trials aimed at the treatment of PD (GDNF, Co-enzyme Q10, antioxidants, creatine, anti-inflammatory agents, RNAi, STAZN, Tempol, improved dopamine cell implantation methods, BDNF) (67%)</li> <li>Developed biomarkers or other techniques for early diagnosis (56%)</li> <li>Identified novel genetic marker to screen for PD (Lrrk2, Mitochondrial gene ND5) (33%)</li> <li>Identified novel candidate genes for PD research (22%)</li> <li>Helped to determine changes during PD treatment (11%)</li> <li>Enabled genetic testing to screen for PD genes (11%)</li> <li>Grouped PD patients better based on genetic cohorts (11%)</li> </ul>	<ul style="list-style-type: none"> <li>Developed a potential treatment for PD which is still under investigation (low energy laser, new deep brain stimulation procedures, embryonic stem cell derived dopamine neurons, p75ICD, nicotine, neural transplantation of dopamine cells, AKT viral transduction method, drug delivery pump, transcranial stimulation, small molecules, TrkA agonists, mGluR5) (40%)</li> <li>Produced data that formed the basis for new clinical trials aimed at the treatment of PD (GDNF, Co-enzyme Q10, antioxidants, creatine, anti-inflammatory agents, RNAi, STAZN, Tempol, improved dopamine cell implantation methods, BDNF) (27%)</li> <li>Helped to determine changes during PD treatment (20%)</li> <li>Identified novel genetic marker to screen for PD (Lrrk2, Mitochondrial gene ND5) (13%)</li> <li>Examined role of environment in early onset PD (13%)</li> <li>Developed a novel method for screening drug libraries (cell culture, mouse models, protein degradation pathways, mGluR4 activation, GDNF/trophic factor delivery, SK channel, PARP-1 inhibitors, cPLA2, computer based pharmacology) (7%)</li> <li>Enabled genetic testing to screen for PD genes (7%)</li> <li>Developed virtual reality environment for PD patient training (7%)</li> </ul>

The study team examined Udall publication rates as a method for determining hypothesis generation and its relevance to PD. The study team calculated the total number of publications produced by Udall Investigators and comparison group participants from the time the Udall Center was established until eight years later. On average, Udall Center Investigators maintained a consistently higher publication rate (publications per author per year) than did the comparison group participants. The study team conducted a regression analysis of publication rates for both the Udall Center Investigators and the comparison group participants (see Exhibit 93). The analysis revealed an expected ceiling for Udall Center Investigators that approached 4.5 publications per author per year.

Exhibit 93. Publication Rate per Individual per Year for Udall Center Investigators and Comparison Group Participants



The study team also used the results from Thomson Scientific to evaluate the publications generated by the Udall Investigators and comparison group participants. Publications were first stratified into two researcher categories – Udall Investigator publications and comparison group publications. The study team included 693 original publications (i.e., publications that are not review or editorial) for Udall Investigators, and 200 publications for comparison group participants. The study team then sorted the publication lists by percentile position (see Study Question 5.2 for further information on percentile position) and then divided the publications into 10 equally-sized tiers within each researcher category. Therefore, tier one contained those publications (about 60 for Udall Investigators and 20 for comparison group participants) with the highest percentile position (see Exhibit 95). Tier two contained the next 60 publications for Udall Investigators, and the next 20 for comparison group participants with the next highest percentile position, and so forth.

For each of the tiers, the study team calculated a mean percentile position for each researcher category. The study team then calculated the mean and median percentile positions for Udall Investigators and comparison group participants across all tiers (see Exhibit 94).

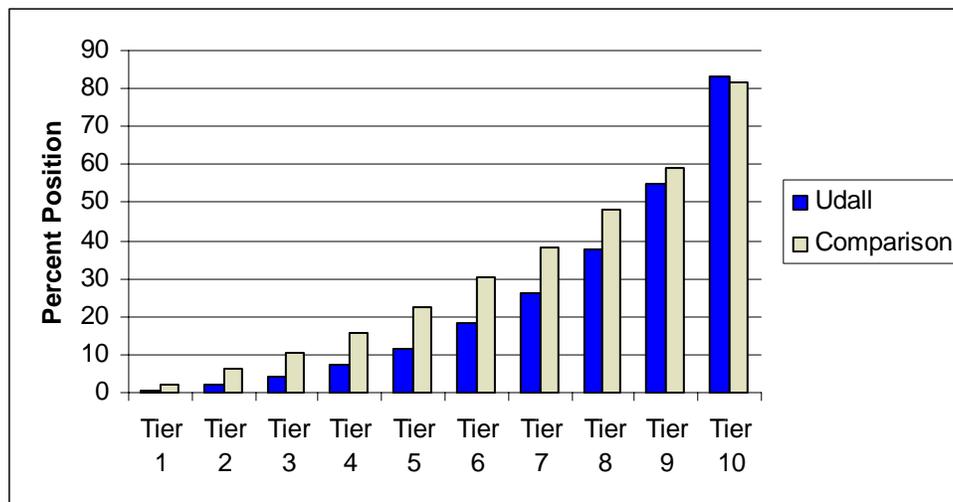
Exhibit 94. Mean and Median Percentile Positions of Publications Across All Tiers for Udall Investigators and Comparison Group Participants

	Udall Investigators	Comparison Group Participants
Mean Percentile Position	24.6	31.5
Median Percentile Position	14.9	26.4

Exhibit 95 shows the individual tiers’ mean values for both Udall Investigators and comparison group participants. As seen in Study Question 5.2, the lower the percentile position, the greater

the estimated value of the publication to the scientific field. With the exception of tier 10, Udall Investigators averaged a lower percentile position than the comparison group participants.

Exhibit 95. Percentile Position of Udall Investigators versus Comparison Group Participants' Publications



### Development and Sharing of Investigational Techniques

The study team asked Udall Investigators and comparison group participants about the impact their discoveries had on the development of new research techniques. The study team grouped the techniques reported into three categories: tools, methods, and research focus. The study team used these same categories to analyze the Udall Center Investigators' responses (see Study Question 6.2).

Of those that participated in the web-based survey, Investigators from 10 of 10 Centers (100%) responded that their discoveries had an impact on the development of new research techniques (i.e., new tools, methods, and research foci) and 19 of 29 comparison group participants (66 percent) responded that their discoveries had an impact.

The Udall Center and comparison group data for the top five tools and methods, and the top two research foci are presented in Exhibit 96. The percentages listed indicate the number of Centers or comparison group participants who addressed a specific impact within the category. For example, 44 percent of Centers (four of nine) reported that their discoveries led to the development of new diagnostic tools for PD.

**Exhibit 96. Udall Center and Comparison Group Participants' Responses on the Generation of Top Five Novel Tools and Methods, and Top Two Research Foci**

Survey Results: Novel Tools, Methods, and New PD Research Foci	
Udall Centers (10)	Comparison Group Participants (19)
<p><b>Tools (9 Centers)</b></p> <ul style="list-style-type: none"> <li>Developed new diagnostic tools for PD (GAT1, new PET method, GirK2, live cell imaging) (44%)</li> <li>Identified new protein for study in PD research (PARP-1, mGluR4, TrkA, DJ1, ubiquitin ligase, synphilin-1, dyt-1) (33%)</li> <li>Developed novel reagents (antibodies, NGF mutant, in vivo biosensors, microarray) (33%)</li> <li>Developed novel animal models (non-human primate, tau mouse, alpha synuclein mouse, Lrrk2 mouse) (33%)</li> <li>Developed novel cell lines (cybrids, inducible synuclein overexpression, ts-p53 line) (33%)</li> </ul> <p><b>Methods (9 Centers)</b></p> <ul style="list-style-type: none"> <li>Established novel techniques for neuronal activity recordings (tetrodes for mice, single unit recordings in basal ganglia, cortical surface electrodes, drug effects in vivo) (22%)</li> <li>Developed novel imaging techniques (PET, tissue culture, fMRI) (22%)</li> <li>Developed better genetic testing methods (22%)</li> <li>Solidified the idea that genomic convergence could rapidly narrow a set of candidate genes (22%)</li> <li>Enabled more sensitive techniques for behavioral testing (in mice) (11%)</li> </ul> <p><b>Research Focus (6 Centers)</b></p> <ul style="list-style-type: none"> <li>Focused PD researchers on the role of inflammation during neurotoxicity (33%)</li> <li>Generated a new field of study for PD research (mtDNA, interneurons, protein folding) (33%)</li> </ul>	<p><b>Tools (13 participants)</b></p> <ul style="list-style-type: none"> <li>Developed new diagnostic tools for PD (GAT1, new PET method, GirK2, live cell imaging) (23%)</li> <li>Identified new protein for study in PD research (PARP-1, mGluR4, TrkA, DJ1, ubiquitin ligase, synphilin-1, dyt-1) (15%)</li> <li>Developed novel reagents (antibodies, NGF mutant, in vivo biosensors, microarray) (15%)</li> <li>Developed novel animal models (non-human primate, tau mouse, alpha synuclein mouse, Lrrk2 mouse) (15%)</li> <li>Developed novel therapeutic delivery system (microfluidics, viral vectors) (15%)</li> </ul> <p><b>Methods (9 participants)</b></p> <ul style="list-style-type: none"> <li>Established novel techniques for neuronal activity recordings (tetrodes for mice, single unit recordings in basal ganglia, cortical surface electrodes, drug effects in vivo) (33%)</li> <li>Developed novel techniques for fetal/stem cells in the treatment of PD (33%)</li> <li>Resulted in a method of neural transplantation of dopamine neurons from stem cells (22%)</li> <li>Developed novel imaging techniques (PET, tissue culture, fMRI) (22%)</li> <li>Developed novel strategies for creating dopamine neurons from stem cells <sup>xiii</sup> (11%)</li> </ul> <p><b>Research Focus (2 participants)</b></p> <ul style="list-style-type: none"> <li>Generated a new field of study for PD research (mtDNA, interneurons, protein folding) (50%)</li> <li>Spurred the investigation of gene/environment interactions (50%)</li> </ul>

The study asked Udall Investigators and comparison group participants if they established any novel strategies to promote collaboration such as sharing of tools, techniques or research foci. The majority of Udall Center Investigators who responded to the interview question indicated an increase in collaboration and the sharing of scientific techniques and research findings at all three levels of interest: within their Udall Center, with other Udall Centers, and with non-Udall PD researchers. When asked to provide examples, Udall Center Investigators highlighted formal methods, such as the sharing of animal models, tools, and reagents, in addition to more general

observations, such as an increase in recognition and visibility throughout the PD research field and the scientific community at large. Comparison group participants highlighted several similar methods and emphasized that these methods allowed them to further their collaboration. These methods include sharing lab personnel with international institutes, sharing a large patient database with many institutions, holding university-wide meetings, and sharing equipment and tissue samples.

### **3.10.1.3 Summary**

On average, Udall Investigators' publications had lower percentile positions (and higher value) than publications by comparison group participants. Additionally Udall Investigators had a consistently higher publication rate than comparison group participants.

The study team grouped most of the discoveries/findings/results that Udall Centers and comparison group participants reported into the area of PD pathophysiology. For Udall Centers, the second most frequent area of research finding were discoveries in clinical investigations (i.e., developing methods for better diagnosis of PD). This differed for comparison group participants where discoveries seemed to focus more on novel treatment options for PD, which included the discovery of new therapeutic mechanisms for PD treatment. Most Udall Centers and comparison group participants reported that their discoveries had an impact on the prevention, diagnosis, and/or treatment strategies for PD. Most Udall Centers reported that their discoveries had an impact on the development of a novel method for screening drug libraries. While most comparison group participants reported the impact of these discoveries on the development of a potential treatment for PD. Udall Centers reported: 1) development of biomarkers or other techniques for early diagnosis, 2) identification of novel candidate genes for PD research, and 3) better grouping of PD patients in genetic cohorts – none of which comparison group participants reported. Conversely, comparison group participants indicated impacts including: 1) the role of the environment in early-onset PD, and 2) development of a virtual reality environment for PD patient training. The Udall Centers did not report an impact in these areas.

Udall Centers and comparison group participants reported a similar impact of their discoveries in terms of development of new research techniques (which the study team categorized into new tools, methods, and research foci). Both groups reported the development of new diagnostic tools for PD (including GAT1, a new PET method, GirK2, live-cell imaging) as the greatest area of impact their discoveries had on the generation of new tools for PD research. In terms of new methods, both groups again reported the establishment of novel methods for neuronal activity recordings. Though both groups reported the generation of a new field of study for PD research (e.g., mtDNA, interneurons, protein folding) as their area of impact on a new research focus, the Udall Centers also reported that they focused on the role of inflammation during neurotoxicity. The comparison group participants did not report this area of impact and instead reported the investigation of gene/environment interactions as an impact of their research. Regardless of the types of new research techniques reported, both groups reported that the sharing of their tools promoted collaboration.

### 3.11 Study Question 9

Were the Udall Center researchers more successful than a comparable group of researchers in collaborating with researchers at other institutions to advance PD research?

#### 3.11.1.1 Approach

The study team used interview, survey, and publication data to compare collaborative efforts of Udall Investigators and comparison group participants. For both groups, the study team explored whether the Udall Investigators and comparison group participants felt that collaboration had impacted their ability to achieve their research goals. In addition, the study team reviewed the publications by Udall Center Investigators and comparison group participants and determined the number of publications that involved collaboration between two or more institutions as well as those that were multidisciplinary in nature. For this analysis, the study team compared a random sample of 25 research publications each from 1999, 2002, and 2005 by Udall Investigators to a random sample of 25 research publications from the comparison group participants across all years (see question 5.5 for details on the selection methodology). An analysis of the comparison group publications for the years of 1999, 2002 and 2005 was not possible due to the small number of publications (less than 25) produced by comparison group participants during those years. For the purposes of this analysis, multidisciplinary was defined as collaborations with investigators in other fields or departments. The data sources for this question are presented in Exhibit 97.

Exhibit 97. Data Sources and Questions for Research Question 9

Data Sources and Questions for Research Question 9.0	
Data Sources	Questions
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>How has collaboration had an impact on your Center's ability to achieve your research goals?</li> </ul>
Web-Based Survey (Comparison Group)	<ul style="list-style-type: none"> <li>How has collaboration had an impact on your group's ability to achieve your research goals? Have there been any specific collaborative processes that you found particularly useful?</li> </ul>
Thomson Scientific	N/A

#### 3.11.1.2 Results

The study team asked both Udall Investigators and comparison group participants to address whether they felt that collaboration had an impact on their ability to achieve their research goals. As shown in Exhibit 98, in both groups, the majority responded positively. They provided similar supporting examples of how collaboration has been beneficial, including the sharing of materials, methods, and knowledge. To note, a slightly greater percentage of the comparison group (85 percent) than the Udall Investigators (77 percent summing across the “positive impact” and “some impact” categories) indicated that collaboration impacted research goals; this slight difference may simply reflect how the responses for the Udall Investigators are coded,

given that the remaining 23 percent of the Udall Investigators included responses from Core Leads – who felt that their main function was to support research and did not view themselves as collaborators – and individuals who noted that limited collaboration occurred. It appears that a reasonably similar percentage of PD researchers took a collaborative approach, whether in the Udall Centers Program or not.

Exhibit 98. Comparison of Responses: Impact of Collaboration on Achieving Research Goals

INTERVIEW RESULTS Center Directors and Project/Core Leads	SURVEY RESULTS* Group Participants
<p>Collaboration had a positive impact on research (21; 70%)</p> <ul style="list-style-type: none"> <li>• Collaboration allowed us to make faster progress on our research, helped to unify our approach, re-directed our research (7)</li> <li>• With collaboration, we received and/or shared materials, tissues, reagents, animal models, and discoveries (7)</li> <li>• Collaboration helped our knowledge base and technical resources; exchanged protocols, had access to unpublished information, exchanged personnel, exchanged techniques, shared methods, and compared data results (5)</li> <li>• Collaborated outside of the Center was much more than it otherwise would have been (without the Udall) (2)</li> </ul> <p>Collaboration had little impact on research (7; 23%)</p> <ul style="list-style-type: none"> <li>• Collaboration hasn't helped research goals; wasn't relevant for the cores (5)</li> <li>• Collaboration helped toward our goals but the impact wasn't huge, would have happened absent of the Udall structure (2)</li> </ul> <p>Collaboration had some impact on research (2; 7%)</p> <ul style="list-style-type: none"> <li>• Collaborated but it was not on efforts toward primary research goals – was outside of initial goals, was on secondary research goals (2)</li> </ul>	<p>Collaboration had a positive impact on research (22; 85%)</p> <ul style="list-style-type: none"> <li>• Non-specific (4)</li> <li>• Shared study methods (4)</li> <li>• Leveraged skill sets (e.g., pharmacology, electrophysiology) (4)</li> <li>• Shared imaging techniques (3)</li> <li>• Joined with other groups for complex or expensive studies (3)</li> <li>• Shared genetic methods (2)</li> <li>• Collaborated with a Udall Center on training, data modeling, and data exchange (1)</li> <li>• Collaborated with other organizations such as labs and biotech companies (1)</li> </ul> <p>Collaboration had little impact on research (4; 15%)</p> <ul style="list-style-type: none"> <li>• No collaboration occurred (3)</li> <li>• Findings led to collaboration after study period (1)</li> </ul>

*\*Due to the limitations of the data source, comparison group participants' responses are less detailed than those of the Udall Center Investigators.*

As another marker of collaboration, the study team compared the multidisciplinary nature of the research publications produced by the Udall Investigators and the comparison group participants. The study team selected a sample of publications from 1999, 2002 and 2005<sup>43</sup> and examined

<sup>43</sup> The study team selected 1999 for its baseline data and selected 2002 and 2005 because the two different comparison points helped ensure that the findings were not simply the result of a particular year being an outlier. In addition, 2002 represented an approximate midpoint in the funding period between 1998 and 2006, while 2005 represented the last year for which the study team had complete (i.e., full year) publication data. Please see study question 5.5 for further information.

whether the articles were multidisciplinary in nature. As shown in Exhibit 99, a comparison of the findings from the Udall Investigators and the comparison group participants reveals similar results: across years, the percentage of publications by the Udall Investigators that were multidisciplinary in nature was 88 percent whereas the percentage of publications by the comparison group participants that were multidisciplinary in nature was 84 percent.

Exhibit 99. Comparison of Responses: Multidisciplinary PD Publications

Investigators	Total Number of Publications	Random Sample Size	Number of Multidisciplinary Publications	Percentage of Multidisciplinary Publications
Udall Center Investigators (1999)	61	25	22	88%
Udall Center Investigators (2002)	172	25	23	92%
Udall Center Investigators (2005)	223	25	21	84%
Comparison Group (across years)	289	25	21	84%

**3.11.1.3 Summary**

The results showed that a considerable degree of collaboration is occurring in PD research – both within the Udall Centers Program and beyond. Based on the study team’s analysis of the interview and survey data on collaboration, as well as an examination of the multidisciplinary nature of publications, there did not appear to be a large difference in collaboration among Udall Investigators versus comparison group participants during the specified time period. This may reflect an increasing trend toward collaboration that occurred across the PD research community overall. It also is possible that these results are affected by the definition of collaboration; that is, while there were many positive responses that collaboration occurred, it is feasible that collaboration occurred at differing degrees in each of the two different groups. Additional research would be needed to explore this issue further.

### 3.12 Study Question 10

Were the Udall Center researchers more successful than a comparable group of researchers in increasing the number of new faculty and trainees [independent research scientists] conducting PD research?

#### 3.12.1.1 Approach

The study team relied on interviews with Udall Center Investigators, survey responses from both Udall Investigators and comparison group participants, and secondary data sources – such as progress reports and the IMPAC II database – to determine the success of Udall Center Investigators in increasing the number of independent PD research scientists.<sup>44</sup> After collecting the data, the study team analyzed the information from two perspectives: short-term goals (recruiting faculty and trainees) and long-term goals (increasing the number of independent PD researchers). Discussion of the Udall Center Investigators' success in both recruiting faculty and trainees and increasing the number of independent researchers can be found in Study Questions 4.1, 5.4 and 6.3. In Study Question 10, these earlier findings are analyzed in relation to the success of the comparison group in achieving these same goals. The data sources used to inform this Study Question are listed in Exhibit 100.

---

<sup>44</sup> As in study question 6.3, The study team considered a researcher to be a new independent PD research scientist if: (1) He/She did not receive funding for PD-related research *prior* to their participation with the Udall Center, *and* (2) He/She received NIH funding for a PD-related research project after their involvement with a Udall Center (the researcher must be named as the Principal Investigator on the research grant). If a scientist was involved in PD research prior to his/her participation with a Udall Center, he/she was determined to already be part of the PD field and was not considered to be an “eligible researcher” for the analysis of this question.

Exhibit 100. Data Sources and Questions for Research Question 10

Data Sources and Questions for Research Question 10	
Data Source	Questions
Progress Reports	N/A
IMPAC II	N/A
Interviews (Udall Investigators)	<ul style="list-style-type: none"> <li>Did the Udall infrastructure have an impact on the number/types of research training opportunities (e.g., courses, workshops, seminars, journal clubs, mentoring) your Center was able to offer during its first 5 years? Please describe.</li> </ul>
Web-Based Survey (Udall Investigators)	<ul style="list-style-type: none"> <li>What effect did your Center have on building the future leaders of PD research (e.g., did funding stimulate others to get involved in PD research) during the first five (5) years? Have the new PD researchers (whether junior trainees or more senior researchers joining the PD community) been fully engaged in the research, and have they made progress? If so, in what ways?</li> </ul>
Web-Based Survey (Comparison Group)	<ul style="list-style-type: none"> <li>Between 1998 and 2004, did the PD research infrastructure associated with your funding have any impact on the number/types of research training opportunities (e.g., courses, workshops, seminars, journal clubs, mentoring) offered by your group? Please describe.</li> <li>During 1998-2004, what effect did your group have on building the future leaders of PD research (e.g., did funding stimulate others to get involved in PD research?)? Have the trainees (whether junior researchers or more senior researchers joining the PD community) been fully engaged in the research, and have they made progress? If so, in what ways?</li> </ul>

### 3.12.1.2 Results

#### Short-term Goals: Recruiting Faculty and Trainees

During the interview, the study team asked Udall Center Investigators to comment on the numbers and types of training opportunities the Udall Centers were able to offer during the first five years of the Program. As seen in Exhibit 101, Center Directors and Project/Core Leads indicated that the Udall Center structure allowed them to provide a number of program developments to their research trainees, including an increased number of journal clubs, workshops and mentoring opportunities. On the web-based survey, comparison group participants highlighted an increase in similar areas, which are presented below in Exhibit 101.

Exhibit 101. Comparison Group: Research Training Opportunities as a Result of R01 PD Funding

Comparison Group: Research Training Program Developments
<ul style="list-style-type: none"> <li>• Offered mentoring to residents, fellows, post-doctoral trainees, graduate students and undergraduate students (9)</li> <li>• Held regular journal clubs (6)</li> <li>• Organized a seminar series (5)</li> <li>• Offered graduate courses in PD (5)</li> <li>• Gave presentations to local and professional groups (4)</li> <li>• Implemented training grants (3)</li> <li>• Organized workshops (2)</li> <li>• Hosted special lectures on PD research (1)</li> <li>• Developed a new pre-doctoral training program (1)</li> <li>• Held a satellite symposium (1)</li> </ul>

Twelve comparison group participants (43 percent) indicated that the PD research infrastructure associated with their R01 funding had no impact on the number/types of research training opportunities offered by their group – a much higher number (and percentage) than reported by the Udall Center Investigators (only two Project/Core Leads reported no impact, 6 percent). Overall, however, Udall Center Investigators and comparison group participants highlighted parallel program developments for research trainees that resulted from either Udall Center funding or R01 PD research funding (see Exhibit 102).

Exhibit 102. Research Training Program Developments: Udall Centers and Comparison Group Participants

Research Training Program Developments	Udall Center	Comparison Group
Increased the number of seminars, journal clubs, and brainstorming workshops	X	X
Increased the number of post-doctoral trainees for basic and clinical research	X	X
Increased mentoring opportunities	X	X
Increased training opportunities for students	X	X
Enabled young scientists to start and develop their careers in PD research	X	X
Increased overall collaboration	X	
Enabled young scientists to participate in PD meetings	X	X
Enabled opportunities to present PD research to local and professional groups		X

**Long-term Goals: Increasing the Number of Independent Researchers**

One of the long-term goals of the Udall Centers Program is to increase the number of independent researchers focusing on PD research. In study questions 5.4 and 6.3, the progress of the Udall Center Investigators in achieving this goal is discussed in detail. The majority (34 out of 36, or 94 percent) of Center Directors and Project/Core Leads who responded to the relevant

survey and interview questions indicated that the Udall Centers Program had a large impact on developing trainees – as well as junior faculty – into independent and contributing members to the PD research field.

In the survey, comparison group participants reported similar successes. Faculty and trainees recruited by comparison group laboratories developed an interest in PD research because of the R01 PD research funding received by comparison group participants. Many of these faculty and trainees went on to pursue careers and/or projects in PD or PD-related fields. Of the 28 comparison group participants, 25 (89 percent) indicated that their research funding had an effect or direct effect on developing the future leaders of PD research. Thematic responses provided by comparison group participants are presented below in Exhibit 103.

Exhibit 103. Comparison Group: Development of New PD Researchers

The Development of New and Independent PD Researchers (Comparison Group)
<b>Faculty &amp; Colleagues</b>
<ul style="list-style-type: none"> <li>• Senior &amp; Junior faculty in other departments who shared an interest in PD (including: Psychiatry, Cell Biology, Developmental Biology, Neuroscience, Physiology, and Pharmacology) collaborated with the project researchers (3)</li> <li>• Neurosurgery and Neurology residents &amp; fellows learned surgical procedures and neurology related to pre- and post-operative evaluation (1)</li> <li>• One research associate became an Assistant Professor in PD research (1)</li> <li>• Three senior collaborators started their own PD projects (1)</li> <li>• Junior researchers and senior researchers who were recruited have published papers, and are participating in the development of new funding initiatives and projects (1)</li> </ul>
<b>Post-Doctoral Trainees</b>
<ul style="list-style-type: none"> <li>• Several post-doctoral trainees were recruited and are still working in PD research (4)</li> <li>• Three post-doctoral trainees were recruited and two now hold academic jobs &amp; are working on related problems in PD (one constructing new models and one evaluating the cognitive sequelae of PD) (1)</li> <li>• One post-doctoral trainee became an Assistant Professor in PD research (1)</li> </ul>
<b>Graduate Trainees</b>
<ul style="list-style-type: none"> <li>• Several graduate students, who trained with the project, published papers, took/taught relevant classes, and graduated to work in PD or related fields (1)</li> <li>• One former doctoral student is seeking therapies for neurodegenerative disorders (1)</li> <li>• Two PhD students were supported by the research project and one is actively involved in the care of patients with PD (1)</li> <li>• Two PhD students became Assistant Professors in PD research (1)</li> <li>• Five PhD students accepted PD-focused placements at universities (1)</li> </ul>
<b>Undergraduate Trainees</b>
<ul style="list-style-type: none"> <li>• Seven undergraduate trainees contributed to the research project and four are in careers related to the technical aspects of the work (1)</li> </ul>
<b>Unspecified</b>
<ul style="list-style-type: none"> <li>• Several students, postdoctoral fellows and junior faculty were recruited and many continued in PD research (3)</li> <li>• Four trainees have gone on to professional careers involving neurodegenerative disease, but not necessarily in PD (2)</li> <li>• No trainees joined the PD field (2)</li> <li>• Three trainees now have independent research positions at universities and/or with the pharmaceutical industry related to PD (1)</li> </ul>

Though the study team obtained specific information on the number and total amount of NIH PD grants awarded to new independent PD researchers from the Udall Centers (please see Research Question 6.3), these data were not available for the comparison group participants.<sup>45</sup>

### **3.12.1.3 Summary**

Udall Center Investigators and comparison group participants reported similar experiences in both recruiting faculty and trainees into their PD research projects and in increasing the number of independent investigators focused on PD research. Both Udall Center Investigators and comparison group participants reported success in recruiting trainees – from undergraduate students to post-doctoral fellows – and faculty to work on PD-related projects. However, 43 percent of comparison group participants indicated that their R01 PD research funding had no impact on the number or types of research opportunities made available to research trainees, compared to just 6 percent of Udall Center Investigators.

While quantitative data were not available for the comparison group participants – and therefore an evaluation of these researchers in relation to Udall Center Investigators was not possible – both groups of researchers reported that their PD research funding (whether Udall Center funding or R01 funding) had a large impact on increasing the number of independent PD researchers. Only two of the 36 Udall Center Investigators and three of the 28 comparison group participants indicated that the funding had little or no effect on developing the future leaders of PD research.

---

<sup>45</sup> The names of individual researchers and trainees who were part of the Udall Centers during the first five years of the Udall Centers Program were available in Center progress reports and applications for grant continuations. For the comparison group, the data source was limited to survey responses only. While two comparison group participants did list specific individuals who were part of their research projects in their survey responses, there was not sufficient consistency to justify using these responses as a parallel data source.

## 4.0 NGO Discussion<sup>46</sup>

Many non-governmental organizations (NGOs) expressed an interest in the evaluation. These NGO representatives provided input on the content of the Udall Act and their continued interest in the Udall Centers Program's success, the study team (without NINDS leadership) conducted one-on-one discussions with six NGOs. The study team sought the NGO participants' comments on:

- The historical context of the Udall Centers Program;
- The strengths and weaknesses of the Udall Program; and
- Tangible improvements that the Udall Program could make.

### Historical Context

NGOs representatives provided their perspectives on the purpose and/or direction of the Udall Centers Program. One NGO representative stated that the Program's original intent was to translate research into treatments for PD and that Centers were to focus on translational research. Two other NGO representatives commented that the Program started because not enough funding was being put toward PD research, and that NINDS had not assigned a specific individual to focus on the funding for, or the research of, PD.

### *RFAs & Review Process*

One NGO representative expressed concern that the review criteria for the applications were not congruent with the language in the Udall Act. Three of the six NGO representatives provided specific comments on the review process of the applications received for the 1997 and 1998 issued RFAs. Two NGO representatives stated that the reviewers scored the Udall applications as if they were R01 grants. One NGO representative further stated that the reviewers' focus seemed to be on the individual projects' science and not on the potential of the Centers as a whole. All NGO representatives felt that reviewers did not rank applications focused on clinical research as highly as those focused on non-clinical research. [Note: The study team is unaware as to whether the NGO representatives reviewed the Udall Center grant applications or summary statements.]

### Strengths & Weaknesses

Most of the NGO representatives stated that the Udall Centers Program helped to make PD a visible disease (to the public), and that it started a collaborative effort toward building centers of excellence in PD research. One NGO representative commented that the diversity of projects by the Centers is good for PD research and that it brings together pieces of the scientific puzzle. The NGO representatives expressed specific concerns with the Program's focus on: 1) collaboration, 2) translational and clinical research, and 3) strategy and planning. Comments in each area are outlined below.

---

<sup>46</sup> While a relevant and important component of the Udall Centers Program evaluation, the discussions with the NGOs were not part of the formal Program evaluation framework. The perspectives in this section provide important insights into the PD community's views of the Udall Centers Program.

### *Collaboration*

Five of the six NGO representatives commented on the need for the Program to define a collaborative network. NGO representatives were particularly concerned with the duplication of research by Centers, and felt that the Centers need to approach their research as collaborators in research and not as competitors for funding. The NGO representatives stated that the Alzheimer's research community and the Linked Efforts to Accelerate Parkinson's Solutions (LEAPS) program of the Michael J. Fox Foundation for Parkinson's Research are two models of collaborative research that the Udall Centers Program should consider as examples. Two of the six NGO representatives expressed concern on the use of the Parkinson's Disease Data Organizing Center (PD-DOC). Though they did not provide specific expectations, these two NGO representatives stated that the Centers should use PD-DOC for more than storing and sharing data.

### *Translational & Clinical Research*

All NGO representatives commented that the Udall Centers Program should require more focus on translational and clinical research. NGO representatives conveyed their concern with the lack of specific language in the issued RFAs on clinical, translational and basic research. One NGO representative expressed disappointment that Centers did not address patient and family support.

### *Strategy & Planning*

Three of the four NGO representatives stated that the Udall Centers Program does not have any set performance metrics to measure its achievements, or to assess the success of the individual Centers. The NGO representatives further stated that there do not seem to be any defined goals for the Program. Though all the NGO representatives commended and expressed their respect for the Program Managers of the Udall Centers Program, the NGO representatives felt that NINDS lacks strategic leadership for the Program.

### **Suggested Improvements**

Three of the six NGO representatives suggested that the Udall Centers Program review the LEAPS program for ideas on improvements. One NGO representative explained that the LEAPS program requires a team approach to research where scientists collectively determine a research topic and then develop a proof of concept, measures of success, and scientific milestones to achieve. The NGO representatives provided other suggestions to improve the Udall Centers Program; these are presented below.

Questions posed to NGOs: What suggestions do you have for tangible improving the Program?  
What might the Program need to be more successful moving forward?

- Define the goals and objectives for the program in a strategic plan (e.g., contacting the LEAPS program; reviewing the IOM report on NIH extramural centers; having Centers help define their accountability; developing core competencies within each Center to help focus research for the Center; and involving the advocacy groups in the process) (4)
- Put into place a strategic leader whose only focus is the Udall Program – this person should not necessarily be associated with the NIH or NINDS (3)
- Restructure the annual meetings (e.g., having opportunity for more discussion with non-scientists; presenting data for deeper discussion; and determining ways to strengthen the Program) (3)
- Review the training component of the Centers (e.g., having Centers develop training pieces for providers and reviewing the Centers' training programs to see what the trainees have accomplished) (2)
- Establish guidelines and mechanisms for sharing of findings and networking (includes requiring Centers to clearly communicate their findings to non-scientists, and having PD-DOC incorporate data on animal models, non-human primates, and tissue) (2)
- Find incentives for Centers and Investigators to collaborate on translational research (1)
- Revisit and refocus the program on the provisions in the Udall Act (1)

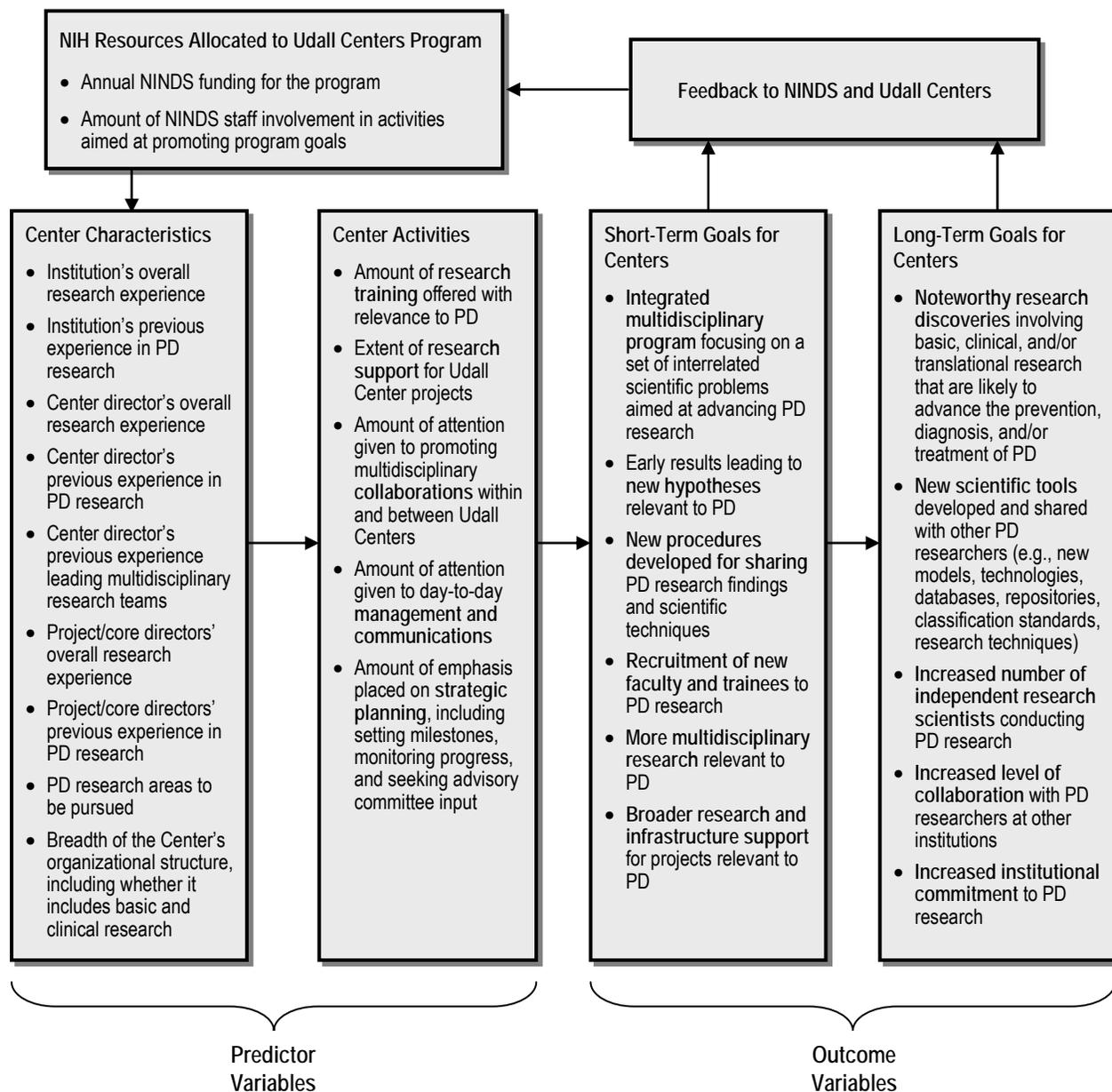
The study team and NINDS Staff also held a group conference call with the NGO representatives during the preparation of the interview and survey questions to collect feedback and gather any additional comments on the evaluation. While the NGO representatives provided useful feedback on the interview/survey instrument that the study team incorporated prior to submission to the OMB, the NGO representatives also expressed concern about their not being involved in the planning for the evaluation, including in the design of the study and in determining the composition of the Working Group.

## END OF REPORT

The study team presented this report to the Working Group in May 2007. The Working Group's recommendations for the NINDS Udall Centers Program, based on their review of this Data Report, are presented in the Recommendations Report.

## Appendices

### Appendix A: Conceptual Framework



## **Appendix B: Working Group Members**

### **Ralph Dacey, Jr., MD (Chair)**

*Schwartz Professor and Chairman, Department of Neurosurgery  
Washington University School of Medicine in St. Louis*

### **Bruce Bean, PhD**

*Professor, Department of Neurobiology  
Harvard Medical School*

### **Thomas Bird, MD**

*Professor of Neurology, Medicine and Psychiatry  
Head, Division of Neurogenetics  
University of Washington School of Medicine*

### **Martha Bohn, PhD**

*Medical Research Institute Council Professor, Department of Pediatrics &  
Department of Molecular Pharmacology and Biological Chemistry,  
Feinberg School of Medicine, Northwestern University*

### **Don Cleveland, PhD**

*Professor of Medicine, Neuroscience and Cellular and Molecular Medicine  
University of California of San Diego  
Ludwig Institute for Cancer Research*

### **Mark Hallett, PhD**

*Chief, Human Motor Control Section,  
National Institute of Neurological Disorders and Stroke, NIH*

### **Prisca Marvin, JD**

*Chairman, Board of Trustees  
National Alliance for Autism Research*

### **Richard Moxley, MD**

*Professor of Neurology and Pediatrics, Division of Medicine  
Director of Neuromuscular Disease Center, Department of Neurology  
University of Rochester*

### **Harry Orr, PhD**

*Tulloch Professor of Genetics, Department of Laboratory Medicine and Pathology  
Director, Institute of Human Genetics  
University of Minnesota*

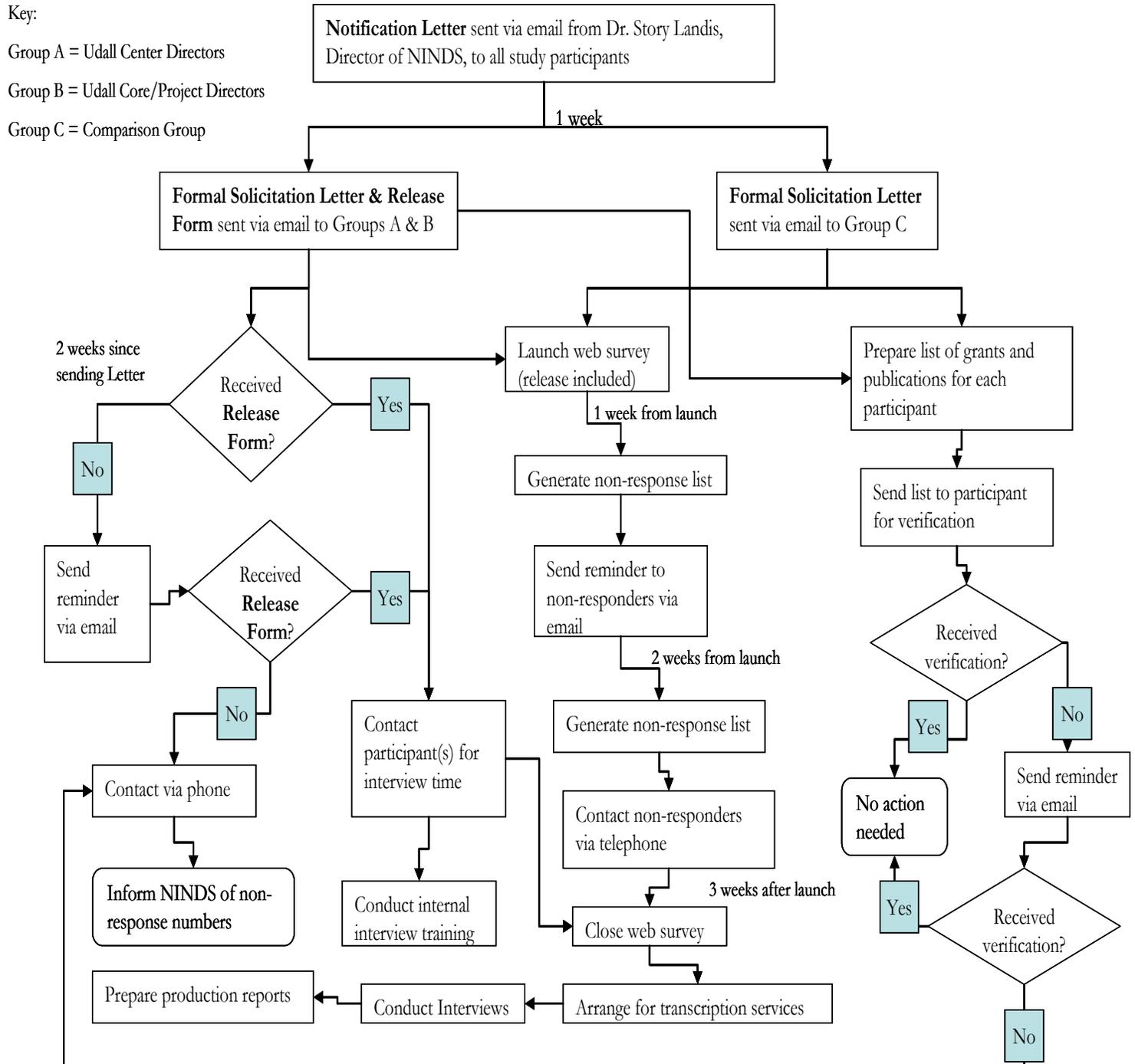
### **Creighton Phelps, PhD**

*Director, Alzheimer's Disease Centers Program,  
National Institute on Aging, NIH*

### **Amy Comstock Rick, JD**

*Chief Executive Officer, Parkinson's Action Network*

### Appendix C: Primary Data Collection Flow



## Appendix D: Release Form

The release form signed by the Working Group members contained the following:

In accordance with the Privacy Act, 5 U.S.C., Section 552(b), my signature below confirms that I agree to the release of my identifiable responses to this interview to the members of the National Advisory Neurological Disorders and Stroke Council Udall Centers Evaluation Working Group (provided in the attached list) and the NIH's supporting contractor Booz Allen Hamilton, Inc. (including but not limited to the individuals on the attached list). I agree and consent to an audio-recording of the phone/teleconference interview and my responses and understand and agree that the interview and my responses will be transcribed and submitted to the aforementioned Working Group and the NIH's supporting contractor.

I agree that I will not disclose any proprietary and/or confidential information in the interview process. I represent that I am authorized to release and disclose all information to be contained in my responses to the interview. I also confirm that my participation in this interview and release of my responses are entirely voluntary and I understand that there will be no adverse effects if I decline to participate.

## Appendix E: Interview Questions

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
1	<ul style="list-style-type: none"> <li>• On a scale of 1 to 5 (1=very poor, 2=poor, 3=average, 4=good, 5=very good), how would you rate your impression of the initial RFAs on the following dimensions:               <ul style="list-style-type: none"> <li>○ Clarity of NINDS goals for the program</li> <li>○ Clarity of the characteristics needed for a successful application.</li> </ul> </li> <li>• If you rated either of these dimensions a 1, 2, or 3, please elaborate.</li> <li>• Do you think the original Udall RFAs should have had a greater emphasis on translational and clinical research or on any other activities?</li> </ul>	X	X
2	<ul style="list-style-type: none"> <li>• As you were writing the application did you or your staff contact NINDS for assistance with the application?</li> <li>• If so, on a scale of 1 to 5 (1=very poor, 2=poor, 3=average, 4=good, 5=very good), please rate your experience with NINDS during that process (e.g., Fiscal years 1998 – 2004) for each of the following dimensions:               <ul style="list-style-type: none"> <li>○ Providing guidance</li> <li>○ Responsiveness to questions/concerns</li> <li>○ Clarity of information provided</li> <li>○ Overall quality of assistance.</li> </ul> </li> <li>• If you rated these dimensions a 1, 2, or 3 please elaborate.</li> </ul>	X	X
3	<ul style="list-style-type: none"> <li>• Could NINDS staff improve the assistance it provides to applicants during the application/pre-award period?               <ul style="list-style-type: none"> <li>○ If so, in what ways</li> </ul> </li> </ul>	X	X
4	<ul style="list-style-type: none"> <li>• After you submitted your application – during the application review process, did you or your staff contact NINDS with questions?</li> <li>• If so, on a scale of 1 to 5 (1=very poor, 2=poor, 3=average, 4=good, 5=very good), please rate your experience with NINDS during that process (e.g., Fiscal years 1998 – 2004) for each of the following dimensions:               <ul style="list-style-type: none"> <li>○ Providing guidance</li> <li>○ Responsiveness to questions/concerns</li> <li>○ Clarity of information provided</li> <li>○ Overall quality of assistance.</li> </ul> </li> <li>• If you rated these dimensions a 1, 2, or 3 please elaborate.</li> </ul>	X	X
5	<ul style="list-style-type: none"> <li>• Could NINDS staff improve the assistance it provides to applicants during the application review process?</li> <li>• If so, in what ways</li> </ul>	X	X
6	<ul style="list-style-type: none"> <li>• During the post award process, did you or your staff contact NINDS for assistance or with questions?</li> <li>• If so, on a scale of 1 to 5 (1=very poor, 2=poor, 3=average, 4=good, 5=very good), please rate your experience with NINDS during that process (e.g., Fiscal years 1998 – 2004) for each of the following dimensions:               <ul style="list-style-type: none"> <li>○ Providing guidance</li> <li>○ Responsiveness to questions/concerns</li> <li>○ Clarity of information provided</li> <li>○ Overall quality of assistance.</li> </ul> </li> <li>• If you rated these dimensions a 1, 2, or 3 please elaborate.</li> </ul>	X	X
7	<ul style="list-style-type: none"> <li>• Could any of the post-award assistance from NINDS listed above be improved?               <ul style="list-style-type: none"> <li>○ If so, which and in what ways?</li> </ul> </li> </ul>	X	X

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
8	<ul style="list-style-type: none"> <li>• Now we want to talk about your experience with the Udall application process as compared to other programs to which you may have applied. Please indicate the programs to which you submitted these applications:               <ul style="list-style-type: none"> <li>○ Other NINDS (non-Udall)</li> <li>○ Other NIH (non-NINDS)</li> <li>○ Other Federal program (Non-NIH)</li> </ul> </li> </ul>	X	X
9	<ul style="list-style-type: none"> <li>• How did the Udall program submission and selection process compare to these other program application experiences?</li> </ul>	X	X
10	<ul style="list-style-type: none"> <li>• Do you have any additional comments regarding the application and review process?</li> </ul>	X	X
11	<ul style="list-style-type: none"> <li>• On a scale of 1 to 3 (where 3= provided significant support, 2= provided some support, 1= provided no support), to what extent did NINDS provide communication, networking opportunities, or other forms of support: (1) directly to your Center to facilitate collaboration within your Center, (2) with other Centers, and/or (3) with outside researchers?               <ul style="list-style-type: none"> <li>○ Directly to your Center to facilitate collaboration within your Center?</li> <li>○ With other Centers?</li> <li>○ With outside researchers?</li> </ul> </li> <li>• Please describe the communication or other support they provided and your rating rationale.</li> </ul>	X	X
12	<ul style="list-style-type: none"> <li>• How useful were the annual Udall investigator meetings during the initial period of funding (e.g., meetings held prior to 2005)?</li> <li>• How have you used the annual Udall Investigator meetings to further your research (e.g., making connections, learning alternate strategies/techniques, identifying other ways to collaborate with other Centers, sharing ideas with colleagues, participation in the PD community)</li> </ul>	X	X
13	<ul style="list-style-type: none"> <li>• Do you feel that the NINDS facilitated collaboration (within and among the Centers) in any other ways?               <ul style="list-style-type: none"> <li>○ If yes, please describe.</li> </ul> </li> <li>• Do you view the Centers as a network?               <ul style="list-style-type: none"> <li>○ If not, would it be useful for the Udall program to move in this direction?</li> </ul> </li> </ul>	X	X
14	<ul style="list-style-type: none"> <li>• We understand that your research is ongoing, but we are interested in learning about any collaboration processes you have employed to attain those goals.</li> <li>• How has collaboration had an impact on your Center's ability to achieve your research goals in terms of pre-publication collaboration?</li> </ul>	X	X
15	<ul style="list-style-type: none"> <li>• Did the act of becoming a Udall Center increase your collaborative efforts (e.g., increased communication and joint research efforts including sharing of tools, techniques, concepts, and research findings):               <ul style="list-style-type: none"> <li>○ Within your Center?</li> <li>○ With other Udall Centers?</li> <li>○ And/or with non-Udall researchers?</li> </ul> </li> </ul>	X	X
16	<ul style="list-style-type: none"> <li>• If applicable to your work, did you develop any new animal models in the first five years of your Udall funding?               <ul style="list-style-type: none"> <li>○ If yes, have you shared these models with other researchers?</li> <li>○ And by what mechanisms?</li> </ul> </li> </ul>	X	X

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
17	<ul style="list-style-type: none"> <li>• Prior to becoming a Udall Center, describe your organizational structure for conducting:               <ul style="list-style-type: none"> <li>○ PD research?</li> <li>○ Other research?</li> </ul> </li> <li>• Since becoming a Udall Center, how has that structure changed?</li> <li>• Prior to becoming a Udall Center, please estimate the percentage of research related to basic, translational, and clinical research.               <ul style="list-style-type: none"> <li>○ What was the percentage after becoming a Udall Center?</li> </ul> </li> <li>• Prior to becoming a Udall Center, did any of this research involve multidisciplinary research teams?</li> <li>• After becoming a Udall Center, to what extent did your research involve multidisciplinary teams?</li> <li>• Did the Udall funding help you to achieve additional research goals that you would not have been able to achieve prior to becoming a Center?</li> </ul>	X	
18	<ul style="list-style-type: none"> <li>• Did the Udall infrastructure have an impact on the number/types of research training opportunities (e.g., courses, workshops, seminars, journal clubs, mentoring) your Center was able to offer during its first 5 years? Please describe.</li> </ul>	X	X
19	<ul style="list-style-type: none"> <li>• Is there anything else you would like to add about the Udall Centers Program?</li> <li>• Do you have any suggestions for improving the Udall Centers Program for the future?</li> </ul>	X	X
20	<ul style="list-style-type: none"> <li>• What factors influenced your decision not to reapply for Udall Center funding? (asked only to Centers that did not reapply for Udall Center funding)</li> </ul>	X	

## Appendix F: Survey Questions

### CENTER DIRECTOR & PROJECT/CORE LEAD SURVEY QUESTIONS

**INSTRUCTIONS:** In this survey, we are interested in learning about your Udall Center's structure and operations during its first five years, and how these features contributed to your Center's subsequent discoveries/findings/results in Parkinson's Disease (PD) research. We are also interested in learning about your Center's interactions with NINDS, how the Udall Center infrastructure impacted your research collaborations and training, and Center opportunities and goals. Please answer each question in as much detail as you deem necessary. Remember that you do not have to complete the survey in one sitting. Should you leave the survey, all your answers on previous pages will have been saved.

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
1-5	<p>In the questions that follow, please discuss the top five key discoveries/findings/results in terms of basic, translational and clinical research.</p> <p>Basic Research is defined as pure research, without any constraint of practical application.</p> <p>Translational Research is the process of applying ideas, insights, and discoveries generated through basic scientific inquiry to interventions, prevention, understanding mechanisms, and/or management of human disease.</p> <p>Clinical Research is defined as:</p> <p>(a) Patient-oriented research. Research conducted with human subjects (or on material of human origin such as tissues, specimens and cognitive phenomena) for which an investigator (or colleague) directly interacts with human subjects. This area of research includes:</p> <ul style="list-style-type: none"> <li>• Mechanisms of human disease</li> <li>• Therapeutic interventions</li> <li>• Clinical trials</li> <li>• Development of new technologies</li> </ul> <p>(b) Epidemiologic and behavioral studies</p> <p>(c) Outcomes research and health services research.</p>	X	X
1 (a-c)	<ul style="list-style-type: none"> <li>• What is one of the top discoveries/findings/results from your Udall Center's research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>	X	X
2 (a-c)	<ul style="list-style-type: none"> <li>• What is another one of the top discoveries/findings/results from your Udall Center's research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>	X	X

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
3 (a-c)	<ul style="list-style-type: none"> <li>• What is another one of the top discoveries/findings/results from your Udall Center's research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>	X	X
4 (a-c)	<ul style="list-style-type: none"> <li>• What is another one of the top discoveries/findings/results from your Udall Center's research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>	X	X
5 (a-c)	<ul style="list-style-type: none"> <li>• What is another one of the top discoveries/findings/results from your Udall Center's research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>	X	X
6	<ul style="list-style-type: none"> <li>• Please discuss the role, if any, the Udall Center structure has played in your Center's results. What do you feel you have accomplished that you could not have without the structure of the Udall Centers Program?</li> </ul>	X	X
7	<ul style="list-style-type: none"> <li>• Within the first five years of its existence, would you describe your research Center as becoming more focused on interrelated scientific problems than it was prior to becoming a Udall Center? <ul style="list-style-type: none"> <li>○ If yes, in what ways?</li> <li>○ If not, please elaborate.</li> </ul> </li> </ul>	X	X
8	<ul style="list-style-type: none"> <li>• To what extent, if at all, did your institution's commitment to Parkinson's Disease (PD) research increase as a result of becoming a Udall Center? <ul style="list-style-type: none"> <li>○ Please describe facilities, recognition, research positions added, changes in recruitment policies, etc.</li> </ul> </li> </ul>	X	X
9	<ul style="list-style-type: none"> <li>• How did your Center set goals and establish milestones?</li> <li>• Were there any particular approaches or techniques that you utilized?</li> </ul>	X	
10	<ul style="list-style-type: none"> <li>• How did your Center monitor, and measure its progress towards reaching goals and achieving milestones?</li> <li>• Were there any particular approaches or techniques that you utilized?</li> </ul>	X	
11	<ul style="list-style-type: none"> <li>• How did your Center identify and plan for operational improvements (e.g., acquisition of equipment, improving processes, etc.)?</li> <li>• Were there any particular approaches or techniques that you used that assisted you in that planning process? Please elaborate.</li> </ul>	X	

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
12	<ul style="list-style-type: none"> <li>• Please rate the extent to which the research support functions provided by Udall funding were sufficient to meet your needs during its first five years. Only one rating (More Than Adequate, Adequate, Inadequate) may be chosen for each category.                             <ul style="list-style-type: none"> <li>○ Facilities</li> <li>○ Cores</li> <li>○ Equipment &amp; Supplies</li> <li>○ Personnel</li> <li>○ Services such as biostatistical, data management, IT &amp; grants assistance</li> </ul> </li> </ul>	X	X
13	<ul style="list-style-type: none"> <li>• If you indicated that any of the previous support functions were inadequate, please elaborate.</li> <li>• Also note if there were other needs you had that were or were not met</li> </ul>	X	X
14	<ul style="list-style-type: none"> <li>• Did your Center maintain a list of priorities and resource needs throughout the funding period?                             <ul style="list-style-type: none"> <li>○ If so, did you identify timeframes for those priorities and resource needs?</li> </ul> </li> <li>• For both questions, please elaborate on why/why not.</li> </ul>	X	
15	<ul style="list-style-type: none"> <li>• Were your resource needs met through the initial funding of the project? (Yes/No)</li> </ul>	X	
16	<ul style="list-style-type: none"> <li>• Did you convey to NINDS that your resource needs were not met through the initial funding of the project? (Yes/No)</li> </ul>	X	
17	<ul style="list-style-type: none"> <li>• Was NINDS able to meet any of these needs through supplemental funding or other programmatic tools/mechanisms?                             <ul style="list-style-type: none"> <li>○ Yes (go to 18b)</li> <li>○ No (go to 18a)</li> </ul> </li> </ul>	X	
18a	<ul style="list-style-type: none"> <li>• Why do you feel NINDS was not able to meet these needs?</li> </ul>	X	
18b	<ul style="list-style-type: none"> <li>• In what ways was NINDS able to meet your additional needs?</li> </ul>	X	
19	<ul style="list-style-type: none"> <li>• During your Center's first five years of funding, please discuss how NINDS' formal activities such as program enhancements, improvements/additions etc., (e.g., the Parkinson's Disease Data Organizing Center and the increased funding ceiling as well as any others) and informal efforts have assisted you in meeting your needs.</li> <li>• What impact have the formal activities and informal efforts had on your research?</li> </ul>	X	X
20	<ul style="list-style-type: none"> <li>• Did your Center use advisors?                             <ul style="list-style-type: none"> <li>○ If so, in what ways, and how were they related to your Center (i.e., from within your institution or from outside your institution, etc.)?</li> </ul> </li> </ul>	X	
21	<ul style="list-style-type: none"> <li>• What effect did your Center have on building the future leaders of PD research (e.g., did funding stimulate others to get involved in PD research) during its first 5 years?</li> <li>• Have the new PD researchers (whether junior trainees or more senior researchers joining the PD community) been fully engaged in the research, and have they made progress?                             <ul style="list-style-type: none"> <li>○ If so, in what ways?</li> </ul> </li> </ul>	X	X
22	<ul style="list-style-type: none"> <li>• How did the Center structure change your management practices (for example, more formal research planning, improved organization of labor/resources, etc.)?</li> </ul>	X	

#	Question	Asked of Center Directors and/or Project/Core Leads:	
		Center Directors	Project/Core Leads
23	<ul style="list-style-type: none"> <li>Is there anything else you would like to add about the Udall Centers Program?</li> <li>Do you have any suggestions for improving the Udall Centers Program for the future?</li> </ul>	X	X

## COMPARISON GROUP SURVEY QUESTIONS

**INSTRUCTIONS:** In this survey, we are interested in learning about your research in Parkinson's Disease (PD) based on the NINDS R01 grant(s) you held during the years of 1998 through 2004. We are interested in learning about the impact that these grants had on your research group's subsequent discoveries/findings/results in PD research, your group's PD research collaborations and training, and on your institution's PD research structure during this time period only. Please answer each question in as much detail as you deem necessary. Remember that you do not have to complete the survey in one sitting. Should you leave the survey, all your answers on previous pages will have been saved.

#	Comparison Group Questions
1-5	<p>In the questions that follow, please discuss the top five key discoveries/findings/results in terms of basic, translational and clinical research.</p> <p>Basic Research is defined as pure research, without any constraint of practical application.</p> <p>Translational Research is the process of applying ideas, insights, and discoveries generated through basic scientific inquiry to interventions, prevention, understanding mechanisms, and/or management of human disease.</p> <p>Clinical Research is defined as:</p> <p>(a) Patient-oriented research. Research conducted with human subjects (or on material of human origin such as tissues, specimens and cognitive phenomena) for which an investigator (or colleague) directly interacts with human subjects. This area of research includes:</p> <ul style="list-style-type: none"> <li>Mechanisms of human disease</li> <li>Therapeutic interventions</li> <li>Clinical trials</li> <li>Development of new technologies</li> </ul> <p>(b) Epidemiologic and behavioral studies</p> <p>(c) Outcomes research and health services research.</p>
1 (a-c)	<ul style="list-style-type: none"> <li>What is one of the top discoveries/findings/results from your research?</li> <li>What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>
2 (a-c)	<ul style="list-style-type: none"> <li>What is another one of the top discoveries/findings/results from your research?</li> <li>What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>
3 (a-c)	<ul style="list-style-type: none"> <li>What is another one of the top discoveries/findings/results from your research?</li> <li>What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>

4 (a-c)	<ul style="list-style-type: none"> <li>• What is another one of the top discoveries/findings/results from your research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>
5 (a-c)	<ul style="list-style-type: none"> <li>• What is another one of the top discoveries/findings/results from your research?</li> <li>• What impact did this discovery/finding/result have on the development of new research techniques?</li> <li>• What impact did this discovery/finding/result have on the development of new therapies, prevention strategies, etc.?</li> </ul>
6	<ul style="list-style-type: none"> <li>• To what extent, if at all, did your institution's commitment to Parkinson's Disease (PD) research increase as a result of receiving this PD grant award(s) from the NIH? Please describe facilities, recognition, research positions added, changes in recruitment policies, etc.</li> </ul>
7	<ul style="list-style-type: none"> <li>• During 1998-2004, what effect did your research group have on building the future leaders of PD research (e.g., did funding stimulate others to get involved in PD research)? Have the trainees (whether junior researchers or more senior researchers joining the PD community) been fully engaged in the research, and have they made progress? If so, in what ways?</li> </ul>
8	<ul style="list-style-type: none"> <li>• During 1998-2004 (the time you held the R01 grant(s)), did your group engage in collaborative activities that impacted your group's ability to achieve your research goals? Were there any specific collaborative processes that you found particularly useful?</li> </ul>
9	<ul style="list-style-type: none"> <li>• During 1998-2004, did you establish novel strategies to promote collaboration (e.g., increased communication and joint research efforts including sharing of tools, techniques and concepts) within your group, or with other researchers both at your institution and outside of your institution? Please describe.</li> </ul>
10	<ul style="list-style-type: none"> <li>• If applicable to your work, did you develop any new animal models during 1998-2004? If yes, have you shared these models with other researchers and by what mechanisms?</li> </ul>
11	<ul style="list-style-type: none"> <li>• During 1998-2004, did the PD research infrastructure associated with your funding have any impact on the number/types of research training opportunities (e.g., courses, workshops, seminars, journal clubs, mentoring) offered by your group? Please describe.</li> </ul>

## Appendix G: Research Definitions

The Working Group agreed upon the following definitions for research:

**Basic** Research is defined as pure research, without any constraint of practical application.

**Translational** Research is the process of applying ideas, insights, and discoveries generated through basic scientific inquiry to interventions, prevention, understanding mechanisms, and/or management of human disease.

**Clinical** Research is defined as:

(a) Patient-oriented research. Research conducted with human subjects (or on material of human origin such as tissues, specimens and cognitive phenomena) for which an investigator (or colleague) directly interacts with human subjects. This area of research includes:

- Mechanisms of human disease
- Therapeutic interventions
- Clinical trials
- Development of new technologies

(b) Epidemiologic and behavioral studies

(c) Outcomes research and health services research.

**Multidisciplinary** Research brings experts from diverse disciplines, for example, clinicians from different specialties (pediatrician, infectious disease specialist, epidemiologist, clinical trialist, and a pharmacologist) to address collectively a common complex problem.

## Appendix H: Activity Code Descriptions for Multidisciplinary Research

### K 07 Academic/Teacher Award (ATA)

To create and encourage a stimulating approach to disease curricula that will attract high quality students, foster academic career development of promising young teacher-investigators, develop and implement excellent multidisciplinary curricula through interchange of ideas and enable the grantee institution to strengthen its existing teaching program.

### P 01 Research Program Projects

For the support of a broadly based, multidisciplinary, often long-term research program which has a specific major objective or a basic theme. A program project generally involves the organized efforts of relatively large groups, members of which are conducting research projects designed to elucidate the various aspects or components of this objective. Each research project is usually under the leadership of an established investigator. The grant can provide support for certain basic resources used by these groups in the program, including clinical components, the sharing of which facilitates the total research effort. A program project is directed toward a range of problems having a central research focus, in contrast to the usually narrower thrust of the traditional research project. Each project supported through this mechanism should contribute or be directly related to the common theme of the total research effort. These scientifically meritorious projects should demonstrate an essential element of unity and interdependence, i.e., a system of research activities and projects directed toward a well-defined research program goal.

### P 30 Center Core Grants

To support shared resources and facilities for categorical research by a number of investigators from different disciplines who provide a multidisciplinary approach to a joint research effort or from the same discipline who focus on a common research problem. The core grant is integrated with the Center's component projects or program projects, though funded independently from them. This support, by providing more accessible resources, is expected to assure a greater productivity than from the separate projects and program projects.

### P 50 Specialized Center

To support any part of the full range of research and development from very basic to clinical; may involve ancillary supportive activities such as protracted patient care necessary to the primary research or R&D effort. The spectrum of activities comprises a multidisciplinary attack on a specific disease entity or biomedical problem area. These grants differ from program project grants in that they are usually developed in response to an announcement of the programmatic needs of an Institute or Division and subsequently receive continuous attention from its staff. Centers may also serve as regional or national resources for special research purposes.

### **P 51 Primate Research Center Grants (NCRR)**

To support Centers which include a multidisciplinary and multi-categorical core research program using primate animals and to maintain a large and varied primate colony which is available to affiliated, collaborative, and visiting investigators for basic and applied biomedical research and training.

### **T 90 Interdisciplinary Research Training Award**

To support comprehensive interdisciplinary research training programs at the undergraduate, predoctoral and/or postdoctoral levels, by capitalizing on the infrastructure of existing multidisciplinary and interdisciplinary research programs.

### **U 19 Research Program – Cooperative Agreements**

To support a research program of multiple projects directed toward a specific major objective, basic theme or program goal, requiring a broadly based, multidisciplinary and often long-term approach. A cooperative agreement research program generally involves the organized efforts of large groups, members of which are conducting research projects designed to elucidate the various aspects of a specific objective. Substantial Federal programmatic staff involvement is intended to assist investigators during performance of the research activities, as defined in the terms and conditions of award. The investigators have primary authorities and responsibilities to define research objectives and approaches, and to plan, conduct, analyze, and publish results, interpretations and conclusions of their studies. Each research project is usually under the leadership of an established investigator in an area representing his/her special interest and competencies. Each project supported through this mechanism should contribute to or be directly related to the common theme of the total research effort. The award can provide support for certain basic shared resources, including clinical components, which facilitate the total research effort. These scientifically meritorious projects should demonstrate an essential element of unity and interdependence.

### **U 54 Specialized Center – Cooperative Agreements**

To support any part of the full range of research and development from very basic to clinical; may involve ancillary supportive activities such as protracted patient care necessary to the primary research or R&D effort. The spectrum of activities comprises a multidisciplinary attack on a specific disease entity or biomedical problem area. These differ from program project in that they are usually developed in response to an announcement of the programmatic needs of an Institute or Division and subsequently receive continuous attention from its staff. Centers may also serve as regional or national resources for special research purposes, with funding component staff helping to identify appropriate priority needs.

### **SOURCE**

Activity Codes, Organization Codes, and Definitions Used in Extramural Programs. IMPAC. Planning, Communications & Outreach Branch, Division of Extramural Information Systems, Office of Policy for Extramural Research Administration, Office of Extramural Research, Office of the Director, National Institutes of Health. June 2004.

## Appendix I: Supporting Data for Research Sub-Question 3.4

The Number of Projects by Research Type (Basic, Translational, or Clinical) for Each Center

Center	Basic	Translational	Clinical
A	3	0	4
B	1	3	0
C	3	1	1
D	6	1	2
E	4	0	3
F	3	2	0
G	4	0	1
H	3	0	3
I	5	0	2
J	0	0	6
K	2	0	3
Average	3	1	2

The Number of Projects Proposed By Type of Project Across All Udall Centers

Proposed Project:	# of Project Types Proposed by All Udall Centers	% of Project Type of All Project Types Proposed for All Udall Centers
Studies on $\alpha$ -synuclein	10	16%
Mechanisms of neurodegeneration	7	11%
Genetic linkage studies	7	11%
Novel Model of PD	6	10%
Neuropathology	5	8%
Functional imaging	4	7%
Receptor function in basal ganglia	4	7%
Expression studies	4	7%
Dopamine dysfunction	4	7%
Degeneration prevention studies	4	7%
Behavior analysis of PD model	2	3%
Studies on Parkin	2	3%
Gene Mapping	2	3%

## Appendix J: Supporting Data for Research Sub-Question 5.2

### Top Research Finding Responses<sup>47</sup> by both Udall and Comparison Group Participants

Top discoveries leading to new hypothesis	Center Directors	Project/Core Leads	Comparison
<b>Novel Discoveries in PD pathology</b>			
Discovered of novel mechanisms of PD pathogenesis (mitochondrial DNA cybrids, axonal transport, Parkin/synuclein interaction with synphilin, IRE1-alpha and PERK)	5	13	3
Discovered proteins which are either neuroprotective or neurodegenerative (NOS-2A, PARP1, Girk2, Sepiapteri reductase, GST-P1, UCP2)	5	10	5
Made novel discoveries involving Alpha-synuclein (change in olfaction, anxiety, cognition, digestion, lysosomal degradation, transcriptional dysregulation, MPTP protection (synuclein KO), gene dosage, sensorimotor gating, increased ex cell dopamine, interaction with synphilin-1, N-term truncation, synaptic dysfunction, cortical deposits, oxidative stress)	5	13	
Studied role of trophic factors in P.D. (BDNF, GDNF, NGF, myr-AKT, NGF – TrkA binding/associated proteins, K channel synthesis and trafficking, macroendocytosis, neurotrophin receptor ubiquitination, retrograde transport of, MAPK activation, p75 neurotrophin receptor)	2	3	13
Made novel discoveries about mitochondrial dysfunction and PD (Complex I, mitochondrial DNA effects, Lewy Body formation, UCP2, aberrant movement of, maternal inheritance factors, Co-Enzyme Q, cholesterol)	2	8	4
Made novel discoveries involving Parkin (sensorimotor gating, increased ex cell dopamine, interaction with synphilin-1, synaptic dysfunction, age of PD onset)	3	3	2
Made novel discoveries involving LRRK2 (pathophysiology, gene interactions, protein interactions, clinical presentation)	1	5	1
Discovered correlation with other known neurodegenerative diseases (ataxia genes, Huntington, neuropathy target esterase, APOE4, dystonia, depression, tauopathy)		5	3
Found the effect of proteasome and protein folding dysfunction in neurodegeneration (heat shock protein chaperones, Ub of neurotrophin receptors, IRE1-alpha and PERK)	3		2
Found alterations in pro-inflammatory molecules in PD (iNOS, Il1-beta, COX-2, DA neuron antigen presentation)	1	3	
Examined the relationship of PD and environmental toxins (pesticides, welding)		1	3
Made novel discoveries involving DJ-1			2
Studied role of hydrogen peroxide in PD and neurodegeneration			2
Studied role of neuromelanin in microglia activation and degeneration		1	

<sup>47</sup> The study team grouped responses into like discoveries. Therefore this table lists the number of responses for each grouped discovery; a Udall Investigator or comparison group participant could have reported more than one discovery that is in the same grouped response.

Top discoveries leading to new hypothesis	Center Directors	Project/Core Leads	Comparison
<b>Clinical investigations into PD</b>			
Identified novel gene as marker or potential cause of PD (Park3 locus)	2	5	3
Developed methods for better diagnosis of PD	2	4	2
Studied deficits in PD patients (sensory/motor defects, dopamine replacement Rx, sub-movements, l-dopa dyskinesias, micrographia, motor activation, reach-to-grasp movements, task switching, eye saccade )		1	7
Studied the effects of current stimulation therapies for PD treatment		2	2
Performed clinical study to identify novel differences between normal and PD metabolic brain function		1	
Developed novel method for phenotypic analysis of PD models.		1	
<b>Technological Developments</b>			
Developed novel PD animal model(s) Mice: (Rotenone, Parkin KO, Alpha synuclein overexpression) Non-human primate (milder form of PD) Novel Cell line: (cybrids, other)	3	8	1
Developed novel reagent for PD and neurodegeneration research (NGF mutant, small molecules, alternative to GDNF, carboxyfullerene)	1	2	4
Examined neuronal cell development (late dopamine neurons more susceptible to degeneration, embryonic neuron rejection and aging)			3
<b>Novel Treatment Options</b>			
Discovered novel therapeutic mechanism for PD treatment (GDNF, Tempol, ghrelin, minocyclin, estrogen, nitric oxide based therapeutics, antioxidants, viral vectors, low energy laser)	2	5	8
Explored the use of stem/fetal cell therapy as a treatment for PD (dopamine neuron production from stem cells, prevention of tumor formation using stem cells, age related tissue rejection, need for immunosuppressants, defined media, DA neuron grafts)	1	2	10
Explored mechanisms of prevention of PD (nicotine, NOS-2A, caffeine, and smoking)		2	2
Discovered novel target for PD drug therapy (mGluR, K-ATP channels)		1	2
Explored neuronal survivability after prosthetic implantation			1
<b>Dopamine Signaling</b>			
Revealed important aspects of dopamine dysfunction in PD model (changes in D1 receptor activation, dopamine replacement therapy, glutamate/gaba dysfunction, synaptic changes (neureglins))	1	2	4
Identified alterations in DA intracellular signaling (cybrid studies, PKA2 to COX-2, p53, JNK, MAPK, D1 receptors in neocortex)	1	3	2
Carried out basic studies in dopamine signaling (dopamine increases: GABA signaling, TH regulation, vGAT regulation via dopamine, change in mGluR subtypes, glutamate receptors via postsynaptic mech, Ca <sup>+</sup> dependent release, GAD dysfunction in PD, DAT GFP mouse)		1	5

Top discoveries leading to new hypothesis	Center Directors	Project/Core Leads	Comparison
<b>Basal Ganglia Function</b>			
Identified changes in neuronal activity in a model of PD (single unit recordings)		4	4
Understanding neuronal pathways involved in striatal function (habitual learning, cortical convergence)	1	1	2
Studied basal ganglia firing as in normal and PD models			4
Studied the role of receptors in basal ganglia function (mGluRs, GABA A)		1	1
Modeled basal ganglia circuit to make predictions about movement disorders			1

## Appendix K: Methodology for Question 7

The study team created a database to analyze Question 7, which included a measure or measures for each of the characteristics, activities, and goals identified in Questions 3-6. The following exhibits display the measures and how they were operationalized.

Once the data were in the database, the study team conducted several data analyses, including correlation analyses and t-tests, to determine if statistically significant relationships existed. Any significant findings were reported in sections 7a and 7c.

The study team used a multi-step process to score success with goal attainment (for sections 7b and 7d). To start, the study team rank ordered, by Center, the data for every *goal* variable in the database. As appropriate, variables were reverse-coded to ensure that all data were in a consistent direction. The study team then created an overall average rank, for each Center, from the per-variable rankings. These overall average rankings were used to determine a final rank order. The Centers were grouped into three groups (highest ranking, middle ranking, and lowest ranking), with consideration for natural cut points.

### Characteristics

#	Characteristic	Measure	Database Coding
3.1	• Overall research experience of the institution, pre-Udall	• Funding per institution, pre-Udall	• Funding, in dollars
	• Overall research experience of the Center Director, pre-Udall	• Funding per Center Director, pre-Udall	• Funding, in dollars
	• Overall research experience of the Project/Core Directors, pre-Udall	• Funding per Project/Core Director, pre-Udall	• Funding, in dollars
3.2	• Overall PD research experience of the institution, pre-Udall	• PD Funding per institution, pre-Udall	• Funding, in dollars
	• Overall PD research experience of the Center Director, pre-Udall	• PD Funding per Center Director, pre-Udall	• Funding, in dollars
	• Overall PD research experience of the Project/Core Directors, pre-Udall	• PD Funding per Project/Core Director, pre-Udall	• Funding, in dollars
3.3	• Center Director's previous experience leading multidisciplinary research teams	• Grant funding per Center Director	• Funding, in dollars
3.4	• PD research areas to be pursued	• Centers' sub-projects, designated as basic, translational, or clinical	• Percentage – Basic • Percentage – Translational • Percentage – Clinical
3.5	• Breadth of the Center's organizational structure, and whether it includes basic, translational or clinical research	• Organizational structure (e.g., team, group, Center) for conducting PD research and other research prior to becoming a Udall Center	• N/A – Excluded because the measure was based on qualitative data that could not be quantified

### Activities

#	Activity	Measure	Database Coding
4.1	<ul style="list-style-type: none"> <li>Offering research training relevant to PD</li> </ul>	<ul style="list-style-type: none"> <li>Presence of a training core</li> <li>Number of trainees during first five years</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative interview data coded as: 0=no; 1=yes</li> <li>Number of trainees, as reported in progress reports</li> </ul>
4.2	<ul style="list-style-type: none"> <li>Obtaining adequate research support for Udall Center projects</li> </ul>	<ul style="list-style-type: none"> <li>Extent to which the research support functions provided by Udall funding were sufficient to meet your needs during the 1998-2004 timeframe: facilities; cores; equipment and supplies; personnel; services such as bio-statistical, data management, IT, grants assistance</li> <li>Grant supplements awarded</li> </ul>	<ul style="list-style-type: none"> <li>Quantitative survey data recoded as: 0=inadequate, 1=adequate, 2=more than adequate</li> <li>Calculated the average, per Center, for all respondents from the Center</li> <li>Grant supplements, in dollars</li> </ul>
4.3	<ul style="list-style-type: none"> <li>Promoting multidisciplinary collaborations within and between Udall Centers</li> </ul>	<ul style="list-style-type: none"> <li>How has collaboration had an impact on your Center's ability to achieve your research goals in terms of pre-publication collaboration?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative interview data coded as: 0=little impact on research; 1=some impact on research; 2=positive impact on research</li> <li>Calculated the average, per Center, for all respondents from the Center</li> </ul>
4.4	<ul style="list-style-type: none"> <li>Ensuring effective day-to-day management and communications</li> </ul>	<ul style="list-style-type: none"> <li>How did the Center structure change your management practices (for example, more formal research planning, improved organization of labor/resources, etc.)?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative survey data (Center Directors only) coded as: 0=no change of management practices and 1=management practices changed</li> </ul>
4.5	<ul style="list-style-type: none"> <li>Emphasizing strategic planning, including setting milestones, monitoring progress, and seeking advisory committee input</li> </ul>	<ul style="list-style-type: none"> <li>How did your Center set goals and establish milestones? Were there any particular approaches or techniques that you utilized?</li> <li>How did your Center monitor, and measure its progress towards reaching goals and achieving milestones? Were there any particular approaches or techniques that you utilized?</li> <li>How did your Center identify and plan for operational improvements (e.g., acquisition of equipment, improving processes, etc.)? Were there any particular approaches or techniques that you used that assisted you in that planning process? Please elaborate.</li> <li>Did your Center use advisors? If so, in what ways, and how were they related to your Center (i.e., from within your institution or from outside your institution, etc.)?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative survey data (Center Directors only) coded as: 0=negative response; 1=affirmative response</li> <li>Calculated the average across the four survey items</li> </ul>

### Short-Term Goals

#	Short-Term Goal	Measure	Database Coding
5.1	<ul style="list-style-type: none"> <li>Integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research</li> </ul>	<ul style="list-style-type: none"> <li>Please discuss the role, if any, the Center structure has played in your Center's results. What do you feel you have accomplished that you could not have without the structure of the Udall Centers Program?</li> <li>Would you describe your Center within the first 5 years as becoming more focused on interrelated scientific problems? If yes, in what ways, if not, please elaborate.</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative survey data coded as: 0=negative response; 1=affirmative response</li> <li>Calculated the percentage of respondents, per Center, who provided affirmative response</li> <li>Calculated the average percentage across the two survey items</li> </ul>
5.2	<ul style="list-style-type: none"> <li>Early results leading to new hypotheses relevant to PD</li> </ul>	<ul style="list-style-type: none"> <li>Original articles authored by Udall Center Investigators</li> <li>Impact rating per publication</li> </ul>	<ul style="list-style-type: none"> <li>Number of Udall Center Investigators' articles, aggregated by Center</li> <li>Per Center, Calculated the median percentile ranking (impact rating)</li> </ul>
5.3	<ul style="list-style-type: none"> <li>New procedures developed for sharing PD research findings and scientific techniques</li> </ul>	<ul style="list-style-type: none"> <li>Did the act of becoming a Udall Center increase your collaborative efforts (e.g., increased communication and joint research efforts including sharing of tools, techniques, concepts, and research findings) – Within your Center? With other Udall Centers? And/or with non-Udall researchers?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative interview data coded as: 0=negative response; 1=affirmative response</li> <li>For each of the three questions, calculated an average, per Center, for all respondents from the Center</li> <li>For each Center, calculated an average across the three questions</li> </ul>
5.4	<ul style="list-style-type: none"> <li>Recruitment of new faculty and trainees to PD research</li> </ul>	<ul style="list-style-type: none"> <li>What effect did your Center have on building the future leaders of PD research (e.g., did funding stimulate others to get involved in PD research) during its first 5 years? Have the new PD researchers (whether junior trainees or more senior researchers joining the PD community) been fully engaged in the research, and have they made progress? If so, in what ways?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative survey data coded as: 0=negative response; 1=affirmative response</li> <li>Calculated the percentage of respondents, per Center, who provided affirmative response</li> </ul>
5.5	<ul style="list-style-type: none"> <li>More multi-disciplinary research relevant to PD</li> </ul>	<ul style="list-style-type: none"> <li>Change in the percentage of each Center's articles that were deemed multi-disciplinary in 1999 and 2005</li> </ul>	<ul style="list-style-type: none"> <li>Of the sampled articles, stratified by Center and calculated the percentage that were deemed multi-disciplinary in 1999 and 2005</li> <li>Calculated the difference in the 1999 percentage and the 2005 percentage, by Center</li> </ul>
5.6	<ul style="list-style-type: none"> <li>Broader research and infrastructure support for projects relevant to PD</li> </ul>	<ul style="list-style-type: none"> <li>NIH grant totals received by the Udall Investigators for PD research</li> </ul>	<ul style="list-style-type: none"> <li>Funding, in dollars</li> </ul>

### Long-Term Goals

#	Long-Term Goal	Measure	Database Coding
6.1	<ul style="list-style-type: none"> <li>Noteworthy research discoveries involving basic, clinical, and/ or translational research that are likely to advance the prevention, diagnosis and/or treatment of PD</li> </ul>	<ul style="list-style-type: none"> <li>Center's findings in terms of basic, translational and clinical research from the first 5 years: Center's top five (5) key discoveries/findings/results; the impact these discoveries/findings/results have had on the development of new research techniques; the impact these discoveries/findings/results have had on the development of new therapies, prevention strategies, etc.</li> </ul>	<ul style="list-style-type: none"> <li>N/A – Excluded because the measure was based on qualitative data that could not be quantified</li> </ul>
6.2	<ul style="list-style-type: none"> <li>New scientific tools developed and shared with other PD researchers (e.g. new models, technologies, databases, repositories, classification standards, research techniques)</li> </ul>	<ul style="list-style-type: none"> <li>If applicable to your work, did you develop any new animal models in the first five years of your Udall funding? If yes, have you shared these models with other researchers, and by what mechanisms?</li> <li>Did you establish novel strategies to promote collaboration (e.g., increased communication and joint research efforts including sharing of tools, techniques and concepts) within your Center, with other Udall Centers, and/or with non-Udall researchers during the initial funding period?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative interview data coded as: 0=negative response; 1=affirmative response</li> <li>Qualitative survey data coded as: 0=negative response; 1=affirmative response</li> <li>Calculated the composite score by summing across reports of development of animal models, development of investigative tools, development of new techniques, and introduction of a new field to the arena of PD research</li> </ul>
6.3	<ul style="list-style-type: none"> <li>Increased number of independent research scientists conducting PD research</li> </ul>	<ul style="list-style-type: none"> <li>Number of new independent PD research scientists (with new independent PD research scientist defined as individuals who did not receive funding for PD-related research <i>prior</i> to their participation with the Udall Center <i>and</i> who received NIH funding for a PD-related research project after their involvement with a Udall Center (and was named as the Principal Investigator on the research grant)</li> </ul>	<ul style="list-style-type: none"> <li>Number of researchers, as reported in grant histories</li> </ul>
6.4	<ul style="list-style-type: none"> <li>Increased level of collaboration with other PD researchers and the broader PD community</li> </ul>	<ul style="list-style-type: none"> <li>Percentage of publications that are joint publications with other Udall Centers</li> </ul>	<ul style="list-style-type: none"> <li>Tallied the total number of publications and the number of joint publications, by Center</li> <li>Calculated the percentage of publications that were joint publications</li> </ul>
6.5	<ul style="list-style-type: none"> <li>Increased institutional commitment to PD research</li> </ul>	<ul style="list-style-type: none"> <li>To what extent, if at all, did your institution's commitment to Parkinson's Disease (PD) research increase as a result of becoming a Udall Center?</li> </ul>	<ul style="list-style-type: none"> <li>Qualitative survey data coded as: 0=negative response; 1=affirmative response</li> <li>Calculated the percentage of respondents, per Center, who provided affirmative response</li> </ul>

## Appendix L: Supporting Data for Research Question 8

### Udall Investigator and Comparison Group Participant Responses

Research area likely to advance the prevention, diagnosis and/or treatment of PD	Project/Core Leads (40)	Comparison Participants (23)
Developed a potential treatment for PD which is still under investigation (low energy laser, new deep brain stimulation procedures, Embryonic stem cell derived dopamine neurons, p75ICD, nicotine, neural transplantation of dopamine cells, AKT viral transduction method, drug delivery pump, Transcranial stimulation, small molecules, TrkA agonists, mGluR5)	9	6
Developed a novel screening method for screening drug libraries (cell culture, mouse models, protein degradation pathways, mGluR4 activation, GDNF/trophic factor delivery, SK channel, PARP-1 inhibitors, cPLA2, computer based pharmacology)	8	2
Formed the basis for new clinical trials aimed at the treatment of PD (GDNF, Co-enzyme Q10, antioxidants, creatine, anti-inflammatory agents, RNAi, STAZN, Tempol, improved dopamine cell implantation methods, BDNF)	4	4
Developed biomarkers or other techniques for early diagnosis	7	
Identified novel genetic marker to screen for PD (Lrrk2, Mitochondrial gene ND5)	4	3
Helped to determine changes during PD treatment	2	4
Enabled Genetic testing to screen for PD genes	3	1
Identified novel candidate genes for PD research	2	
Determined the role of environment in early onset PD (Herbicides, welding)		2
Found a better grouping of PD patients based on genetic cohorts	1	
Developed Virtual Reality environments for PD patient training		1