ICARE Epilepsy Research Portfolio Analysis

ICARE meeting April 13, 2015

National Institute of Neurological Disorders and Stroke

Goals for a comprehensive analysis

- to better inform the ICARE group and interested public about the funding landscape for epilepsy research

- to assess progress being made against the epilepsy research priorities as defined by the 2014 NINDS Benchmarks and the recommendations from the 2012 IOM report "Epilepsy Across the Spectrum".

- to help guide future funding priorities by highlighting current gaps and opportunities in epilepsy research

Analysis Design

- A working group was established to set the goals and design of the analysis

- Data was collected in four different areas:
    1. Award Information
        project, investigator(s), award type and amount
    2. Award Research Categories
        research classification, type, and epilepsy type
    3. NINDS 2014 Benchmark Areas
    4. IOM 2012 Recommendations

- All ICARE member organizations categorized their funded epilepsy research according to the four areas.

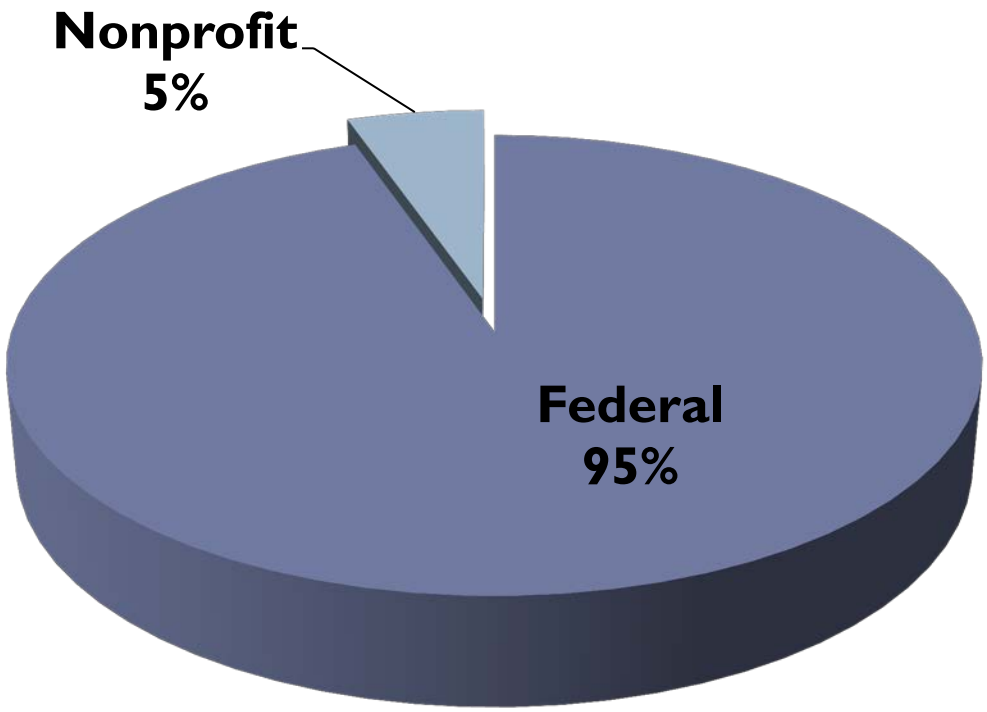
- Data contributed by: NIH, CDC, VA, PCORI, CURE, TS Alliance, AES, EF, and ELC (Dravet Syndrome Foundation, Phelan-McDermid Syndrome Foundation and PCDH19 Alliance).

The ICARE Epilepsy portfolio analysis working group

Jan Buelow, EF
David Eckstein, NCATS, NIH
Margaret Jacobs, AES
Mary Anne Meskis, Dravet Foundation – ELC
Julie Milder, CURE
Rob Moss, Seizure Tracker – ELC
Steve Roberds, TSA

Tom Cheever, NINDS
Brandy Fureman, NINDS
Miriam Leenders, NINDS

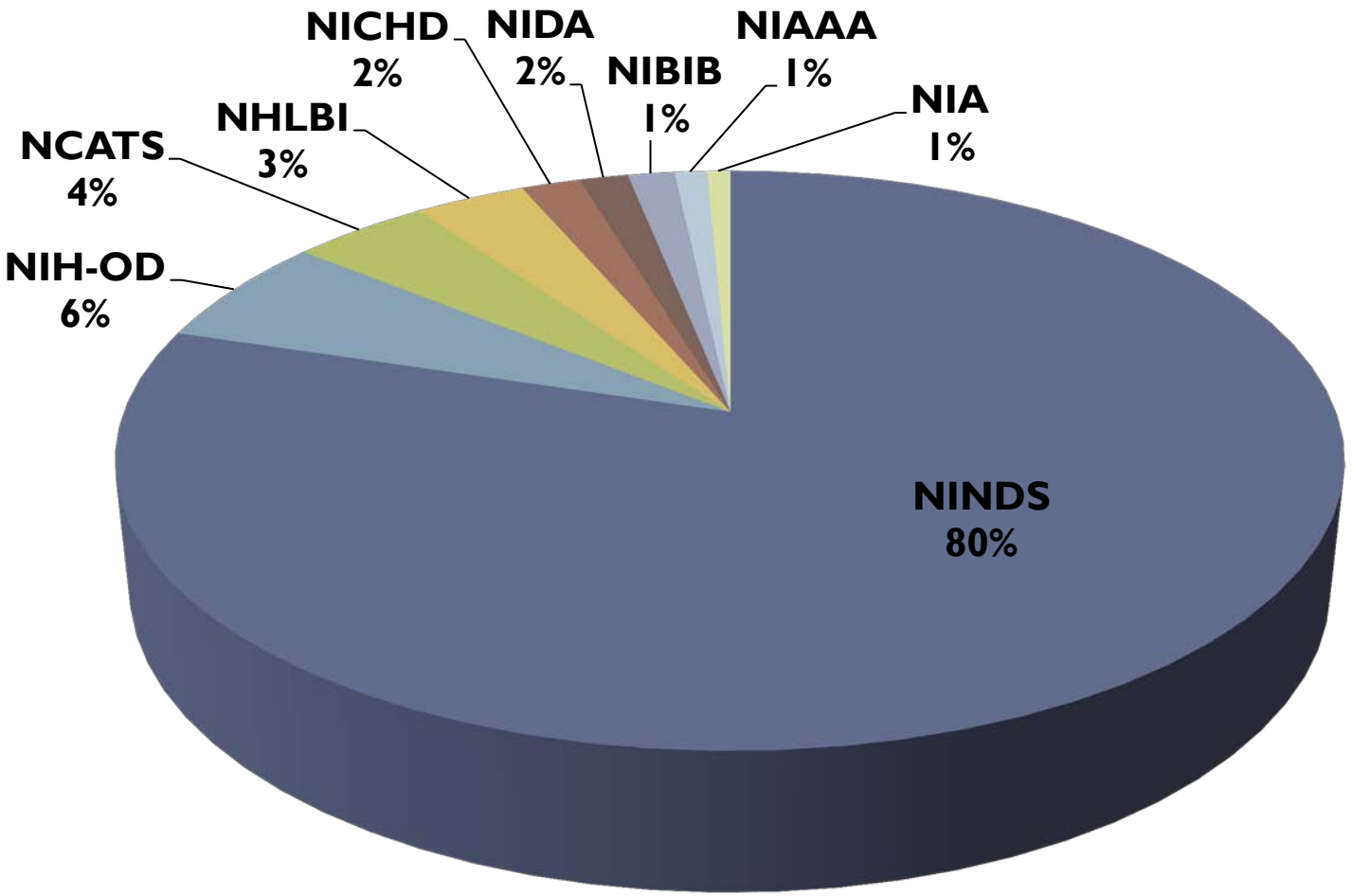
Federal Funding Dramatically Outpaces Non-profit Funding for Epilepsy Research



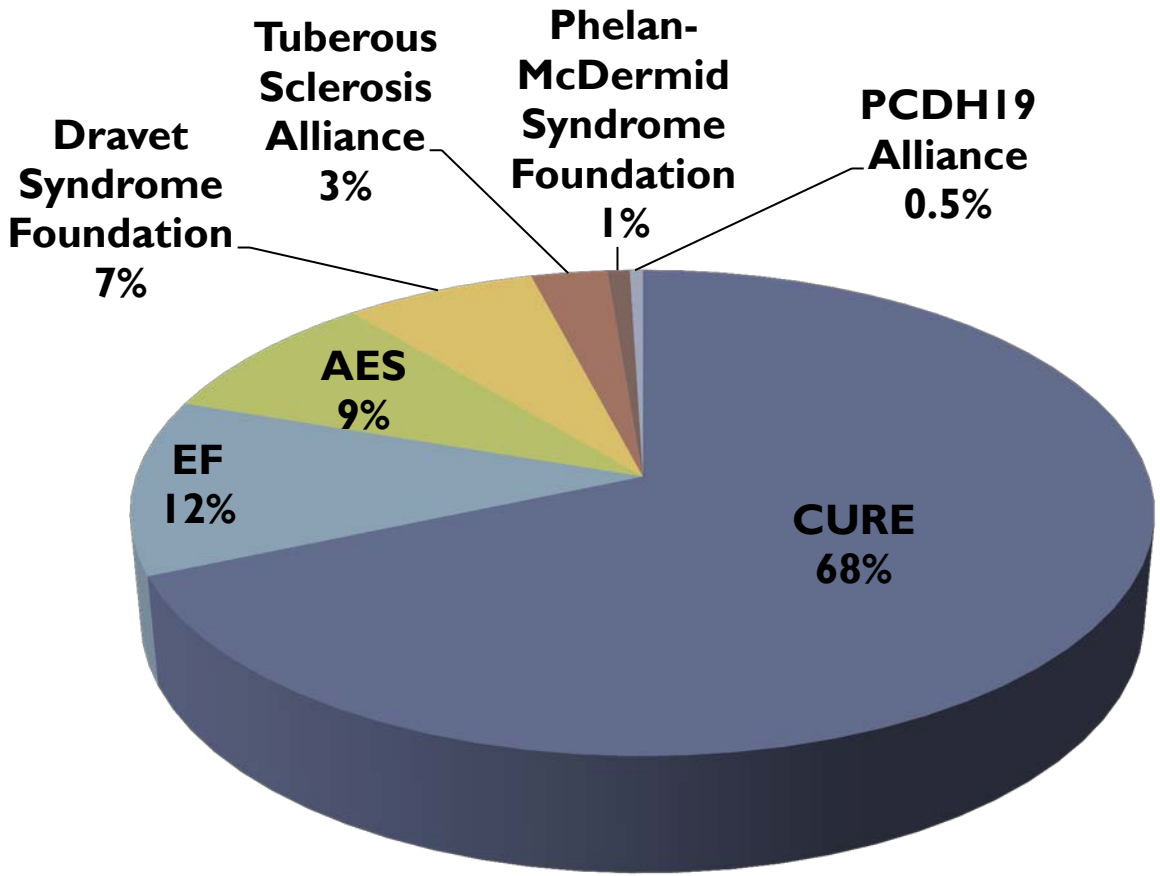
Federal vs Nonprofit Funding for Epilepsy Research in 2013 (total funding $148.9M)

Funding Agency/Organization	Number of projects	Total Funding
NIH	393	$136,385,334
CURE	41	$4,285,114
VA	15	$2,325,000
CDC	10	$2,212,135
PCORI	2	$1,684,562
EF	15	$730,000
AES	17	$547,500
Dravet Syndrome Foundation	6	$435,500
Tuberous Sclerosis Alliance	6	$174,322
Phelan-McDermid Syndrome Foundation	1	$50,000
PCDH19 Alliance	1	$30,000
Grand Total	507	$148,859,467

NINDS Supports Large Majority of NIH Funding



CURE Supports Large Majority of Epilepsy Leadership Council (ELC) Funding



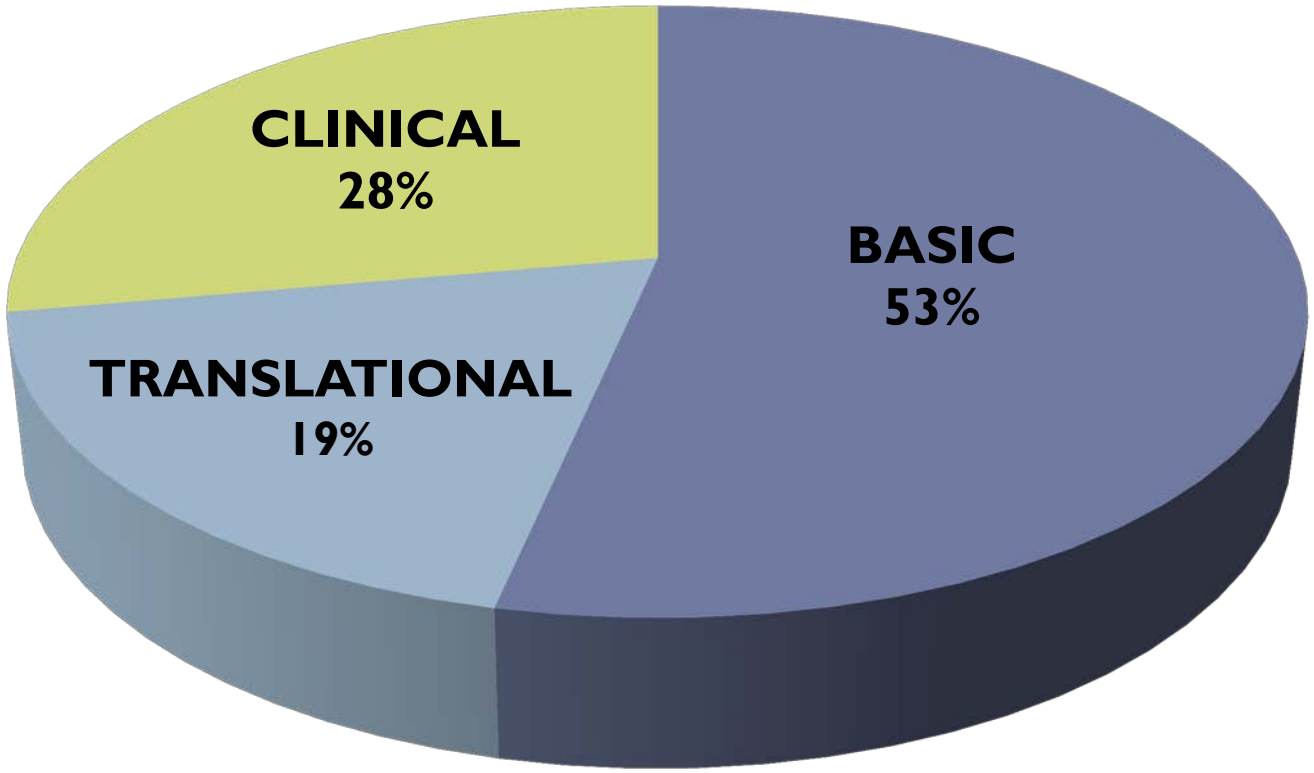
Most Investigators are Supported by a Single Project

507 projects - 408 Investigators

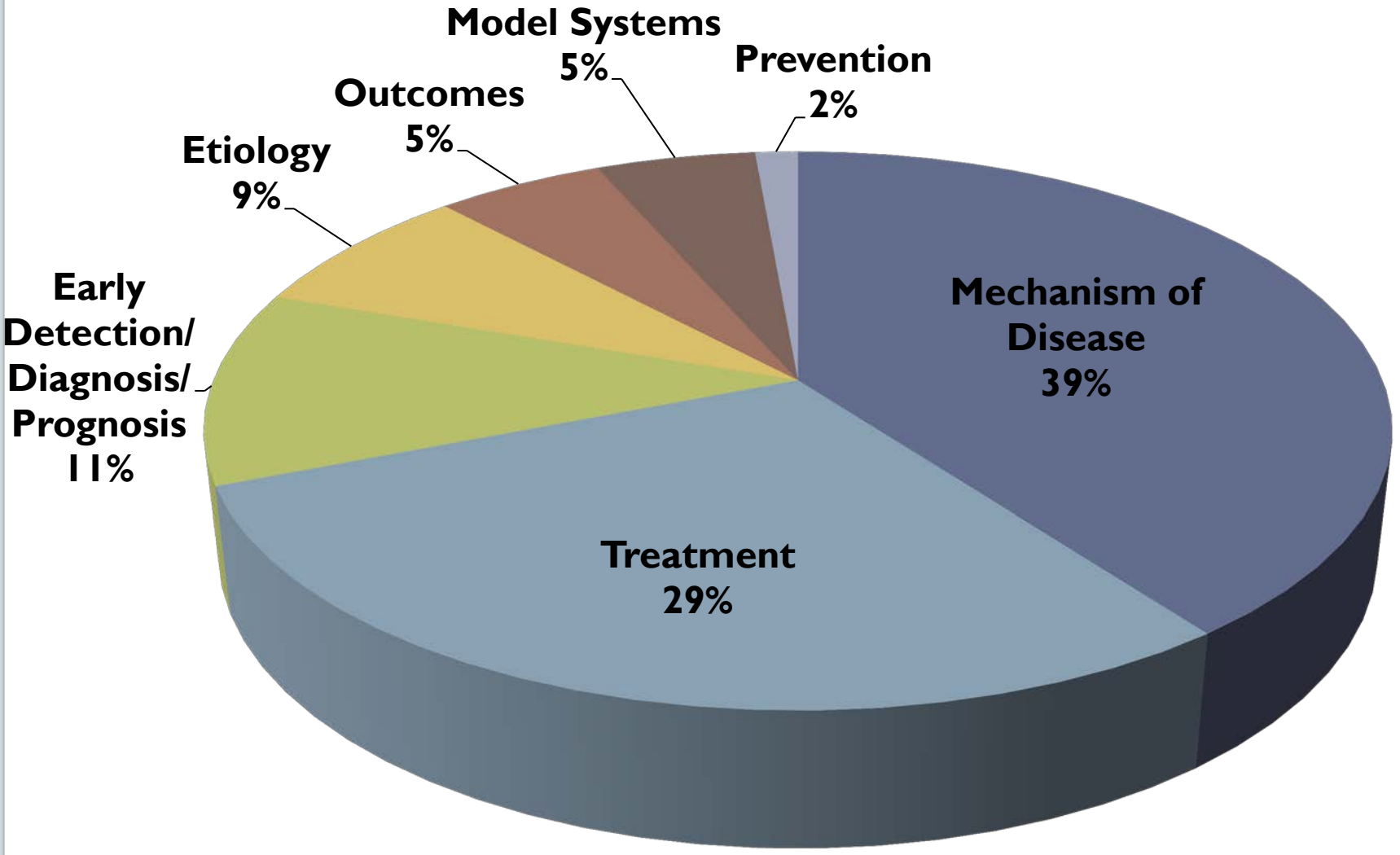
81% of investigators have 1 project; 15% have 2 projects, 2% have 3, 1% have 4 and 1% have 5.

5% of investigators received >$1M in funding in FY2013

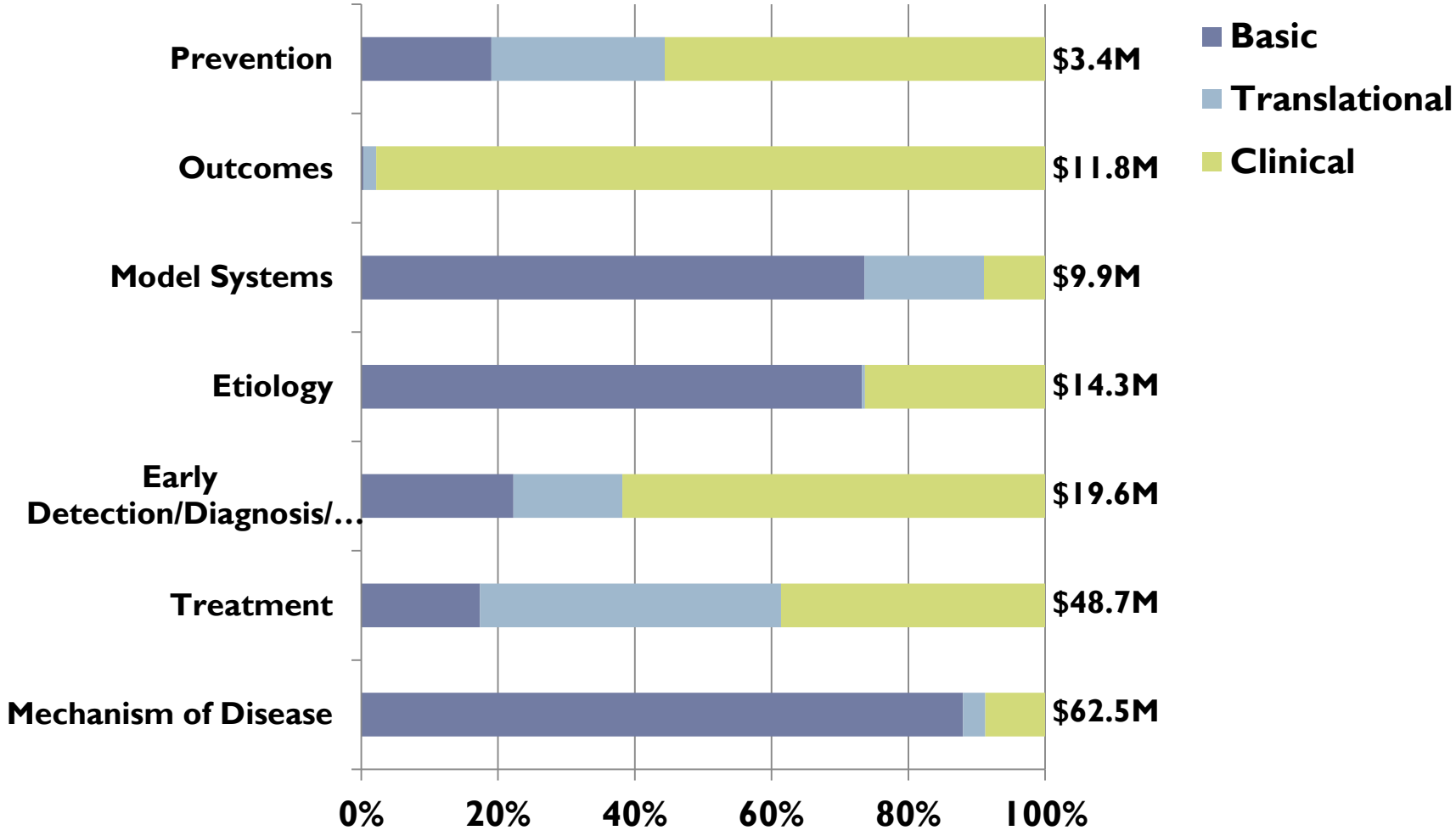
Most Funded Epilepsy Research is Basic



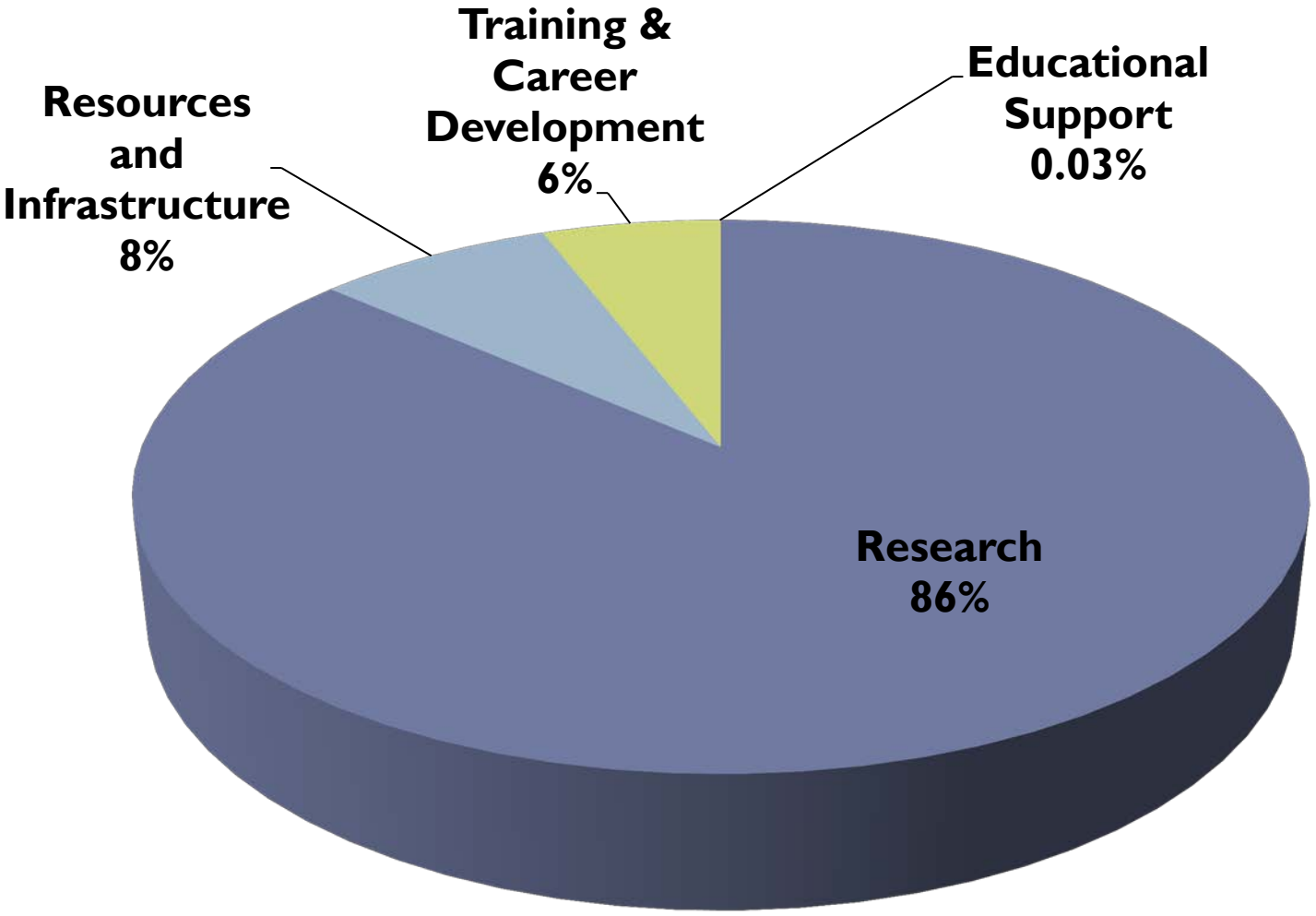
Most Funded Epilepsy Research is on Mechanism of Disease or Treatment



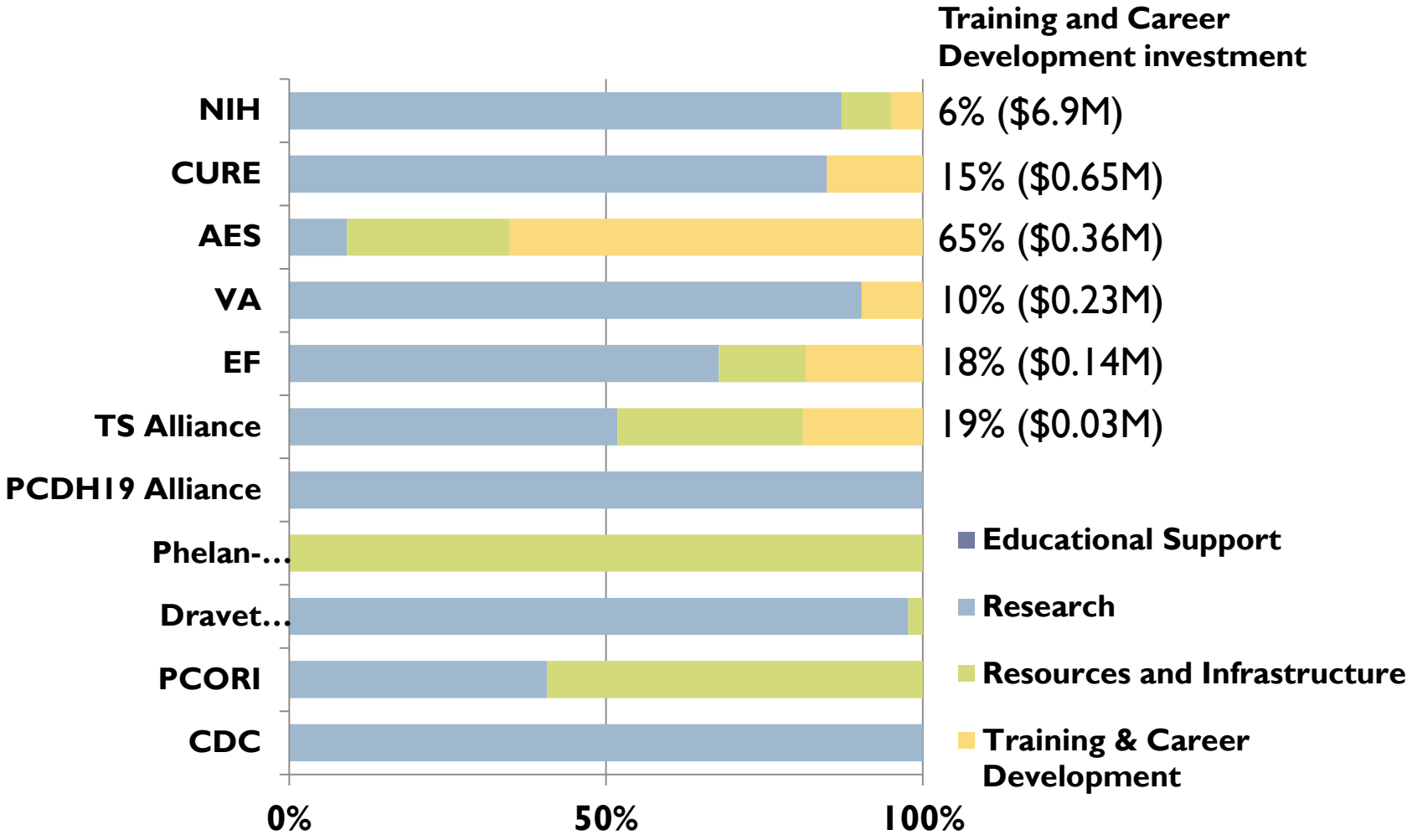
Largest Fraction of Funding goes to Research on Mechanism of Disease; Smallest to Prevention



Funding for Structured Training in Epilepsy Research is a Small Percentage of Overall Funding

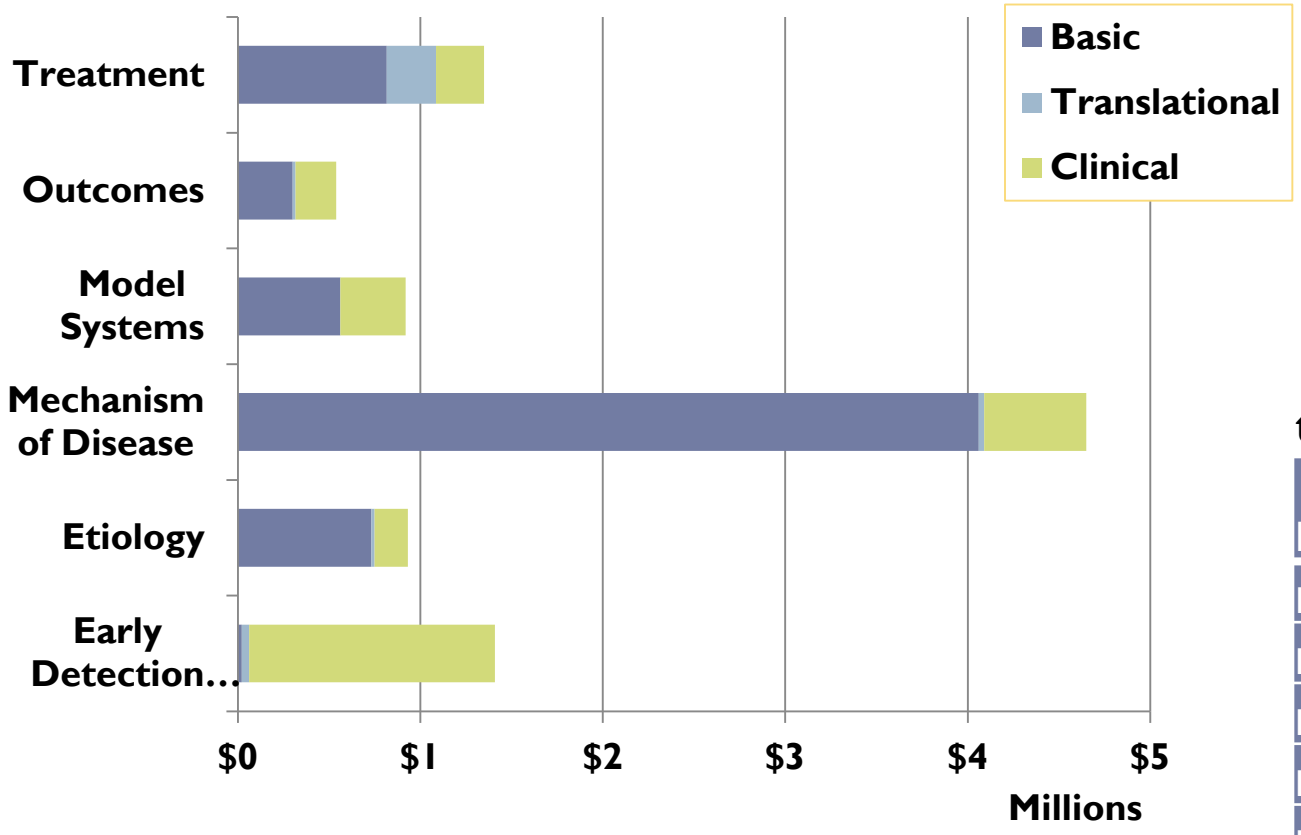


Funding for Structured Training is Provided by a Subset of Organizations



Majority of Training and Career Development Awards Support Basic Research

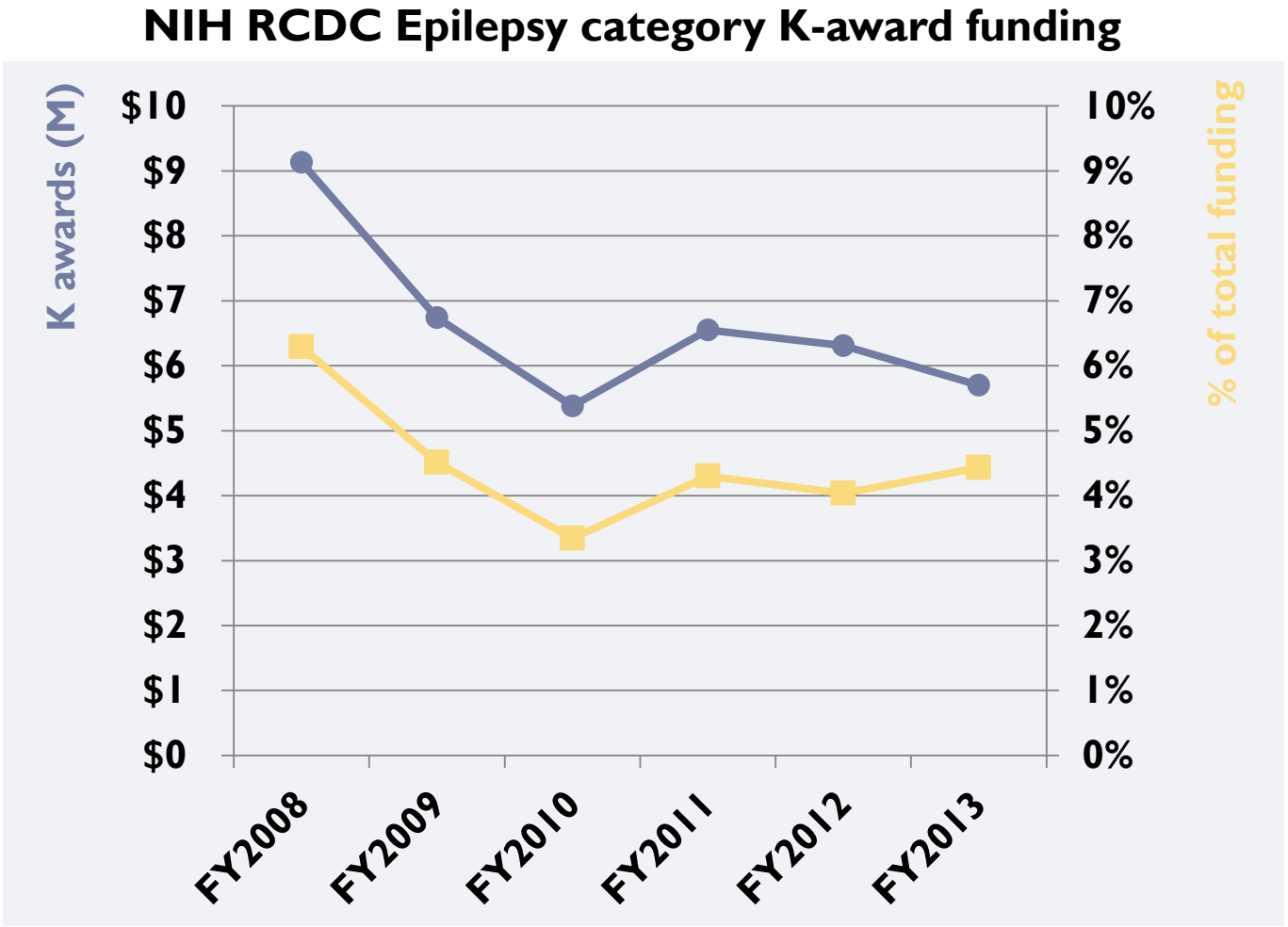
Investment of training awards by Research Classification and Type



Degrees of training awardees

Degree	# of trainees
PHD	48
MD, PHD	18
MD	14
MS	3
BS	7
other	2

NIH Epilepsy Career Development Award Funding Decrease Between FY2008 – FY2013



NIH Epilepsy Career Development Award Funding Decreased More Compared to Other Diseases

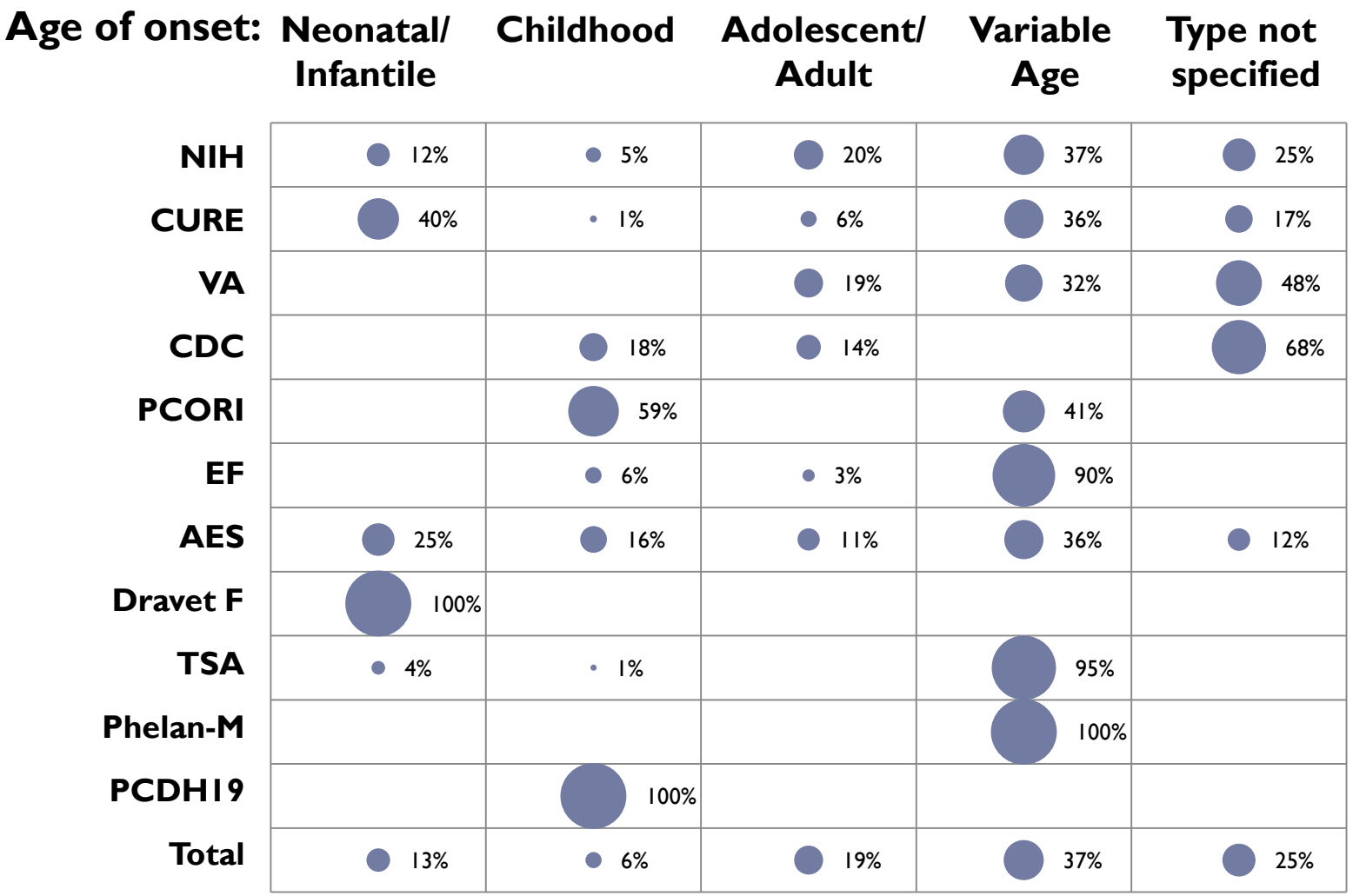
NIH RCDC disease categories K-award funding

	2008		2013	
NIH RCDC Disease Category	K awards (M $)	% of total ($)	K awards (M $)	% of total ($)
Epilepsy	$9.1	6.3%	$5.7	4.4%
Stroke	$11.6	3.9%	$9.9	3.5%
Parkinson's	$6.0	4.0%	$5.6	4.1%
Brain Cancer	$5.1	2.6%	$6.1	2.2%
Multiple Sclerosis	$5.0	3.0%	$3.0	2.7%
ALS	$0.9	2.1%	$1.1	2.8%
Autism	$4.1	3.5%	$5.3	2.9%

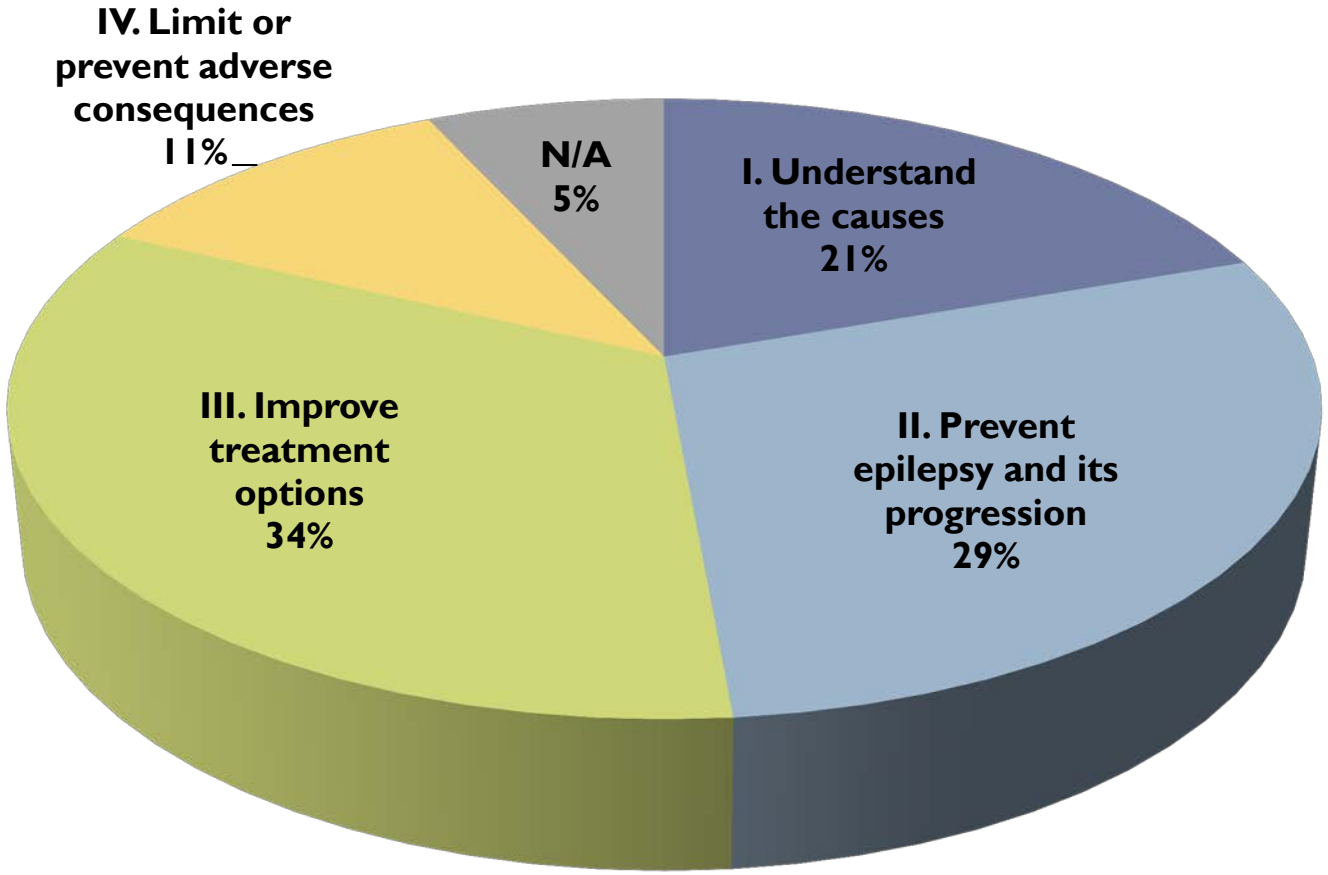
NIH R01 funding obtained by NS Epilepsy K Awardees

Active K award in FY 2008,2009 or 2010, and the award has ended before 2015.	# of awardees	% of awardees
NS Epilepsy K-awardees	53	
applied for R01 funding	38	72%
awarded R01 funding	29	55%
project focused on Epilepsy	*22*	*76% of R01s*

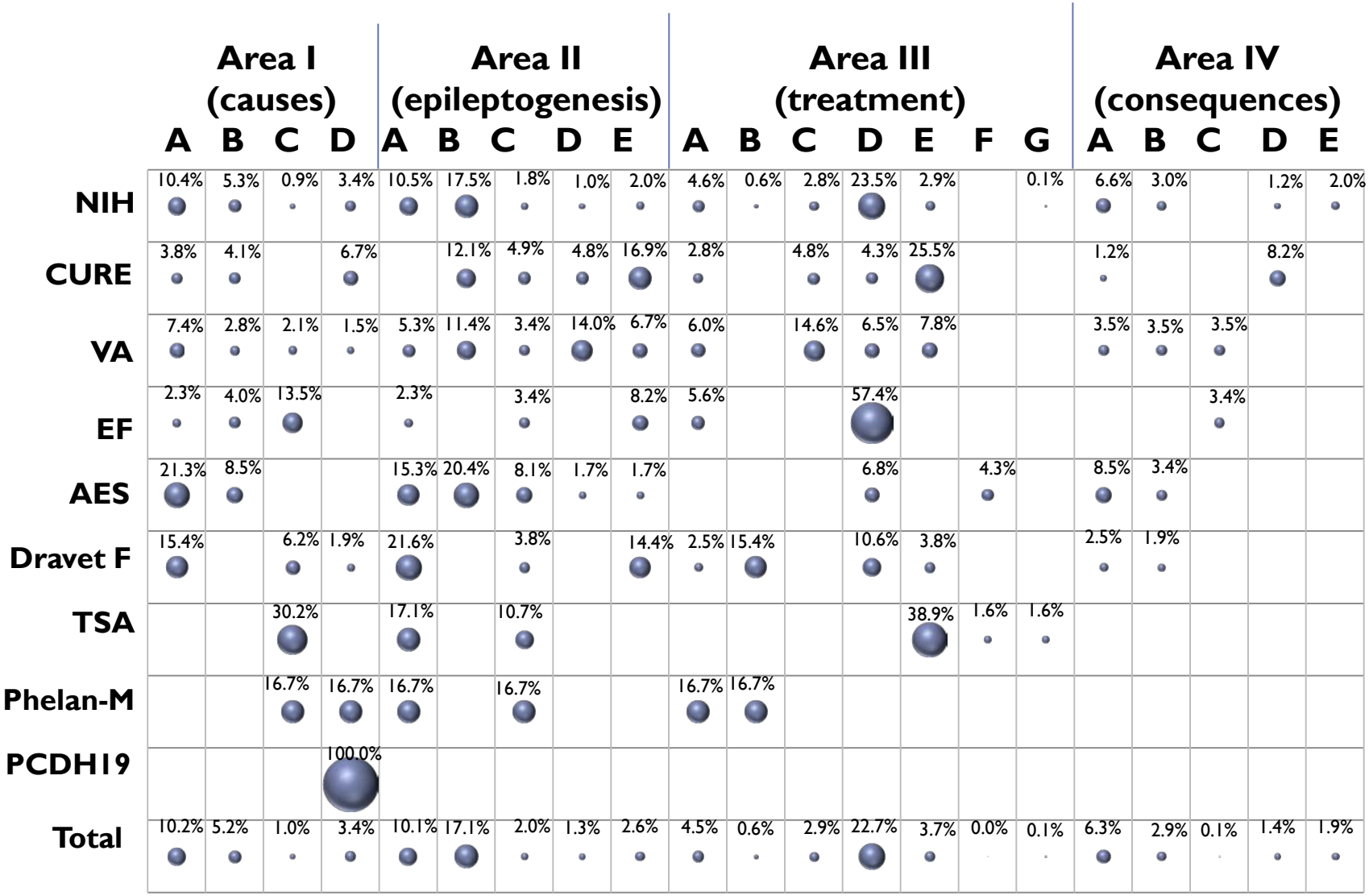
Disparities in Funding for Different Epilepsy Types



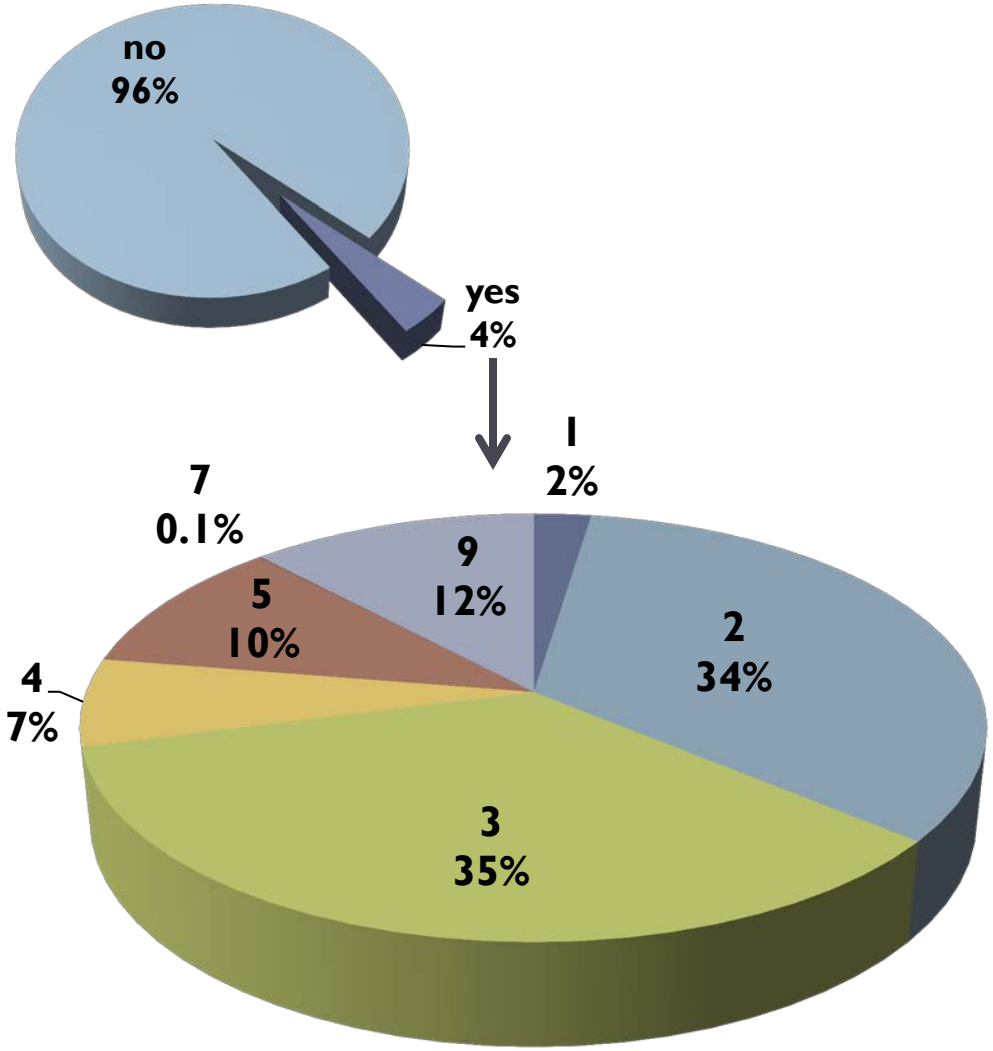
Research on the Causes and Consequences of Epilepsy Receives Less Funding



Disparities in Funding across Benchmark Areas



Little Funding Dedicated to 2012 IOM Recommendations



1. Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement
2. Continue and Expand Collaborative Surveillance and Data Collection Efforts
3. Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences
4. Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions
5. Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care
7. Improve Health Professional Education About the Epilepsies
9. Improve and Expand Educational Opportunities for People with Epilepsy and Their Families

Conclusions from 2013 Funding Data

1) Epilepsy research funding spans a range of organizations with different missions and funding capacity
2) Federal funding significantly outpaces nonprofit research funding
3) Funding from federal sources is highly concentrated at NIH
4) Limited Support for structured training in epilepsy research; is this sufficient?
5) Epilepsy research funding is unevenly distributed among the Epilepsy Benchmark priorities
6) Epilepsy research funding for IOM Research Recommendations is very limited.