

ICARE Epilepsy Research Portfolio Analysis

ICARE meeting April 26, 2019




National Institute of
Neurological Disorders
and Stroke





ICARE Epilepsy Research Portfolio


INTERAGENCY COLLABORATIVE TO ADVANCE RESEARCH IN EPILEPSY

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Interagency Collaborative to Advance Research in Epilepsy Research Portfolio

The Portfolio provides information on epilepsy research projects funded by the ICARE members, including federal and nonprofit organizations. [Learn More »](#)



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<http://icarerp.nih.gov/>

Website developed by NINDS, NIH Library Custom Information Solutions, and Webfirst

Federal and Nonprofit Funders 2013-2017



National Institutes of Health



Centers for Disease Control



United States Department of
Veterans Affairs



Health Resources and
Services Administration



LGS Foundation



Patient-Centered Outcomes
Research Institute



Pediatric Epilepsy Research
Foundation



Wishes for Elliott



Department of Defense -
Congressional Directed
Medical Research Programs



Citizens United for Research
in Epilepsy



American Epilepsy Society



Epilepsy Foundation



Child Neurology Foundation



Batten Disease Support and
Research Association



The Epilepsy Study
Consortium



Dup15q Alliance



Dravet Syndrome Foundation



Tuberous Sclerosis Alliance



PCDH19 Alliance



Phelan-McDermid Syndrome
Foundation



International Foundation for
CDKLS Research

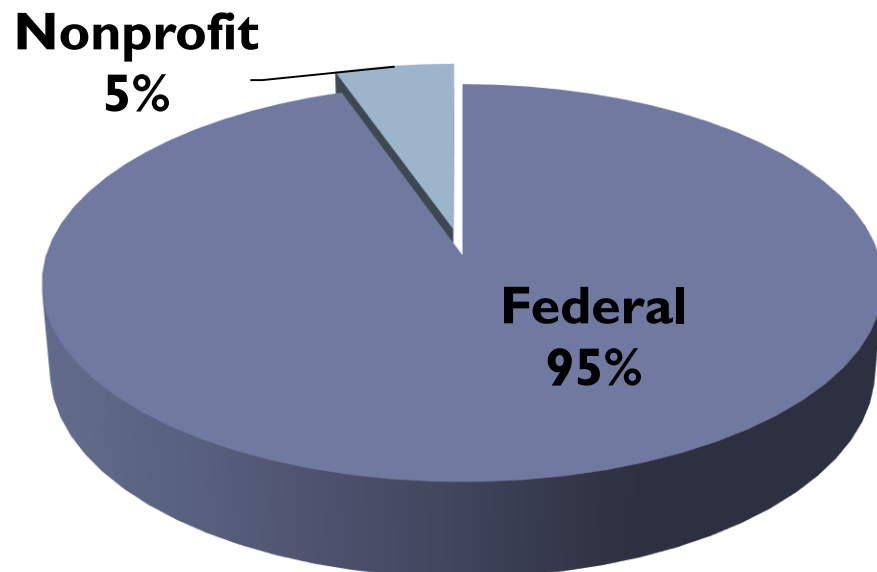


Ring14 USA



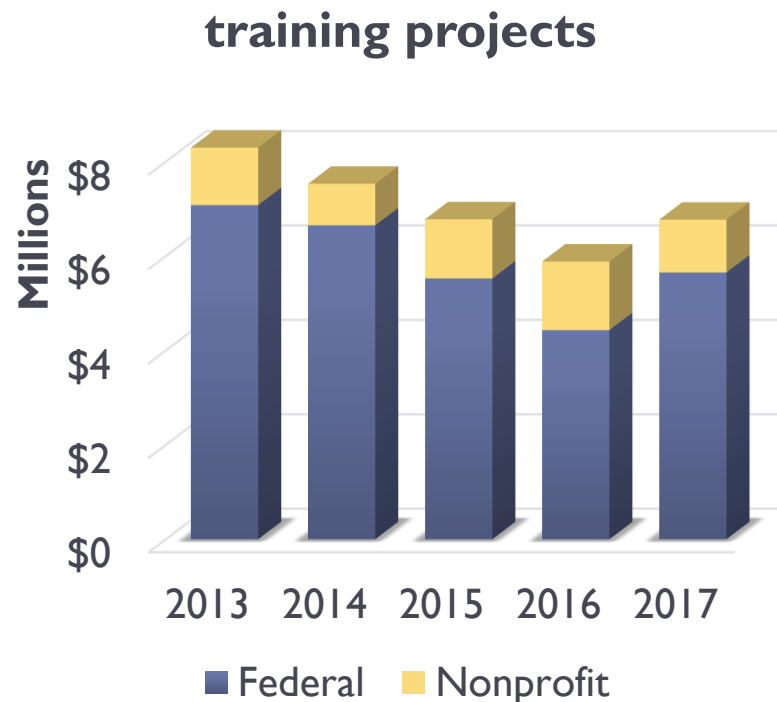
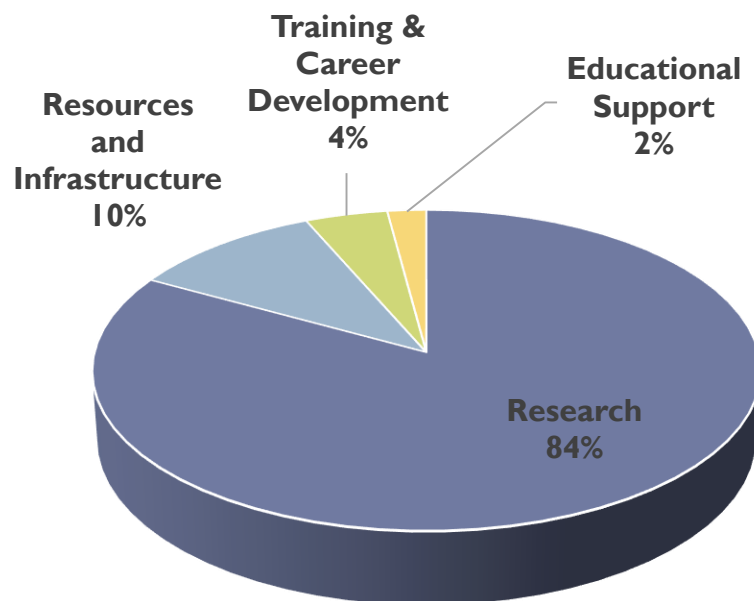
TESS Research Foundation

Federal Funding Dramatically Outpaces Non-profit Funding for Epilepsy Research

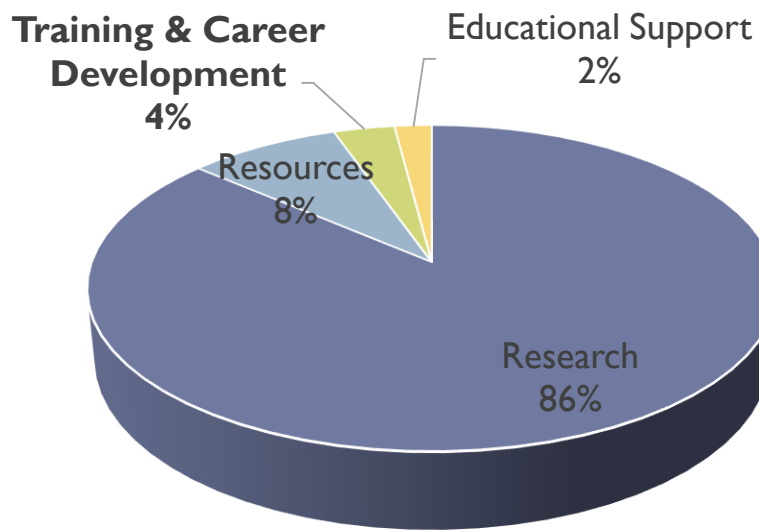


Organization	2013	2014	2015	2016	2017
Federal	\$141.0	\$172.0	\$183.2	\$195.8	\$188.0
Nonprofit	\$8.4	\$6.7	\$9.3	\$14.0	\$6.7
All	\$149.4	\$178.7	\$192.6	\$209.8	\$194.7
\$ Millions					

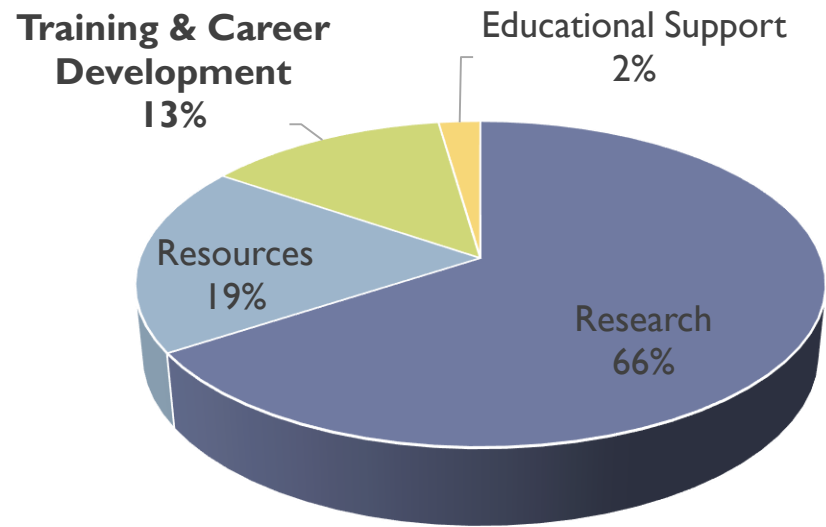
Funding for Structured Training in Epilepsy Research is a Small Percentage of Overall Funding



Nonprofit Funders Allocate a Larger Percentage of Funding Towards Training Awards

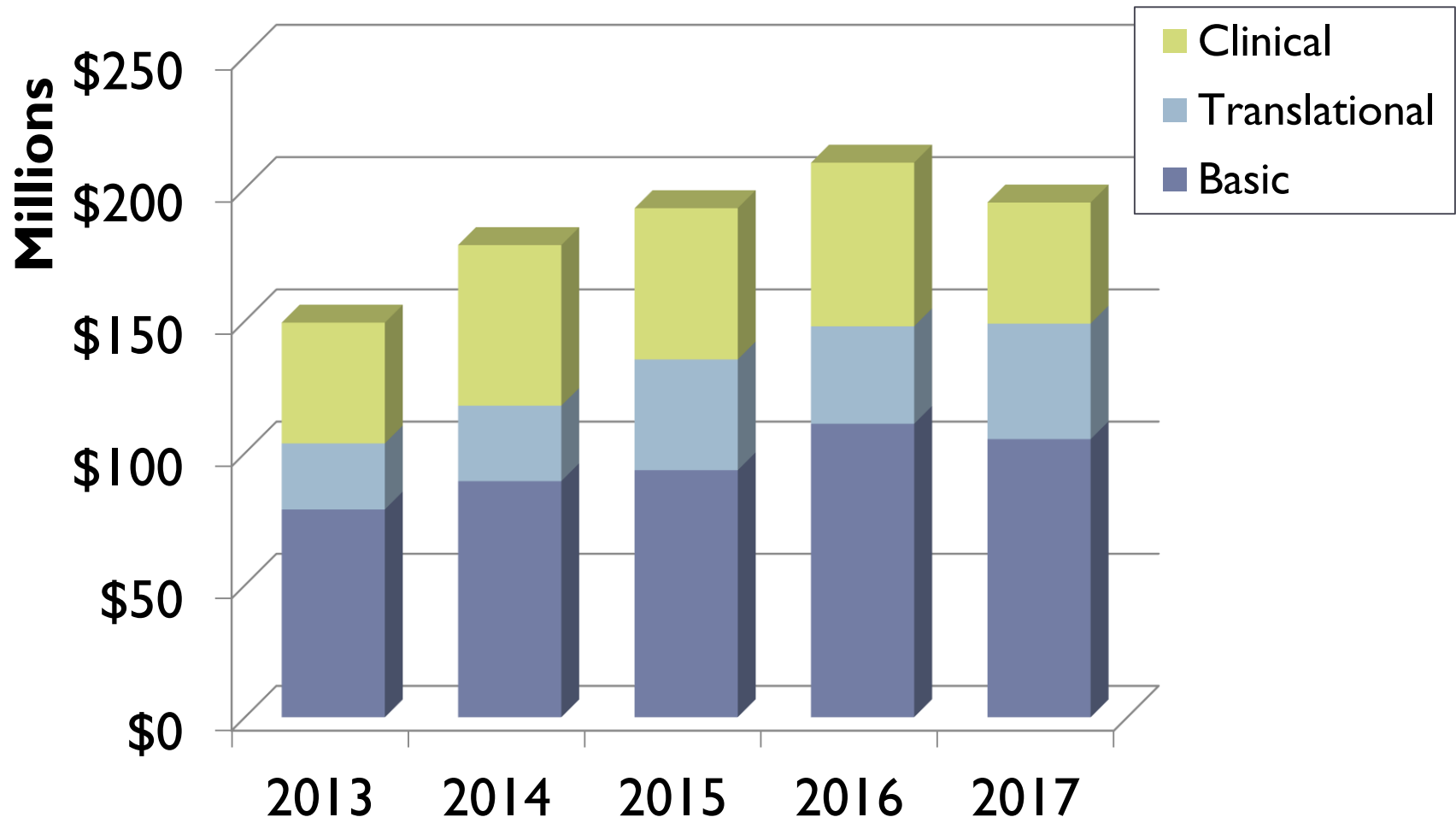


Federal

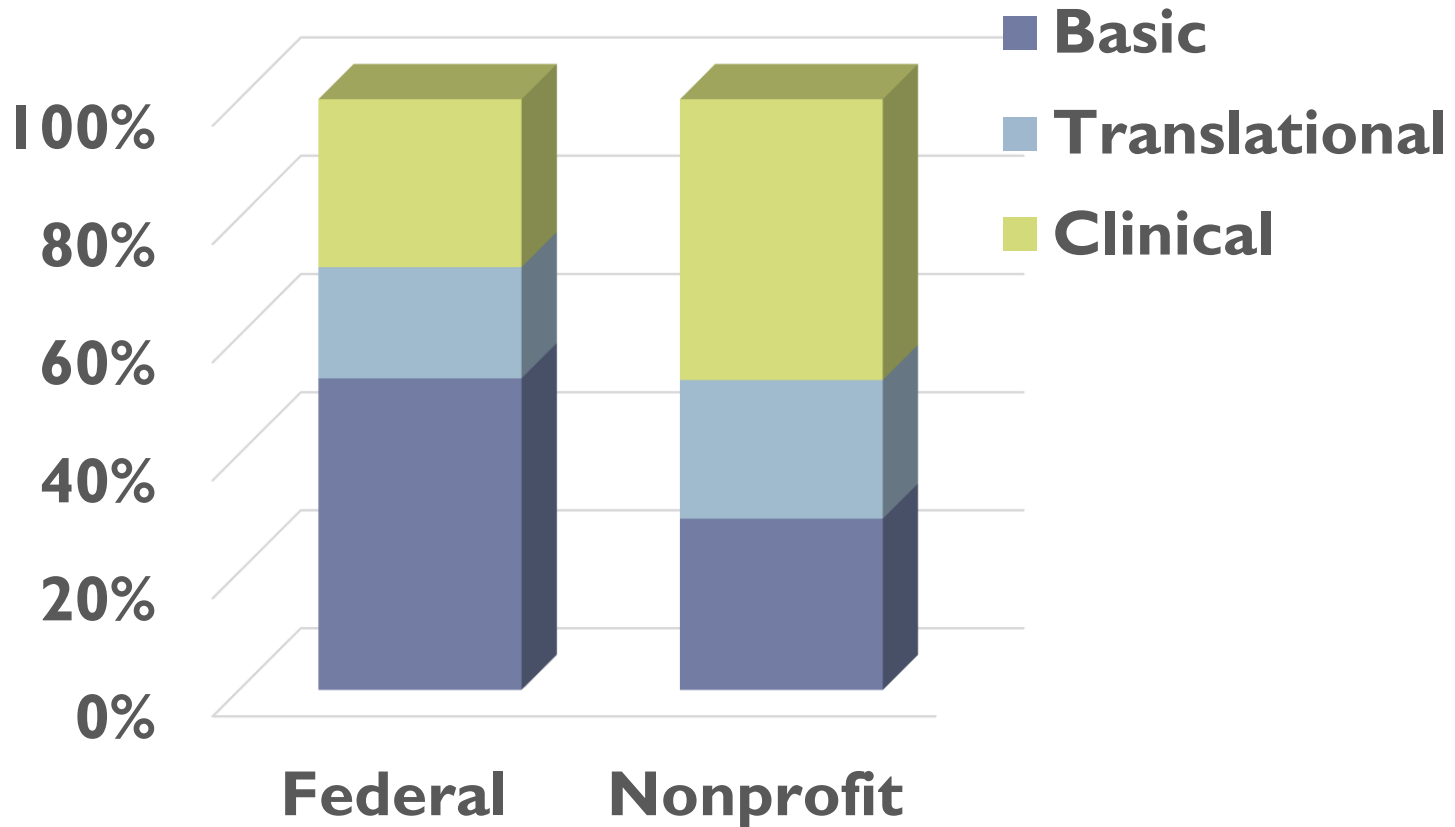


Nonprofit

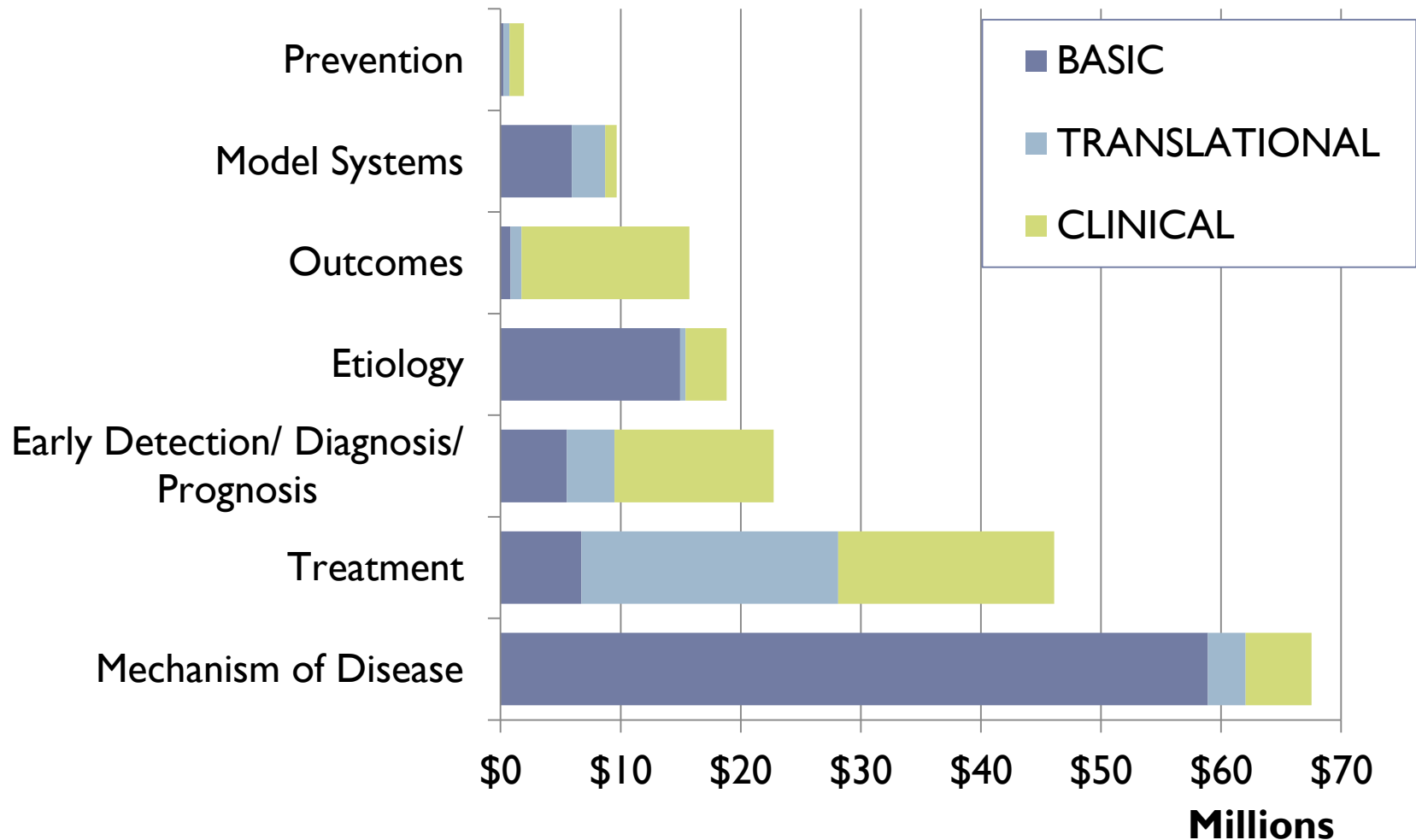
Most Funded Epilepsy Research is Basic



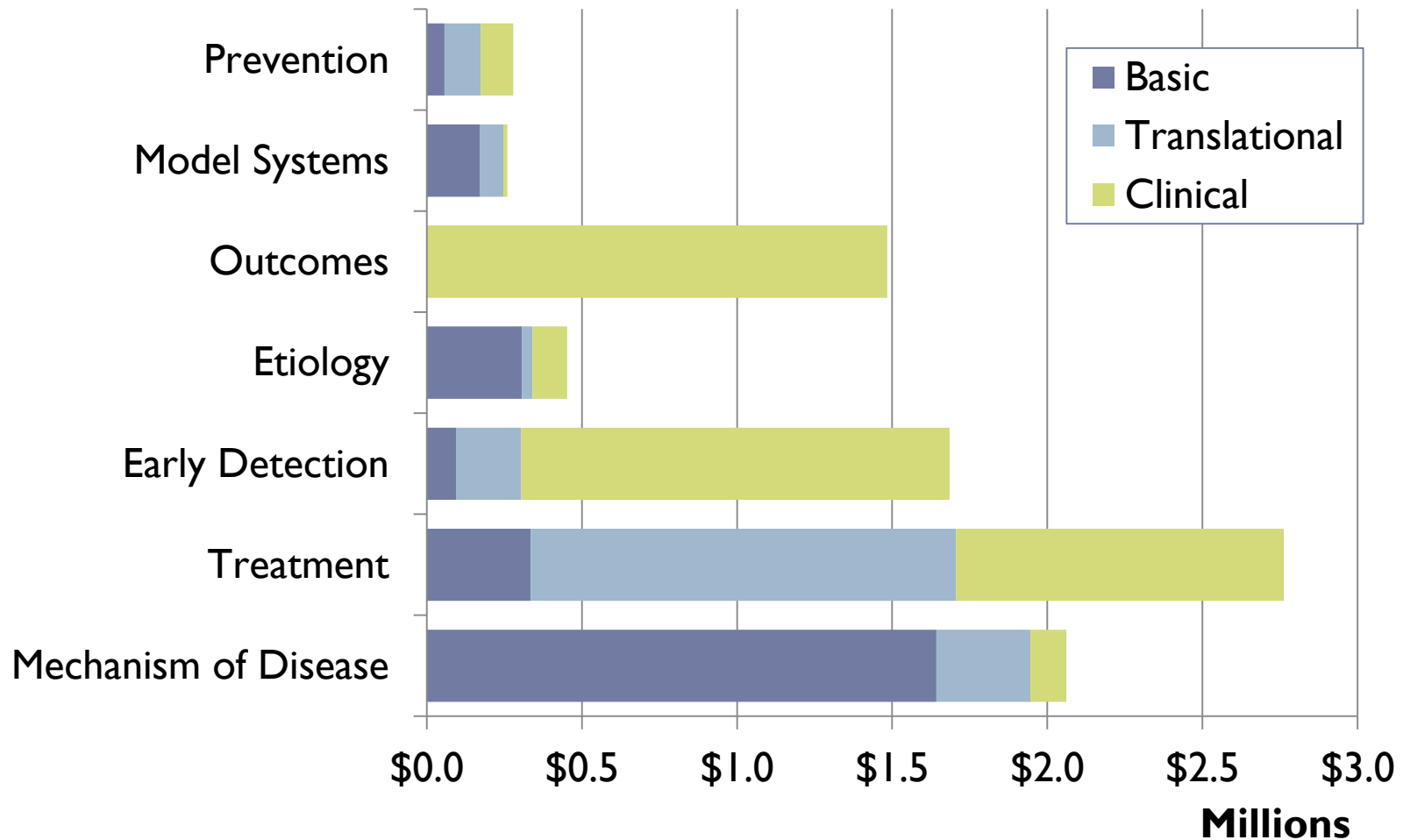
Most Nonprofit Funded Epilepsy Research is Clinical



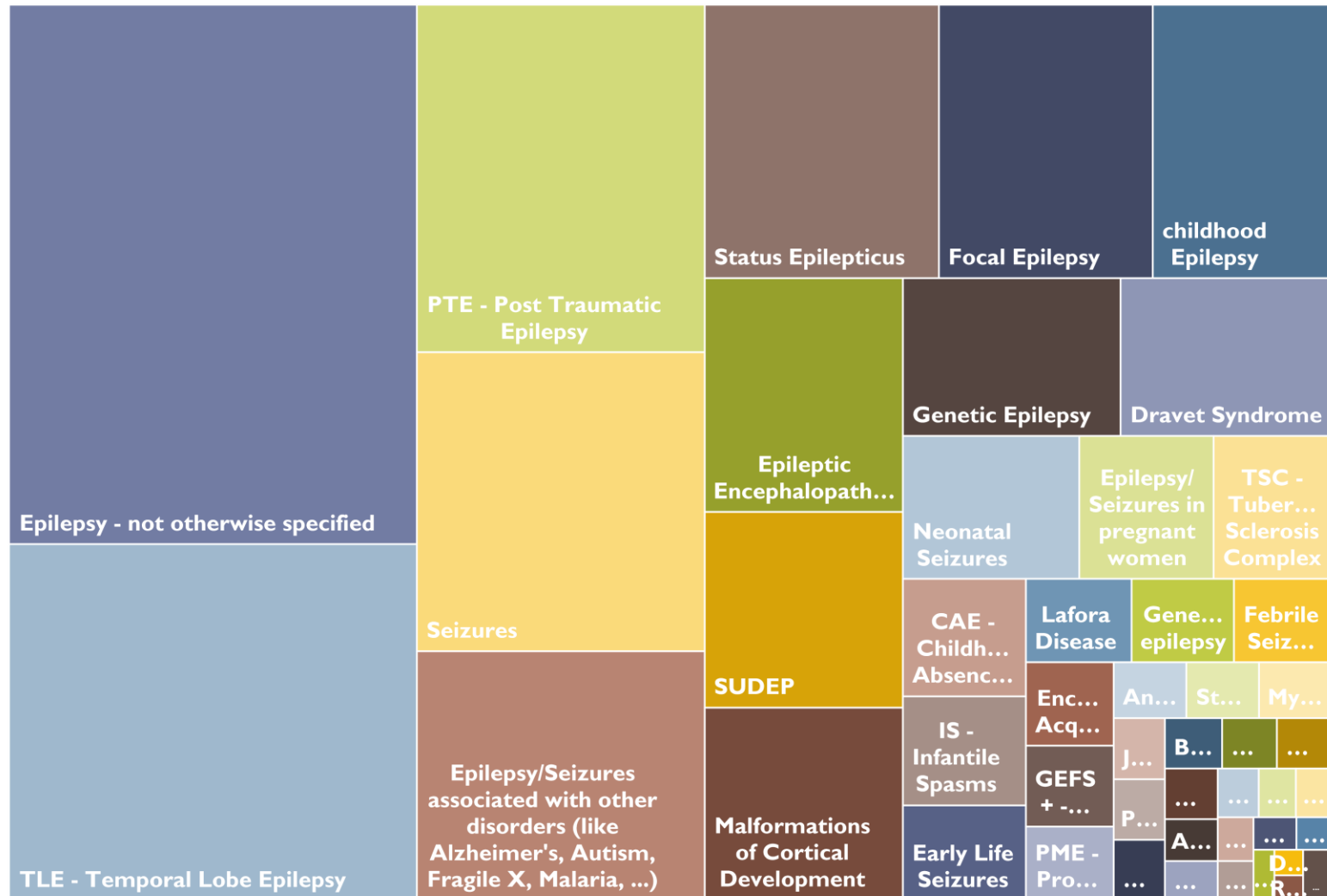
Most Funded Epilepsy Research is Basic Mechanism of Disease



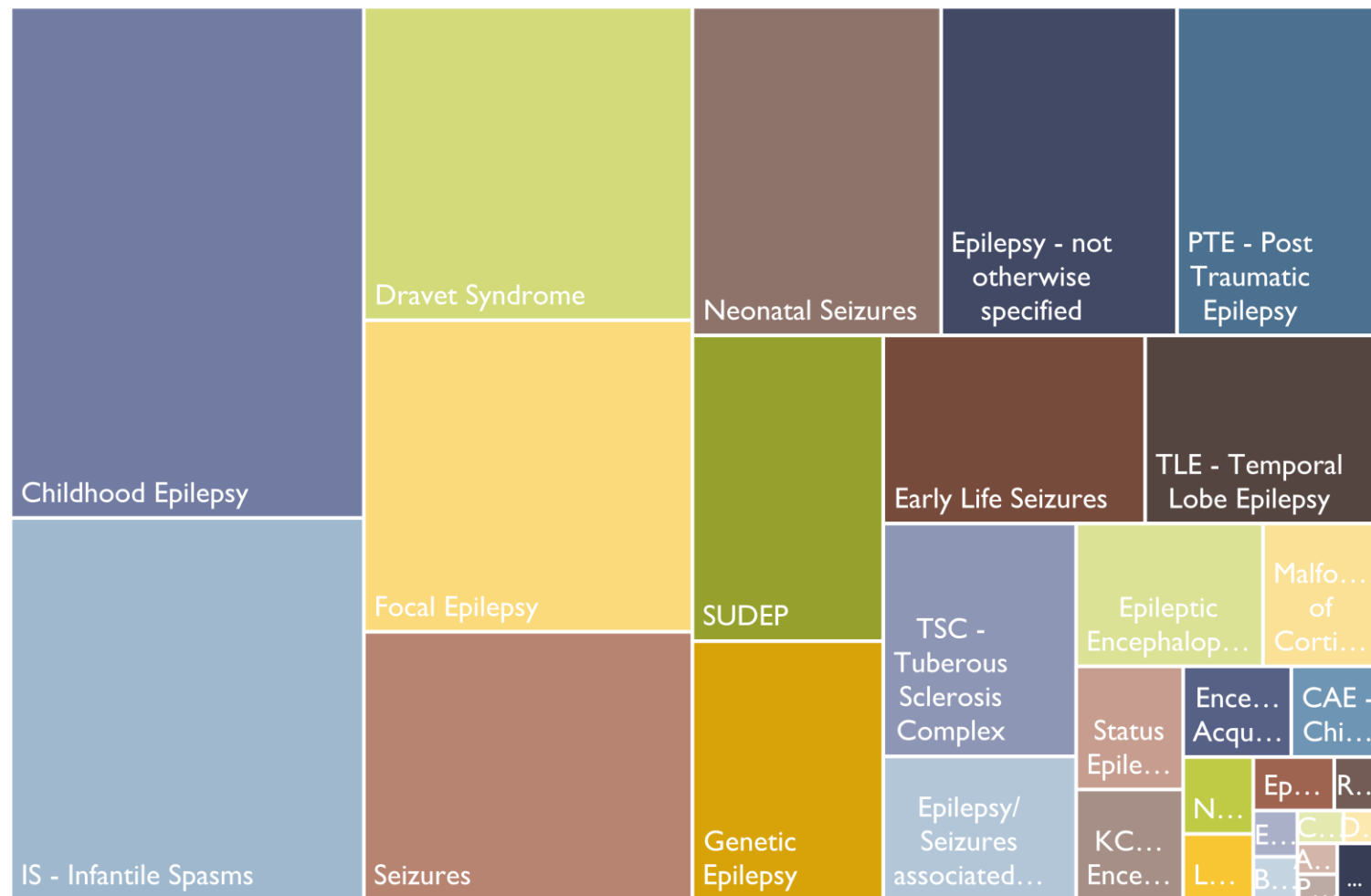
Most Nonprofit Funded Epilepsy Research is Clinical Outcomes, Early Detection, and Treatment



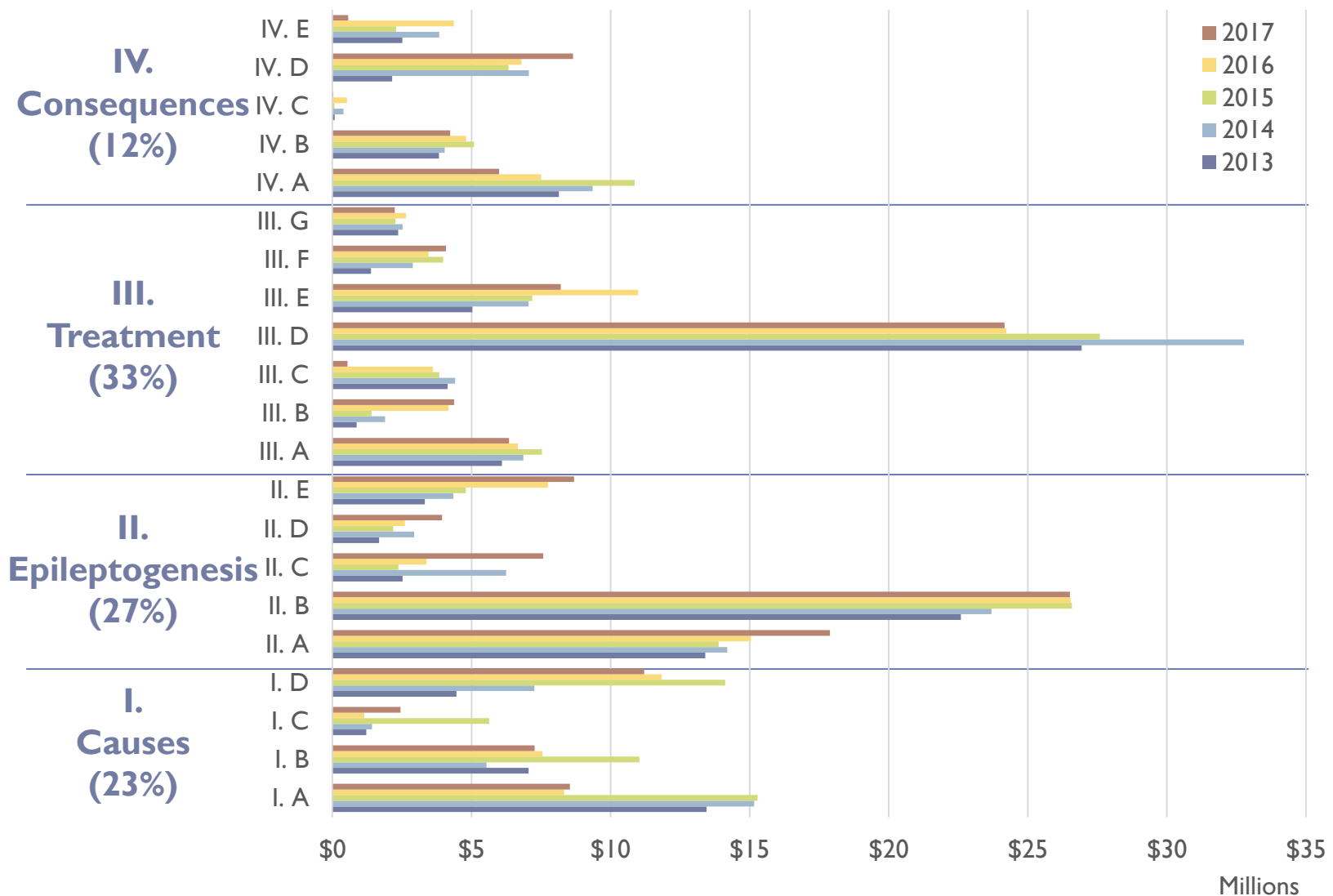
Most Funded Epilepsy Research is not Specified to One Epilepsy Syndrome



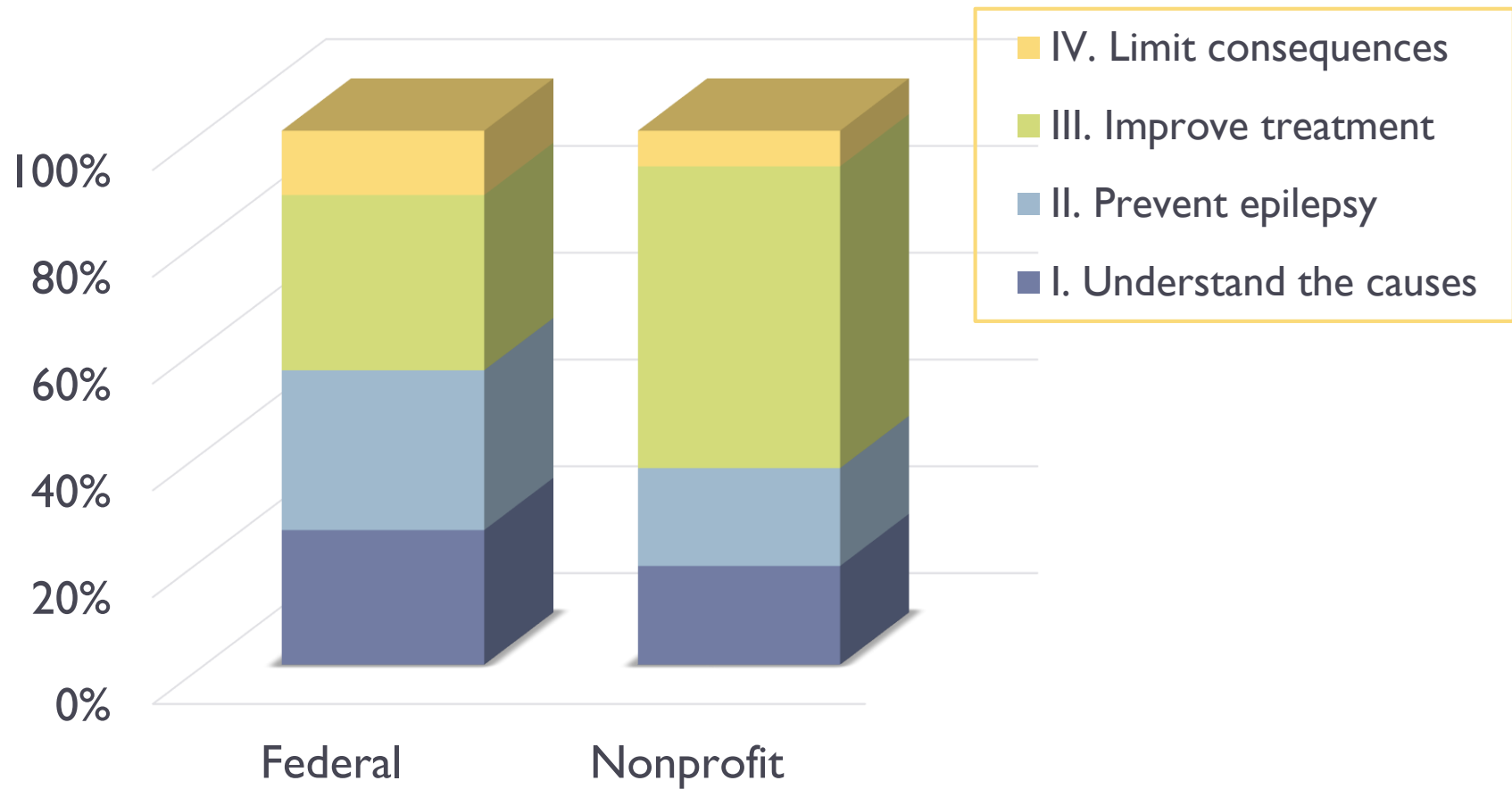
Most Nonprofit Funded Epilepsy Research is on Childhood Epilepsies



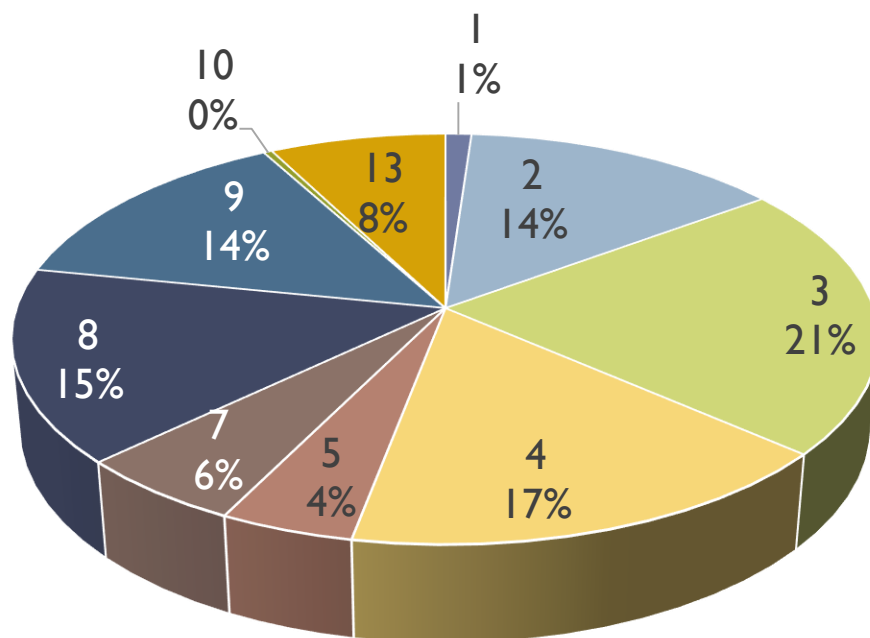
Disparities in Funding across Benchmarks



Disparities in Funding across Benchmark Areas



Less than 10% of Funding is 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

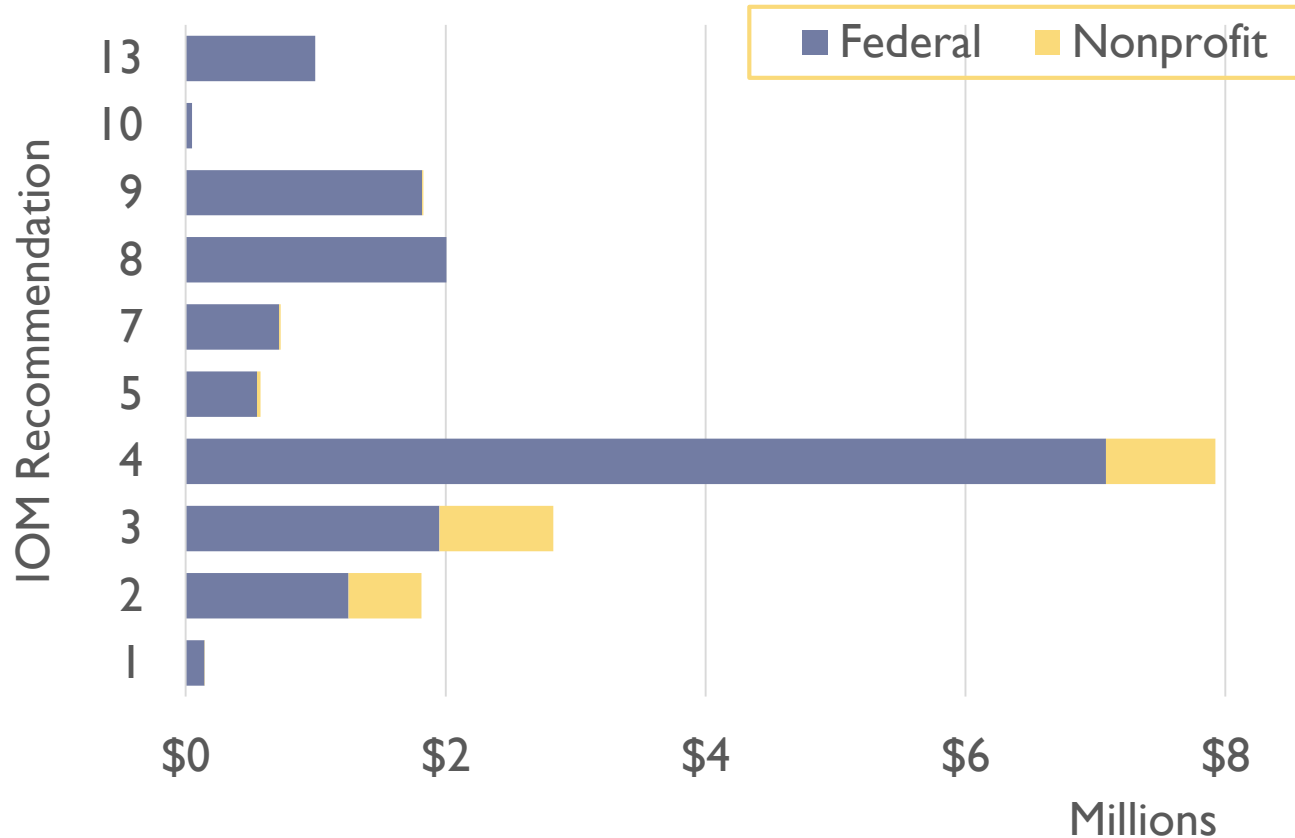
8. Improve the Delivery and Coordination of Community Services

9. Improve and Expand Educational Opportunities for People with Epilepsy and Their Families

10. Inform Media to Improve Awareness and Eliminate Stigma

13. Engage in Education, Dissemination, and Advocacy for Improved Epilepsy Care and Services

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
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