

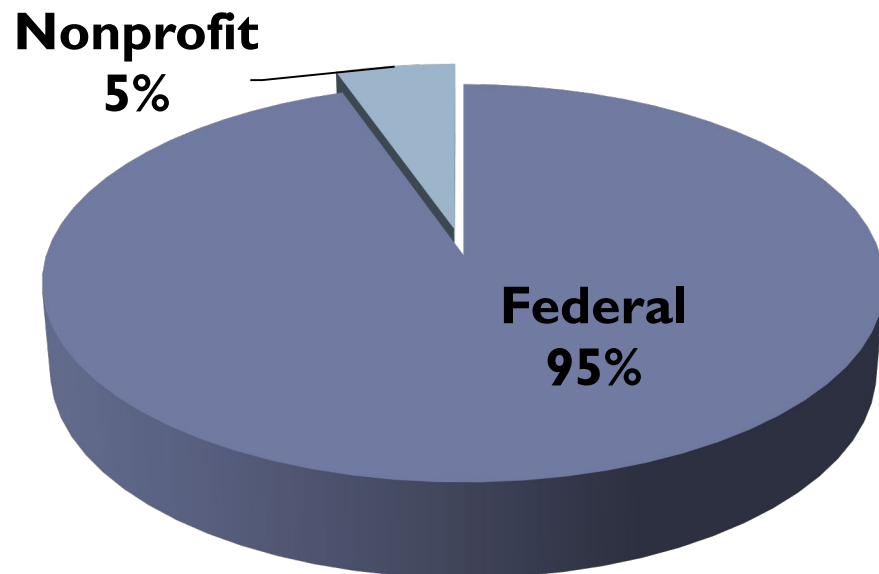
# **ICARE Epilepsy Research Portfolio Analysis**

**ICARE meeting April 12, 2018**



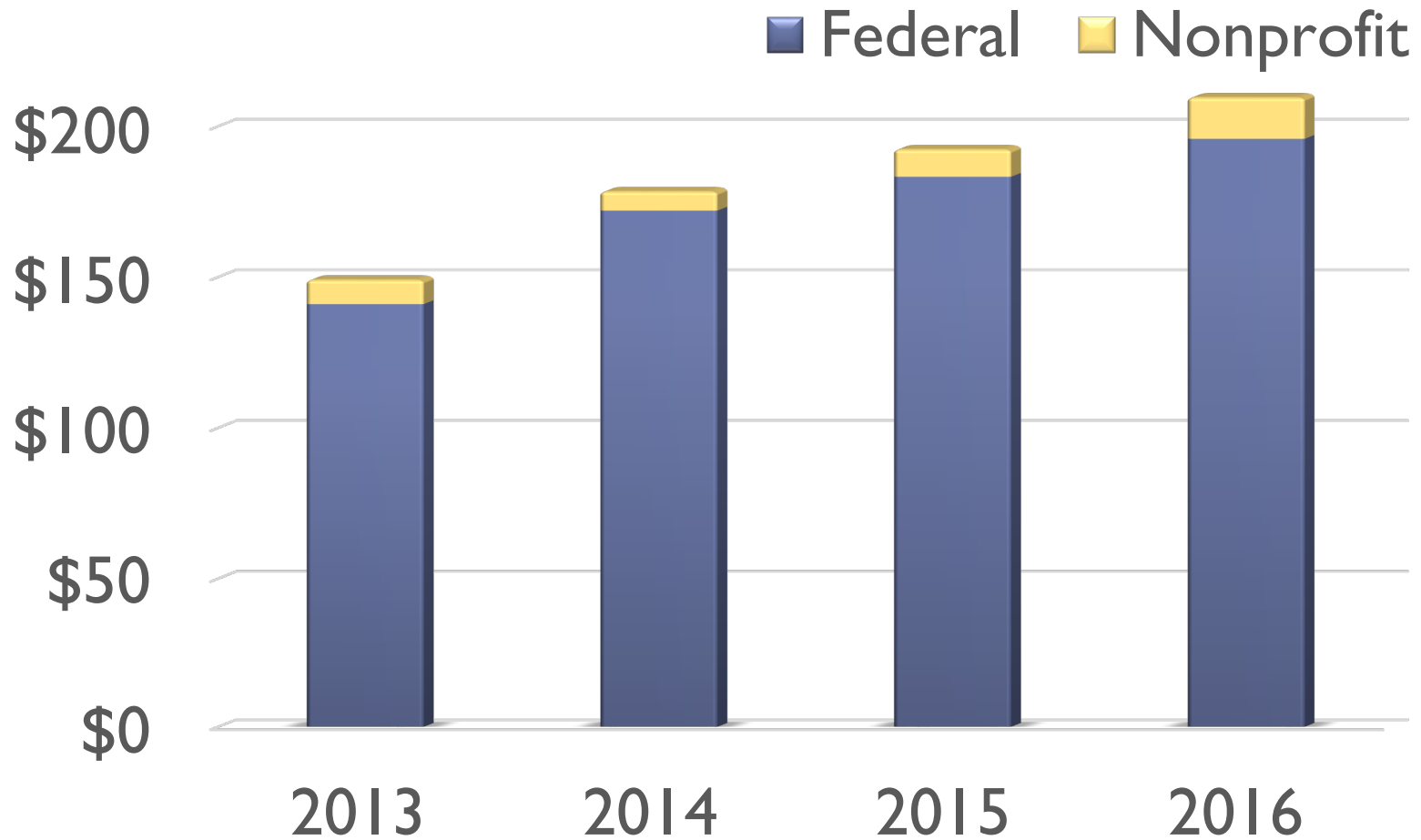
National Institute of  
Neurological Disorders  
and Stroke

## Federal Funding Dramatically Outpaces Non-profit Funding for Epilepsy Research



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

## Federal and Nonprofit Funding - Increasing trend between 2013-2016



# Federal and Nonprofit Funding - Increasing trend between 2013-2016

## Data contributors since 2013



National Institutes of Health



Centers for Disease Control



United States Department of  
Veterans Affairs



Health Resources and  
Services Administration



Citizens United for Research  
in Epilepsy



American Epilepsy Society



Epilepsy Foundation



Dravet Syndrome Foundation



Tuberous Sclerosis Alliance



PCDH19 Alliance



Phelan-McDermid Syndrome  
Foundation



LGS Foundation

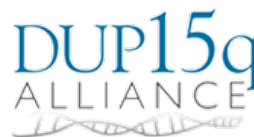


Patient-Centered Outcomes  
Research Institute



Pediatric Epilepsy Research  
Foundation

## 2015 - 2016 new contributors








# ICARE Epilepsy Research Portfolio


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## Interagency Collaborative to Advance Research in Epilepsy Research Portfolio

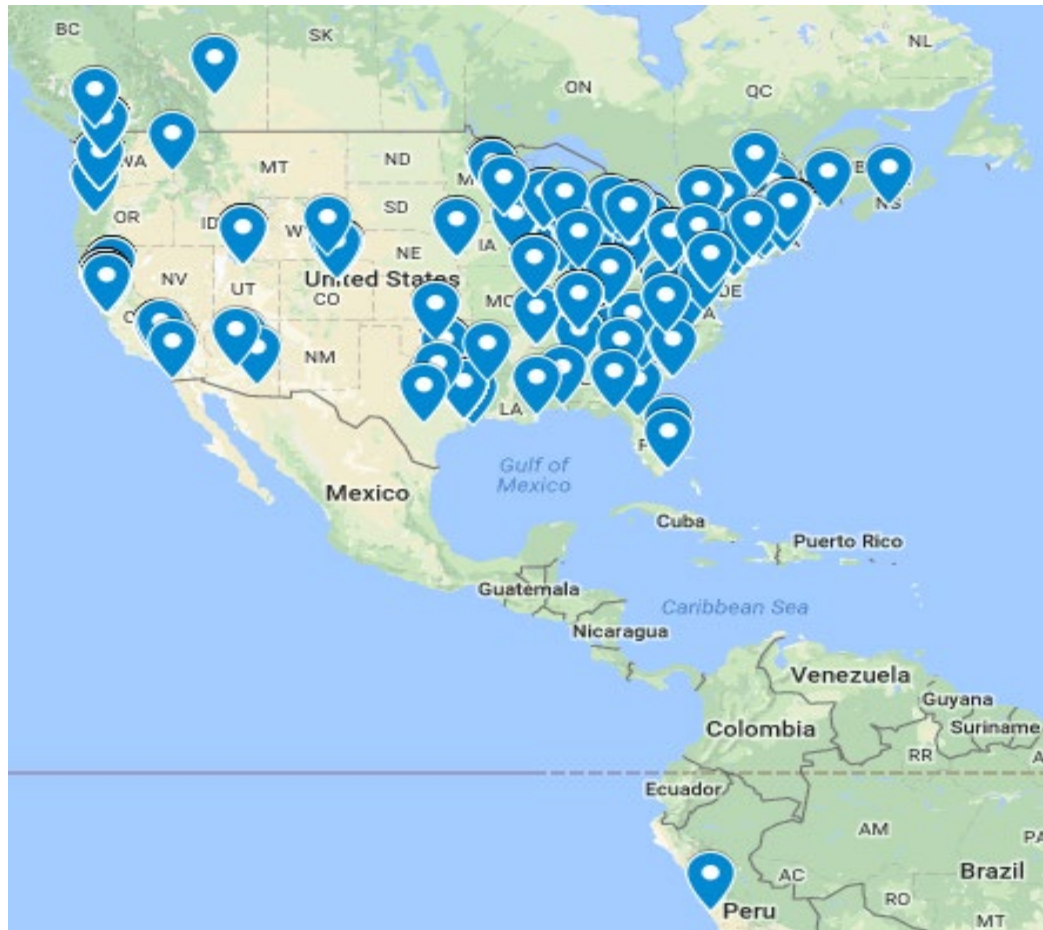
The Portfolio provides information on epilepsy research projects funded by the ICARE members, including federal and nonprofit organizations. [Learn More »](#)



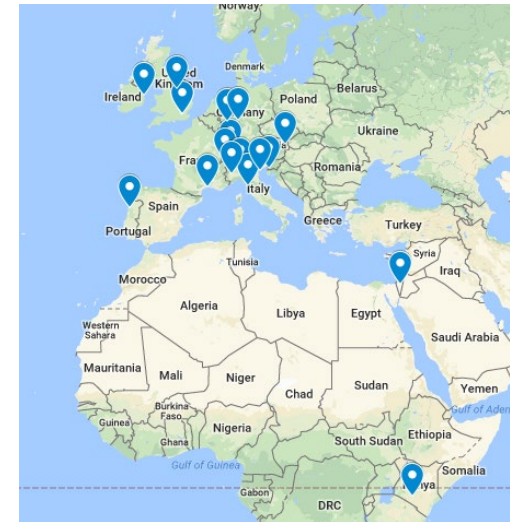
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<http://icarerp.nih.gov/>

# Most Investigators are Supported by a Single Project



420 - 494 Investigators



83% of investigators have 1 project; 13% have 2 projects,  
2.5% have 3, 1% have 4 and 0.5% have 5.  
6% of investigators received >\$1M in funding/year

# ICARE Portfolio Ontology Research Categories



## ICARE Epilepsy Research Portfolio

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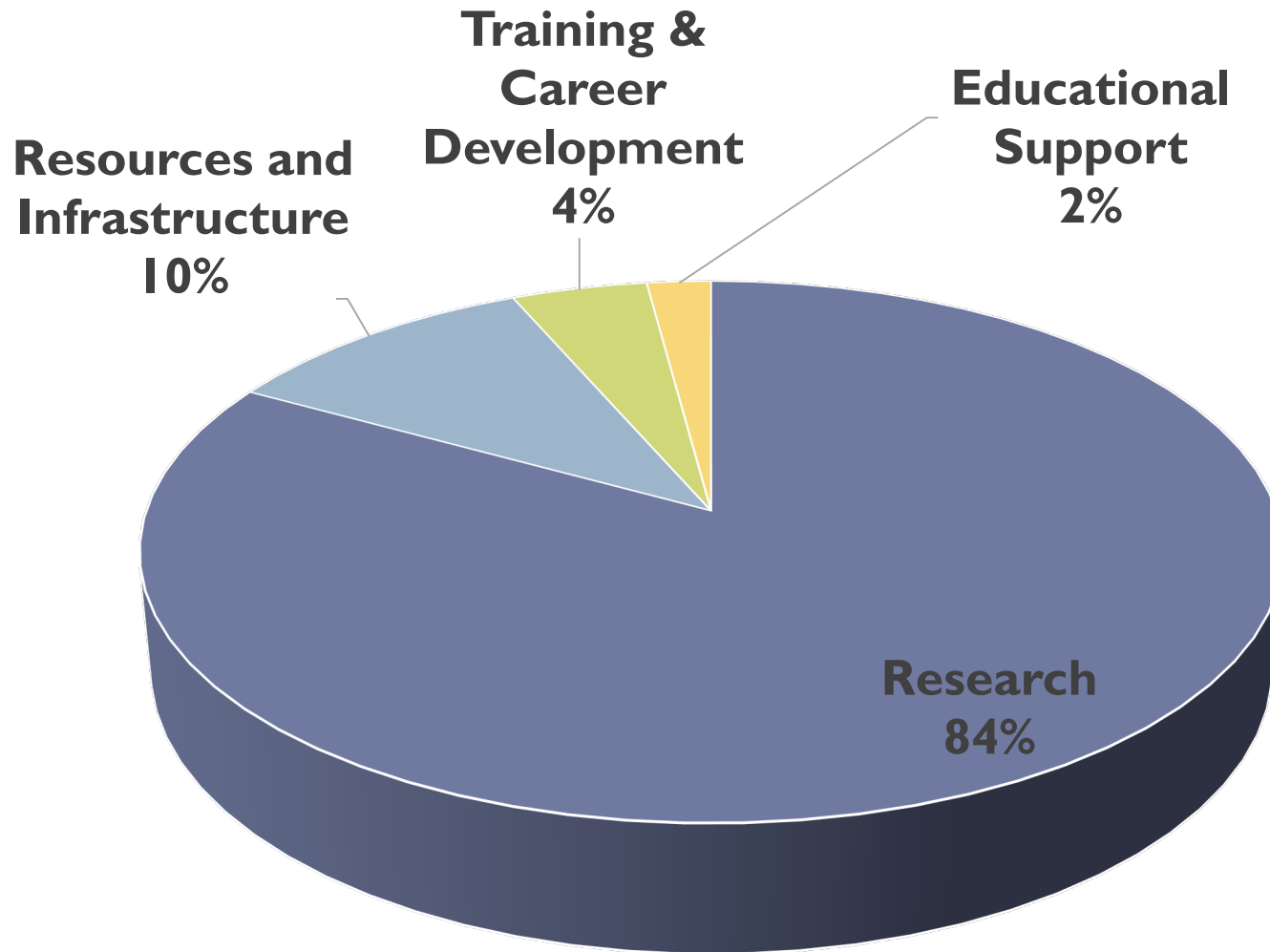
## ICARE Epilepsy Research Portfolio Ontology

For the development of the database a data collection template was designed by a working group of several representatives of the ICARE member organizations. The template allows for categorization of the epilepsy research by different layers of data categories: 1. Award Information, 2. Award Research Categories, 3. Benchmark Areas.

### Award Information

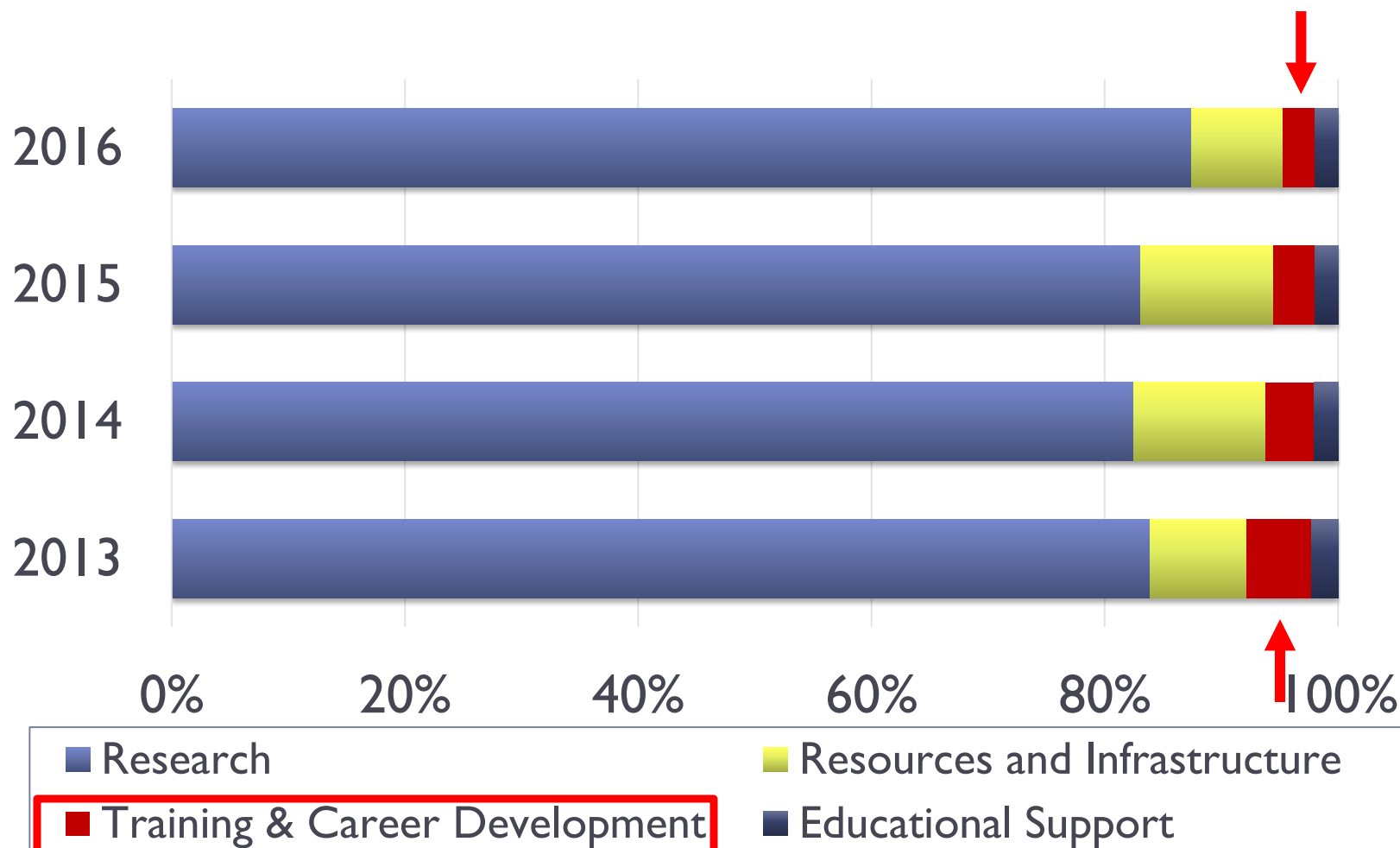
This category is to collect basic information about the award such as ID, Investigator information and [award type](#) and [purpose](#) information. Award type distinguishes individual, team, institutional or industry awards and purpose denotes research, training, resources, and educational support awards.

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

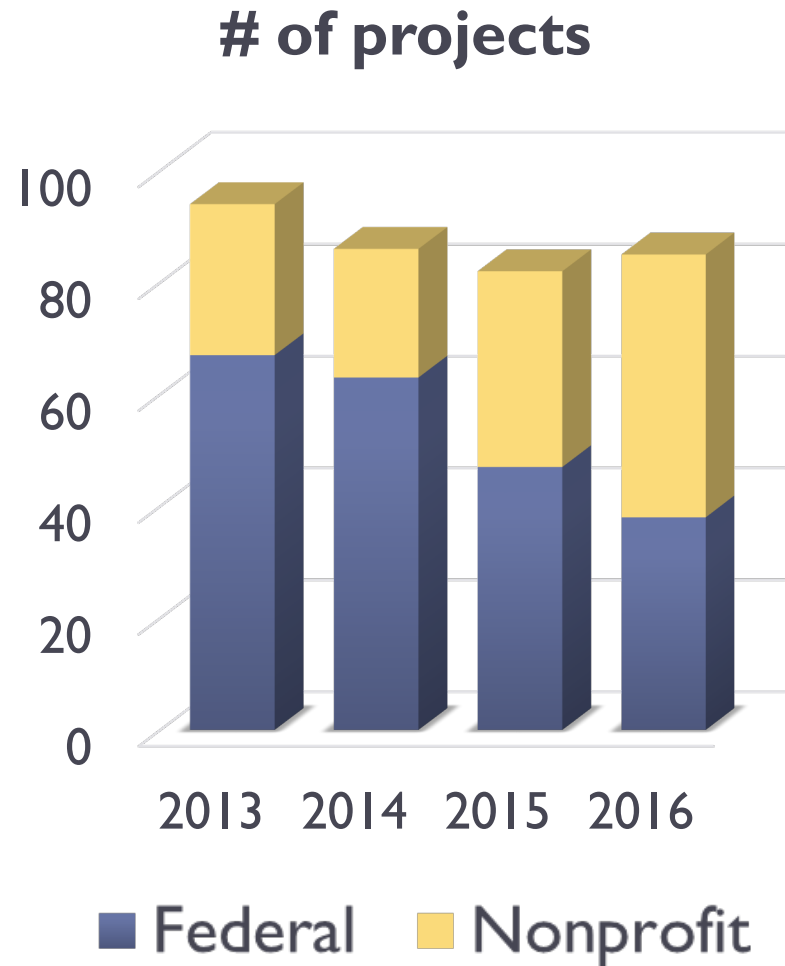
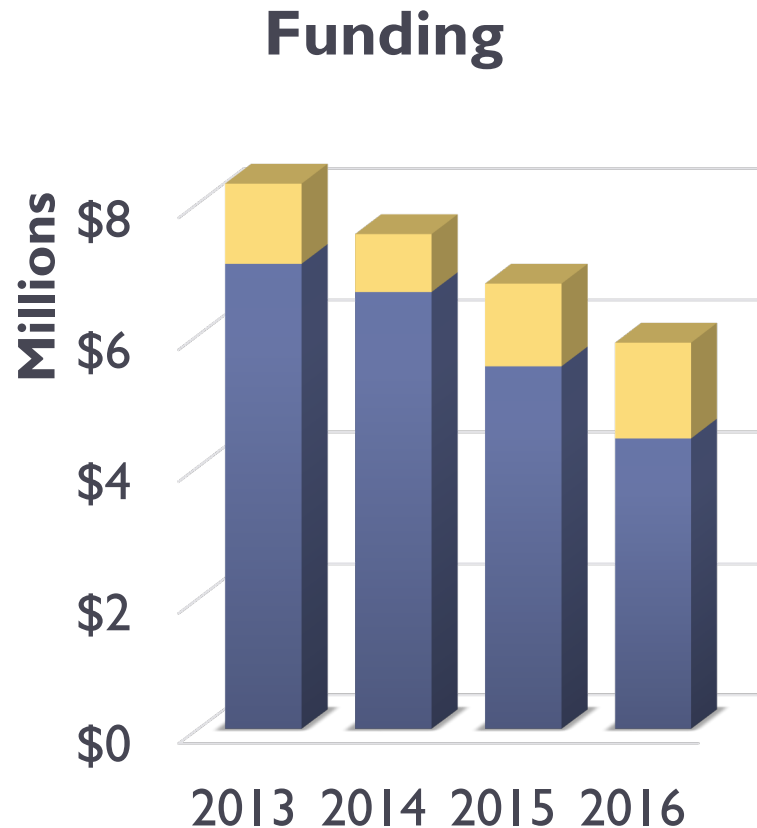




## Funding for Structured Training in Epilepsy Research – decreasing trend between 2013-2016



## Funding for Structured Training in Epilepsy Research – increasing trend of nonprofit funding between 2013-2016



# ICARE Portfolio Ontology Research Categories



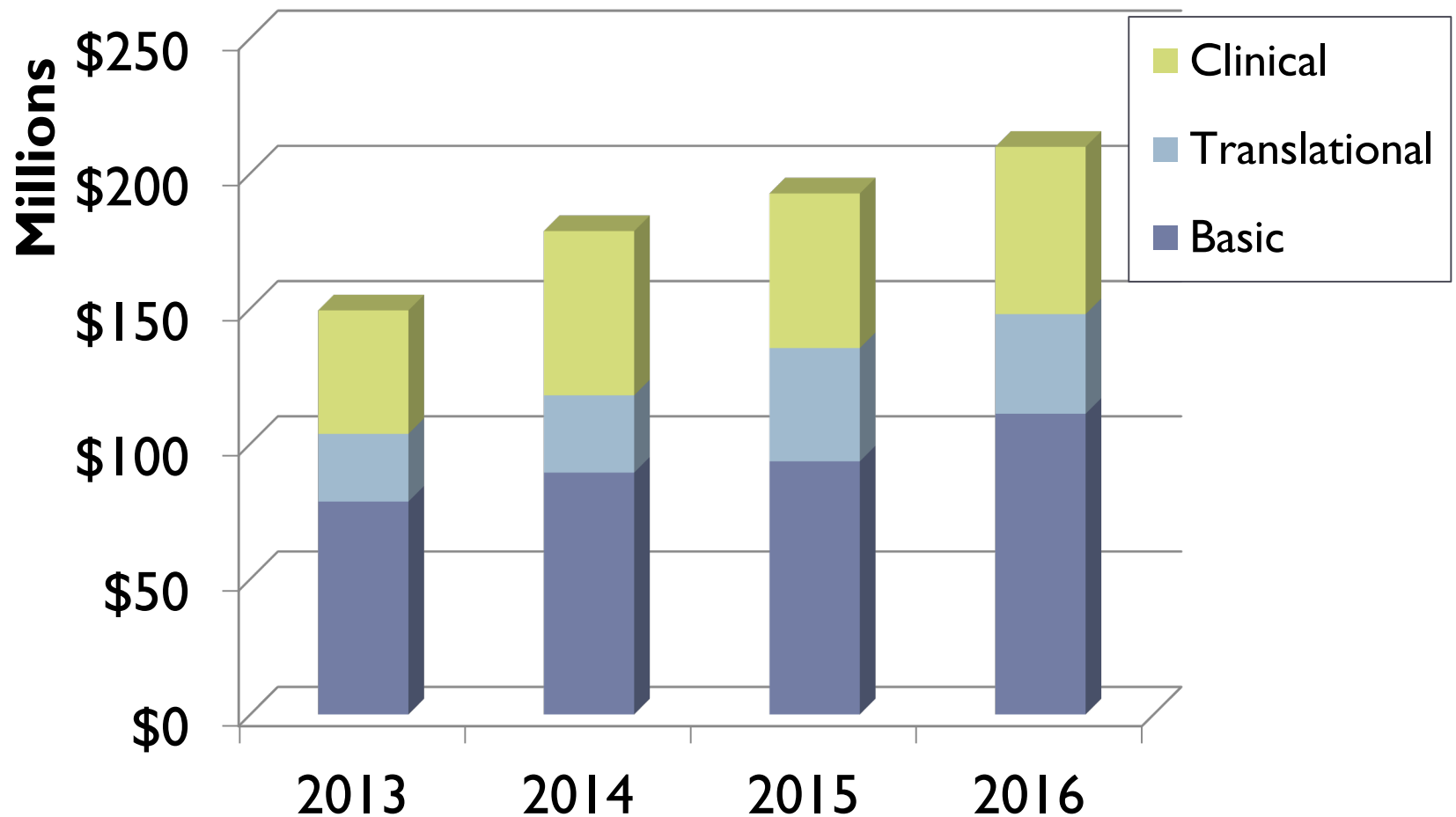
## ICARE Epilepsy Research Portfolio Ontology

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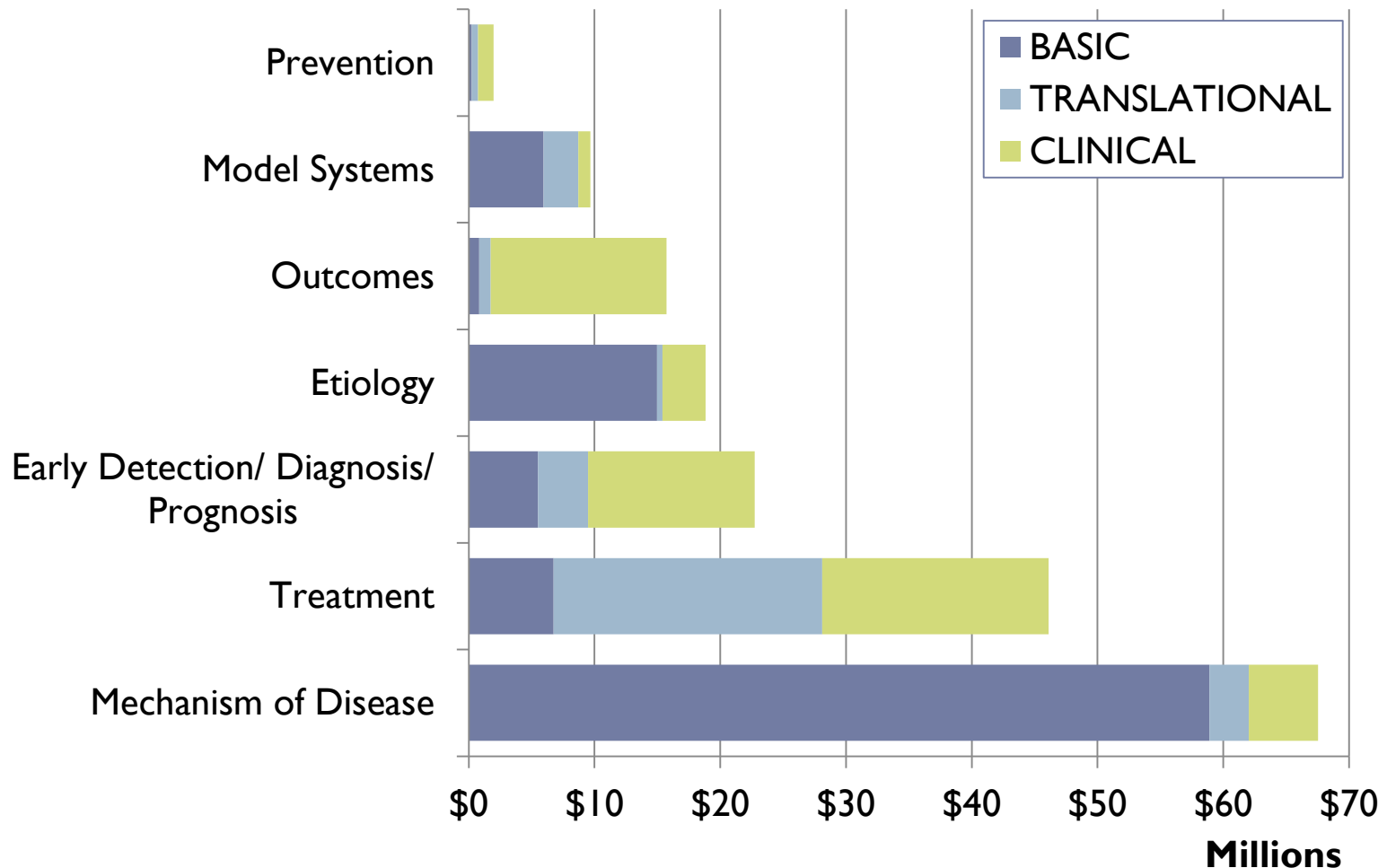
### Research Categories

The research proposed for each project is classified in three categories. First is the broad category of basic, translational or clinical [research type](#). Second is the [research classification](#) of etiology, biology, prevention, diagnosis and biomarkers, treatment, outcomes and model systems. And third is according to the [epilepsy and/or seizure syndromes](#).

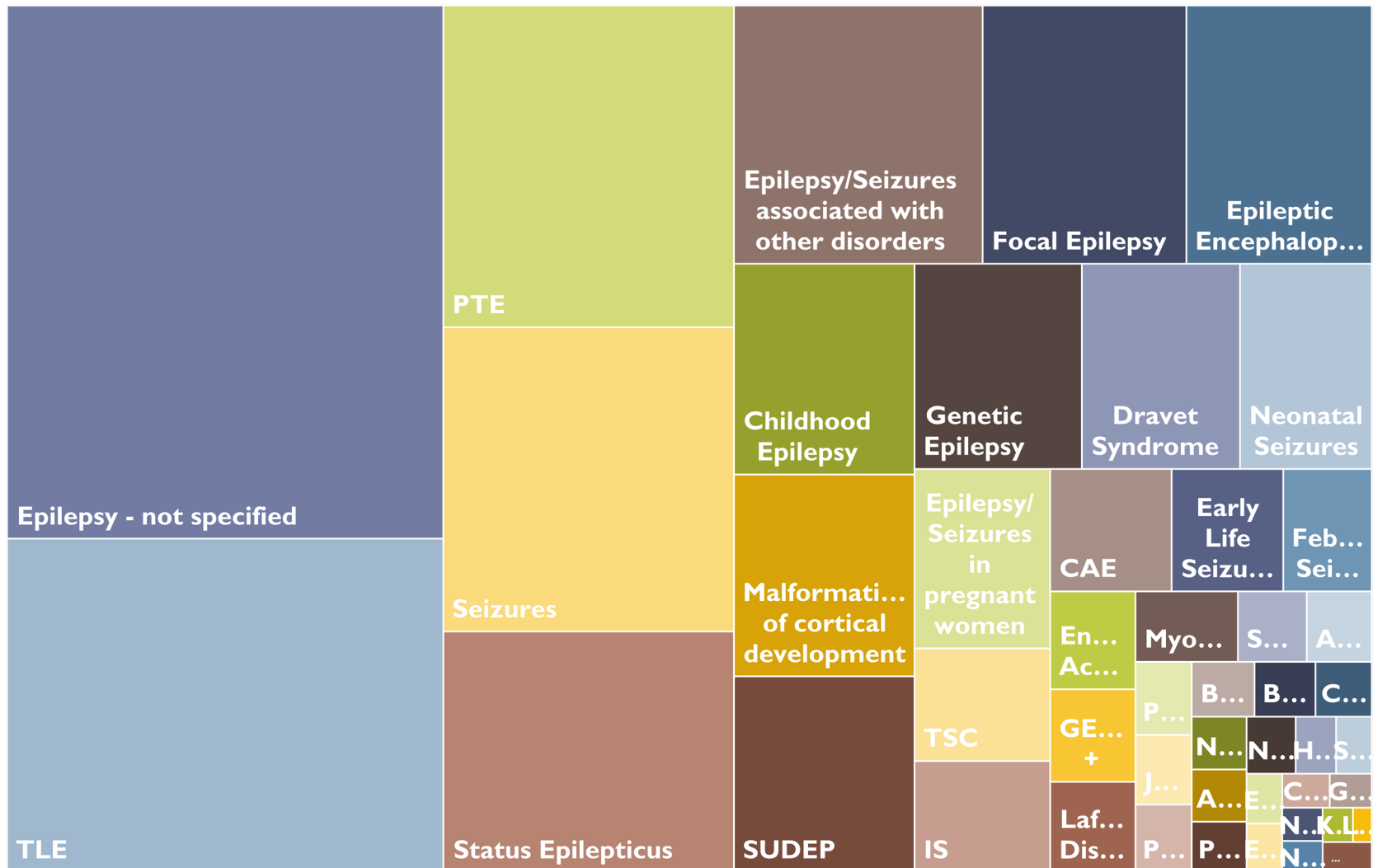
## Most Funded Epilepsy Research is Basic



## Most Funded Epilepsy Research is Basic Mechanism of Disease



## Most Funded Epilepsy Research is not specified to one epilepsy syndrome



# ICARE Portfolio Ontology Benchmarks

## ICARE Epilepsy Research Portfolio

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## ICARE Epilepsy Research Portfolio Ontology

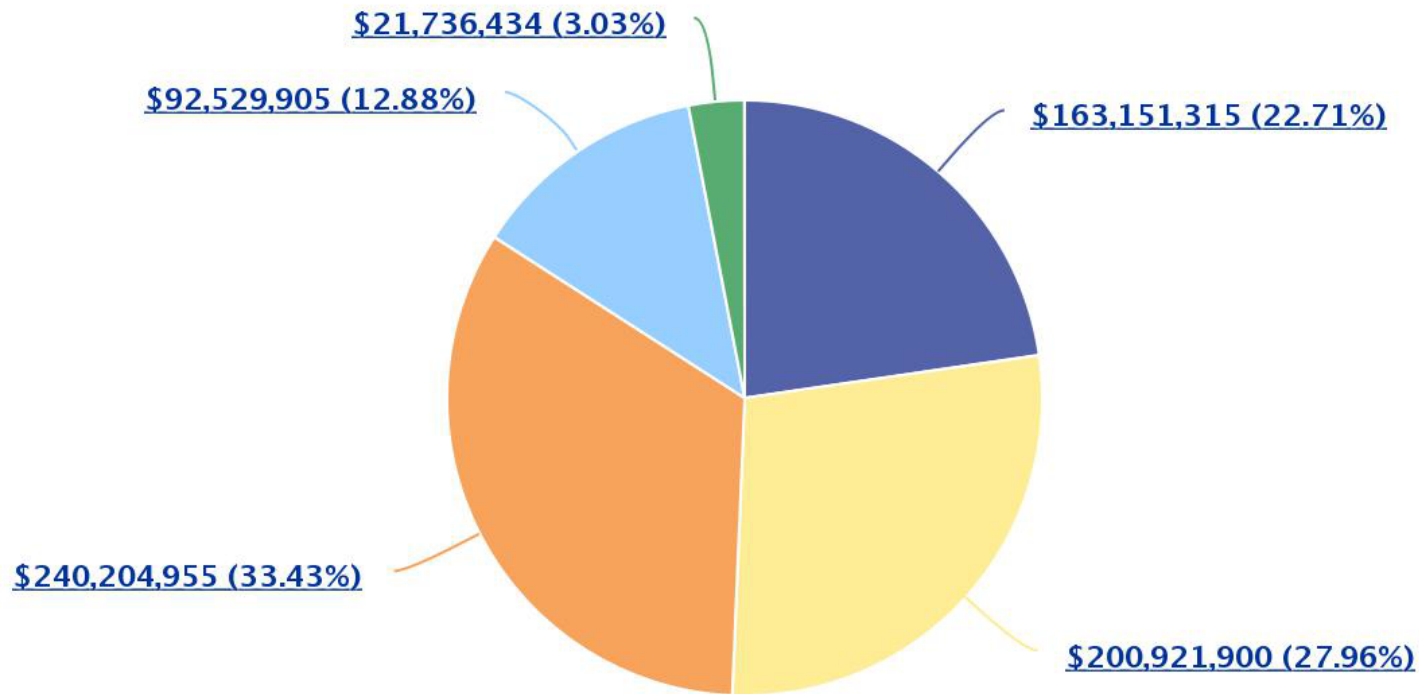
### 2014 NINDS Benchmarks for Epilepsy Research

All projects are assessed against the 2014 NINDS Benchmarks for Epilepsy Research. The 2014 NINDS benchmarks are research priorities identified by the epilepsy research community. The broad goals are intended to serve as a shared framework for focusing the community's efforts and benchmarking important advances in the field as they are achieved. They are organized as a two tier system around four main research areas, with each area having four to seven identified benchmarks (see: <http://www.ninds.nih.gov/research/epilepsyweb/2014Bechmarks-Final-PDF.pdf> ).

#### The four areas are:

- Understand the causes of the epilepsies and epilepsy-related neurologic, psychiatric, and somatic conditions
- Prevent epilepsy and its progression.
- Improve treatment options for controlling seizures and epilepsy-related conditions without side effects.
- Limit or prevent adverse consequences of seizures and their treatment across the lifespan.

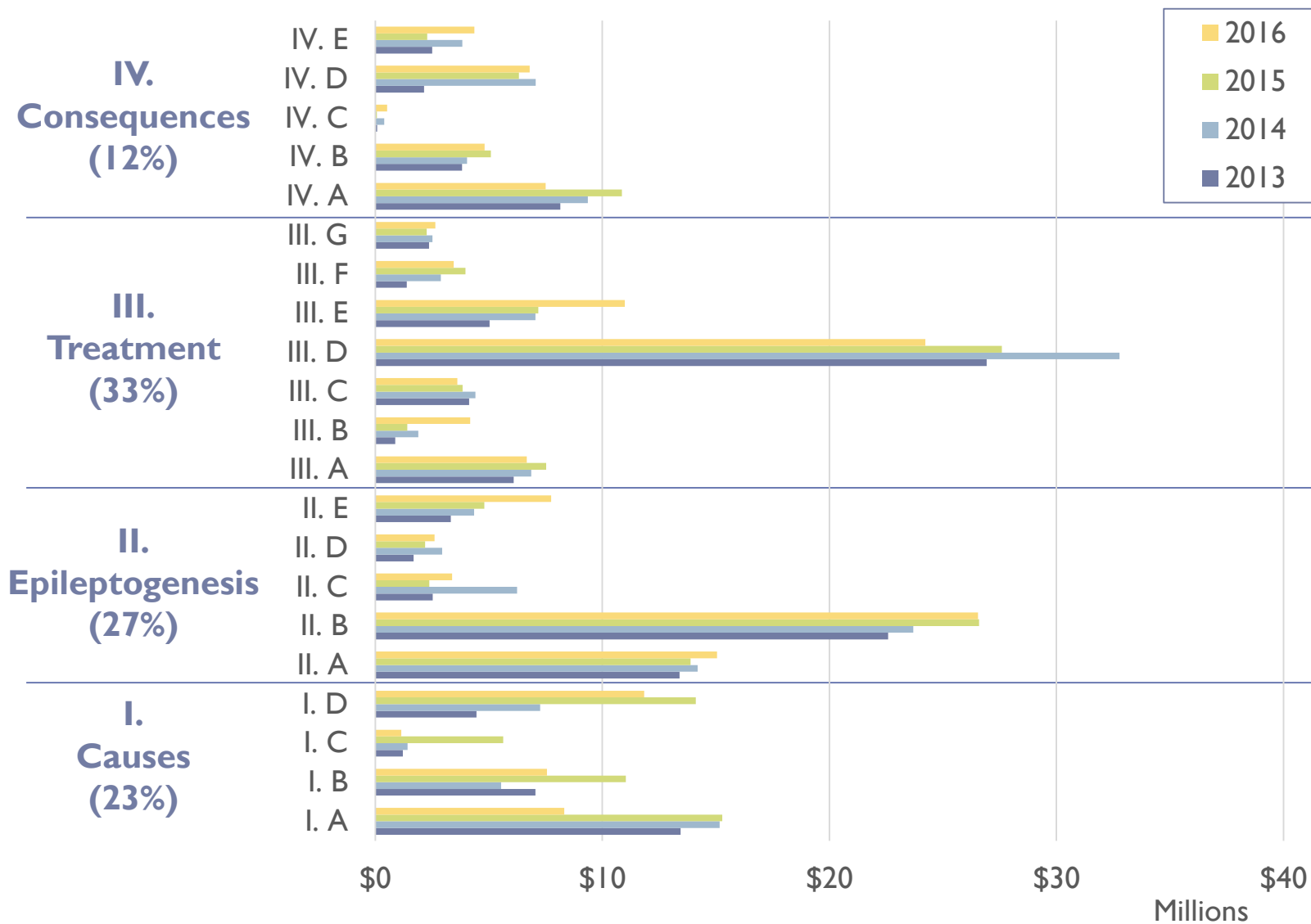
# Research on the Causes and Consequences of Epilepsy Receives Less Funding



- I. Understand the causes of the epilepsies
- II. Prevent epilepsy and its progression
- III. Improve treatment options
- IV. Limit or prevent adverse consequences
- V. Not Applicable



# Disparities in Funding across Benchmarks








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