

# **ICARE Epilepsy Research Portfolio Analysis**

**ICARE meeting April 14, 2016**




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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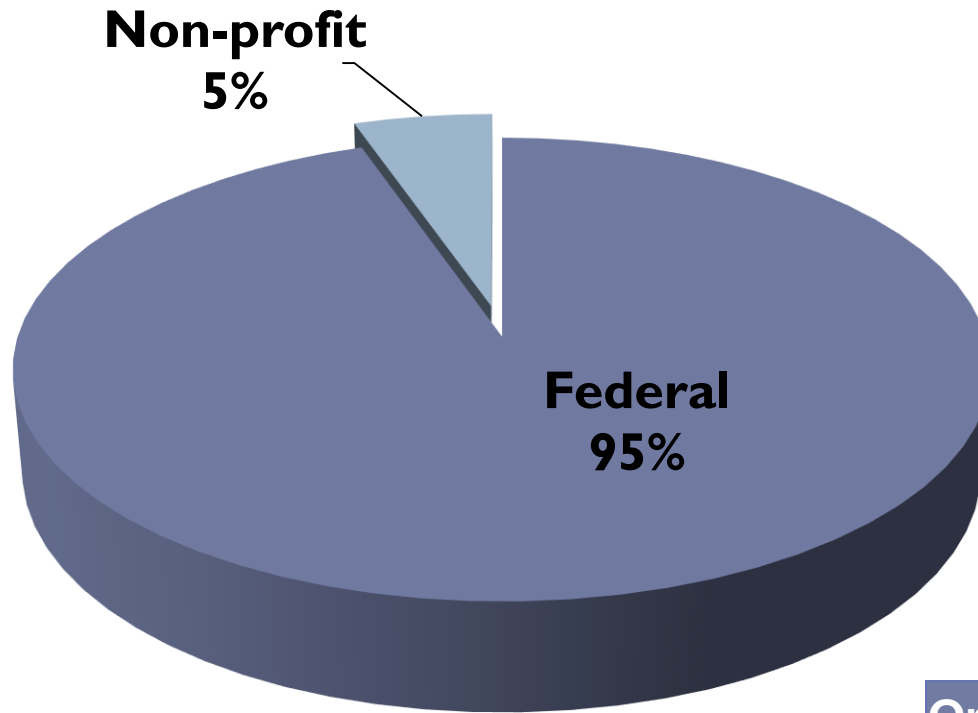
## **Goals for a comprehensive analysis**

- 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

- 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.
- Two years of data collected so far, 2013 and 2014

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

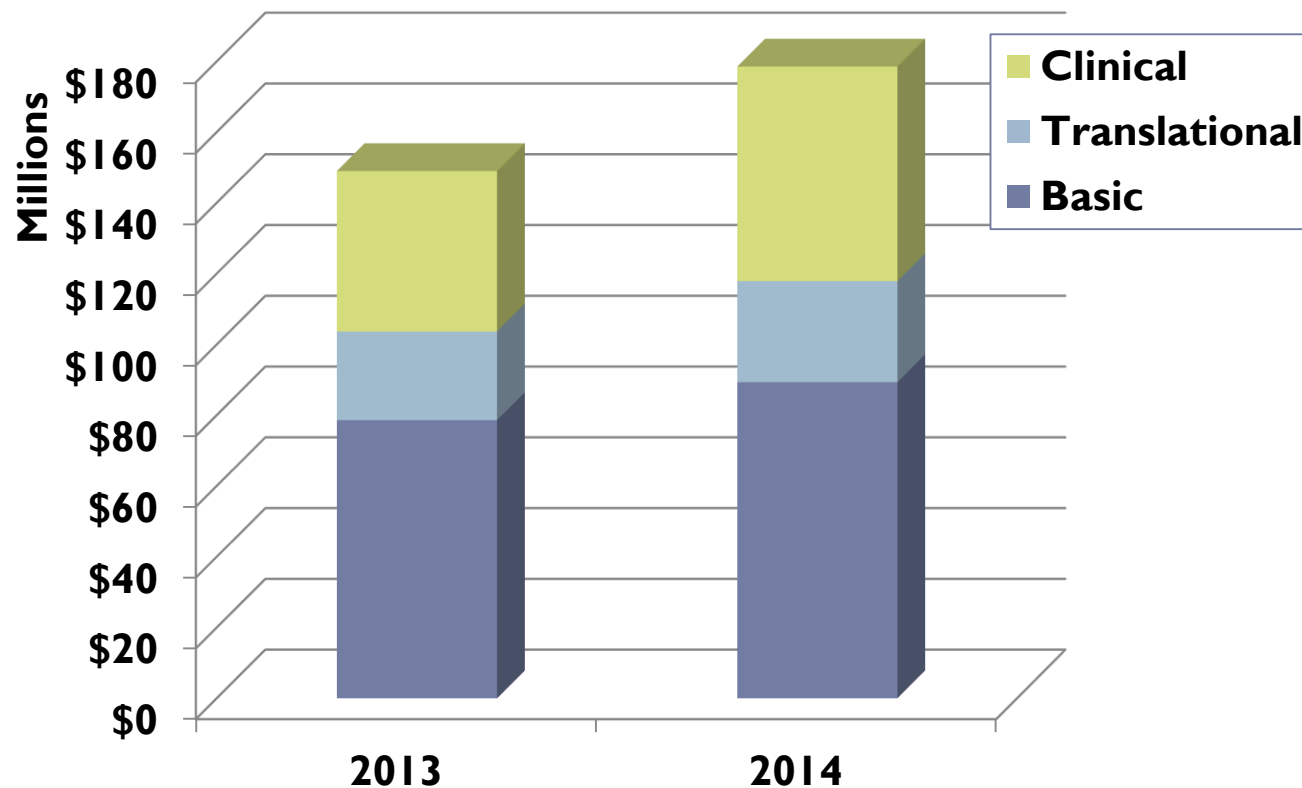


Organization	2013	2014
Federal	\$141.0M	\$172.0M
Non-profit	\$8.4M	\$6.7M
All	\$149.4M	\$178.7M

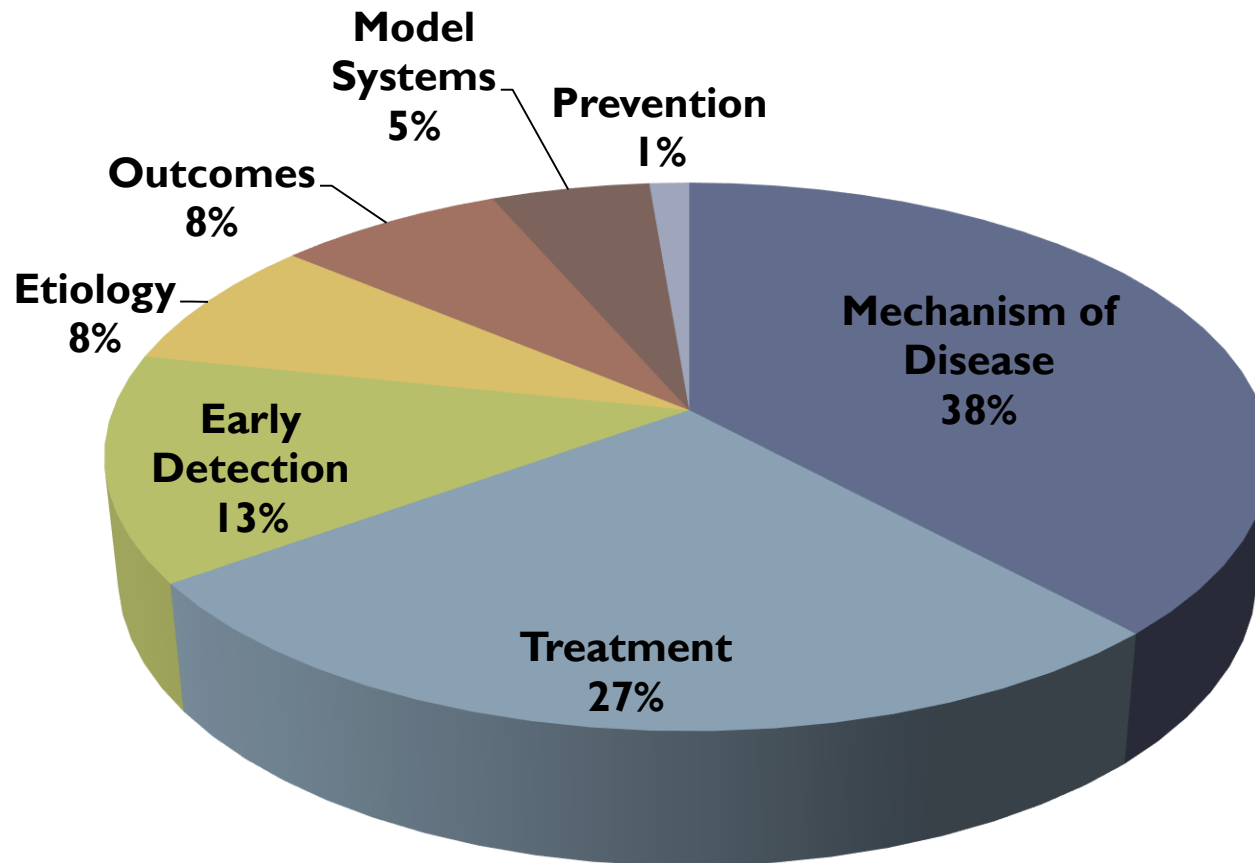
## Federal vs Nonprofit Funding for Epilepsy Research in 2013 (\$149.4M) and 2014 (\$178.7M)

	2013		2014	
	#	\$	#	\$
<b>Federal</b>	<b>420</b>	<b>\$141.00</b>	<b>451</b>	<b>\$172.01</b>
NIH	387	\$133.09	415	\$163.70
HRSA	8	\$3.37	8	\$3.47
VA	15	\$2.33	16	\$2.62
CDC	10	\$2.21	12	\$2.22
<b>Nonprofit</b>	<b>93</b>	<b>\$8.40</b>	<b>112</b>	<b>\$6.73</b>
CURE	41	\$4.29	48	\$3.73
PCORI	2	\$1.68	2	\$0.27
EF	15	\$0.73	16	\$0.81
AES	19	\$0.59	23	\$0.69
Dravet SF	6	\$0.44	10	\$0.62
PERF	2	\$0.42	2	\$0.21
TS Alliance	6	\$0.17	4	\$0.14
Phelan-McDermid SF	1	\$0.05	4	\$0.19
LGS			2	\$0.05
PCDH19 Alliance	1	\$0.03	1	\$0.01
<b>All</b>	<b>513</b>	<b>\$149.40</b>	<b>563</b>	<b>\$178.73</b>

# Most Funded Epilepsy Research is Basic



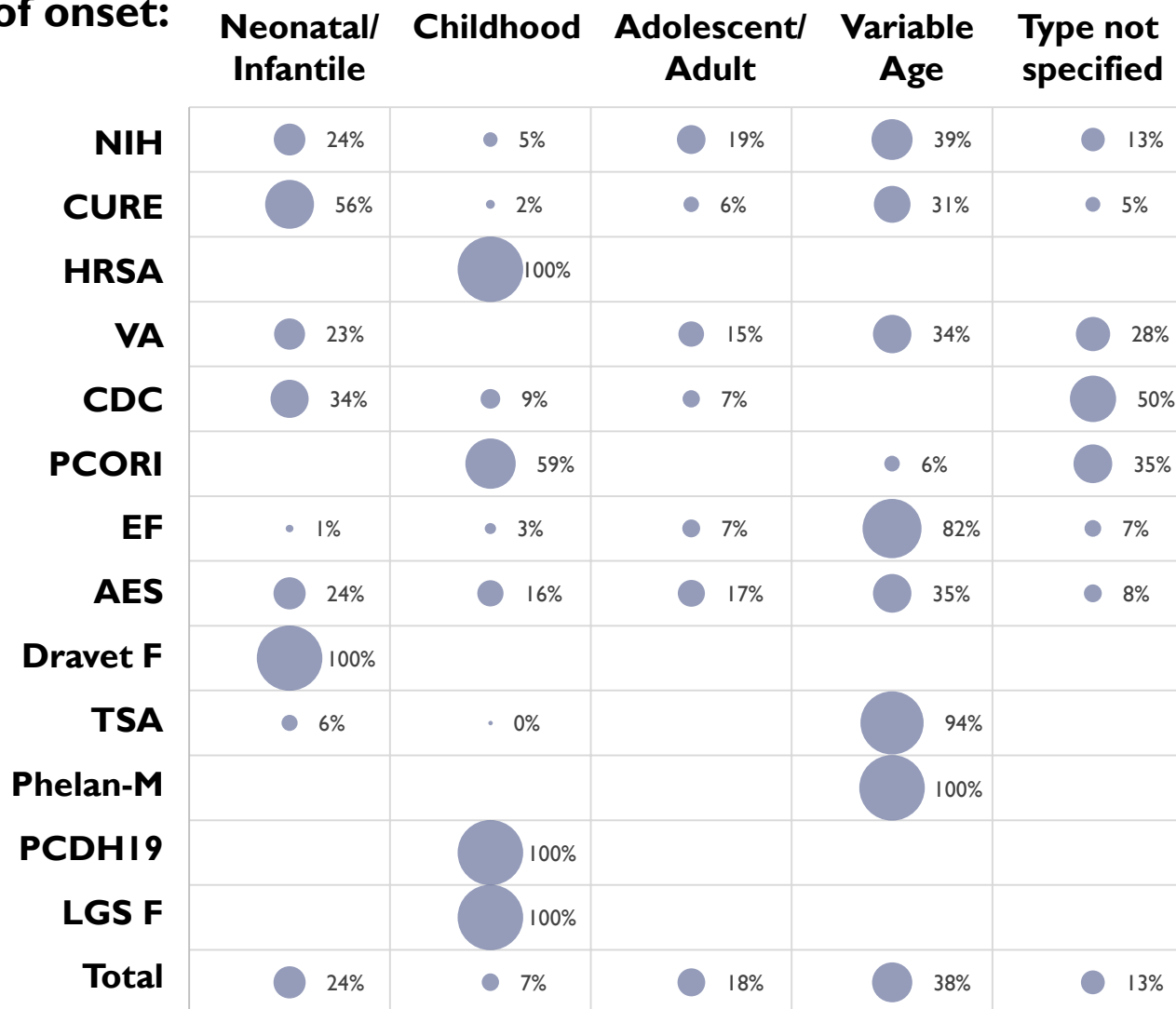
## **Largest Fraction of Funding goes to Research on Mechanism of Disease; Smallest to Prevention**



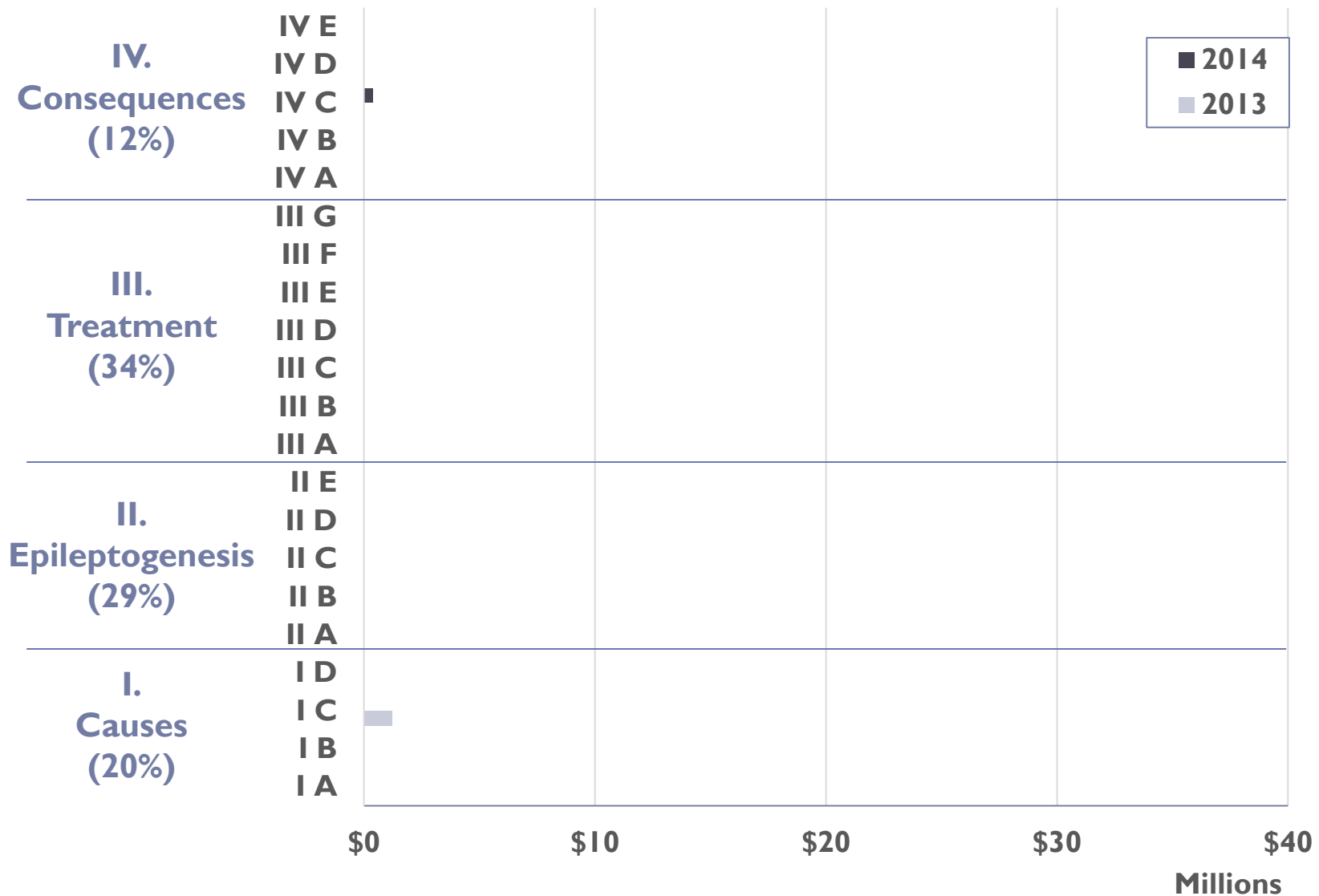


# Disparities in Funding for Different Epilepsy Types

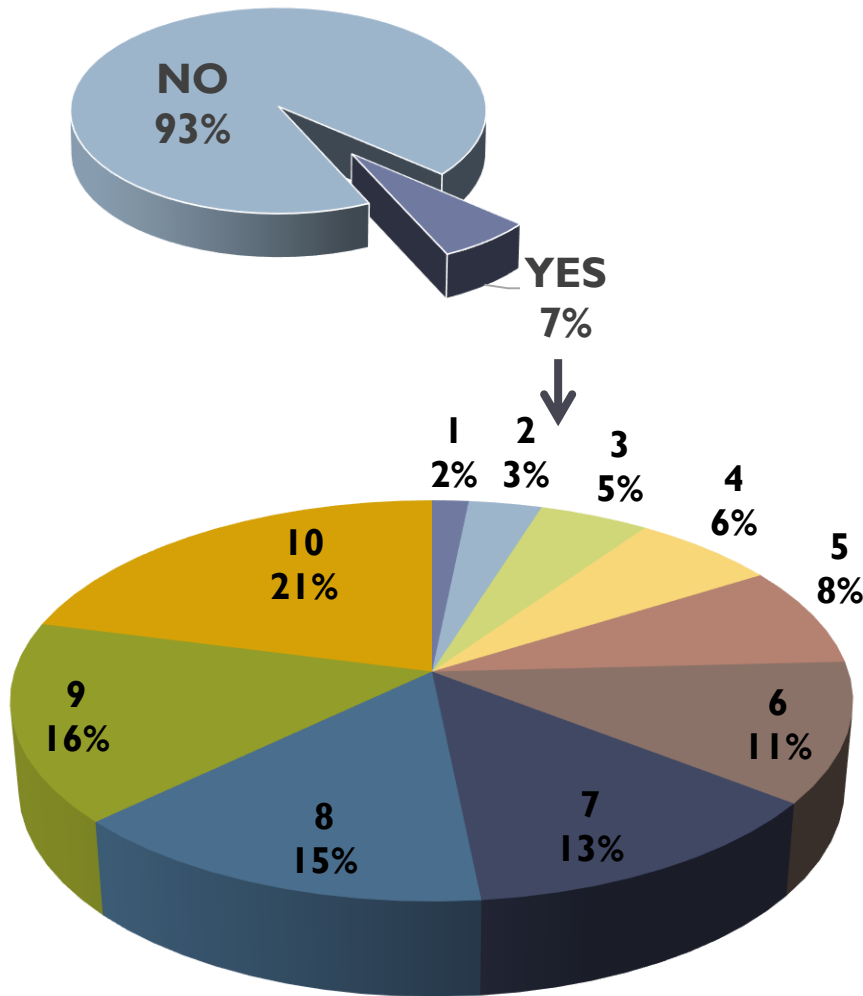
Age of onset:



# Disparities in Funding across Benchmark Areas



# Little Funding Dedicated to 2012 IOM Recommendations

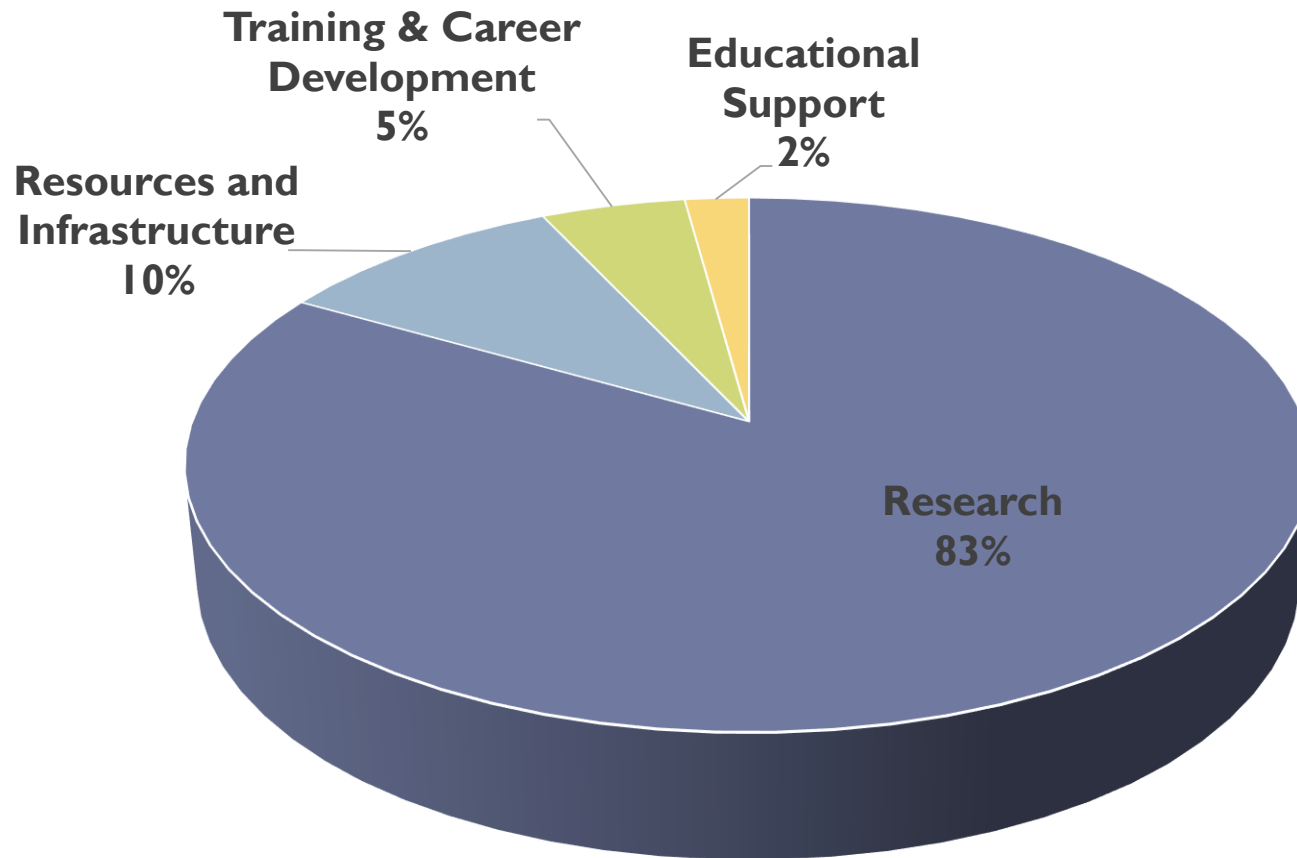


1. Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement
2. Continue and Expand Collaborative Surveillance and Data Collection Efforts
3. Develop and Evaluate Prevention Efforts for Epilepsy 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
6. Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network
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

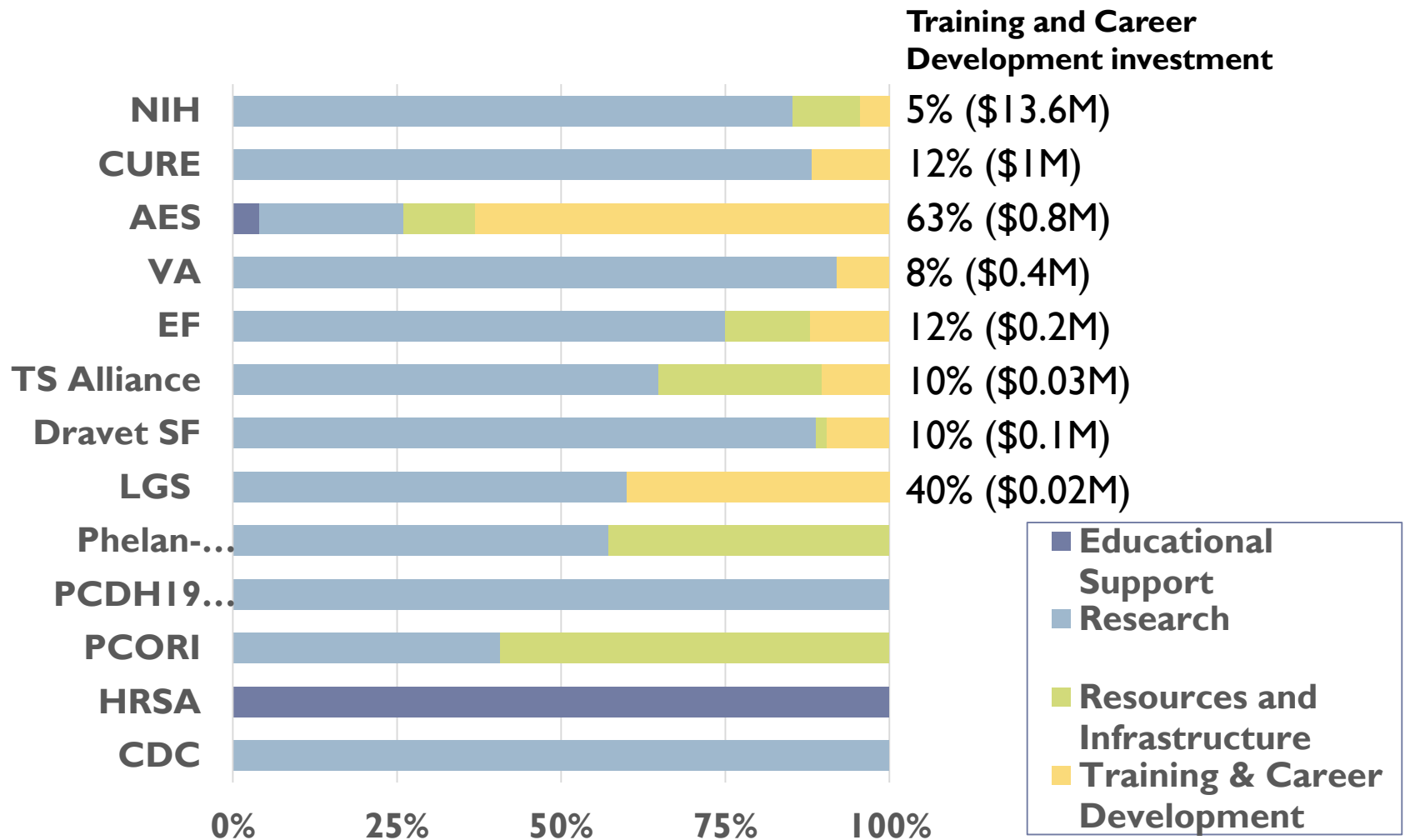
## **Conclusions**

- 1) Epilepsy research funding spans a range of organizations with different missions and funding capacity
- 2) Federal funding significantly outpaces nonprofit research funding. Funding from federal sources is highly concentrated at NIH
- 3) Epilepsy research funding is unevenly distributed among the Epilepsies
- 4) Epilepsy research funding is unevenly distributed among the Epilepsy Benchmark priorities

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

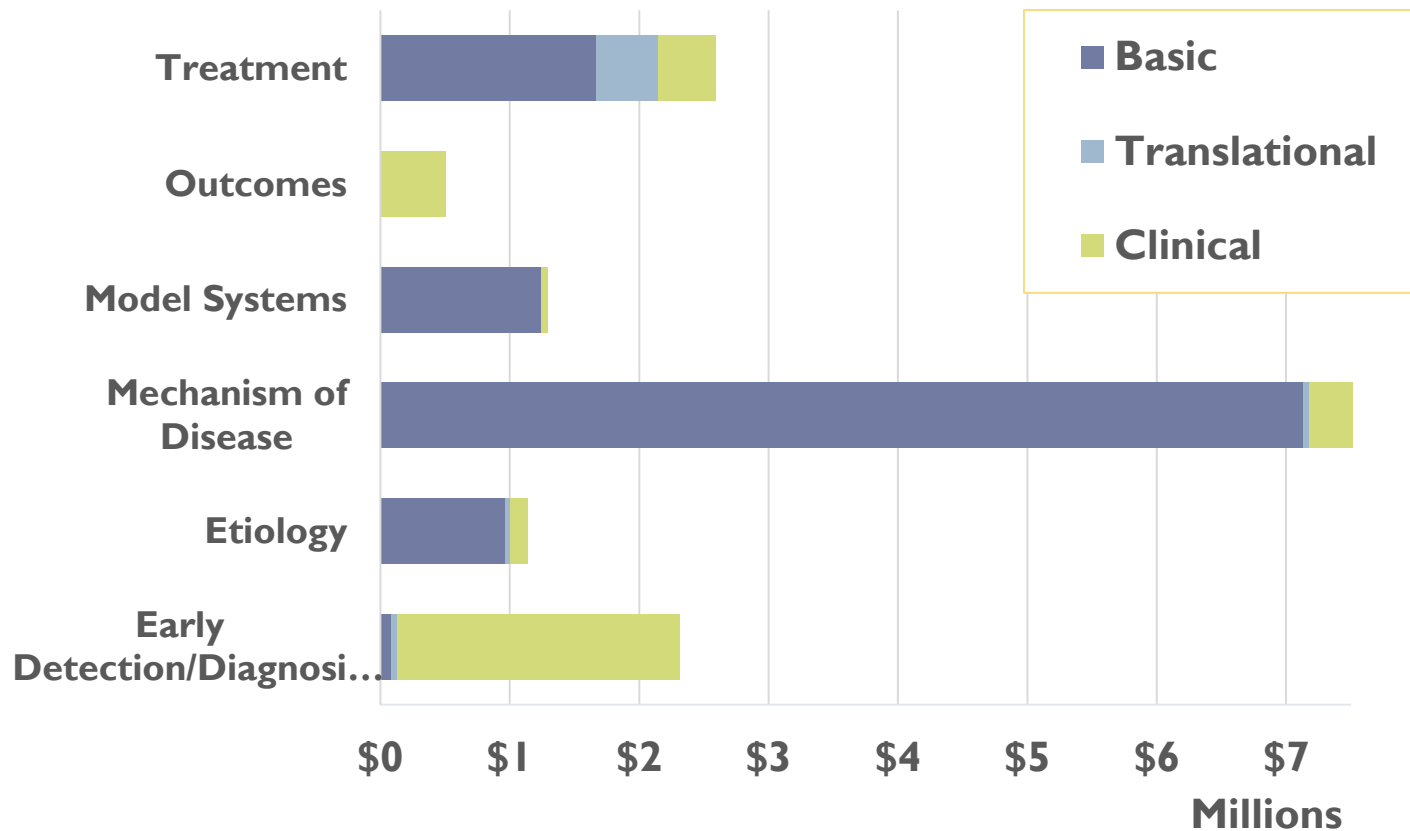


# Funding for Structured Training is Provided by a Subset of Organizations



# Majority of Training and Career Development Awards Support Basic Research

Investment of training awards by Research Classification and Type



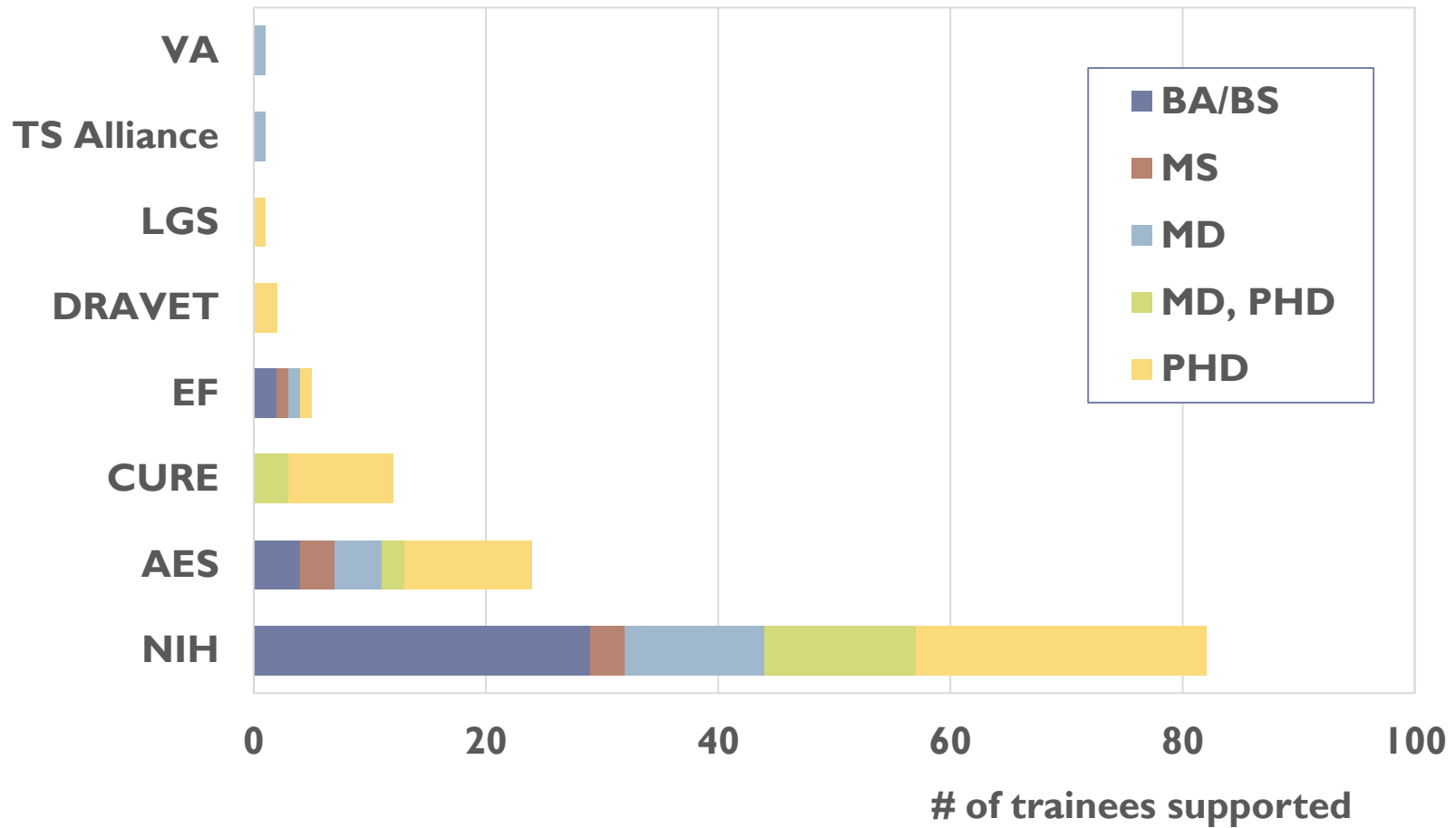
## Majority of Supported Trainees hold a PhD Degree

Degree*	2013	2014	Total
<b>PHD</b>	30	32	47
<b>MD, PHD</b>	13	14	18
<b>MD</b>	15	13	18
<b>MS</b>	5	3	7
<b>BA/BS</b>	27	20	33
<b>Trainee total</b>	<b>90</b>	<b>82</b>	<b>123</b>

**\*Degree of trainees at time of award**



# Majority of Trainees are supported by the NIH



## **60% of Trainees supported by non-profits have applied for NIH funding**

<b>Funder</b>	<b># Trainees</b>	<b>Applied for NIH funding</b>	<b>Awarded NIH funding</b>
<b>AES</b>	24	12	4
<b>CURE</b>	11	9	3
<b>Dravet SF</b>	2	2	
<b>EF</b>	4	1	1
<b>LGS Foundation</b>	1	1	
<b>TS Alliance</b>	1	1	
<b>All Non profit</b>	<b>44</b>	<b>26</b>	<b>8</b>

**50% of all Trainees applied for NIH funding  
with a success rate of 35%**

Degree	All	Applied	Award
BA/BS	33	5	2
MS	7	2	
MD	18	14	3
MD, PHD	18	13	5
PHD	47	28	12
All	123	62	22

## Conclusions


- 1) Limited Support for structured training in epilepsy research
- 2) Subset of organization support training; and only subset of them support graduate trainees
- 3) Majority of funds support training in basic research
- 4) Majority of trainees hold a PhD degree
- 5) **Preliminary** follow up analysis on trainees: 50% apply for NIH funding, 35% success rate





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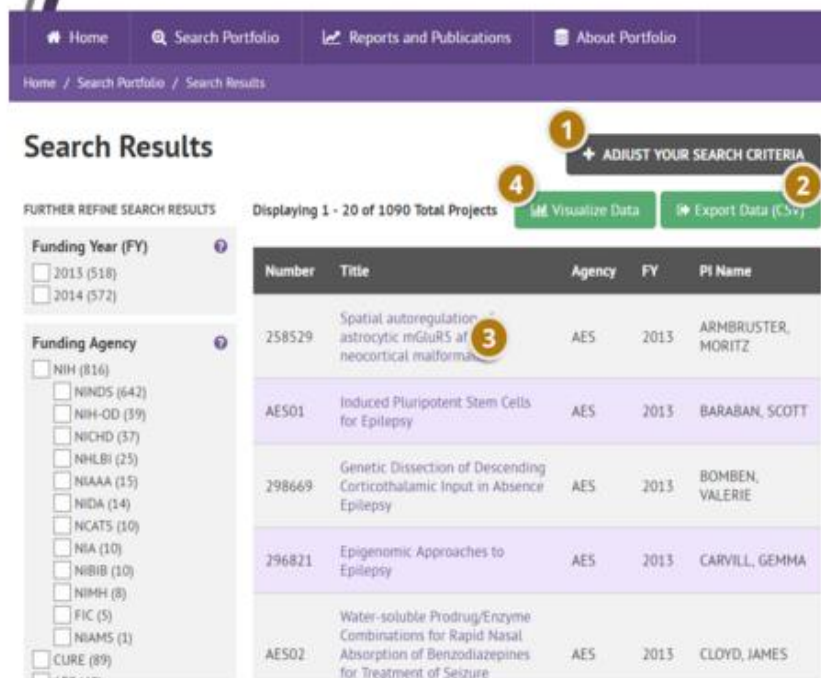


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## KEY FEATURES

1. Click on the **adjust your search criteria button** to change your search parameters
2. Click on the **export data button** the exports the results in CSV (Comma Delimited) format
3. Click on the **title of an individual project** to see detailed information of that particular project
4. Click on the **visualize data button** to see the results represented in graph format



The screenshot shows the 'Search Results' page of the ICARE Epilepsy Research Portfolio. The page has a purple header with navigation links: Home, Search Portfolio, Reports and Publications, and About Portfolio. Below the header, a breadcrumb trail reads 'Home / Search Portfolio / Search Results'. The main content area is titled 'Search Results' and displays 'Displaying 1 - 20 of 1090 Total Projects'. On the left, there are filters for 'Funding Year (FY)' (2013: 518, 2014: 572) and 'Funding Agency' (NIH: 816, NINDS: 642, NIH-OD: 39, NICHD: 37, NHLBI: 25, NIAAA: 15, NIDA: 14, NCATS: 10, NIA: 10, NIBIB: 10, NIMH: 8, FIC: 5, NIAMS: 1, CURE: 89). On the right, there are two buttons: 'Visualize Data' (callout 4) and 'Export Data (CSV)' (callout 2). Above these buttons is a button labeled '+ ADJUST YOUR SEARCH CRITERIA' (callout 1). The main table lists projects with columns: Number, Title, Agency, FY, and PI Name. The first four rows are highlighted in light purple. Callout 3 points to the title of the first project: 'Spatial autoregulation astrocytic mGluR5 at neocortical malformations'.

Number	Title	Agency	FY	PI Name
258529	Spatial autoregulation astrocytic mGluR5 at neocortical malformations	AES	2013	ARMBRUSTER, MORITZ
AES01	Induced Pluripotent Stem Cells for Epilepsy	AES	2013	BARABAN, SCOTT
298669	Genetic Dissection of Descending Corticothalamic Input in Absence Epilepsy	AES	2013	BOMBEN, VALERIE
296821	Epigenomic Approaches to Epilepsy	AES	2013	CARVILL, GEMMA
AES02	Water-soluble Prodrug/Enzyme Combinations for Rapid Nasal Absorption of Benzodiazepines for Treatment of Seizure	AES	2013	CLOYD, JAMES



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## Search Results

FURTHER REFINE SEARCH RESULTS

### Funding Year (FY)

☐ 2013 (518)

### Funding Agency

☐ NIH (392)

☐ NINDS (316)

☐ NIH-OD (19)

☐ NHLBI (15)

☐ NICHD (11)

☐ NCATS (7)

☐ NIAAA (7)

☐ NIDA (7)

☐ NIA (5)

☐ NIBIB (5)

☐ CURE (41)

☐ AES (19)

☐ EF (15)

☐ Veterans Affairs (15)

☐ CDC (10)

☐ ...

[+ ADJUST YOUR SEARCH CRITERIA](#)

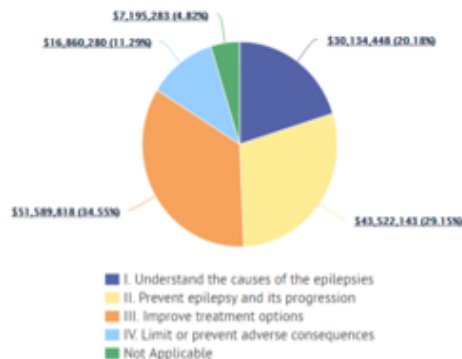
[View Results](#)

[Export Data \(CSV\)](#)

Visualizing data for 518 Total Projects

### Distribution of Funding by Benchmark

Click on a Benchmark Area slice to view the distribution of funding by Individual Benchmark.



## KEY FEATURES

1. Choose any of the **check boxes** in the left hand search facets to drill down within your search results and the graphs will be updated to represent new search results
2. To save a graph click on the **three bar icon** at the right top corner of a graph to see a print/download option menu
3. Click on the **view results button** to go back to the project listing search results

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

## About the ICARE Epilepsy Research Portfolio

The Interagency Collaborative to Advance Research in Epilepsy (ICARE) is a voluntary working group of public and non-profit organizations in the United States that provide sustained funding for epilepsy research and training. ICARE was established in 2010 and meets annually to better coordinate research-related activities among these groups, and to encourage collaborations where compelling opportunities exist. At the 2014 meeting, the group discussed and agreed upon the potential benefits of a community-wide portfolio analysis. The database of funded epilepsy research projects contributed by the [ICARE member organizations](#) will provide a means to better inform the group about the landscape of funded epilepsy research and is expected to aid with coordination strategies, leverage resources, avoid duplication of effort and assess progress being made against the epilepsy research priorities as defined by the [2014 NINDS Benchmarks for Epilepsy Research](#) and the [recommendations](#) from the 2012 IOM report "Epilepsy across the Spectrum". Furthermore, the shared [ontology](#) created by the categorization of research according to scientific areas and types of support (e.g., basic, translational, clinical research; research projects, training and career awards, resources) will provide for the mapping of funding opportunities across organizations to help epilepsy researchers at different career stages identify potential sources of support. [Click here](#) for a complete description of the ICARE portfolio ontology.

Please check it out and  
provide feedback at  
[leenderm@ninds.nih.gov](mailto:leenderm@ninds.nih.gov)

### ICARE Portfolio Data Contributors



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Citizens United for Research  
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American Epilepsy Society



Epilepsy Foundation



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