

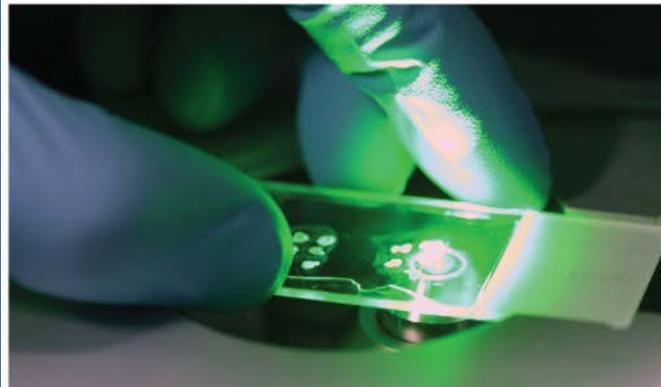
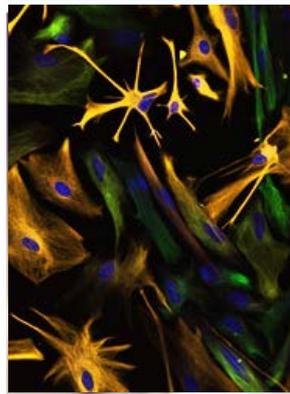


National Institute of
Neurological Disorders
and Stroke

Interagency Collaborative to Advance Research in Epilepsy 2015 Meeting

Walter J. Koroshetz, M.D.
Acting Director, National Institute of
Neurological Disorders and Stroke, NIH

April 13, 2015



New Transitions for ICARE Members

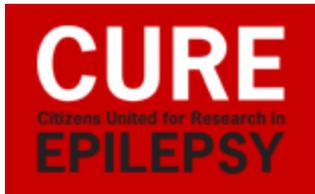


- **The NINDS/AES Benchmark Stewards** became a committee of the **American Epilepsy Society (AES)**
 - The Stewards are at work on mid-course progress reports for the Epilepsy benchmarks, plans to publish in *Epilepsy Currents* in 2016
- Vision 20-20 adopted a new organizational structure and name - The **Epilepsy Leadership Council (ELC)**.

Current Activities / Opportunities



- **AES** recently launched a survey tool called **Q-Pulse** - allows for rapid collection of data from epilepsy specialists on current clinical practice.
 - *NEW* Strategic plan- education, research, best practices, awareness



- **CURE** continues to support its **Infantile Spasms Bedside to Bench to Bedside Initiative**



- **PCORI** supported **Rare Epilepsy Network (REN)**, administered by the **Epilepsy Foundation-Dravet, Ohtahara, Aicardi, CDKL5, Dup15q, Hypothalamic Hamartoma, Lennox Gestaut, PCDH19, Phelan McDermid, Tuberous sclerosis,**



- The **CDC** has several active initiatives likely of interest to ICARE:
 - **Managing Epilepsy Well**
 - Resources to advance epilepsy self-management .
 - Network of universities to facilitate high quality research to advance the science of epilepsy self management
 - **Project to Learn about Youth – Mental Health (PLAY-MH)**
 - cross-sectional epidemiologic studies within schools to characterize the underlying prevalence, diagnosis and treatment of children’s mental, emotional, and behavioral disorders – includes epilepsy

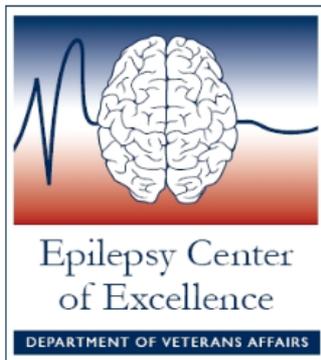
Current Activities (Continued)



- The **ELC, AES, CURE, EF, TS Alliance, NINDS**, and others supported the **Partners Against Mortality in Epilepsy Meeting (PAME)** in 2014



- The **TS Alliance** and **NINDS** hosted a **strategic planning workshop** for TSC in March
 - The TS alliance is already moving forward with plans to expand its natural history database to include biospecimens

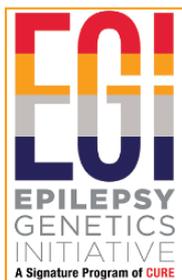


- The **VA** and their Epilepsy Centers of Excellence continue to have a major interest in post-traumatic and non-epileptic seizures
 - In addition, VA ECoE Basic Science and Clinical Research Workgroups continue to be open to anyone interested in participating and collaborating.

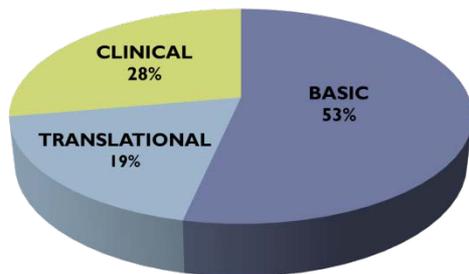
New Partnerships



- **AES and ELC** launched the **Epilepsy Research Connection (ERC)** website at the beginning of this month
 - Website serves as a one-stop destination for investigators to search for epilepsy research funding opportunities
 - (Rob Moss will be demoing the ERC later today)

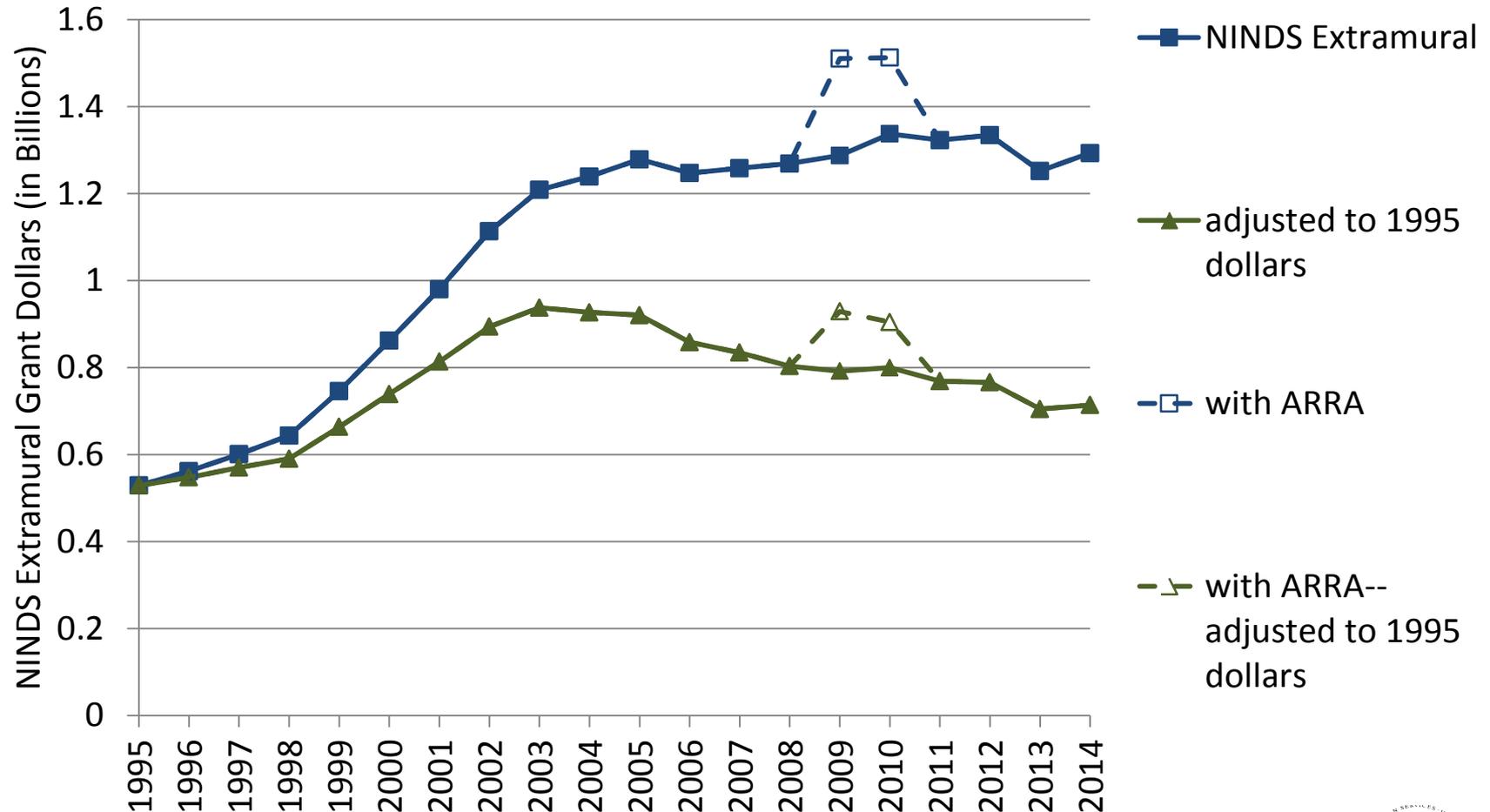


- **Epilepsy Genetics Initiative (EGI)** created by **CURE** in partnership with the NINDS-supported Epi4K Centers without Walls
 - (Tracy Dixon-Salazar from CURE will be discussing this in more detail later today)



- **ICARE 2013 Portfolio Analysis**

Total NINDS Extramural Grants Budget



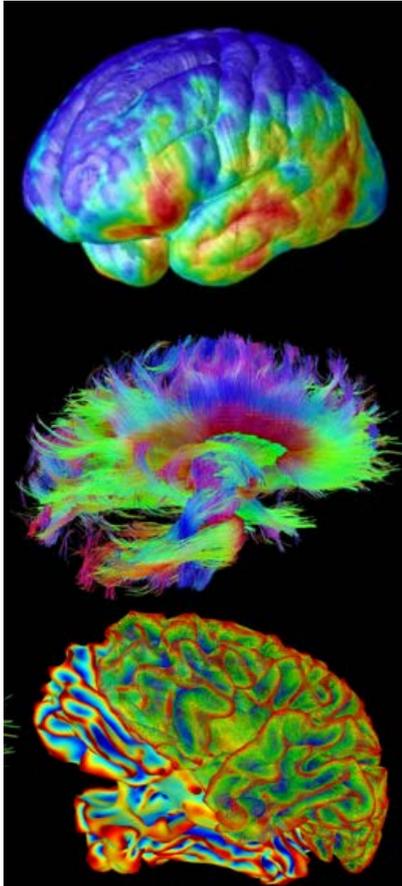
NIH/NINDS Investment in Epilepsy

Estimates of Funding from Research, Condition, and Disease Categories (RCDC)

(Dollars in millions and rounded)	FY 2010	FY 201 ARRA	FY 2011	FY 2012	FY2013	FY2014
NIH	134	25	152	144	128	153
NINDS	109	20	127	125	114	130

- NIH/NINDS is the leading funder of neuroscience research, including research on Epilepsy
- NINDS is committed to:
 - Building a strong *foundation* of research discovery
 - Rapidly *translating* basic research findings into clinical practice

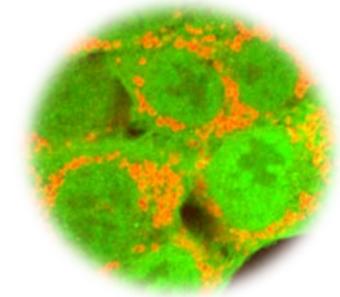
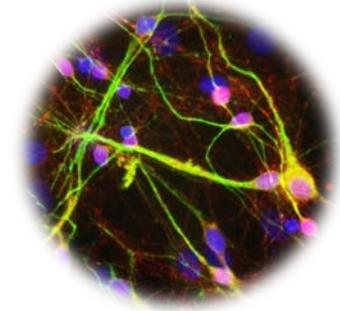
Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative



- **Goal**: To map the circuits of the brain, measure and understand the fluctuating patterns of electrical and chemical activity flowing within those circuits
- We need to be able to see the circuits in action to:
 - Understand how the brain forms memories
 - Determine how to therapeutically modulate brain activity
 - Improve motor control in Parkinson's Disease
- **Funding in FY 2014**
 - \$46M invested in 58 projects across six different funding opportunities
 - > 100 investigators in 15 states and three countries
- **Funding in FY 2015**
 - Investment expands to \$80M
 - 13 different funding opportunities
- Other Federal Agencies include NSF, FDA, IARPA, and DARPA
 - DARPA System-Based Neurotechnology for Emerging Therapies (SUBNETS) focuses on developing next-generation devices inspired by current Deep Brain Stimulation (DBS) technology

NINDS Supports Epilepsy Research Across the Spectrum

- Molecular mechanisms, genetic and environmental risk factors
- **Centers without Walls**
 - *Epi4K*
 - *Center for SUDEP Research (CSR)*
- **Translational Programs**
 - Blueprint Neurotherapeutics, IGNITE, CREATE
- **Clinical research**
 - ESETT (status epilepticus), MONEAD (maternal outcomes)
- Training next generation of researchers and clinicians
- **Resources**
 - Anticonvulsant Screening Program
 - Sudden Death in Young Registry with CDC, NHLBI
 - Seizure Detection and Prediction Challenge



New Representatives to ICARE

- **Amy Brooks-Kayal, MD** *AES*
- **Barbara Kroner, PhD** *Epilepsy Leadership Council (ELC)*
- **Anthony Pacifico, PhD** *DOD, CDMRP*
- **Abigail Hemani** *Dravet Syndrome Foundation*

ICARE 2015

Let's get started!

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*Seeking Knowledge about the Brain,
Reducing the Burden of Disease*

