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

NINDS Extramural Grant Dollars (in Billions)

- NINDS Extramural
- adjusted to 1995 dollars
- with ARRA
- with ARRA--adjusted to 1995 dollars
NIH/NINDS Investment in Epilepsy

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

<table>
<thead>
<tr>
<th>(Dollars in millions and rounded)</th>
<th>FY 2010</th>
<th>FY 2011</th>
<th>FY 2012</th>
<th>FY 2013</th>
<th>FY 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIH 134</td>
<td>25</td>
<td>152</td>
<td>144</td>
<td>128</td>
<td>153</td>
</tr>
<tr>
<td>NINDS 109</td>
<td>20</td>
<td>127</td>
<td>125</td>
<td>114</td>
<td>130</td>
</tr>
</tbody>
</table>

• 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!

Walter J. Koroshetz, M.D.
Acting Director
National Institute of Neurological Disorders and Stroke
Email: koroshetzw@ninds.nih.gov
Website: http://www.ninds.nih.gov/

Follow me @NINDSdirector
NINDS
Seeking Knowledge about the Brain, Reducing the Burden of Disease