

ICARE Member Reports

- *Eunice Kennedy Shriver* National Institute for Child Health and Human Development (NICHD), National Institutes of Health (NIH)
- NICHD mission “is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.”

ICARE Member Reports: NICHD, NIH

- Major topics of interest in epilepsy research
 - Clinical research on pediatric seizures consequent to various environmental insults (e.g. hypoxia/ischemia) or gene mutations leading to neurodevelopmental disorders (e.g. Fragile X)
 - Neural cell function and protection in hypoxia/ischemia and traumatic brain injury (TBI)
 - Neuronal migration, cortical plasticity and limbic functional circuitry
 - High frequency neural activity in children with epilepsy
 - Technology development: non-invasive monitoring of brain function
- Types of research support or other activities
 - Three clinical networks: neonatal, pharmaceutical and TBI
 - About 20 research project grants
 - Three institutional training grants in rehabilitation
 - Infrastructure support funded by 14 P30 center core grants

ICARE Member Reports: NICHD

- Resources available for shared use or other opportunities for collaboration
 - *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Centers (P30) provide core support for peer-reviewed projects including epilepsy-related research at 14 institutions nationwide. URL: <http://www.aucd.org/ddrcportal/template/index.cfm>
 - Neonatal Research Network (NRN) performs trials and follow up on infants with hypoxic ischemic encephalopathy at 16 sites nationwide. Seizures are among the secondary outcomes that are being assessed. Further, the NRN collects information about seizures and seizure medications in infants <29 weeks-old in a generic database and infants < 27 weeks-old for follow-up at 18-22 months. URL: <http://neonatal.rti.org>

ICARE Member Reports: NICHD

Resources available for shared use or other opportunities for collaboration (cont.)

- In response to the Best Pharmaceuticals for Children Act (BPCA), the NICHD will assemble a 2010 Neurology Working Group of experts to identify therapeutic gaps in the treatment of seizures and migraines in children—based on the BPCA Priority List of Needs in Pediatric Therapeutics. URL: <http://bpca.nichd.nih.gov>
- NICHD Brain and Tissue Bank for Developmental Disorders at the University of Maryland at Baltimore includes samples from a wide age range of individuals with epilepsy or seizure disorders. URL: <http://www.btbank.org>

ICARE Member Reports: NICHD

- Priorities for future activities
 - Complete BPCA sponsored randomized, double-blinded, adaptive design trial to determine the efficacy and safety of lorazepam compared to diazepam for pediatric status epilepticus
 - Complete TBI Clinical Trials Network investigation of the efficacy and value of continuous video-EEG monitoring in patients with moderately-severe to severe TBI
 - Advance treatment of seizures and migraines in children via 2010 Neurology Working Group recommendations
 - Intensify translation of basic knowledge about environmental and genetic causes of pediatric seizures into interventions
 - Attract more electrophysiologists to study pediatric seizures