

IS GLOBAL COLLABORATION NEEDED FOR RESEARCH ON THE EPILEPSIES?

Vicky Holets Whittemore, PhD
National Institutes of Health
National Institute for Neurological Disorders and Stroke
Bethesda, Maryland
USA



Yes, because:



- ▣ The epilepsies are a global problem
- ▣ Issues with access to care affect all nations
- ▣ Treatment is not effective for 30-40% of individuals who do receive appropriate care
- ▣ Treatments stop seizures but with the consequence of enduring side effects
- ▣ Impact of early life seizures on brain development leaves individual with a lifetime of disability
- ▣ Study of rare epilepsies can only be accomplished through international collaborations

Potential Benefits of Collaboration

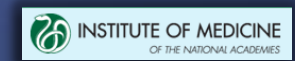
- ▣ Access to unique data sources and opportunities to learn from varied approaches
 - Different systems for health surveillance and health care delivery
 - Experience with treatments approved in different countries
- ▣ Ability to engage the collective expertise of researchers regardless of geographic location
- ▣ Maximize resources through expanded cooperation toward shared goals

Public Health Impact of the Epilepsies in the USA

- ▣ **The epilepsies are collectively common**
 - Represents the 4th most common neurological disorder in the USA after migraine, stroke, and Alzheimer's disease
 - 1 in 26 people will develop epilepsy in their lifetime
 - Risk is significantly higher for the young and elderly
 - Direct costs of the epilepsies in the USA are \$9.6 - \$12.5 billion per year
- ▣ **For many, epilepsy can be treated, BUT**
 - Many people do not receive adequate care
 - Among those who do, up to 40% continue to experience seizures and other consequences
 - Existing treatments are associated with adverse side effects
- ▣ **We do not know how to prevent epilepsy in those at risk**

Epilepsy Across the Spectrum: Promoting Health and Understanding

- ▣ **Recent report by the USA Institute of Medicine on the public health dimensions of the epilepsies in USA**
- ▣ **All stakeholders participated in the process**
- ▣ **Ongoing efforts across all sponsors and other partners to address recommendations and priorities to improve the lives of people with epilepsy**



Collaboration and Communication

Individuals with Epilepsy and
Non-governmental Organizations

Health Care
Professionals



Government
Agencies

Researchers



U.S. Department of Health and Human Services

Operating Divisions

Administration for
Children &
Families (ACF)

Administration for
Community Living
(ACL)

Agency for
Healthcare
Research &
Quality (AHRQ)

Agency for Toxic
Substances &
Disease Registry
(ATSDR)

Centers for
Disease Control &
Prevention (CDC)

Centers for
Medicare &
Medicaid Services
(CMS)

Food and Drug
Administration
(FDA)

Health Resources
& Services
Administration
(HRSA)

Indian Health
Service (IHS)

**National
Institutes of
Health (NIH)**

Substance Abuse &
Mental Health
Services
Administration
(SAMHSA)



National Institutes of Health Office of the Director

National Cancer
Institute

National Eye
Institute

National Heart, Lung
And Blood Institute

National Institute on
Deafness and Other
Communication Disorders

National Institute
on
Aging

National Institute on
Alcohol Abuse and
Alcoholism

National Institute of
Allergy
and Infectious Disease

National Institute of
Arthritis And
Musculoskeletal and
Skin Diseases

National Institute of
Biomedical
Imaging and
Bioengineering

National Institute of Child
Health and Human
Development

National Human
Genome Research
Institute

National Institute
of Dental and
Craniofacial
Research

National Institute of
Diabetes and Digestive
and Kidney
Diseases

National Institute
on Drug Abuse

National Institute of
Environmental Health
Sciences

National Institute of
General Medical
Sciences

National Institute of
Mental Health

National Institute on
Minority Health and
Health Disparities

National Institute of
Neurological Disorders
And Stroke

National Institute of
Nursing Research

National Library
of Medicine

John E. Fogarty International
Center for Advanced Study
In the Health Sciences

National Center
For Advancing
Translational
Sciences

National Center
For Complementary
And Alternative
Medicine

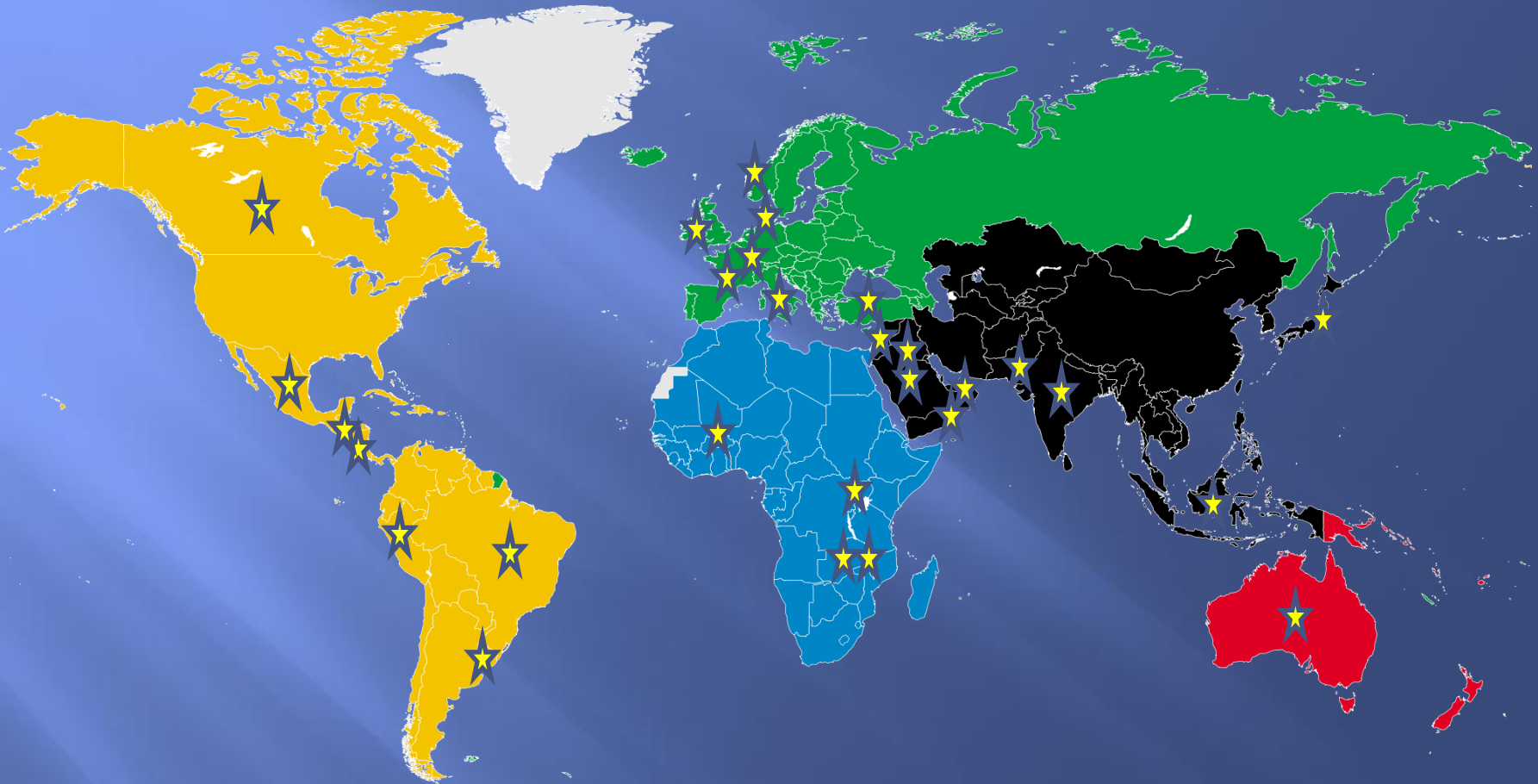
Clinical Center

Center for Information
Technology

Center for Scientific
Review



NIH Support for Research on the Epilepsies Worldwide



NIH Initiatives in the Epilepsies

- ▣ **Center Without Walls Initiative**
 - ▣ **Epi4K**
 - ▣ **Workshops and conference**
 - ▣ **Grants and contracts**
 - ▣ **Anticonvulsant Screening Program (ASP)**
 - ▣ **International Epilepsy Electrophysiology Portal**
- ▣ **Specific Research Initiatives**
 - ▣ **SUDEP**
 - ▣ **Epileptogenesis**
 - ▣ **Stigma**



CURING THE EPILEPSIES 2013: PATHWAYS FORWARD

APRIL 17-19, 2013

- ▣ **Third conference in series (2000, 2007, 2013)**
- ▣ **NINDS Epilepsy Research Benchmarks**
 - **Benchmarks Area I: Prevent epilepsy and its progression.**
 - **Benchmarks Area II: Develop new therapeutic strategies and optimize current approaches to cure epilepsy.**
 - **Benchmarks Area III: Prevent, limit, and reverse the comorbidities associated with epilepsy and its treatment.**

Epi4K Center Without Walls



- **Goal is to elucidate the genetic bases of the epilepsies with an ultimate goal to improve the care of patients with epilepsy**
- **Involves investigators from Australia, Canada, England, Ireland and USA**
- **Validated data will be deposited in public database (dbGAP)**
- **www.epi4k.org**



International Epilepsy Electrophysiology Portal

- ▣ Advance research towards the understanding of epilepsy by providing a platform for sharing data, tools and expertise between researchers
- ▣ Portal includes a large database of scientific data and tools to analyze these datasets
- ▣ <https://www.ieeg.org/>

Epilepsy Common Data Elements



- ▣ **Repository and dissemination tool for all NINDS Common Data Elements (CDEs)**
- ▣ **Utilize for trials being planned, and ongoing research**
- ▣ **Website assists clinical researchers by providing access to CDE, definitions, and sample data collection forms**
- ▣ **Working with ILAE to expand use and ensure global applicability of CDEs for the epilepsies**
- ▣ **http://www.ninds.nih.gov/research/clinical_research/toolkit/common_data_elements.htm**

International Initiative for Traumatic Brain Injury Research (InTBIR)

- ▣ **Collaboration between:**
 - the European Commission (Directorate-General for Research and Innovation)
 - Canadian Institutes of Health Research (CIHR),
 - National Institutes of Health (USA) and US Department of Defense (DOD)
- ▣ **Goal is to improve patients' outcomes and decrease the global burden of TBI by 2020**
- ▣ **Achieved through three main components:**
 - Standardization of data collection;
 - Creation of an open-source registry to share the data; and
 - Re-orientation of research questions by shifting towards a comparative effectiveness research approach

Global Issues in the Epilepsies Require a Collaborative Effort

- ▣ **More collaborative research is needed to identify unknown causes of the epilepsies and develop new and better therapies**
- ▣ **Need new strategies to prevent the onset of epilepsy for those at risk**
- ▣ **Many ways in which we can collaborate and improve communication to speed research**
- ▣ **Working together we can improve the lives of individuals with epilepsy**
- ▣ **www.nih.gov**