Epilepsy: A Model for Collaborating – Post IOM Report

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EPILEPSY IS COMMON

• Estimate of up to 3 million people in the US with epilepsy
• 50 million worldwide
• Highest incidence of new cases at the 2 ends of life
• Prevalence changing as population ages
  • Increase in elderly
  • 1 in 26 people will develop epilepsy in their lifetime
  • Lifetime risk of epilepsy (recurrent seizures) is 3.3%
Epilepsy Spectrum Disorder

SEIZURES

Attention deficit  Cognitive deficits  Psychiatric disorders  Dementia  Mental retardation  SUDEP

- Spectrum of seizure syndromes
- Spectrum of etiologies
- Spectrum of severity
- Spectrum of non-ictal symptoms

NINDS Epilepsy Benchmarks Area III: Prevent, limit, and reverse the co-morbidities associated with epilepsy and its treatment.
The paradox

- Our issues
  - Epilepsy awareness and stigma
  - Inconsistent access to health care delivery
  - Outdated incidence and prevalence data

- Our advances
  - Expanding research base relating to mechanisms
  - Expanding armamentarium of new diagnostic technology
  - Expanding list of newly introduced therapies
• Institute of Medicine Report on “Public Health Dimensions of the Epilepsies”
• Purpose: to suggest priorities and propose strategies for dealing with barriers and gaps in knowledge that diminish quality of life for people with epilepsy and their families
Questions to be addressed:

• How can the public health burden of epilepsy for patients and families be more accurately assessed?
• What priorities for future population health studies could inform treatment and prevention?
• How can the access to health and human services and the quality of care for people with epilepsy be improved?
• How can the education and training of professionals who work with people with epilepsy be improved?
• How can the understanding of epilepsy in patients and the general public be improved to create supportive communities?
Statement of Task

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1. Public health surveillance, collection & data integration
2. Population & public health research
3. Health policy, healthcare & human services
4. Education for patients/families, providers, & the public

Parameters

- Domestic focus, yet identify international issues
- Consider current budget climate and ongoing healthcare reform
- Focus should not be on biomedical research priorities covered by 2007 NINDS Epilepsy Research Benchmarks
IOM Committee Sponsors

• **Vision 20-20**
  - American Epilepsy Society
  - Citizens United Research Epilepsy
  - Dravet.org
  - Epilepsy Foundation
  - Epilepsy Therapy Project
  - Finding a Cure for Epilepsy & Seizures
  - Hemispherectomy Foundation
  - Internatnl League Against Epilepsy
  - National Assn. of Epilepsy Centers
  - Preventing Teen Tragedy
  - Rasmussen’s Encephalitis Children’s Fdn.
  - Tuberous Sclerosis Alliance

• **Governmental/Federal**
  - National Institutes of Health (NIH)
    - NINDS (Neurology)
    - NICHD (Child Health)
    - NIA (Aging)
    - NIMH (Mental Health)
  - Health and Human Services (HHS)
    - Administration on Developmental Disabilities
    - Office of the Asst. Secretary for Health
    - Office for Women’s Health
    - Assistant Secretary for Planning and Evaluation
  - Center for Disease Control (CDC)
    - Chronic Disease and Health Prevention
    - National Center for Birth Defects and DD
  - Food and Drug Administration (FDA)
    - Division of Drug Information (CDER)
    - Center for Devices and Radiological Health (CDRH)
Vision 20-20
IOM Report Timeline

- Jan 2010-
  - idea conceived, abstract brought forward by AES to Howard Koh, MD, MPH, Assistant Director HHS
- Mar 2010 –
  - first meeting of Vision 2020 group at AES board meeting, partnering of NGOs with federal agencies for common goal/message
- May 2010 –
  - formal request from Vision 2020
- September 2010 –
  - Stakeholders finalize funding (~$1.5M total, with $250K from NGO group)
- December 2010 –
  - IOM committee formed
- January 2011-
  - First public meeting of IOM committee (2 days)
- March 2011-
  - Second public meeting of IOM committee (2 days)
- June 2011-
  - Third public meeting of IOM committee
- Spring 2012
  - PUBLICATION OF IOM REPORT ON EPILEPSIES
Pre-Report Process

- Input into Statement of Work
- Recommendations for Committee Members
- Monthly calls between IOM staff and sponsors
- Advanced copy of recommendations/call with IOM staff
- Vision 20-20 Working Groups
  - Healthcare Services and Advocacy
  - Patient Advocacy and Stigma
  - Therapy
  - Pediatrics
  - Comorbidities
Working Groups

- Prepared written and oral testimonies for each Workshop
- One representative from each group presented; rotated among organizations
- Collaborations were surprisingly successful
- Groups were able to put goals above differences
- Some issues among groups
- Set precedent for what followed report release
IOM Report – Released March 31, 2012

• Recommendations #1-3 Surveillance and Prevention
• Recommendations #4-7 Healthcare Providers
• Recommendations #8-11, 13 Patients, Families and Education
• Recommendation #12 Vision 20-20 Working Groups and Collaborative Partnerships.
Post Release

- Formation of Governmental and Vision 20-20 Working Groups
- Organizational inventories by recommendation
- Monthly IOM calls continued – not just with sponsors
- Support of HHS
- Healthy People 2020 – For the first time public health goals for epilepsy will be included in detail and the IOM report on epilepsy will be used as an evidenced-base resource on access to care.
- Several publications
- An MOU has been established between NINDS and NHLBI expanding their Sudden Death Registry to include SUDEP.
Post Release

• Four Vision 20-20 Working Groups were formed to implement the report: Surveillance/Prevention; Healthcare Providers; Patient/Family/Education; Clinical Trials
• Two workshops sponsored by IOM have been held – on the patient tool and one on dissemination of report recommendations.
• Presidential Symposium at AES
• Define essential epilepsy knowledge and skills (developing epilepsy curriculum for maintenance of certification (MOC))
• Conduct surveys of health professionals to identify knowledge gaps (self assessment tests for educational programs)
• Ensure educational materials reflect current research, clinical guidelines and best practices (AES Annual Meeting, PAME)
• Disseminate educational materials and tools widely to health professional educators
My Seizures, Know More

• Empowers patients to communicate their concerns with their care providers.

• Guides patients to seek more specialized epilepsy care if they are having seizures, side-effects from drugs, other health problems, or social or educational issues.

• It can be placed on any website or blog.
○ Answer six critical questions
○ Create a report to share with your care provider
○ Take Action!
A collaborative effort of multiple epilepsy organizations. Made possible through Vision 2020.
EpilepsyHERO.org:

• Provides a clear explanation of clinical research
• Answers many frequently asked questions
• Includes informational videos featuring patients and researchers in the epilepsy community
• Makes it easier for individuals to find and enroll in clinical studies and advance epilepsy research.
Current Activities

• Monthly IOM calls
• Rare Epilepsy Network (REN) of PCORI
• Vision 20-20 Special Interest Group
• Resources in Epilepsy Research website- [epilepsyresearchresource.org](http://epilepsyresearchresource.org)
• PAME Conference, June 19-22, 2014
Lessons Learned

- Supportive and engaged IOM personnel crucial
- Individual organizational identities are important to maintain but collaborations are possible and essential
- Identify and emphasize commonalities
- Paid staff coordination helps
Challenges

- Funding – projects and personnel
- Administration of Vision 20-20
- Messaging
- Maintaining momentum
Search for the cure(s) and improving lives of people is focus and keeps us going