Presidential Symposium
IOM Report 2012: Epilepsy Across the Spectrum – Promoting Health and Understanding

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American Epilepsy Society | Annual Meeting
Disclosure

Nothing to disclose.
Magnitude

- At least 2.2 million people in the United States and more than 65 million people worldwide have epilepsy;
- 150,000 new cases of epilepsy are diagnosed in the United States annually;
- 1 in 26 people in the United States will develop epilepsy at some point in their lifetime;
- Children and older adults are the fastest-growing segments of the population with new cases of epilepsy;
- Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer’s disease

Courtesy, IOM
Incidence of Epilepsy by Age—Composite of 12 Studies in Developed Countries, 1988-2005

Courtesy David Thurman
Epilepsy Spectrum Disorder

SEIZURES

- 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.

• Seizures are the tip of the iceberg

• Neurobiology of epileptogenesis is shared with the pathophysiology of “non-ictal” symptoms (comorbidities)
  – Developmental disorders, autism
  – Cognitive impairment, attention deficits
  – Psychiatric disorders
  – SUDEP

• Implications for diagnosis and treatment beyond the seizures
Epilepsy in 2012

- Explosion of new information from basic and clinical neurosciences redefining this disease
- Inadequate assessment of populations at risk, incidence, prevalence, with wider definition of the disease
- Complex therapeutic landscape emerging
  - Pharmacologic, nutritional, surgical and device-driven
  - Pipeline is a problem from T1 to T4
  - No cure yet, only symptom suppression at best
- Problematic delivery of care to heterogeneous population from demographic and symptomatic standpoint
- Lack of awareness and stigmatized

- Ideal time for an IOM study: Our field is poised for advancement

Epilepsy Across the Spectrum: Promoting Health and Understanding
IOM Report Timeline

- **Approach**
  - HHS/IOM

- **IOM Committee**
  - Forms

- **Committee**
  - Jan 2011
  - Mar 2011
  - June 2011
  - Sept 2011
  - Jan/Feb 2012

- **NAS Review**
  - RELEASE
  - MARCH 29, 2012

- **Participants**
  - 20+ organizations
  - 1 Committee members
  - HHS, NAS/IOM staff
  - >100 individuals contributing to testimonies
No longer silos

Patients community

Health care providers

NGOs

Federal HHS, VA

Magnitude: Surveillance, data collection

Health care quality: access, education, treatment

Awareness: public, patient, professional education

Quality of life for people with epilepsy
New Partnerships

• The whole is greater than the sum of its parts

• Patient care
• Public health
• Research
Learning Objectives
(Why does this matter to you?)

• Recognize the impact of current gaps in diagnosis and treatment, as well as quality of life issues for patients with epilepsy

• Utilize information from emerging surveillance efforts to assess incidence and prevalence of epilepsy in the population across all age ranges to define clinical needs in their communities

• Understand significant areas of need for clinical, basic, and epidemiological research related to epilepsy and its comorbidities and their relationship to NINDS Epilepsy Benchmarks in order to define their research goals
Learning Objectives (cont.d)

• Identify and engage others devoted to provision of care in order to coordinate management of patients with epilepsy
• Manage care of patients based on established quality measures and desired improvement strategies in order to optimize patient outcomes.
Agenda

• The IOM Process and Committee Discussion
  Joseph I. Sirven, MD
• The Context of the IOM Report: A View from HHS Leadership
  Howard Koh, MD, MPH
• What the IOM Report Means for Basic and Clinical Research
  Story Landis, PhD
• How the IOM Report Will Impact the Lives of Patients with Epilepsy
  Susan Axelrod
Epilepsy Across the Spectrum: Institute of Medicine Process and Recommendations

Joseph I. Sirven, MD
Professor and Chairman
Department of Neurology
Mayo Clinic
Phoenix, Arizona USA
Disclosure

UCB, MAP, Vertex, Eisai, Neuropace, NIH, Upsher-Smith

Research Support

Epilepsy therapy Project

Time Support
Learning Objectives

• Review IOM Process for the Epilepsy Report
• Outline Epilepsy Report Recommendations
The Institute of Medicine

• The IOM is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public.

• Established in 1970, the IOM is the health arm of the National Academy of Sciences, which was chartered under President Abraham Lincoln in 1863.
The IOM serves as adviser to the nation to improve health

- Unbiased, authoritative advice
- Evidence-based recommendations
- Committees composed to avoid conflicts of interest
- Neutral venue for open dialogue and discussion
- Honorific organization
The IOM’s **Unique Study Process**

- **Study Defined**
- **Committee Selection and Approval**
- **Committee Meetings, Information Gathering, Deliberations, and Drafting Report**
- **Report Review and Approval**
- **Report Released**
- **Communication Strategy**
- **Communication**
Statement of Task Highlights

The study focused on providing priorities for healthcare, patient and provider education on the epilepsies for the following four topic areas:

• public health surveillance, collection, and data integration;

• population and public health research;

• health policy, health care, and human services;

• patient, provider, and public education.
IOM Committee-17 members

MARY JANE ENGLAND (Chair), Boston University
JOAN KESSNER AUSTIN, Indiana University School of Nursing
VICKI BECK, Beck Communications, Carlsbad
CHARLES E. BEGLEY, University of Texas Health Science Center
MALACHY L. BISHOP, University of Kentucky
LIONEL CARMANT, University of Montreal
CAROLYN COCOTAS, F·E·G·S Health and Human Services System
SANDRA CUSHNER-WEINSTEIN, Children’s National Medical Center
RAMON DIAZ-ARRASTIA, Uniformed Services University of the Health Sciences
DAVID GRANT, University of California, Los Angeles
CHRISTIANNE N. HECK, University of Southern California
DALE C. HESDORFFER, Columbia University
GREGORY L. HOLMES, Dartmouth Medical School
PAUL E. JARRIS, Association of State and Territorial Health Officials
DILIP V. JESTE, University of California, San Diego
PATRICIA OSBORNE SHAFER, Beth Israel Deaconess Medical Center
JOSEPH I. SIRVEN, Mayo Clinic Arizona
24 Study Sponsors

Department of Health and Human Services (HHS) sponsors:
- Administration on Developmental Disabilities
- Center for Devices and Radiological Health (FDA)
- Center for Drug Evaluation and Research (FDA)
- National Center for Chronic Disease Prevention and Health Promotion (CDC)
- National Center on Birth Defects and Developmental Disabilities (CDC)
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (NIH)
- National Institute of Mental Health (NIH)
- National Institute of Neurological Disorders and Stroke (NIH)
- National Institute on Aging (NIH)
- Office of the Assistant Secretary for Health
- Office of the Assistant Secretary for Planning and Evaluation
- Office on Women’s Health

Vision 20-20 nonprofit organization sponsors:
- American Epilepsy Society (AES)
- Citizens United for Research in Epilepsy (CURE)
- Dravet.org
- Epilepsy Foundation
- Epilepsy Therapy Project (ETP)
- Finding a Cure for Epilepsy and Seizures (FACES)
- Hemispherectomy Foundation
- International League Against Epilepsy (ILAE)
- National Association of Epilepsy Centers (NAEC)
- Preventing Teen Tragedy
- Rasmussen’s Encephalitis (RE) Children’s Project
- Tuberous Sclerosis Alliance (TSA)
Timeline

- January 2011 – First committee meeting
- March 2011 – Committee meeting and public workshop on public health surveillance, population health research, and data collection
- June 2011 – Committee meeting and public workshop on health care quality and access and education of patients, families, and providers
- **September and November 2011** – Committee meetings
- January to March 2012 – National Academies’ Report Review
- March 30, 2012 - Report release
Epilepsy – Definition

- **Seizure** – disturbances in the electrical activity of the brain
- **Epilepsy** – two or more unprovoked seizures separated by at least 24 hours

- Epilepsy is a *spectrum of disorders*:
  - Many different types of seizures
  - Many causes
  - Many syndromes and types of epilepsy
The committee believes the term “epileptic” should be discontinued because it has negative connotations.

The committee suggests using terms such as:
- “seizure medications” (to replace “anti-epileptic drugs”)
- “epilepsy seizures” (to replace “epileptic seizures”)
Magnitude

- 2.2 million people in the United States and more than 65 million people worldwide have epilepsy

- 150,000 new cases of epilepsy are diagnosed in the United States annually;

- 1 in 26 people in the United States will develop epilepsy at some point in their lifetime;
Magnitude

- Children and older adults are the fastest-growing segments of the population with new cases of epilepsy;
- Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer’s disease.
Themes

• A common and complex neurological disorder
• Often affects quality of life
• Effective treatments available but access falls short
• Data needed to improve epilepsy knowledge and care and to inform policy
• Strengthen health professionals’ education
• Bolster education efforts for people with epilepsy and their families
• Eliminate stigma
Recommendations

• **Increase surveillance (2)**
  - At present, public health researchers, policy makers, and advocates are “flying blind” due to the lack of adequate epilepsy surveillance data.

• **Prevent epilepsy (1)**
  - Gaps in knowledge about epilepsy’s risk factors, comorbidities, and outcomes limit the ability of programs to prevent epilepsy and its consequences.
Recommendation 1

• Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement

• **CDC** and others should fund, validate and implement standard definitions for epilepsy case ascertainment

  i.e. Get an accurate epilepsy count.
Recommendation 2

• Continue and Expand Collaborative Surveillance and Data Collection Efforts

• CDC should determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations. Data collection efforts should:

  • Include epilepsy data in existing registries for comorbid conditions.

  • Standardize the practices of coroners and medical examiners and work toward a national epilepsy-related death registry.
Recommendation 3

- Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences

- CDC should partner to develop and evaluate culturally appropriate and health literate prevention efforts that focus on:
  - preventing neurocysticercosis in high-risk populations;
  - preventing continued seizures in people with epilepsy and depression
  - reducing felt stigma
  - preventing epilepsy-related causes of death, including accidents and injuries, SUDEP, and suicide.
Improve Health Care (3)

- Problems with quality, access, and value of health care for people with epilepsy.
- Delays in diagnosis and referral, disparities in access to care, and challenges in co-management between primary care and specialty providers.
Recommendation 4

• Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions

• **AES and AAN** should lead a collaborative effort to:

  • Develop and validate screening tests for early identification of epilepsy
  • Establish and disseminate a standard screening protocol for comorbidities
Recommendation 5

- **National Quality Measurement and Improvement Strategy**

- AES, in conjunction with other professional organizations, should initiate the development of a national quality measurement and improvement strategy for epilepsy care.

  - The strategy should:

    - develop and implement a plan to disseminate existing clinical guidelines
    - define performance metrics
Recommendation 6

• Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network

• **NAEC and the AES** should collaborate with relevant organizations to establish accreditation criteria and processes with independent external review mechanisms for accreditation of epilepsy centers.

• Accredited epilepsy centers should work together to form an Epilepsy Care Network
Gaps were found in the education of health care professionals related to epilepsy

“20% of US Medical School do not require a Neurology clerkship”
Recommendation 7

• Improve Health Professional Education About the Epilepsies

• **AES and AAN** should collaborate with relevant organizations to ensure that health professionals are sufficiently knowledgeable and skilled. These organizations should:

  • Define essential epilepsy knowledge and skills.
  • Develop interactive materials and tools for integration into existing curricula and programs.
  • Explore and promote the use of innovative interdisciplinary approaches.
  • Disseminate educational materials and tools widely.
Improve Quality of Life (1)

• Living with epilepsy is about much more than seizures. Children have challenges in school, adults face uncertainties about social and employment situations. Others have limitations on driving a car, and questions about living independently.

• Health care and community services are often fragmented, uncoordinated, and difficult to obtain.
Recommendation 8

• Improve the Delivery and Coordination of Community Services

**CDC** should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy.

• Specific attention should be given to identifying needs and improving community services for underserved populations.

• These efforts should:
  • Link people to local and regional resources.
  • Maintain effective transportation, employment, and housing programs.
  • Identify evidence-based best practices in employment programs.
  • Develop best practices for coordination of health care and community services.
  • Provide a 24/7 nonmedical help line.
Improve Education for People with Epilepsy and Their Families (1)

• People with epilepsy and their families have significant information needs about epilepsy and its management.

• Access to resources and programs that are accurate, up-to-date, easy to understand, and linguistically and culturally appropriate is inconsistent.
Recommendation 9

• Improve and Expand Educational Opportunities for Patients and Families

• To ensure that people with epilepsy and their families have access to accurate, clearly communicated educational materials and information, epilepsy organizations should:
  • Develop a central website with links to other online resources.
  • Support the development and use of self-management and educational programs.
  • Explore the development of a certificate program for epilepsy educators.
Raise Public Awareness (2)

- Public misperceptions and misinformation about epilepsy continue to exist.
- Stigma and internalized fears of discrimination and prejudice affect the quality of life of people with epilepsy.
Recommendation 10

• Inform Media to Improve Awareness and Eliminate Stigma

**CDC and other Vision 20-20 organizations** should support and bolster programs that provide information to the media to improve public knowledge and combat stigma. Efforts should:

• Promote frequent, accurate, and positive story lines about characters with epilepsy.
• Encourage high-profile individuals with epilepsy to speak openly.
• Continue to work with media on news and human interest stories about epilepsy.
Recommendation 11

• Coordinate Public Awareness Efforts

• **EF and CDC** should lead a collaborative effort with relevant organizations to educate the public through awareness efforts, promotional events, and educational materials and should:

  • Establish an advisory council.

  • Explore the feasibility of an ongoing, coordinated, large-scale, multimedia, multiplatform, sustainable public awareness campaign.
Strengthen Stakeholder Collaboration (2)

• Epilepsy advocacy and research organizations and government agencies should work together to create a strong, united voice for change.

• People with epilepsy and their families who are willing to speak out can be persuasive advocates for better services.
Recommendation 12

• **Continue and Expand Vision 20-20 Working Groups and Collaborative Partnerships**

  • The members of Vision 20-20 should continue their efforts and expand ongoing working groups
  
  • The working groups should focus on:
  
    • health policy, health reform, and advocacy
    • surveillance and epidemiologic and health services research
    • health care and community resources and services
    • education of health professionals
    • education of people with epilepsy and their families
    • public education and awareness
Engage People with Epilepsy and Their Families (1)

• Among the most persuasive advocates and educators are people with epilepsy and their families who are willing to speak out to provide a more complete picture of the disorder and its impact.
Recommendation 13

- Engage in Education, Dissemination, and Advocacy for Improved Epilepsy Care and Services
Research Priority Areas

1. Increase the power of data & prevent epilepsy
2. Improve health care
3. Improve health professional education
4. Improve quality of life
5. Improve education for patients & families
6. Raise public awareness
Welcome

• Free PDFs of the report are available: www.iom.edu/epilepsy

• Twitter hashtag: #IOMepilepsy