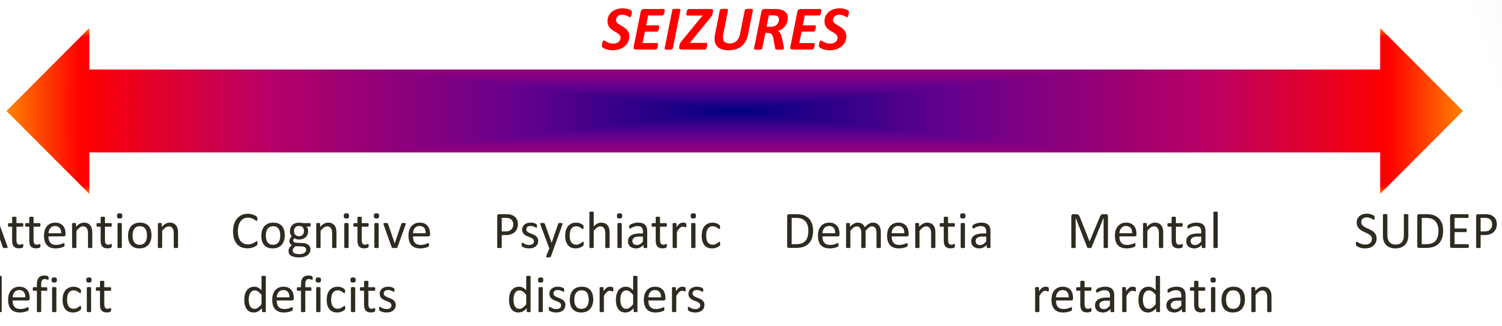
Epilepsy: A Model for Collaborating – Post IOM Report

Margaret Prosnit Jacobs
Science Community Liaison
American Epilepsy Society

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.

http://www.ninds.nih.gov/research/epilepsyweb/2007_benchmarks.htm

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  - Outdated incidence and prevalence data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
OF THE NATIONAL ACADEMIES

- 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

Statement of task

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 <u>not</u> 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


The Charlie Foundation
PMGawareness.org
FACES
Aicardi Syndrome Foundation
American Epilepsy Society
National Association of Epilepsy Centers
NAEC
ICE Epilepsy Alliance
DUP15q Alliance
CDC
Danny Did foundation
www.dannydid.org
National Institute of Neurological Disorders and Stroke
The Anita Kaufmann Foundation
Educating the public not to fear epilepsy
Visit – www.akfus.org
Hope4Harper
hope for a cure - CDKL5
Hypothalamic Hope Hamartomas
dravet.org
HHV-6 Foundation
U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
ILAE
Tuberous Sclerosis Alliance
SUDEP Aware
Dravet Syndrome Foundation
Epilepsy Centers of Excellence
CURE
Citizens United for Research in Epilepsy
My Epilepsy Story
ring14 USA
R-E Children's Project
Phelan-McDermid Syndrome Foundation
Epilepsy Foundation
epilepsy
International Foundation for CDKL5
LGS Foundation
Lennox-Gastaut Syndrome
PPC Physician-Parent Caregivers

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

NO

www.MySeizuresK~~no~~wMore.com

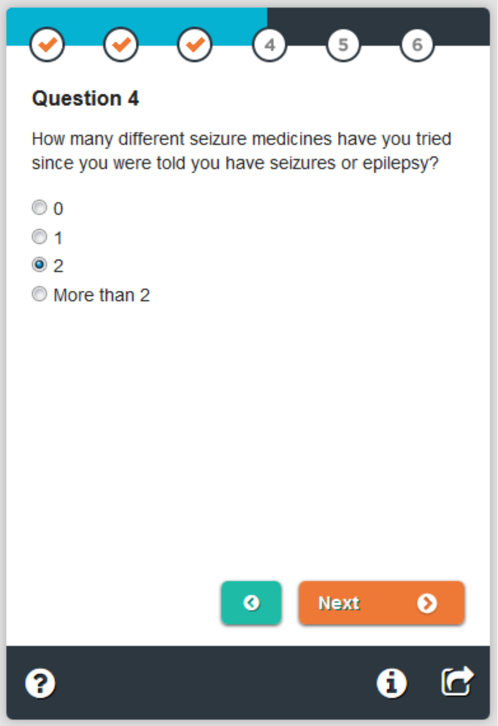
Get the Right Help at the Right Time

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.

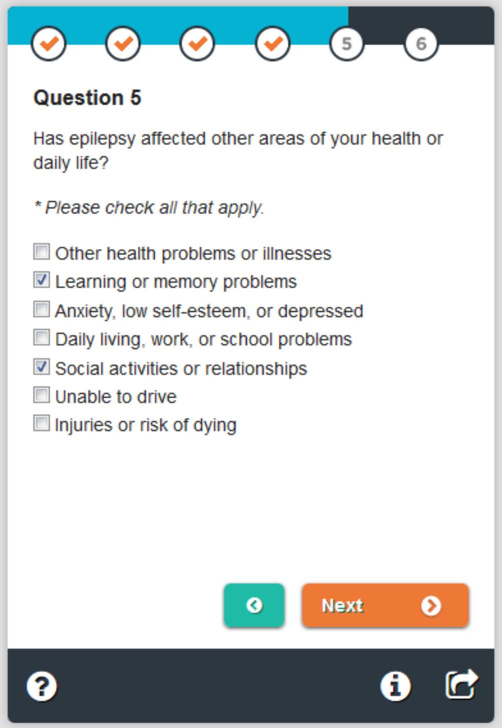
- It can be placed on any website or blog.



Question 4

How many different seizure medicines have you tried since you were told you have seizures or epilepsy?

○ 0
○ 1
● 2
○ More than 2

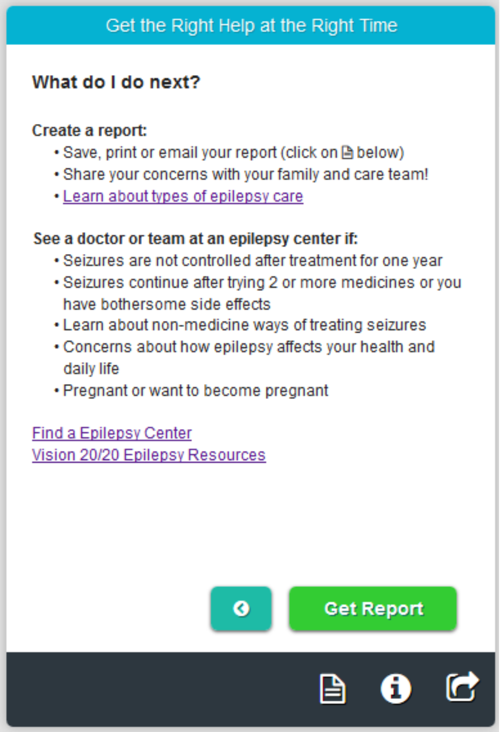


Question 5

Has epilepsy affected other areas of your health or daily life?

** Please check all that apply.*

☐ Other health problems or illnesses
☑ Learning or memory problems
☐ Anxiety, low self-esteem, or depressed
☐ Daily living, work, or school problems
☑ Social activities or relationships
☐ Unable to drive
☐ Injuries or risk of dying


Get the Right Help at the Right Time

What do I do next?

Create a report:
- Save, print or email your report (click on below)
- Share your concerns with your family and care team!
- Learn about types of epilepsy care

See a doctor or team at an epilepsy center if:
- Seizures are not controlled after treatment for one year
- Seizures continue after trying 2 or more medicines or you have bothersome side effects
- Learn about non-medicine ways of treating seizures
- Concerns about how epilepsy affects your health and daily life
- Pregnant or want to become pregnant

Find a Epilepsy Center
Vision 20/20 Epilepsy Resources

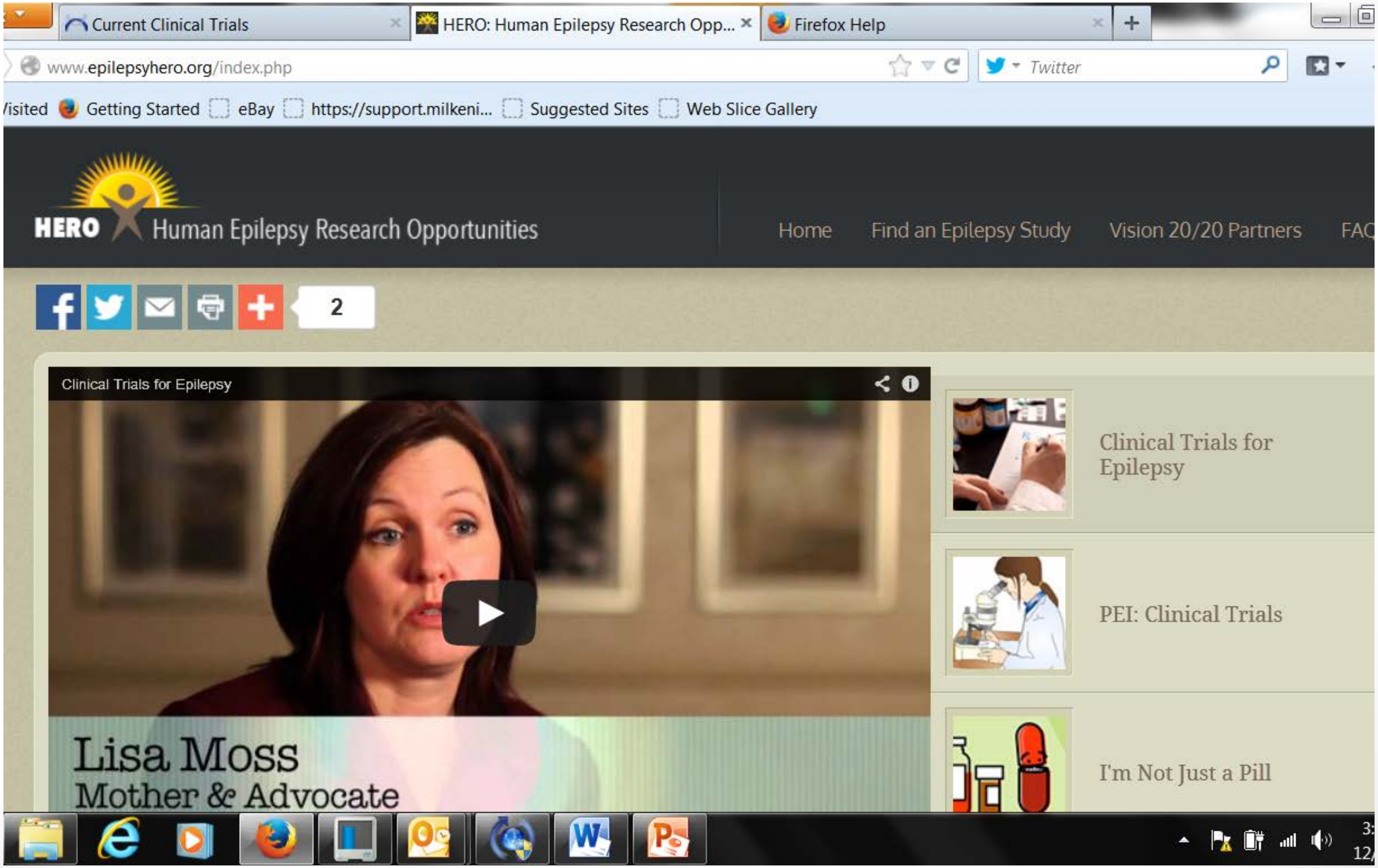
- Answer six critical questions
- Create a report to share with your care provider
- **Take Action!**

NO
www.MySeizuresK~~now~~More.com
Get the Right Help at the Right Time

HERO Human Epilepsy Research Opportunities

www.epilepsyhero.org

A collaborative effort of multiple epilepsy organizations.
Made possible through Vision 2020.



HERO Human Epilepsy Research Opportunities

Clinical Trials for Epilepsy

PEI: Clinical Trials

I'm Not Just a Pill

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
- 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