Welcome to the first Partners Against Mortality in Epilepsy Conference

Evanston, Illinois

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Program Co-directors

Partners Against Mortality in Epilepsy Conference - June 21-24, 2012
Disclosures

Jeffrey Buchhalter – Nothing to disclose

Gardiner Lapham – Nothing to disclose
Housekeeping

- Phones/pagers - off or vibrate
- Disclosures
- Medical Education Evaluator & Certificates
- Conference Overview
- Visit the Posters
How We Got Here

- 2006- AES and EF individually recognize need for SUDEP movement- Task Force
- June 2007- Task Force meeting, C.U.R.E. & NINDS became partners
- Nov 2008- NINDS SUDEP Workshop
- Mar 2009- SUDEP Coalition
- Oct 2010- CDC Mortality in Epilepsy project
  - Idea for PAME floated
Report of the American Epilepsy Society and the Epilepsy Foundation Joint Task Force on Sudden Unexplained Death in Epilepsy


Epilepsia 2009;50(4):917-922
Task Force Topics

- SUDEP definitions
- Current state of autopsy confirmation of SUDEP
- Current state of SUDEP research
- Discussion of lay public awareness
- Issues related to the discussion of SUDEP with patients and families: “if, when and how”
Task Force Recommendations

• Convene multidisciplinary workshop to refine and identify additional areas of SUDEP research
• Survey patients, families, and caregivers to identify effective means of SUDEP education to enhance research participation
• Conduct campaign to emphasize need for complete autopsy examinations for patients with suspected SUDEP
• Create a consortium of centers to conduct prospective research towards SUDEP prevention
  – Develop uniform criteria for SUDEP determination and autopsy protocols
  – Establish how core functions will be provided to centers in study consortium
  – Facilitate individual, hypothesis-driven, clinical, and basic science investigations of SUDEP risk factors and mechanisms
Abbreviated Report of the NIH/NINDS Workshop on Sudden Unexplained Death in Epilepsy

Hirsch LJ, Donner EJ, So EL, Jacobs M, Nashef L, Noebels J, Buchhalter J

*Neurology.* 2011;76(22):1932-1938
Recommendations - Research Agenda for Basic/Translational Science

- Animal models
- Clinical investigations
- Genetics
- Medical Devices
- Case identification
- Collaborative research/SUDEP Coalition
Recommendations- Research Agenda for Education

• Determine if low risk patients want to be told
• Determine how patients/families learn best
• Determine readiness” to learn
• Determine barriers to discussion
• Determine barriers to guidelines
• Determine effect of education on anxiety, QOL, treatment compliance
Progress Report

• **Organizational:** SUDEP Coalition, AES SUDEP Task Force, EF Task Force, CURE, ETP, Daddy Did

• **Education/Awareness**
  – SUDEP AWARE
  – EF
  – AAN/EFNS- SUDEP guidelines in development

• **Research Funding**
  – NINDS – Center without Walls
  – NYU- SUDEP Registry
  – CDC- Mortality in Epilepsy
  – C.U.R.E- targeted funding

• **Research**
  – Basic and clinical
  – EF survey of affiliates
  – AES facilitated survey of practitioner attitudes (Friedman et al)
Progress Report

• 2012 Institute of Medicine, *Epilepsy Across the Spectrum*

• Recommendation 3- Develop & Evaluate Prevention Efforts for Epilepsy and Its Consequences

  – “preventing epilepsy-related causes of death, including accidents and injuries, SUDEP, and suicide.”
This 3-day learning event is the first Partners Against Mortality in Epilepsy (PAME) conference devoted exclusively to Sudden Unexpected Death In Epilepsy (SUDEP), where clinical, basic science and patient/family attendees will come together to understand and support each other. This is a joint effort of SUDEP Coalition partners (AES, CDC, CURE, EFA, ETP/FACES, NINDS, SUDEP Aware), with meeting coordination and production by the American Epilepsy Society.

For more information, visit the website at http://www.aesnet.org/pame

PAME Conference
June 21-24, 2012
Hilton Orrington/Evanston
Chicago, IL

Conference Sessions

Mortality in Epilepsy
SUDEP: Where are we now?
Research Methodology – Clinical Studies
Research Methodology – Bench Research
Talking About SUDEP
Physiologic Mechanisms
Molecular & Genetic Mechanisms
SUDEP Prevention
Role of Lay Community in Facilitating Research
Where Do We Go From Here?
What Does it Take to Create a Conference?

• Steering Committee

• Support/Resources

• Motivation
Formation of the Steering Committee

- SUDEP Coalition
  - American Epilepsy Society
  - Citizens United for Research in Epilepsy
  - Epilepsy Foundation
  - Center for Disease Control & Prevention
  - National Institutes of Neurological Disease & Stroke
Formation of the Steering Committee

- American Epilepsy Society
- CURE
- Center for Disease Control & Prevention
- Epilepsy Foundation
- National Institutes of Neurological Disease & Stroke
- Epilepsy Therapy Project/FACES
- Intractable Childhood Epilepsy
- RTI
- SUDEP AWARE
Steering Committee

Co-Chairs
Jeff Buchhalter, MD, PHD, SUDEP Coalition, AES SUDEP Task Force
Gardiner Lapham, RN, CURE

Committee Members
Elizabeth Donner, MD, FRCPC, Hospital for Sick Children, SUDEP Aware
Sandy Finucane, Epilepsy Foundation
Alica Goldman, MD, PhD, Baylor College of Medicine
Lawrence J. Hirsch, MD, Yale Comprehensive Epilepsy Center
Vera Jackson, Epilepsy Foundation
Tamzin Jeffs, MSc, SUDEP Aware
Barbara L. Kroner, PhD, MPH, Epidemiology & Statistics Program, RTI
Kim Macher, Epilepsy Therapy Project
George Richerson, MD, PhD, University of Iowa
Liz Schreiber, Epilepsy Foundation
Tess Sierzant, MS, RN, APRN, BC, CNRN, Neuroscience Nursing Foundation
Elson So, MD, Mayo Clinic, College of Medicine
Steering Committee

Committee Members (cont.)

David Thurman, MD, MPH, CDC
Michelle Welborn, PharmD, ICE Alliance
Cyndi Wright, Stormlab Consulting
Tess Sierzant, MS, RN, APRN, BC, CNRN, Neuroscience Nursing Foundation
Elson So, MD, Mayo Clinic, College of Medicine
David Thurman, MD, MPH, CDC
Michelle Welborn, PharmD, ICE Alliance
Cyndi Wright, Stormlab Consulting

American Epilepsy Society Staff

Paul Levisohn, MD, Medical Liaison
Jeffrey Melin, MEd., CMP, Director of Education
Sandy Pizzoferrato, Education Projects
JoLynn Amsden, Education Project Manager
Elizabeth Kunsey, Senior Meeting Planner
Kathy Hucks, Membership Administrator
Intent of the conference

• Provide an opportunity for all those involved in SUDEP to meet & exchange information. To learn from each other

• Provide a state-of-the-art “snapshot” of SUDEP activities
  • Advocacy
  • Basic science
  • Clinical/translational science
  • Education
  • Lay/bereaved
Structure of the conference

- Overall meeting
  - Standard (1 day each)
    - Clinical science
    - Basic science
    - Advocacy, education
  - Integrated
    - Each day, each topic addressed
    - Attempt to have related topics
- Sessions
  - Standard: 30-50 min talks
  - PAME: 10 – 15 min talks with moderator summary
Challenges

• Flow
  • Group similar topics when possible
• Not enough depth for each audience
• Too much depth for some part of audience
  • Moderator introduction & summary
• Limited time for talk & discussion
  • Respect time allotted for each
  • Questions written on cards
  • Keep discussion focused
  • Additional discussion end of each day
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Support

- Educational grants
  - UCB, Inc
  - Lundbeck, Inc
  - Esai, Inc
  - Questcor Pharmaceuticals
  - Cyberonics

- Friday evening reception
  - Lundbeck, Inc
  - Sunovian Pharmaceuticals
Chris Donalty

• Seizure onset senior in high school
• College junior & senior years- continued seizures
• Died February 21, 2002; 21 years old

“There is nothing…nothing worse than losing a child, no matter the age or cause. But a sudden death, out of the blue, something that you were never told could happen, somehow makes it particularly cruel. All the unanswered questions….the what ifs..”

Jeanne Donalty
Partner Organizations

- American Epilepsy Society
- Cure Epilepsy
- Epilepsy Foundation
- Epilepsy Therapy Project
- SUDEP Aware
- Faces
- Danny Did Foundation
- RTI International
- ICE Epilepsy Alliance
- CDC
- National Institute of Neurological Disorders and Stroke
- LGS Foundation
- The Pittsburgh Foundation