WORKING TOGETHER TO PREVENT MORTALITY IN EPILEPSY
Friends,

Welcome to the 2018 PAME Conference. We are glad to have you join us at the preeminent meeting on epilepsy mortality.

Mortality in epilepsy is a difficult issue, often painful to address; we appreciate the patients, families, clinicians, researchers, and other advocates who have traveled across North America and from around the world to be here with us this weekend. We are a diverse group united by a shared goal of preventing mortality in epilepsy.

In the time since our last PAME Conference, there have been exciting new developments in research and advocacy, including publication of the joint American Academy of Neurology/American Epilepsy Society SUDEP guidelines. This weekend we will have the opportunity to learn about and discuss these important advances. However, we recognize that there is still much work left to do, and this meeting is also a valuable opportunity for us to strategize together about the gaps that remain. The productive discussions that occur among us can serve to guide our future efforts in research, clinical practice, and advocacy.

PAME has always been based on the premise of partnership, and this year is no exception. We would like to thank all of the volunteers who partnered with us to plan the conference, and the American Epilepsy Society management team for their support. We owe special thanks to all of the partner organizations, individuals, and corporate donors whose financial support made this meeting possible.

Finally, our sincere thanks to each of you for sharing your insight and experience here at the conference, and for being a part of our global PAME community. The conference will conclude this weekend, but our efforts towards progress will not. We are grateful to have you partner with us as we continue to reduce the burden of mortality in epilepsy.
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The Partners Against Mortality in Epilepsy Conference is proud to recognize the following partners:

**Visionary Level**
- American Epilepsy Society (AES)
- Epilepsy Foundation (EF)

**Innovator Level**
- Citizens United for Research in Epilepsy (CURE)
- Danny Did Foundation (DDF)

**Discovery Level**
- Finding a Cure for Epilepsy and Seizures (FACES)

**Insight Level**
- Gardiner and Nick Lapham
- Mayo Clinic
- Patrick Ring Foundation
- University of Iowa

**Trendsetter Level**
- American Clinical Neurophysiology Society (ACNS)
- Charlie Foundation for Ketogenic Therapies
- Child Neurology Foundation
- Dravet Syndrome Foundation
- Dup15q Alliance
- Lennox-Gastaut Syndrome Foundation
- National Association of Epilepsy Centers (NAEC)
- NORSE Institute
- Tuberous Sclerosis Alliance
- Wishes for Elliott

**Supporter Level**
- Hope for Hypothalamic Hamartomas
- Mickie’s Miracles
About Partners Against Epilepsy Mortality (PAME)
As awareness of epilepsy-related mortality has increased, so has the demand for information about cutting-edge research, effective patient/provider communication, and opportunities for multi-stakeholder collaboration. The PAME conference was created to fill that need and to provide a unique opportunity for diverse stakeholders to come together to better understand, address, and ultimately reduce mortality in epilepsy.

2018 Steering Committee
The Steering Committee includes volunteer representatives from various organizations and perspectives, spanning clinical, research, patient, and family advocate. Many thanks to the members of the Steering Committee for their dedicated efforts to plan the 2018 conference.

- Elizabeth Donner, M.D., Hospital for Sick Children – Co-chair
- George Richerson, M.D., Ph.D., University of Iowa – Co-chair
- Tom Stanton, M.P.P., Danny Did Foundation – Co-chair
- Brandy Fureman, Ph.D., Epilepsy Foundation
- Liz Higgins, Citizens United for Research in Epilepsy
- Eileen Murray, M.M., American Epilepsy Society
- Steve Owens, M.D., M.P.H, M.A., Epilepsy Foundation
- Sally Schaeffer, Epilepsy Foundation SUDEP Institute
Conference Hotel
PAME sessions and events are all being held at:

The Westin Alexandria
400 Courthouse Square
Alexandria, Virginia, USA, 22314

(703) 253-8600

Registration Hours
Thursday, June 14 — 4:00 pm – 7:30 pm
Friday, June 15 — 7:00 am – 5:30 pm
Saturday, June 16 — 7:00 am – 5:30 pm

Registration and Badges
Appropriate badges must be worn at all times while in attendance at the meeting and are required for admittance to all meeting activities.

Family Lounge
A family lounge will be available throughout the conference. Patients and families can use the lounge as a place to connect with each other or as a respite from the meeting. The lounge will be conveniently located in the Hopkins Foyer at the end of the hall for easy access. Supported by LivaNova.

Hours:
Thursday, June 14 — 12:00 pm – 7:30 pm
Friday, June 15 — 7:00 am – 7:30 pm
Saturday, June 16 — 7:00 am – 5:30 pm

No Smoking Policy
For the comfort and health of all attendees, smoking is not permitted at any PAME Conference functions. This includes educational sessions, meetings and all food functions. The Westin Alexandria is a smoke-free facility; there is a $250 fee if you smoke in the room. Also, smoking is not permitted in public buildings, restaurants or bars.

Safety and Security Information
The PAME Conference is committed to providing a secure meeting environment. A formal security plan is in place with the Security Department at the Westin Alexandria.

• Remove your badge once you leave the meeting facilities.
• Carry important telephone numbers with you.
• Do not display or carry large amounts of cash.
• Walk in groups, especially at night.
• Lock your hotel room door.
• Always verify hotel room repair or service calls.
• Do not disclose your room number to anyone.
• Never give your personal information (credit card, room number, etc.) over the phone; instead, go to the front desk if the hotel calls with questions.
Westin Alexandria
2nd Floor
This is the vision of the American Epilepsy Society. AES serves as a resource for members, as a champion of research, and as an organizer for the entire epilepsy community.

- Professional community through membership, AES Annual Meeting, and knowledge sharing
- Clinical excellence through educational programs and the respected journal Epilepsy Currents
- Scientific advancement with grant support, resource creation, and mentoring
- Collaboration through organization-to-organization cooperation and partnerships

Learn more at www.AESnet.org
Learn more about how we work with many epilepsy organizations to find the answers to SUDEP and help families with epilepsy by contacting us at SUDEP@efa.org or at epilepsy.com/SUDEP-Institute
CURE IS A PROUD SPONSOR OF THE PAME CONFERENCE

CURE would like to thank the courageous families who inspire us to advance our understanding of SUDEP through research.

We would also like to thank the generous donors who allow us to fund promising research aimed at eliminating mortality in epilepsy.

CURE

CITIZENS UNITED FOR RESEARCH IN EPILEPSY

With the generous support of the BAND Foundation, CURE has funded research to end SUDEP, including recent grants to:

Franck Kalume, PhD, who is investigating the impacts of interventions on sudden unexpected death phenotypes.

Judy Liu, MD, PhD, who is investigating which stages of sleep are vulnerable to breakthrough seizures and whether altering sleep stages affects frequency or intensity of seizures.

To learn more about CURE’s research and discoveries, subscribe to email alerts at CureEpilepsy.org/Subscribe.

DANNY DID FOUNDATION

PROTECTING KIDS WITH EPILEPSY

Danny Did wants to help families, caretakers, and the public understand more about epilepsy. We work to advance awareness of the risks that accompany epilepsy - including Sudden Unexpected Death in Epilepsy, or SUDEP - and to promote access to devices and technologies that can alert to seizures. Together we are stronger!

Proud to be a Partner Supporter of PAME 2018

DannyDid.org  @DannyDid

@DannyDidOrg  @Danny_Did_Foundation

PLEASE GO AND ENJOY YOUR LIFE. DANNY DID.
and the
North American SUDEP Registry
proudly sponsors
PAME

Thank you PAME steering committee for your inspired and thoughtful planning efforts.

And thank you PAME attendees for being part of this powerful movement to save lives.

— Gardiner Lapham
OVERVIEW
Mortality in epilepsy remains an area of concern that brings together scientists, clinicians and families/advocates with a shared goal of preventing mortality. This meeting provides a forum the aim of which is to prevent mortality in epilepsy. This meeting will:

1. identify trends & gaps in the field and opportunities to advance mortality research and prevention;
2. facilitate interaction between family and lay advocates with scientists and clinicians to provide an important viewpoint to direct research and clinical care;
3. disseminate information to lay advocates; and
4. provide opportunities for collaborations among stakeholders, including people with epilepsy, researchers, families, clinicians and advocates.

a. Clinicians will improve their competence related to discussions of epilepsy-related mortality, including risk factors and prevention strategies.

b. Researchers will identify goals for future research and build collaborations with other scientists as well as clinicians and families/advocates.

c. Families/advocates will learn about research and will advance SUDEP awareness and education by facilitating collaborations among support groups, funding sources, health care professionals and others. Families will share their stories and be provided opportunities to provide support to one another.

TARGET AUDIENCE
Neurologists, epileptologists, allied healthcare professionals, and families.

STATEMENT OF NEED
The need for this activity has been determined based on identifying professional practice gaps, previous course evaluations and the data from the AES Self-Assessment Examinations. The educational content of this activity was based upon current issues and topics provided by the Planning Committee, membership and other stakeholders to include patients, researchers, families, clinicians and advocates.

LEARNING OBJECTIVES
Following participation in this live course, learners should be able to:

- Critically evaluate the incidence, risk factors, and prevention strategies for mortality in epilepsy.
- Describe the progress made and future directions for research regarding mortality in epilepsy.
- Gain skills in advocacy to build public awareness and impact public policy regarding epilepsy mortality.
ACCREDITATION
This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the American Epilepsy Society and the Epilepsy Foundation, Sudden Unexpected Death in Epilepsy (SUDEP) Institute/Epilepsy Foundation, and the Citizens United for Research in Epilepsy (CURE). The American Epilepsy Society is accredited by the ACCME to provide continuing medical education for physicians.

AMA CREDIT DESIGNATION
Physicians: The American Epilepsy Society designates this live activity for a maximum of 14.25 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

International Credits: The American Medical Association has determined that non-US. licensed physicians who participate in this CME activity are eligible for AMA PRA Category 1 Credits™.

Nurse Practitioners and Registered Nurses: For the purpose of recertification, the American Nurses Credentialing Center (ANCC) may accept AMA PRA Category 1 Credit™ issued by organizations accredited by ACCME. Please prospectively check with the ANCC and your state nursing board regarding whether or not they will accept AMA PRA Category 1 Credits™ towards recertification/relicensure.

Physician Assistants: AAPA accepts certificates of participation for educational activities certified for AMA PRA Category 1 Credits™ from organizations accredited by ACCME or a recognized state medical society. Physician assistants may receive a maximum of 14.25 hours of Category 1 credit for completing this program.

How to Claim CME Credit:
Information on how to claim CME Credit is available at the Registration Desk. For assistance following the meeting, contact AES staff at education@aesnet.org or call 312.883.3800.

RESOLUTION OF CONFLICTS OF INTEREST
It is the policy of the American Epilepsy Society to ensure balance, independence, objectivity and scientific rigor. All persons involved in the selection, development and presentation of content are required to disclose any real or apparent conflicts of interest. In accordance with the ACCME Standards for Commercial Support of CME, the AES implemented the mechanisms of prospective peer review of this CME activity, to identify and resolve any conflicts. Additionally, the content of this activity is based on the best available evidence.

UNAPPROVED USE DISCLOSURE
The American Epilepsy Society requires CME authors to disclose to learners when products or procedures being discussed are off-label, unlabeled, experimental, and/or investigational (not FDA approved); and any limitations on the information that is presented, such as data that are preliminary or that represent ongoing research, interim analyses, and/or unsupported opinion. This information is intended solely for continuing medical education and is not intended to promote off-label use of these medications. If you have questions, contact the medical affairs department of the manufacturer for the most recent prescribing information. Information about pharmaceutical agents/devices that is outside of U.S. Food and Drug Administration approved labeling may be contained in this activity.

DISCLAIMER
This CME activity is for educational purposes only and does not constitute the opinion or endorsement of, or promotion by, the American Epilepsy Society. Reasonable efforts have been taken to present educational subject matter in a balanced, unbiased fashion, and in compliance with regulatory requirements. However, each activity participant must always use his or her own personal and professional judgment when considering further application of this information, particularly as it may relate to patient diagnostic or treatment decisions including, without limitation, FDA-approved uses and any off-label, investigational and/or experimental uses.

PROGRAM CHANGES
The American Epilepsy Society and PAME Partners cannot assume liability for any changes in the program due to external or unforeseen circumstances.
COMMERCIAL SUPPORT DISCLOSURE
This activity is supported in part by educational grants from:
- Eisai Inc.
- Greenwich Biosciences, Inc.
- LivaNova
- Lundbeck
- Sunovion Pharmaceuticals Inc.
- Supernus Pharmaceuticals, Inc.
- Upsher-Smith Laboratories, LLC
- Zogenix, Inc.

PLANNING COMMITTEE MEMBER DISCLOSURE INFORMATION
The following Planning Committee Members have indicated they have no financial relationships to disclose (*Indicates also faculty member):
- Lisa Bateman, M.D.
- *Brandy Fureman, Ph.D.
- *Jane Hanna, M.A., OBE
- Liz Higgins
- Eileen Murray, M.M.
- *Jeffrey Noebels, M.D., Ph.D.
- Steven Owens, M.D., M.P.H., M.A.
- *John Popovich
- *George Richerson, M.D., Ph.D.
- *Sally Schaeffer
- *Tom Stanton, M.P.P.
- Mark Stevenson, B.S., MHA, M.S.
- Vicky Whittemore, Ph.D.

The following Planning Committee Members have disclosed financial relationships:
- *Elizabeth Donner, M.D.; Eisai, UCB (Honoraria)
- *Daniel Friedman, M.D.; Eisai, GW Pharmaceuticals, Penumbra (Consulting fees), UCB (Contract research), Neuropace (Contract research and honoraria), Adamas Pharmaceuticals (Contract research and membership on advisory committees/boards, review panels), Neuroview Technology (Intellectual property rights and ownership interest — stock, stock options, etc., excluding diversified mutual funds)
- *Carl Faingold, Ph.D.; Zogenix Inc (Contract research)
- *Rainer Surges, M.D.; Bial, UCB Pharma (Honoraria, membership on advisory committees/boards, review panels), Eisai, LivaNova, Novartis, (Honoraria)

FACULTY DISCLOSURE INFORMATION
The following faculty have indicated they have no financial relationships to disclose:
- Nicholas Abend, M.D., MSCE
- Onur Afacan, Ph.D.
- Berj Bardakjian, Ph.D.
- Gordon Buchanan, M.D., Ph.D.
- Orrin Devinsky, M.D.
- Jeanne Donalty
- Sonya Dumanis, Ph.D.
- Cam Escoffery, Ph.D., M.P.H.
- Sarah Friebert, M.D.
- Alica Goldman, M.D., Ph.D.
- Kimberly Brorson
- William Heetderks, M.D., Ph.D.
- Lori Isom, Ph.D.
- Stiliyan Kalitzin, Ph.D.
- Andres Kanner, M.D.
- Marissa Kellogg, M.D., Ph.D.
- Lauren Knepper
- Alison Kukla
- Samden Lhatoo, M.D.
- Gardiner Lapham, RN, M.P.H.
- Sylvia Palm
- Dilip Pandey, M.D., Ph.D.
- Rosemary Panelli, Ph.D.
- Rajesh Ramachandran Nair, M.D., MBBS
- Becca Rudolph-Setzer
- Kristina Simeone, Ph.D.
- Doug Simmons
- Tanya Spruill, Ph.D.
- Roland Thijs, Ph.D.
- Jenniafer Walters
- Nora Wong
The following faculty have disclosed financial relationships:

- **Peter Carlen, M.D.**: Avertus Inc. (Intellectual property rights and ownership interest — stock, stock options, etc., excluding diversified mutual funds)
- **William Gaillard, M.D.**: Ovation Pharmaceuticals, King Pharmaceuticals, Eisai, Eisai Medical Research, Inc., PRA International (Other), Johnson and Johnson, Lily, Glaxo-SmithKline, Pfizer, Siemens, General Electric (Ownership Interest — stock, stock options, held with spouse), etc. excluding diversified mutual funds); Spouse: Actavis/Forest/Allerga (Consultant/advisor, contracted research), Brackett, Ironshore Pharmaceuticals, Rhodes Pharmaceuticals, Tris Pharma (Consultant/advisor), Lundbeck, Pfizer, Supernus, SyneuRx (Contract research)
- **Alfred George, Jr., M.D.**: Amgen (Honoraria and membership on advisory committees/boards, review panels), Otsuka Pharmaceuticals (Honoraria and membership on advisory committees/boards, review panels), Praxis Precision Medicines (Membership on advisory committees/boards, review panels), Merck (Contract research)
- **Lawrence Hirsch, M.D.**: Eisai, Upsher-Smith, and Monteris (Contract research), Wiley and UpToDate (Royalties), Ceribell, Eisai, Monteris, Neuropace, Sun Pharma, and Engage Therapeutics (Consulting fees), Neuropace (Honoraria)
- **Barbara Jobst, M.D., Ph.D.**: Neuropace, Inc., Sunovion, Inc., Medtronics, Inc. (Contract research)
- **Brian Litt, M.D.**: Blackfynn, Neuropace, MC10 (Ownership Interest — stock, stock options, etc. excluding diversified mutual funds)
- **Jack Parent, M.D.**: Epygenix Therapeutics, Inc (Consulting fees), Zogenix, Inc. (Contract research)
- **Martha Sajatovic, M.D.**: Otsuka, Alkermes, Janssen (Consultant research), Brackett, Otsuka, Sunovion, Neurocrine, Supernus, Health Analytics (Consulting fees)
- **David Thurman, M.D., M.P.H.**: UCB Pharma (Contract research)

**CME REVIEWER DISCLOSURE INFORMATION**

The following Content Reviewers have indicated they have no financial relationships to disclose:

- Timothy Ambrose, M.D.
- Susanta Bandypadhyay, M.D., Ph.D.
- Gordon Buchanan, M.D., Ph.D.
- Marjorie Bunch, M.D.
- Jocelyn Cheng, M.D.
- Lauren Frey, M.D.
- Camilo Gutierrez, M.D.
- Marissa Kellogg, M.D.
- Pamela McDonnell, M.D.
- Ignacio Valencia, M.D.
- Jennifer Wong, Ph.D.

The following Content Reviewers have disclosed financial relationships:

- Vinita Acharya, M.D.: Lundbeck, LLC (Consulting fees, other financial or material support, travel expenses to meeting), Sunovion (Honoraria, other financial or material support, travel expenses to meeting), UCB Pharma (Honoraria)
- Jay Salpekar, M.D.: Lundbeck (Contracted research)
- Mona Sazgar, M.D.: Sunovion (Honoraria); UCB Pharma (Honoraria)

**AES STAFF DISCLOSURE INFORMATION**

AES staff involved in this activity have indicated they have no relevant financial relationships with industry to disclose.

- JoLynn Amsden
- Susan Carlson, M.S.Ed
- Joanna Crooks, M.A.
THURSDAY, JUNE 14

**Noon - 3:00 pm**

Capitol Hill Visits (Optional)

**Noon - 7:30 pm**

**Hopkins Foyer**

Family Lounge Open, Supported by LivaNova

**4:00 pm - 7:30 pm**

**Edison Ballroom Foyer**

Registration Open

**4:30 pm to 6:30 pm**

**Edison E**

Family Welcome Session

Gardiner Lapham, RN, M.P.H.; Sally Schaeffer; Jeff Buchhalter, M.D.; Brandy Fureman, Ph.D.

This session does not offer CME credit

**6:30 pm - 7:30 pm**

**Edison Ballroom Foyer**

Welcome Reception, Supported by Empatica

Walter Koroshetz, M.D.; Michele Walsh, M.Ed.

FRIDAY, JUNE 15

**7:00 am - 5:30 pm**

**Edison Ballroom Foyer**

Registration Open

**7:00 am - 7:30 pm**

**Hopkins Foyer**

Family Lounge Open, Supported by LivaNova

**7:00 am - 8:00 am**

**Edison Ballroom Salon C & D**

Continental Breakfast Available, Supported by LivaNova

**Edison E — Patients & Family Members**

**Edison Ballroom Salon C&D — Professionals/Advocates**

**8:00 am - 8:15 am**

**Edison Ballroom Salon C & D**

Welcome: Conference Overview and Goals

Elizabeth Donner, M.D.; George Richerson, M.D., Ph.D.; Tom Stanton, M.P.P.

Introduction of the 2018 PAME Chairs

Shlomo Shinnar, M.D., Ph.D.

**8:15 am - 10:15 am**

**Edison Ballroom Salon C & D**

Plenary 1: Chairs’ Plenary — Combating Mortality in Epilepsy: Looking Back and Looking Ahead

Productive Dialogue and Partnerships with Other Stakeholders

Gardiner Lapham, RN, M.P.H.; William Gaillard, M.D.

Advocacy: Past Progress & Future Prospects

Tom Stanton, M.P.P.

Mortality in Epilepsy: From our Homes and Clinics to Guidelines and Beyond

Elizabeth Donner, M.D.

Current Controversies & Future Directions in Basic Science of SUDEP

George Richerson, M.D., Ph.D.

Update from the Center for SUDEP Research

Samden Lhatoo, M.D.
## FRIDAY, JUNE 15

### 10:15 am - 10:30 am
**Break, Supported by UCB, Inc.**

*Edison Ballroom Foyer*

### 10:30 am - Noon
**Plenary 2: Basic Mechanisms**

**Family/Patient Speaker**
Alison Kukla

- Ion Channels and Precision Therapy of Sudden Cardiac Death
  Alfred George, Jr., M.D.
- Imaging Connectomic Biomarkers in SUDEP Brain
  Onur Afacan, Ph.D.
- Links Between Sleep and SUDEP
  Gordon Buchanan, M.D., Ph.D.
- Similarities and Potential Shared Mechanisms of SIDS and SUDEP
  George Richerson, M.D., Ph.D.

*Edison Ballroom Salon C & D*

### Noon - 1:15 pm
**Lunch Buffet Available, Supported by Brain Sentinel, Inc.**

*Edison Ballroom C & D, Salon E*

### 1:30 pm - 3:30 pm
**Plenary 3: Creating Urgency & Change — The Role Advocacy Plays in Understanding and Preventing Mortality**

**Family/Patient Speaker**
Sally Schaeffer

- Importance of Awareness & Advocacy Engagement
  Gardiner Lapham, RN, M.P.H.
- Advocacy As An Expression of Grief
  Jane Hanna, M.A., OBE
- The Global History of SUDEP Advocacy
  Rosey Panelli, Ph.D.
- Increasing SUDEP Awareness Through State Legislation
  Jeanne Donalty
- Provider Engagement in Advocacy & Awareness Efforts
  Orrin Devinsky, M.D.
- Staying Engaged: A Takeaway Advocacy Toolkit
  Tom Stanton, M.P.P.; Sally Schaeffer

*Edison Ballroom Salon C & D*

### 3:30 pm - 3:45 pm
**Break, Supported by UCB, Inc.**

*Edison Ballroom Foyer*
## FRIDAY, JUNE 15

### 3:45 pm - 5:00pm

**Edison Ballroom Salon C & D**

**Breakout Sessions**

- **Closing the Loop of Communication**
  - SUDEP: Living with the Knowledge
    - Rajesh Ramachandran Nair, M.D., MBBS
  - Ethical Framework for SUDEP Discussion
    - Sarah Friebert, M.D.
  - Discussing SUDEP with Patients and Families
    - Jennifer Walters; Doug Simmons

**Edison Ballroom Salon E**

- **Functional Biomarkers for SUDEP: A Discussion from the Bedside to the Bench**
  - Searching for a Clinical Biomarker for SUDEP
    - Elizabeth Donner, M.D.
  - EEG Signal Processing - Ictal Cessation & PGES
    - Stiliyan Kalitzin, Ph.D.
  - Animal Studies: Brainstem Seizures and Cardio-Respiratory Abnormalities
    - Peter Carlen, M.D.
  - Machine Learning of Patient Data to Identify SUDEP Biomarkers
    - Berj Bardakjian, Ph.D.

### 5:00 pm - 7:00 pm

**Edison Ballroom Foyer**

- **Poster Reception & Exhibits Open, Supported by Lundbeck**

## SATURDAY, JUNE 16

### 7:00 am - 5:30 pm

**Edison Ballroom Foyer**

- **Registration Open**

### 7:00 am - 5:30 pm

**Hopkins Foyer**

- **Family Lounge Open, Supported by LivaNova**

### 7:00 am - 8:00 am

**Edison Ballroom C&D**

- **Continental Breakfast Available**

### 8:00 am - 8:10 am

**Edison Ballroom Salon C&D**

- **Welcome & Updates**
  - Elizabeth Donner, M.D.; George Richerson, M.D., Ph.D.; Tom Stanton, M.P.P.
PARTNERS AGAINST MORTALITY IN EPILEPSY

SATURDAY, JUNE 16

8:10 am - 10:00 am
Edison Ballroom
Salon C & D

Plenary 4: Nocturnal Supervision, Seizure Detection and SUDEP Prevention. What is the Evidence?

Family/Patient Speaker
John Popovich

Supervision, Seizure Detection & SUDEP Prevention
Daniel Friedman, M.D.

Invasive EEG-based Seizure Detection & Closed Loop Systems
Brian Litt, M.D.

Wearable Devices
Rainer Surges, M.D.

Remote (Video & Audio) and Mattress Sensors
Roland Thijs, Ph.D.

Regulatory Considerations for Approval of Devices to Reduce Risk of SUDEP or Life-threatening Seizures
William Heetderks, M.D., Ph.D.

10:00 am - 10:15 am
Edison Ballroom Foyer

Break, Supported by UCB, Inc.

10:15 am - Noon
Edison Ballroom
Salon C & D

Breakout Sessions

PATHOPHYSIOLOGY ROUNDTABLE
Pathophysiology of Brainstem Depolarization
Jeff Noebels, M.D., Ph.D.

Human Dravet Syndrome IPSCs
Jack Parent, M.D.

Cardiac Ion Channels
Lori Isom, Ph.D.

Physiological Changes Associated with the Timing of Death
Kristina Simeone, Ph.D.

Edison Ballroom
Salon E

NEW ONSET REFRACTORY STATUS EPILEPTICUS (NORSE): AN EMERGING CAUSE OF EPILEPSY MORTALITY
FIRES/NORSE Definitions, Etiology, Treatment
Nicholas Abend, M.D., MSCE

Connections Between NORSE and SUDEP
Orrin Devinsky, M.D.
Breakout Sessions (Continued from page 18)

NORSE/FIRES Epidemiology and Mortality
Marissa Kellogg, M.D., M.P.H.

Family Experience
Nora Wong

Noon - 1:15 pm
Edison Ballroom
Salon C&D

Lunch Buffet Available

1:30 pm - 3:15 pm
Edison Ballroom
Salon C & D

Plenary 5: Epilepsy Mortality Beyond SUDEP

Family/Patient Speaker
Becca Rudolph-Setzer

Mortality Related to Status Epilepticus, Its Underlying Conditions, and Opportunities for Prevention
Lawrence Hirsch, M.D.

Epidemiology of Mortality Beyond SUDEP: Injuries in People with Epilepsy
David Thurman, M.D., M.P.H.

Suicidality, Underlying Mechanisms, and Opportunities for Prevention
Andres Kanner, M.D.

3:15 pm - 5:00 pm
Edison Ballroom
Salon E

Breakout Sessions

CONSIDERING A DEVICE: QUESTIONS TO ASK AND USER FEEDBACK

Considerations in Selecting a Device
Daniel Friedman, M.D.

Overview of Device Categories
Tom Stanton, M.P.P.

Individual Experiences with Devices
Lauren Knepper, RN; Sylvia Palm; Kimberly Bronson

Seizure Gauge: Understanding the Devices Our Community Wants
Sonya Dumanis, Ph.D.

This session does not offer CME credit.
SATURDAY, JUNE 16

3:15 pm - 5:00 pm
**Breakout Sessions** (Continued from page 19)

*Edison Ballroom*
*Salon C & D*

**EVIDENCE-BASED SELF MANAGEMENT RESEARCH TO ADDRESS RISK FACTORS FOR PREMATURE MORTALITY IN PEOPLE WITH EPILEPSY: A RESEARCH UPDATE FROM THE MANAGING EPILEPSY WELL (MEW) NETWORK**

Introduction to the MEW Network
Barbara Jobst, M.D., Ph.D.

Overview of the MEW Network and Epilepsy Self-management Across the Life-span
Cam Escoffery, Ph.D., M.P.H.

Improving Depression in Epilepsy
Martha Sajatovic, M.D.

Improving Epilepsy Self-management and Mental Health Outcomes in Underserved Groups With Epilepsy
Tanya Spruill, Ph.D.

Scaling up Evidence-based Epilepsy Self-management
Dilip Pandey, M.D., Ph.D.

**Wright Room**

**IMAGING & GENETICS ROUNDTABLE**

Experimental Imaging
Carl Faingold, Ph.D.

Genetics
Alica Goldman, M.D., Ph.D.

5:00 pm - 5:30 pm
**Conference Wrap-up & Next Steps**

*Edison Ballroom*
*Salon C & D*

Closing Remarks
Elizabeth Donner, M.D.; George Richerson, M.D., Ph.D.; Tom Stanton, M.P.P
1. Impact of Severe Rare Childhood Epilepsy on Siblings: Fear of Death in Siblings of Children with Severe Epilepsy, Bailey, L., Gammaitoni, A., Galer, B., Schwartz, L., Schad, C.

2. Deficient Compensation for Seizure-Induced Cardiorespiratory Distress by the Periaqueductal Gray (PAG) May Be Critical for Seizure-Induced Death in the DBA/1 Mouse Model of SUDEP, Faingold, C., Tupal, S., Kommajosyula, S.

3. A Systematic Review of Sudden Unexpected Death in Epilepsy (SUDEP) in Childhood, Abdel-Mannan, O., Taylor, H., Donner, E., Sutcliffe, A.

4. Study of Epileptic Seizure and Mortality in Patients with MELAS, Zhao, X., Yang, X., Lhatoo, S.

5. Nocturnal Supervision and SUDEP Risk at Different Epilepsy Care Settings, van der Lende, M., Hesdorffer, D., Sander, L., Thijs, R.

6. Ictal Autonomic Changes as a Tool for Seizure Detection Devices, van Westrhenen, A., Lazeron, R., Thijs, R.

7. Knowledge and Attitudes Among Epilepsy Health Care Providers About Sudden Death in Epilepsy in Mulago Hospital, Uganda. A Pilot Study, Kaddumukasa, M., Mwesiga, E., Sewankambo, N., Blixen, C., Lhatoo, S., Katabira, E., Sajatovic, M.


9. Cerebral Tissue Oximetry in Patients with Epileptic Seizures, Moseley, B., Privitera, M.


12. The North American SUDEP Registry (NASR): Preliminary Descriptive Analysis of SUDEP Cases, Hussain, C., Verducci, C., Friedman, D., Devinsky, O.


14. Mice Lacking 5-HT2C Receptors Display a Novel Adult-Onset SUDEP Phenotype with Four Seizure Types, Massey, C., Noebels, J.

15. EEG Suppression Following Induced Seizures in Mice Can Be Reduced with Serotonergic Manipulations, Petrucci, A., Buchanan, G.


17. National Surveillance of Mortality in Children with Epilepsy in the UK and Ireland, Abdel-Mannan, O., Sutcliffe, A.

18. Seizure-Related Brainstem Spreading Depolarization in SUDEP-prone Cacna1aS218L Mice, Jansen, N., Schenke, M., van den Maagdenberg, A., Töller, E.


20. Respiratory Abnormalities in the Kcnal1-null Mouse Model of Sudden Unexpected Death in Epilepsy (SUDEP), Dhaibar, H., Gautier, N., Glasscock, E.
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<tr>
<td>22. Evaluation of the Serotonin Receptor Subtype(s) That Mediate the Action of Fenfluramine to Block Seizure-Induced Sudden Death in the DBA/1 Mouse Model of SUDEP, Tupal, C., Faingold, C.</td>
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<td>23. The Incidence and Severity of Calcified Cardiac Lesions Are Dependent on the Number of Generalized Seizures in the DBA/1 Mouse Model of SUDEP, Feng, H., Zhao, H., Schoen, F., Schachter, S.</td>
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<td>25. NORSE and Super-Refractory Status Epilepticus Mortality: A Single-Center Retrospective Chart Review, Rezayee, M., Nguyen, M., Kellogg, M.</td>
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<td>26. Potential SUDEP Detection Using Open-Source Hardware, McKeown, S.</td>
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<td>29. Long-Term Surface Electromyography (sEMG) Seizure Monitoring in the Home, Whitmire, L., Voyles, S., Cardenas, D.</td>
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<td>31. Simultaneous Cardiac and Respiratory Inhibition During Seizure Precedes Death in the DBA/1J Audiogenic Mouse Model of SUDEP, Schilling, W., McGrath, M., Glazebrook, P., Yang, T., Faingold, C., Kunze, D.</td>
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<td>32. The Amygdala Is Required for Peri-ictal Respiratory Dysfunction and SUDEP in DBA/1 and Scn1aR1407X/+ Mice, Bravo, E., Marincovich, A., Kim, Y., Massey, C., Dlouhy, B., Richerson, G.</td>
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<td>33. Differences in SUDEP Identification Among Neurologists and Pathologists, Ho, J., Keller, A., Whitney, R., Pollanen, M., Donner, E.</td>
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<td>35. Cell-Type Specific Contributions to Epilepsy and Sudden Death in Leigh Syndrome, Bard, A., Bolea, I., Sahai, N., Ramirez, J., Quintana, A., Kalume, F.</td>
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<td>36. Effect of the Ketogenic Diet on Monoamine Levels in the Mouse Brain, Teran, F., Kim, Y., Richerson, G.</td>
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<td>38. Structural Abnormalities in the Autonomic Network Beyond the Brainstem in Focal Epilepsy, Mueller, S., Knowlton, R., Laxer, K.</td>
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<td>39. Suicidality in Epilepsy: a Disease Specific Model, Schommer, L., Bujarski, K., Stretzov, N., Andrew, A.</td>
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<td>40. Critical Care Nursing Considerations for the Patient with New Onset Refractory Seizures, Moreda, M.</td>
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- SUDEP Action
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