Organizations leading the PAME partnership are the American Epilepsy Society (AES), Citizens United for Research in Epilepsy (CURE) and the Epilepsy Foundation (EF). See the back cover for a list of additional PAME partners and supporters.
Dear Friends,

Welcome to the foremost meeting on epilepsy mortality, and thank you for joining us.

Our topic this weekend is a difficult one. We applaud all the researchers, clinicians, advocates and especially people impacted by epilepsy—including bereaved families—from around the world who have come to the Washington DC area to share their knowledge and experience. We invite you to embrace the spirit of hope and partnership that underpins the work of Partners Against Mortality in Epilepsy (PAME). All stakeholders are equally welcome and integral to the success of this meeting.

PAME is a diverse group of professional, non-profit, and government organizations that work together to plan the PAME Conference, and to disseminate research and other content from the proceedings. The goal of the meeting is to help prevent mortality by:

- Promoting understanding of the latest developments in SUDEP and epilepsy mortality research in a scientifically rigorous setting
- Stimulating ideas and collaborations to advance discovery
- Accelerating efforts to increase public awareness and education

The meeting is an outflow of significant momentum in the field. This year the PAME Conference seeks to be highly interactive with opportunities for breakout sessions and lively discussions that identify gaps in research and promote clinical discoveries, along with the sharing of personal stories about epilepsy’s impact. We welcome and encourage all to join the conversation.

We are deeply grateful to the many professional and lay volunteers who have planned and organized this meeting. And we owe a special thanks to the meeting management team from the American Epilepsy Society for all of their support. Finally, we genuinely thank the 20 partner organizations plus individual and corporate donors who provided the financial support to make the 2016 PAME Conference possible.

Most of all, thank YOU for your participation in this meeting and for joining the PAME family.

Jeffrey Buchhalter, MD, PhD, FAAN  
PAME Conference Co-Chair

Gardiner Lapham, RN, MPH  
PAME Conference Co-Chair
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## SCHEDULE AT-A-GLANCE

See pages 16 - 22 for full schedule details and locations.

### THURSDAY, JUNE 23

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>noon - 4:00 p.m.</td>
<td>Congressional Visits (Optional for Families and Professionals)</td>
</tr>
<tr>
<td>4:00 p.m. - 8:00 p.m.</td>
<td>Registration</td>
</tr>
<tr>
<td>4:30 p.m. - 6:00 p.m.</td>
<td>Family Welcome and Introductions</td>
</tr>
<tr>
<td>7:00 p.m. - 8:30 p.m.</td>
<td>Welcome Reception for All Attendees</td>
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### FRIDAY, JUNE 24

<table>
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<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>7:00 a.m. - 5:30 p.m.</td>
<td>Registration</td>
</tr>
<tr>
<td>7:00 a.m. - 8:00 a.m.</td>
<td>Continental Breakfast</td>
</tr>
<tr>
<td>8:00 a.m. - 8:30 a.m.</td>
<td>Welcome: Conference Overview and Goals</td>
</tr>
<tr>
<td>8:30 a.m. - 10:15 a.m.</td>
<td>Plenary 1: Mortality in People with Epilepsy - Epidemiology and Surveillance</td>
</tr>
<tr>
<td>10:15 a.m. - 10:30 a.m.</td>
<td>Break</td>
</tr>
<tr>
<td>10:30 a.m. - noon</td>
<td>Plenary 2: Mortality in Children</td>
</tr>
<tr>
<td>noon - 1:15 p.m.</td>
<td>Lunch</td>
</tr>
<tr>
<td>1:30 p.m. - 3:30 p.m.</td>
<td>Plenary 3: What Do We Know about the Factors that Predispose Certain People to Die from a Seizure?</td>
</tr>
<tr>
<td>3:30 p.m. - 3:45 p.m.</td>
<td>Break</td>
</tr>
<tr>
<td>3:45 p.m. - 5:00 p.m.</td>
<td>breakout Sessions</td>
</tr>
<tr>
<td>5:30 p.m. - 7:30 p.m.</td>
<td>Posters and Reception</td>
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### SATURDAY, JUNE 25

<table>
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<th>Time</th>
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<td>7:00 a.m. - 5:30 p.m.</td>
<td>Registration</td>
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<tr>
<td>7:00 a.m. - 8:00 a.m.</td>
<td>Continental Breakfast</td>
</tr>
<tr>
<td>7:00 a.m. - 8:00 a.m.</td>
<td>Family Continental Breakfast</td>
</tr>
<tr>
<td>8:00 a.m. - 8:30 a.m.</td>
<td>Morning Welcome</td>
</tr>
<tr>
<td>8:30 a.m. - 10:00 a.m.</td>
<td>Plenary 4: What Are the Events that Occur During and After a Seizure that Cause a Death in SUDEP?</td>
</tr>
<tr>
<td>10:00 a.m. - 10:15 a.m.</td>
<td>Break</td>
</tr>
<tr>
<td>10:15 a.m. - noon</td>
<td>Breakout Sessions</td>
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<tr>
<td>noon - 1:15 p.m.</td>
<td>Lunch</td>
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<tr>
<td>1:30 p.m. - 3:00 p.m.</td>
<td>Plenary 5: Prevention – What Are the Options for Prevention Now and in the Future?</td>
</tr>
<tr>
<td>3:00 p.m. - 3:15 p.m.</td>
<td>Break</td>
</tr>
<tr>
<td>3:15 p.m. - 5:00 p.m.</td>
<td>Breakout Sessions</td>
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### SUNDAY, JUNE 26

<table>
<thead>
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<th>Time</th>
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<tr>
<td>7:00 a.m. - 11:30 a.m.</td>
<td>Registration</td>
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<td>7:00 a.m. - 8:00 a.m.</td>
<td>Continental Breakfast</td>
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<tr>
<td>8:00 a.m. - 9:15 a.m.</td>
<td>Plenary 6: Advocacy Perspectives; How Can We Speed Up Awareness and Prevention?</td>
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<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Plenary 7: Updates and Discussion on Select Programs in Mortality Research</td>
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<tr>
<td>10:15 a.m. - 10:30 a.m.</td>
<td>Break</td>
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<tr>
<td>10:30 a.m. - 11:20 a.m.</td>
<td>Tying It All Together</td>
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<tr>
<td>11:20 a.m. - 11:30 a.m.</td>
<td>Final Remarks and Farewell</td>
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PARTNERS AGAINST MORTALITY IN EPILEPSY
is proud to recognize the following partners

<table>
<thead>
<tr>
<th>Visionary Level</th>
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<tbody>
<tr>
<td>American Epilepsy Society (AES)</td>
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<td>Citizens United for Research in Epilepsy (CURE)</td>
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<td>Epilepsy Foundation (EF)</td>
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<tr>
<th>Innovator Level</th>
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<tr>
<td>Danny Did Foundation</td>
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<tbody>
<tr>
<td>Finding a Cure for Epilepsy and Seizures (FACES)</td>
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<td>Patrick Ring Foundation</td>
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<tr>
<th>Insight Level</th>
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<tr>
<td>Emma Bursick Memorial Fund</td>
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<td>Mayo Foundation</td>
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<td>SUDEP Action</td>
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<td>University of Iowa</td>
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<td>Dravet Syndrome Foundation</td>
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<tr>
<td>Charlie Foundation for Ketogenic Therapies</td>
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<td>Cute Syndrome Foundation</td>
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<tr>
<td>DUP15q Alliance</td>
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<tr>
<td>Intractable Childhood Epilepsy (ICE) Alliance</td>
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<tr>
<td>Lennox-Gastaut Syndrome Foundation (LGS)</td>
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<td>National Association of Epilepsy Centers (NAEC)</td>
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<td>SeizeTheFacts.org</td>
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<th>Supporter Level</th>
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<tr>
<td>Hope for Hypothalamic Hamartomas</td>
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<tr>
<td>Tuberous Sclerosis Alliance (TSA)</td>
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<tr>
<th>Additional Conference Support</th>
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<tr>
<td>BAND Foundation</td>
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<td>Green Park Foundation</td>
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</table>
**Conference Hotel**

PAME sessions and events are all being held at:

The Westin Alexandria
400 Courthouse Square
Alexandria, Virginia 22314
Telephone: 703.253.8600

**Parking and Transportation**

Overnight valet parking is available for $30 and daily parking is available for $12. Complimentary shuttle service is offered by the Westin Alexandria within the surrounding area (within a 1.5-mile radius) on a first-come, first-served basis. To request service, call the hotel in advance at 703.253.8600, service express 0. The shuttle operates every day 7:00 a.m. – 10:00 p.m.

**Business Center**

The self-service business center at The Westin Alexandria is accessible 24 hours-a-day to all guests by using your guest room key.

**Information for International Travelers**

For a listing of the foreign embassies in the Washington DC metropolitan area please visit this website: [http://www.state.gov/s/cpr/rls/dpl/32122.htm](http://www.state.gov/s/cpr/rls/dpl/32122.htm)

**Gratuities**

Gratuities are not automatically added to the bill, except in some cases for large groups. Waiters and waitresses are usually given 15% to 20% of the bill.

Taxi drivers usually receive 15% of the fare. Doormen, skycaps and porters are normally tipped $2 per bag. Chambermaids are usually given $2 per day, which may be left on the pillow.

**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 Coalition Partners are 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.
GENERAL INFORMATION

Registration Hours
Thursday, June 23 ......................4:00 p.m. - 8:00 p.m.
Friday, June 24 ..........................7:00 a.m. - 5:30 p.m.
Saturday, June 25 ........................7:00 a.m. - 5:30 p.m.
Sunday, June 26 ..........................7:00 a.m. - 11:30 a.m.

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.

Meeting Attire
The PAME Conference promotes casual business attire for the duration of the meeting. Consider bringing a light jacket or sweater with you since meeting room temperatures and personal comfort levels vary.

Food and Beverage
The PAME Conference offers the following food and beverage included in your conference registration:

Two Receptions
• Thursday evening, Welcome Reception
• Friday evening, Poster Reception

Three Continental Breakfasts
• Friday, Saturday and Sunday mornings

Family Continental Breakfast
• Saturday morning

Two Buffet Lunches
• Friday and Saturday

Two Afternoon Breaks
• Friday and Saturday

Please note: To keep registration fees low, mid-morning breaks (snacks & beverages) are offered on a cash basis in the ballroom foyer on Friday, Saturday and Sunday mornings. As noted above, complimentary continental breakfast is provided on those days.

Internet Access
To log-in on the internet in your guestroom:
• Choose “Westin Guestrooms”
• Various packages will show with corresponding pricing. Choose the package you prefer. Charges will be waived for attendees who confirmed reservations through the PAME 2016 group block.
• Enter your last name and room number
• Agree to the terms and conditions
• Hit connect (Note: The access code can be ignored as it is not applicable)

To log-in on the internet in a 2nd floor meeting room:
• Choose “Westin Meeting Rooms”
• Click on the box, “I agree to the terms and conditions”
• Scroll down towards the bottom and enter the access code, “PAME”
• Then, hit “connect”
• Access will be provided in the meeting rooms from Friday, June 24 – Sunday June 26

ONLINE RESOURCES
Visit the PAME website to find conference resources:
» Full Text of Scientific Poster Abstracts
» Glossary of Clinical and Scientific Terms
» Presentation Slide Sets and Handouts

pame.AESnet.org
PAME Conference Welcome Reception
Thursday, June 23 from 7:00 p.m. – 8:30 p.m.
All attendees are invited to attend the kickoff to the 2016 PAME Conference.

*Inventors Foyer outside Edison Ballroom*
Sponsored by Lundbeck

**Family Lounge**
Connect with other families attending the conference. The Family Lounge hours are as follows:

- **Friday, June 24**  10:30 a.m. – 6:00 p.m.
- **Saturday, June 25**  10:30 a.m. – 6:00 p.m.
- **Sunday, June 26**  9:00 a.m. – 11:00 a.m.

*2nd floor, Hopkins Foyer*
Sponsored by Upsher-Smith Laboratories, Inc.

**Family Breakfast**
Saturday, June 25 from 7:00 a.m. – 8:00 a.m.
Join an informal gathering for those affected by epilepsy and/or epilepsy-related mortality. Share stories, provide support and discuss meeting content during a continental breakfast.

*Edison Ballroom, Salon E*
Sponsored by Supernus Pharmaceuticals, Inc.
TO ERADICATE EPILEPSY AND ITS CONSEQUENCES.

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.

Find out more at www.AESnet.org

AES SUPPORTS:

- Professional community through membership, 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
CURE • A Pioneer of SUDEP Research
Proud to be a Visionary Partner of the 2016 PAME Conference

Since 2004, CURE has worked with bereaved families to promote awareness of sudden death in epilepsy and develop a targeted research program. To date, CURE has funded 30 SUDEP-focused grants to 41 investigators in 8 countries totaling more than $3.7 million.

To learn more about CURE’s transformative research, visit www.cureepilepsy.com/research
Proud Visionary Partner of the 2016 PAME Conference

- Carries out SUDEP education and awareness programs for people touched by epilepsy and medical professionals.
- Drives and supports research into the causes of and ways to predict and prevent SUDEP.
- Offers a support network providing counseling, community, and resources for individuals and families affected by SUDEP.

Learn more about how we work with many epilepsy organizations to find the answers to SUDEP and help families with epilepsy at epilepsy.com/SUDEP-Institute
Is proud to support PAME

And the creation of the

North American SUDEP Registry (NASR).
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 conference provides a forum the aim of which is to prevent mortality in epilepsy. This conference will:

1) Identify trends and 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.

All attendees will have the opportunity to advance their learning:

- Clinicians will improve their competence related to discussions of epilepsy-related mortality, including risk factors and prevention strategies.
- Researchers will identify goals for future research and build collaborations with other scientists as well as clinicians and families/advocates.
- Families/advocates will learn about research and will advance Sudden Unexpected Death in Epilepsy (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 support one another.

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

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

- Identify trends in the incidence and mortality of SUDEP.
- Describe the progress made in the latest research regarding SUDEP.
- List and discuss the risk factors and prevention strategies for SUDEP.
- Identify future research opportunities in SUDEP.
- Delineate greater insights and identify opportunities for collaboration derived from the interaction between patients, families, clinicians, researchers, advocates and policymakers.
- Delineate strategies and methods for building public awareness of SUDEP.

ONLINE RESOURCES
Visit the PAME website to find conference resources:
- Full Text of Scientific Poster Abstracts
- Glossary of Clinical and Scientific Terms
- Presentation Slide Sets and Handouts

pame.AESnet.org
COMMERCIAL SUPPORT DISCLOSURE
This activity is supported in part by educational grants from:

- Acorda Therapeutics
- Eisai Inc.
- GW Pharmaceuticals
- LivaNova
- Lundbeck
- Sunovion Pharmaceuticals Inc.
- Supernus Pharmaceuticals, Inc.
- UCB, Inc.
- Upsher-Smith Laboratories, Inc.

PLANNING COMMITTEE MEMBER DISCLOSURE INFORMATION
The following Planning Committee Members have indicated they have no financial relationships to disclose:

- Anne Anderson, MD
  Associate Professor
  Baylor College of Medicine
- Jeanne Donalty
  CURE Board of Directors
- Debra Gist, MPH
  Director of Education and Professional Development
  American Epilepsy Society
- Kevin Graber, MD
  Clinical Associate Professor
  Neurology and Neurological Sciences
  Stanford University
- Amy Haugen
  Outreach Coordinator
  Epilepsy Foundation of Minnesota
- Lori Isom, PhD
  Professor and Interim Chair of Pharmacology
  University of Michigan Medical School
- Andres Kanner, MD
  Chief, Epilepsy Division
  Professor of Clinical Neurology
  University of Miami Miller School of Medicine
- Kari Knapp
  Member, Epilepsy Foundation
- Eileen M. Murray, MM, CAE
  Executive Director
  American Epilepsy Society
- Maromi Nei, MD
  Associate Professor, Neurology
  Thomas Jefferson University
- Ignacio Valencia, MD
  Associate Professor, Pediatrics
  Drexel University College of Medicine

The following Planning Committee Members have disclosed financial relationships:

- Torbjörn Tomson, MD, PhD: Contract Research: GSK Research support to case control study of SUDEP; Advisory Board: Eisai, UCB (paid to hospital).

FACULTY DISCLOSURE INFORMATION
(*Indicates also participated as a Planning Committee Member):

The following faculty have indicated they have no financial relationships to disclose:

- Lisa Bateman, MD
- Anne Berg, MD
- Hal Blumenfeld, MD, PhD
- Gordon Buchanan, MD, PhD*
- Linda Coughlin-Brooks, RN, BSN
- Laura Crandall
- Orrin Devinsky, MD*
- Tracey Dixon-Salazar, PhD*
- Brian Dlouhy, MD
- David Fowler, MD
- Greg Funk, PhD
- Brandy Fureman, PhD
- Brian Gehlbach, MD
- Alica Goldman, MD, PhD*
- David Goldstein, PhD
- Jane Hanna*
- Dale Hesdorffer, PhD*
DISCLOSURE INFORMATION

Barbara Jobst, MD
Franck Kalume, PhD*
Sanjeev Kothare, MD*
Gardiner Lapham, RN, MPH*
Chen Liu, PhD
Margaret Moore, MPH*
Susanne Mueller, MD, PhD
Jennifer Murphy, MPH*
Doug Nordli, MD
Karen Osland*
Rosemary Panelli, MPH, PhD*
Rajesh Ramachandran Nair, MD*
George Richerson, MD, PhD*
Helen Scharfman, PhD
Stephan Schuele, MD, MPH*
Masud Seyal, MD, PhD*
Henry Smithson, MB, ChB, MD*
Elson So, MD*
Tom Stanton, MPP*
Mark Stevenson, FACHE, CHIE
James Tao, MD, PhD
Niu Tian, MD, PhD
Margy Warner
Vicky Whitttemore, PhD*
Samuel Wiebe, MD
Elaine Wirrell, MD
Cyndi Wright, BA*

The following faculty have disclosed financial relationships:

Detlev Boison, PhD: Consulting Fee: UCB Biopharma; Royalties: Springer*
Jeffrey Buchhalter, MD, PhD, FAAN: Consultant: Eisai, Upsher-Smith Laboratories*
Elizabeth Donner, MD, FRCP(C): Honoraria: Eisai*
Edward Faught, MD: Consulting Fee: Aprecia, Eisai, Sunovion, Supernus, UCB Pharma; Contract Research: support to Emory University: Brain Sentinel, UCB Pharma; Research data-safety monitoring boards: SAGE, Therapeutics, SK Lifescience, Lundbeck
Daniel Friedman, MD: Consulting Fee: Empatica, Inc.; Review Panel: Cyberonics*
Samden Lhatoo, MD: Speakers Bureau: Sunovion; Advisory Board: Acorda*
Tobias Loddenkemper, MD: Consulting Fees: Zogenix, Lundbeck, Upsher-Smith

Heather MacLeod: Salary: Alcon (spouse)
Brian Moseley, MD: Speakers Bureau: UCB, Cyberonics, Eisai; Advisory Board: UCB
Jeffrey Noebels, MD, PhD: Honoraria/Speaker: UCB; Advisory Board Member: UCB*
Philippe Ryvlin, MD, PhD: Consulting Fee for Advisory Boards: UCB pharma, Eisai, Medtronic; Fees for conferences at sponsored epilepsy meetings: UCB Pharma, Eisai, Cyberonics
Rainer Surges, MD: Speakers Bureau: Cyberonics, Eisai, Novartis, UCB Pharma*
Roland Thijs, MD, PhD: Grant support (conduct trial on cardiac arrythmias in epilepsy): Medtronic

CME REVIEWER DISCLOSURE INFORMATION

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

Lauren Frey, MD
Manu Hegde, MD, PhD
Diego Morita, MD, PhD
Kinshuk Sahaya, MD
Ignacio Valencia, MD
Courtney Wusthoff, MD

The following Content Reviewers have disclosed financial relationships:

David Wheeler, MD, PhD: Contract Research: Novartis

AES STAFF DISCLOSURE INFORMATION

AES staff involved in this activity have indicated they have no relevant financial relationships with industry to disclose.
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 16 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-U.S. 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 16 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.
## SCHEDULE

### THURSDAY, JUNE 23

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| 4:00 p.m. - 8:00 p.m. | Registration  
**Edison Ballroom Foyer**                                                   |
| 4:30 p.m. - 6:00 p.m. | **Family Welcome and Introductions**  
**Epilepsy Mortality Basic Primer for Families**  
**Edison Ballroom, Salon E**  
Moderator: Mark Stevenson, FACHE, CHIE, Epilepsy Foundation  
Panelists:  
Jeff Buchhalter, MD, PhD, FAAN, Alberta Children’s Hospital  
Elizabeth Donner, MD, FRCP(C), The Hospital for Sick Children  
Gardiner Lapham, RN, MPH, CURE  
George Richerson, MD, PhD, University of Iowa  
Tom Stanton, MPP, Danny Did Foundation  
Cyndi Wright, SUDEP Institute |
| 7:00 p.m. - 8:30 p.m. | **Welcome Reception for All Attendees**  
**Edison Ballroom Foyer (Inventors Foyer)**  
Welcome Remarks by PAME Committee and Walter Koroshetz, MD, NINDS |

### FRIDAY, JUNE 24

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<th>Time</th>
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| 7:00 a.m. - 5:30 p.m. | Registration  
**Edison Ballroom Foyer**                                                   |
| 7:00 a.m. - 8:00 a.m. | Continental Breakfast  
**Edison Ballroom Foyer**                                                   |
| 8:00 a.m. - 8:30 a.m. | **Welcome: Conference Overview and Goals**  
**Presentation of Personal Stories**  
**Edison Ballroom, Salon C & D**  
Jeff Buchhalter, MD, PhD, FAAN, Alberta Children’s Hospital;  
Gardiner Lapham, RN, MPH, CURE |
| 8:30 a.m. - 10:15 a.m. | **Plenary 1: Mortality in People with Epilepsy - Epidemiology and Surveillance**  
**Edison Ballroom, Salon C & D**  
Moderator: Vicky Whittemore, PhD, NINDS  
Epidemiology of Epilepsy-related Mortality – Dale Hesdorffer, PhD, Columbia University  
Suicide Among People with Epilepsy: A Population-based Study Results from the Data of U.S. National Violent Death Reporting System, 17 States, 2003-2011 - Niu Tian, MD, PhD, Center For Disease Control  
Case Ascertainment and Registries: What Information Is Currently Being Collected in US/UK/Australia? - David Fowler, MD, Chief Medical Examiner for Maryland; Heather Macleod, MS, CGC, Sudden Death in the Young Registry; Margaret Warner, PhD, Centers for Disease Control |
FRIDAY, JUNE 24

The Sudden Death in the Young Case Registry: Updates and Progress - Heather Macleod, MS CGC, Sudden Death in the Young Registry

**Panel Discussion:** Are we getting at the right data? What populations aren’t we exploring? What additional information should be collected? How do we improve case ascertainment?

10:15 a.m. - 10:30 a.m.  Break

10:30 a.m. - noon  **Plenary 2: Mortality in Children**

*Edison Ballroom, Salon C & D*

Moderator: Elizabeth Donner, MD, FRCP(C), The Hospital for Sick Children

Parent Speaker: Shannon Bursick, MS

The Facts about Mortality in Pediatric Epilepsy - Anne Berg, PhD, Feinberg School of Medicine

SUDEP in Children: Compare and Contrast with Adult Literature - Sanjeev Kothare, MD, NYU Langone Medical Center

Lessons Learned in Sudden Unexpected Death in Childhood (SUDC) Research and Advocacy – Laura Crandall, The SUDC Foundation

**Panel Discussion:** Why is SUDEP reported to be less common in children?

noon - 1:15 p.m.  **Lunch Buffet**

Dine with fellow attendees in the main room or break into small groups.

*Edison Ballroom, Salon C & D; Edison Ballroom, Salon E; Whitney, Banneker or Wright*

1:30 p.m. - 3:30 p.m.  **Plenary 3: What Do We Know about the Factors that Predispose Certain People to Die from a Seizure?**

*Edison Ballroom, Salon C & D*

Moderators: Rainer Surges, MD, University of Bonn; Elson So, MD, Mayo Clinic

Parent Speaker: Trish Barnes

How Does a Disturbed Autonomic Nervous System Facilitate SUDEP? - Brian Moseley, MD, University of Cincinnati

Which Genes Could Play a Role in SUDEP? - Alica Goldman, MD, PhD, Baylor College of Medicine

Are There “Dangerous” and Harmless Seizures? - Philippe Ryvlin, MD, PhD, Lyon University

Why Do People Die During Sleep? - James Tao, MD, PhD, University of Chicago Medical Center

Why Don’t People Take Their Meds and the Effect on SUDEP Risk? - Ed Faught, MD, Emory University School of Medicine

Who Is at Risk for Seizure-related Injuries and Deaths? - Elaine Wirrell, MD, Mayo Clinic

**Panel Discussion:** Where are the gaps in knowledge? What is the end goal for patients with this research? What clinical findings should be explored in the lab? What basic findings are ready to translate to the clinic?

3:30 p.m. - 3:45 p.m.  Break
## FRIDAY, JUNE 24

### Breakout Sessions

#### Breakout 1: Gene Analysis and Discovery in SUDEP

*Edison Ballroom, Salon C & D*

- Moderator: Tracy Dixon-Salazar, PhD, CURE
- Source Tissues and Materials Amenable for Genetic Analysis - Vicky Whittemore, PhD, NINDS
- Research Approaches to Gene Discovery in Human SUDEP; Genetic Diagnostic Results Interpretation And Counseling - David Goldstein, PhD, Columbia University Precision Medicine Initiative
- Precision Models in SUDEP Risk Identification - Tracy Dixon-Salazar, PhD, CURE

#### Breakout 2: Improving Mortality Surveillance and Case Ascertainment

*Edison Ballroom, Salon E*

- Moderator: Daniel Friedman, MD, NYU Comprehensive Epilepsy Center
- How Can Families Help with Surveillance and Case Ascertainment - Jennifer Murphy, MS, Patrick Ring Foundation; Laura Crandall, The SUDC Foundation; Heather MacLeod, MS, CGC, Sudden Death in the Young Registry
- How Case Ascertainment and Death Certification Can Be Improved for Death Investigators - David Fowler, MD, Chief Medical Examiner for Maryland

#### Breakout 3: Frequent Non-SUDEP Causes of Mortality in People with Epilepsy

*Wright, 2nd Floor*

- Moderators: Rainer Surges, MD, University of Bonn and Elson So, MD, Mayo Clinic
- Why Do a Disturbed Immune System and Non-CNS Tumours Cause Premature Death in Epilepsy? - Orrin Devinsky, MD, NYU Langone Medical Center
- Which Factors Enhance the Occlusion of Blood Vessels of the Heart and Brain in Epilepsy? - Stephan Schuele, MD, Northwestern University
- What Increases the Risk of Suicide and Depression in People with Epilepsy? - Elson So, MD, Mayo Clinic

### 5:30 p.m. - 7:30 p.m.  
**Posters and Reception**

*Edison Ballroom Foyer (Inventors Foyer)*
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<td>7:00 a.m. - 8:00 a.m.</td>
<td>Continental Breakfast</td>
<td>Edison Ballroom Foyer</td>
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<tr>
<td>7:00 a.m. - 8:00 a.m.</td>
<td>Family Continental Breakfast</td>
<td>Edison Ballroom, Salon E</td>
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<td>8:00 a.m. - 8:30 a.m.</td>
<td>Morning Welcome</td>
<td>Edison Ballroom, Salon C &amp; D</td>
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<td>Family Speaker: Jennifer Murphy, MS</td>
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<td>8:30 a.m. - 10:00 a.m.</td>
<td>Plenary 4: What Are the Events that Occur During and After a Seizure that Cause a Death in SUDEP?</td>
<td>Edison Ballroom, Salon C &amp; D</td>
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<td>Moderators: Philippe Ryvlin, MD, PhD, Lyon University; Masud Seyal, MD, PhD, UC Davis Health System</td>
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<td>What Have MORTEMUS and Investigations of Actual SUDEP Cases Taught Us About Pathophysiological Mechanisms of Death - Philippe Ryvlin, MD, PhD, Lyon University</td>
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<td>New Insights into Seizure-related Changes in Cardiovascular and Autonomic Function - Roland Thijs, MD, Stichting Epilepsie Instellingen Nederland</td>
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<td>Changes in Respiratory Control Induced by Seizures - George Richerson, MD, PhD, University of Iowa</td>
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<td>Spreading Depression in the Brainstem: The Storm Before the Quiet - Jeff Noebels, MD, PhD, Baylor College of Medicine</td>
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<td>Role of Postictal Generalized EEG Suppression - Samden Lhatoo, MD, Case Western University</td>
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<td>The Role of Sleep-Wakefulness in SUDEP - Gordon Buchanan, MD, PhD, University of Iowa</td>
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<td><strong>Panel Discussion:</strong> Where are the gaps? What is the end goal for patients with this research? What clinical findings should be explored in the lab? What basic findings are ready to translate to the clinic? Where are opportunities for diagnostic biomarkers?</td>
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<td>10:00 a.m. - 10:15 a.m.</td>
<td>Break</td>
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### SATURDAY, JUNE 25

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<th>Time</th>
<th>Event</th>
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| 10:15 a.m. - noon | **Breakout Sessions**  
**Breakout 4: Mechanisms of SUDEP**  
*Edison Ballroom, Salon C & D*  
Moderators: Detlev Boison, PhD, *Legacy Health*; Franck Kalume, PhD, *Seattle Children’s Hospital*  
How Do Seizures in the Forebrain Influence Cardiorespiratory Control - Brian Dlouhy, MD, *University of Iowa*  
Role of Pulmonary Edema - Masud Seyal, MD, PhD, *UC Davis Health System*  
Novel Genes and Pathways with Elusive Modulation of SUDEP Risk - Helen Scharfman, PhD, *NYU Langone Medical Center*  
Mechanisms of SUDEP: Purines and the Control of Breathing - Greg Funk, PhD, *University of Alberta*  
Seizure Effects on Brainstem Serotonergic and Cholinergic Neuronal Activity - Hal Blumenfeld, MD, PhD, *Yale University*  
5-HT2c Receptor: Implications for SUDEP - Chen Liu, PhD, *University of Texas Southwestern Medical Center*  |
| noon - 1:15 p.m. | **Lunch Buffet**  
*Edison Ballroom, Salon C & D*  |
| 1:00 p.m. - 1:15 p.m. | **Last Pyramid Documentary**  
*Edison Ballroom, Salon C & D*  |

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**Panel Discussion:** What are the lessons learned from research studies, support organizations and families?

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*LAST PYRAMID*

*A Documentary Short*

After being cast adrift by her son Kevin’s tragic death from an epilepsy-related drowning accident in 2001, Patricia “Trish” Barnes thought her life was over. A story of healing and creation, this award-winning film chronicles the zenith of Trish Barnes’ 13-year journey of remembrance while using her artistic gifts to give voice and inspiration to those who live with epilepsy.

This documentary is produced by the Epilepsy Foundation and Greg Grunberg, the film’s executive producer and actor in projects including “Heroes” and “Star Wars: The Force Awakens.” Last Pyramid won Film of the Year at the inaugural Northern Virginia International Film Festival (NOVA) in 2015.
SCHEDULE

SATURDAY, JUNE 25

1:30 p.m. - 3:00 p.m.  Plenary 5: Prevention – What Are the Options for Prevention Now and in the Future?
   Edison Ballroom, Salon C & D
   Moderators: Tom Stanton, MPP, Danny Did Foundation; Henry Smithson, MD, University College Cork
   Family Speaker: Margaret Storey
   Seizure Monitoring and Devices - Tobias Loddenkemper, MD, Boston Children’s Hospital
   Disclosing and Managing Risk - Jane Hanna, SUDEP Action
   Tools Not Rules for Discussing SUDEP - Jeff Buchhalter, MD, PhD, FAAN, Alberta Children’s Hospital
   Living With and Managing Epilepsy - Barbara Jobst, MD, Dartmouth-Hitchcock Medical Center
   Panel Discussion: Where are the gaps? Are there clear opportunities for engagement between groups on the needs that are identified from this session? Is there a place for families and generalists to discuss the best way to provide this information and how it can be used at an epilepsy review to reduce future personal risk? What can families do now to engage? Are any of these interventions ready for primetime? What would be needed to get them to patients?

3:00 p.m. - 3:15 p.m.  Break

3:15 p.m. - 5:00 p.m.  Breakout Sessions

Breakout 6: Future Directions for Research to Impact Prevention
   Edison Ballroom, Salon C & D
   Moderators: Brian Gehlbach, MD, University of Iowa; Jeff Noebels, MD, PhD, Baylor College of Medicine
   Is There an Antemortem Imaging Biomarker of SUDEP - Susanne Mueller, MD, University of California San Francisco
   Cardiac Biomarkers for SUDEP Risk - Stephan Schuele, MD, Northwestern University
   Respiratory Biomarkers for SUDEP Risk - Lisa Bateman, MD, Columbia University
   Can EEG Help in SUDEP Risk Assessment? - Doug Nordli, MD, Ann and Robert Lurie Children’s Hospital
   Contribution of Genetics in SUDEP Diagnostics and Prediction? - Alica Goldman, MD, PhD, Baylor College of Medicine

Breakout 7: How Do We Improve SUDEP Risk Disclosure?
   Edison Ballroom, Salon E
   Moderator: Henry Smithson, MD, University College Cork
   Panel Discussion: From the perspectives of families, medical professionals, researchers and advocates: What is currently being disclosed and when? What isn’t disclosed? When and how is disclosure most effective? What isn’t effective? Who is responsible for disclosure? What tools are available to assist with disclosure? What are the challenges to disclosure and how can we overcome those challenges? How can we raise awareness and provide training for the best practices in SUDEP risk disclosure?
## SCHEDULE

### SUNDAY, JUNE 26

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<td>Registration</td>
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<td>7:00 a.m. - 8:00 a.m.</td>
<td>Continental Breakfast</td>
<td>Edison Ballroom Foyer</td>
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<td>8:00 a.m. - 9:15 a.m.</td>
<td>Plenary 6: Advocacy Perspectives: How Can We Speed Up Awareness and Prevention?</td>
<td>Edison Ballroom, Salon C &amp; D</td>
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<td>Panelists: Mark Stevenson, FACHE, CHIE, Epilepsy Foundation</td>
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<td>Karen Osland, SUDEP Action</td>
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<td>Cyndi Wright, SUDEP Institute</td>
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<td>Rosemary Panelli, MPH, PhD, SUDEP Action</td>
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<td>Samuel Wiebe, MSc, MD, FRCPC, International League Against Epilepsy</td>
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<td><strong>Panel Discussion:</strong> How can we scale and speed up research, prevention and awareness?</td>
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<td>9:15 a.m. - 10:15 a.m.</td>
<td>Plenary 7: Updates and Discussion on Select Programs in Mortality Research</td>
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<td>Panelists: Samden Lhatoo, MD, Case Western University</td>
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<td>Brandy Fureman, PhD, Epilepsy Foundation</td>
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<td>10:15 a.m. - 10:30 a.m.</td>
<td>Break</td>
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<tr>
<td>10:30 a.m. - 11:20 a.m.</td>
<td>Tying It All Together</td>
<td>Edison Ballroom, Salon C &amp; D</td>
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<td>Panelists: Jeff Buchhalter, MD, PhD, FAAN, Alberta Children’s Hospital; Gardiner Lapham, RN, MPH, CURE</td>
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<td><strong>Discussion:</strong> What gaps have we identified? What opportunities have we identified to advance science, translation and prevention? What opportunities have we identified to strengthen collaborations or how we pursue goals?</td>
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<td>11:20 a.m. - 11:30 a.m.</td>
<td>Final Remarks and Farewell</td>
<td>Edison Ballroom, Salon C &amp; D</td>
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1. Significance of sleep as a risk factor for SUDEP | All, A., Wu, S., Rose, S., Issa, N., Tao, J.

2. The missing link: Seizure-related modulation of systemic arterial blood pressure in focal epilepsy | Hampel, K., Amthsosselein, J., Elger, C., Surges, R.

3. Caffeine and SUDEP: Benefits and risks | Shen, H., Straub, T., Huneild, M., Omi, W., Boison, D.


5. Postictal apnea is the primary cause of sudden death in a Dravet Syndrome mouse model | Kim, Y., Bravo, E., Richeson, G.


7. Occurrence of central ictal apnea in temporal lobe seizures is independent of seizure spread and laterality of seizure onset: a case study | Sainju, R., Gehlbach, B., Granner, M., Richerson, G.

8. Deficits of 5-HT-mediated arousal are implicated in seizure-induced respiratory arrest | Feng, H., Zhang, H., Zhao, H., Zeng, C., Van Dort, C., Faingold, C., Taylor, N., Solt, K.

9. Center for SUDEP Research: Morphometry Ccoe/Ppre-mortem Imaging: preliminary results | Bateman, L., Mueller, S., Nei, M., Goldman, A.

10. Knowledge of SUDEP among pediatrics in Virginia | Berl, M., Bumbut, A., Kroner, B., Gaillard, W., Goodkin, H.


14. Vigilance state dependent regulation of cardio-respiratory effects and death following maximal electroshock induced seizures in mice | Buchanan, G., Hajeck, M.

15. Autonomic dysfunction and increased arrhythmicogenic potential in mice following status epilepticus | Levine, A., Dao, A., Lai, Y., Born, H., Anderson, A.


17. Dravet Syndrome patient-derived induced pluripotent stem cell cardiac myocytes may predict SUDEP risk | Frasier, C., Zhang, H., Offord, J., Auerbach, D., Parent, J., Isom, L.

18. Effects of vigilance state and genetic elimination of serotonin neurons on seizure susceptibility and the cardio-respiratory impact of seizures in two mouse models of epilepsy | Purnell, B., Claycomb, K., Kruse, S., Buchanan, G.


20. Therapeutic efficacy of Kv7 channel openers in two mouse models of Sudden Unexpected Death in Epilepsy (SUDEP) | Villalba, S., Gautier, N., Glasscock, E.


22. A wristband assessment of accelerometry and autonomic activity of epileptic patients | Caborni, C., Onorati, F., Regalia, G., Migliorini, M., Picard, R.

23. Sudden unexpected death in epilepsy (SUDEP) in children with benign childhood epilepsy with centrotemporal spikes (BECTS): a case series from the North American SUDEP Registry (NASR) | Doumlele, K., Friedman, D., Devinsky, O.


27. Mortality associated with epilepsy in Veterans of the Afghanistan and Iraq Wars | Pugh, M., Amuan, M.


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<td>Jose Herrera, PhD</td>
<td>Methyl-CpG binding-protein 2 function in cholinergic neurons mediates cardiac arrhythmogenesis</td>
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<td>Luisa Londoño-Hurtado</td>
<td>Intracranial electroencephalographic (EEG) correlates of surfacepostictal generalized EEG suppression (PGES)</td>
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<td>Marije van der Lende, MD</td>
<td>Long term ECG recordings in refractory focal epilepsy: an interim analysis</td>
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<td>Gordon Buchanan, MD, PhD</td>
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<td>Amber Levine</td>
<td>Autonomic dysfunction and increased arrhythmogenic potential in mice following status epilepticus</td>
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<td>Nikhil Sahai, BS</td>
<td>Cardiorespiratory dysfunctions and sudden death in two mouse models of intractable epilepsy</td>
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<td>Effects of vigilance state and genetic elimination of serotonin neurons on seizure susceptibility and the cardio-respiratory impact of seizures in two mouse models of epilepsy</td>
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<td>Fatemeh Bahari</td>
<td>Evidence of seizures, spreading depression and SUDEP in a murine model of post-malarial epilepsy</td>
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<tr>
<td>Stephanie Villalba, MS</td>
<td>Therapeutic efficacy of Kv7 channel openers in two mouse models of Sudden Unexpected Death in Epilepsy (SUDEP)</td>
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  National Institute of Neurological Disorders and Stroke (NINDS)
Supernus Pharmaceuticals, Inc.
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WITH APPRECIATION TO:

Centers for Disease Control and Prevention
  Center for SUDEP Research
Epilepsy Leadership Council

THANK YOU TO THESE ORGANIZATIONS:

SUDEP Aware
Chelsea Hutchison Foundation
  Rare Epilepsies Network
Sudden Unexplained Death in Childhood (SUDC)
Organizations leading the Partners Against Mortality in Epilepsy (PAME) partnership are the American Epilepsy Society (AES), Citizens United for Research in Epilepsy (CURE) and the Epilepsy Foundation (EF). A complete list of partners is listed below.

pame.AESnet.org