

2016 PAME CONFERENCE

JUNE 23 - 26, 2016 | WASHINGTON, D.C.



PARTNERS AGAINST MORTALITY IN EPILEPSY

Register for the 2016 Partners Against Mortality in Epilepsy (PAME) Conference — the only meeting in North America focused exclusively on increasing the understanding of mortality in epilepsy, including Sudden Unexpected Death in Epilepsy (SUDEP).

Learn more at pame.AESnet.org

OVERVIEW

The 2016 Partners Against Mortality in Epilepsy (PAME) Conference is unlike any other meeting — completely dedicated to better understanding and preventing mortality in epilepsy.

LEARN

Identify trends in incidence and mortality, gaps in the knowledge base and progress made in the latest research.

SHARE

Come together with people living with epilepsy, families, clinicians, researchers and advocates for greater insights and collaboration.

ACT

Know risk factors and prevention strategies, identify future research opportunities and strengthen ways to build public awareness.

Dates

June 23 – 26, 2016

Location

Washington, D.C.

Information

pame.AESnet.org

Organizations leading the PAME partnership are the American Epilepsy Society (AES), Citizens United for Research in Epilepsy (CURE) and the Epilepsy Foundation (EF). The 2016 PAME Conference is the third biennial meeting hosted by AES and planned by the PAME partnership. For a full list of partners, see page 11.

Clinician Learning Objectives

- Strengthen the capacity of health care providers to discuss epilepsy-mortality broadly and SUDEP specifically, identify risk factors, communicate prevention strategies.
- Address gaps in care for people with epilepsy and provide strategies for improvement.

Researcher Learning Objectives

- Identify progress made in epilepsy mortality and SUDEP research and direction for future research, as well as funding and collaboration opportunities.
- Build collaborations across medical disciplines and among families and advocates to bolster research opportunities and participation.

Families/Advocates Learning Objectives

- Learn about the latest in epilepsy mortality, especially SUDEP research.
- Enable people with epilepsy, families and lay organizations to advance SUDEP awareness and education by facilitating collaborations between support groups, funding sources, health care professionals and others, both nationally and internationally.

Plan now to attend the 2016 PAME Conference — registration is limited.



CONFERENCE REGISTRATION

Registration

Registering for the 2016 PAME Conference is easy at pame.AESnet.org.

Register early and save.

EARLY REGISTRATION By Monday, May 16

\$200 – Medical Professionals
\$100 – Patient, Advocate, Family and Others

STANDARD REGISTRATION Tuesday, May 17 - Sunday, June 26

\$275 – Medical Professionals
\$175 – Patient, Advocate, Family and Others

Registration rates are per person and include all sessions listed in the agenda.

ADA Accommodations: The American Epilepsy Society and our partners fully comply with the legal requirements of the Americans with Disabilities Act and the rules and regulations thereof and welcome people with disabilities. Please make your requests in step three of the online registration. Questions? Please contact Elizabeth Kunsey by phone at 312.338.8300, ext. 108 or email ekunsey@aesnet.org. Requests should be made at least two weeks prior to the conference.

Dietary Restrictions: Special meal requests should be made at least two weeks prior to the conference: kosher, gluten-free, dairy-free, vegan, other. Vegetarian options will be available for everyone. Please make your requests in step three of the online registration. Questions? Please contact Elizabeth Kunsey by phone at 312.338.8300, ext. 108 or email ekunsey@aesnet.org.

For questions about conference registration, call 312.883.3800 or email info@aesnet.org.

Register for the PAME Conference



Online

pame.AESnet.org

Join Your Colleagues

Another way PAME is unique: the conference brings together a cross-section of participants:

- Clinicians discussing epilepsy mortality including risk factors and prevention strategies
- People living with epilepsy, their families as well as bereaved families, sharing personal experiences and learning from one another
- Research scientists investigating mortality in epilepsy and SUDEP
- Nonprofit organizations providing patient support and leading advocacy efforts
- Early career fellows developing research specialties and portfolios

CME Credits

This activity has been approved for AMA PRA Category 1 Credit™. Please refer to the PAME website for additional information on CME Credit.

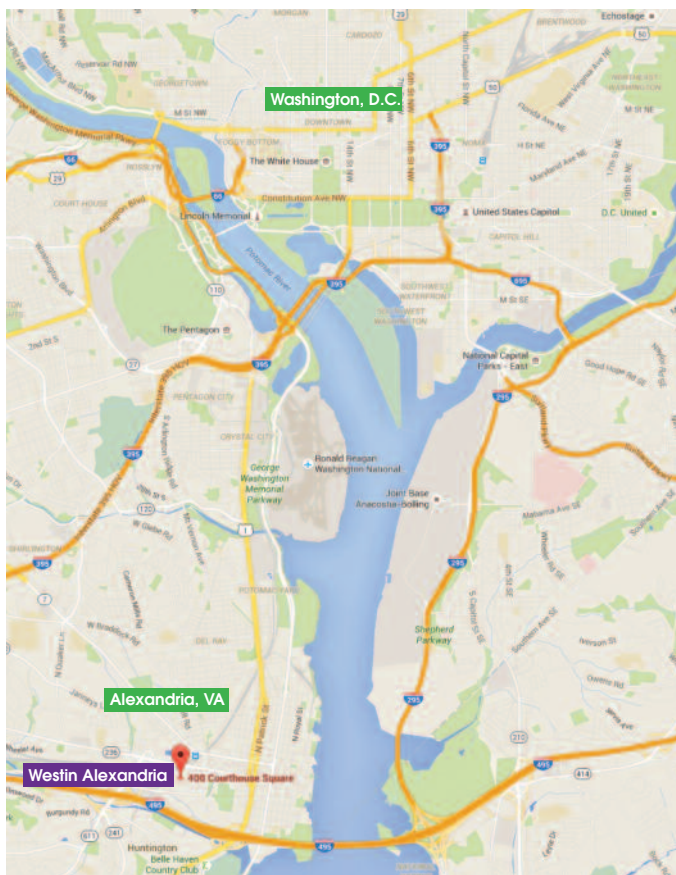


HOTEL RESERVATIONS

Hotel Reservations

The PAME Conference is scheduled for suburban Washington, D.C. Specifically, the meeting location is:

Westin Alexandria
400 Courthouse Square
Alexandria, VA 22314-5700



Book With PAME

- ✓ Convenience of staying at PAME Conference hotel
- ✓ Specially negotiated rates for attendees
- ✓ Changeable/refundable rates up to 72 hours prior to Conference
- ✓ Support for the PAME Conference

Special rates have been negotiated for PAME conference attendees:

- \$167 single/double room per night, plus tax
- \$177 triple room per night, plus tax
- \$187 quad room per night, plus tax

To receive these rates, **the reservation deadline is Wednesday, May 25, 2016**. You are encouraged to confirm a reservation early, as rooms may sell out prior to the deadline.

Hotel check-in is 3:00 p.m.; check-out is noon.

Hotel Cancellation Policy: Cancellations will be accepted through Monday, June 20 by 6:00 p.m. hotel time. Cancellations after this date/time will be charged a one-night stay.

Early Departure Fee: An early departure fee of \$167.00 will apply if you check out prior to your confirmed check out date on your reservation. This fee can be avoided if you modify and/or change your departure date 72 hours prior to arrival by 6 p.m. hotel time.

Planning to arrive a few days early or stay a few days after the conference? The Westin is offering the PAME group rate based on availability. Please contact the Westin directly to extend reservations, by calling Ms. Joji Gamble at 703.253.8626 or by email at Joji.Gamble@westin.com.

For questions about hotel reservations, call 312.883.3800, ext. 108 or email ekunsey@aesnet.org.

Reserve your hotel room



Online

Book online via the Westin Alexandria at bit.ly/1SWPj6



Telephone

Call the Westin toll-free at 1-866.837.4210
Request the PAME conference rate

AGENDA

THURSDAY JUNE 23, 2016

12:00 - 4:00 p.m. **Congressional Visits (Optional for Families and Professionals)**

4:30 - 6:00 p.m. **Family Welcome and Introductions**
Epilepsy Mortality Basic Primer for Families

Moderator: Mark Stevenson

Panelists:

Jeff Buchhalter, MD, PhD, *Alberta Children's Hospital*

Elizabeth Donner, MD, FRCPC, *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 - 8:30 p.m. **Welcome Reception for All Attendees**

Welcome Remarks by PAME Committee and Walter Koroshetz, MD - *NINDS*

FRIDAY JUNE 24, 2016

8:00 - 8:30 a.m. **Welcome. Meeting Overview and Goals**
Presentation of Personal Stories

Jeff Buchhalter, MD, PhD, *Alberta Children's Hospital*; Gardiner Lapham, RN, MPH, *CURE*

8:30 - 10:15 a.m. **Plenary 1: Mortality in People with Epilepsy - Epidemiology and Surveillance**

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, *CDC*

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

AGENDA

FRIDAY JUNE 24, 2016

10:30 a.m. - 12:00 p.m. **Plenary 2: Mortality in Children**

Moderator: Elizabeth Donner, MD, MSc, FRCPC, *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 SUDC Research and Advocacy - Laura Crandall, *The SUDC Foundation*

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

12:00 - 1:15 p.m. **Lunch**

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

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 - 3:45 p.m. **Break**

3:45 - 5:00 p.m. **Breakout Sessions**

Breakout 1: Gene Analysis and Discovery in SUDEP

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*

AGENDA

FRIDAY JUNE 24, 2016

Breakout 2: Improving Mortality Surveillance and Case Ascertainment

Moderator: Daniel Friedman, MD, *NYU Comprehensive Epilepsy Center*

How Can Families Help with Surveillance and Case Ascertainment - Jennifer Murphy, MPH, *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

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

AGENDA

SATURDAY JUNE 25, 2016

7:00 - 8:00 a.m. **Family Breakfast**

8:00 - 8:30 a.m. **Morning Welcome**

Family Speaker - Jennifer Murphy

8:30 - 10:00 a.m. **Plenary 4: What Are the Events that Occur During and After a Seizure that Cause a Death in SUDEP?**

Moderators: Philippe Ryvlin, MD, PhD, *Lyon University*; Masud Seyal, MD, PhD, *UC Davis Health System*

What Have MORTEMUS and Investigations of Actual SUDEP Cases Taught Us About Pathophysiological Mechanisms of Death - Philippe Ryvlin, MD, PhD, *Lyon University*

New Insights into Seizure-related Changes in Cardiovascular and Autonomic Function - Roland Thijs, MD, *Stichting Epilepsie Instellingen Nederland*

Changes in Respiratory Control Induced by Seizures - George Richerson, MD, PhD, *University of Iowa*

Spreading Depression in the Brainstem: The Storm Before the Quiet - Jeff Noebels, MD, PhD, *Baylor College of Medicine*

Role of Postictal Generalized EEG Suppression - Samden Lhatoo, MD, *Case Western University*

The Role of Sleep-Wakefulness in SUDEP - Gordon Buchanan, MD, PhD, *University of Iowa*

Panel Discussion: 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?

10:00 - 10:15 a.m. **Break**

10:15 a.m. - 12:00 p.m. **Breakout Sessions**

Breakout 4: Mechanisms of SUDEP

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-HT_{2c} Receptor: Implications for SUDEP - Chen Liu, PhD, *University of Texas Southwestern Medical Center*

AGENDA

SATURDAY JUNE 25, 2016

Breakout 5: Lessons Learned in Grief and How to Better Support Families

Moderator: Cyndi Wright

Panelists:

Rajesh Ramachandran Nair, MD, *McMaster University*

Henry Smithson, MD, *University College Cork*

Karen Osland, *SUDEP Action*

Rosemary Panelli, MPH, PhD, *SUDEP Action*

Linda Coughlin Brooks, RN, BSN, CT - *Epilepsy Foundation SUDEP Institute*

Jennifer Murphy, MS, MF, CCRA, PMP, *Patrick Ring Foundation*

Panel Discussion: Lessons learned from research studies, support organizations and families.

12:00 - 1:15 p.m.

Lunch

1:30 - 3:00 p.m.

Plenary 5: Prevention – What Are the Options for Prevention Now and in the Future?

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, *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 - 3:15 p.m.

Break

3:15 - 5:00 p.m.

Breakout Sessions

Breakout 6: Future Directions for Research to Impact Prevention

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 & Robert Lurie Children's Hospital*

Contribution of Genetics in SUDEP Diagnostics and Prediction? - Alica Goldman, MD, PhD, *Baylor College of Medicine*

AGENDA

SATURDAY JUNE 25, 2016

Breakout 7: How Do We Improve SUDEP Risk Disclosure?

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?

SUNDAY JUNE 26, 2016

8:00 - 9:15 a.m.

Plenary 6: Advocacy Perspectives: How Can We Speed Up Awareness and Prevention?

Moderator: Jane Hanna, *SUDEP Action*

Panelists:

Mark Stevenson, FACHE, CHIE

Karen Osland, *SUDEP Action*

Cyndi Wright, *SUDEP Institute*

Rosemary Panelli, MPH, PhD, *SUDEP Action*

Samuel Wiebe, MSc, MD, FRCPC, *International League Against Epilepsy*

Panel Discussion: How can we scale and speed up research, prevention and awareness?

9:15 - 10:15 a.m.

Plenary 7: Updates and Discussion on Select Programs in Mortality Research

Moderator: Maggie Moore, MPH, *CDC*

Panelists:

Samden Lhatoo, MD, *Case Western University*

Brandy Fureman, PhD, *Epilepsy Foundation*

Tracy Dixon-Salazar, PhD, *CURE*

Samuel Wiebe, MSc, MD, FRCPC, *International League Against Epilepsy*

10:15 - 10:30 a.m.

Break

10:30 - 11:20 a.m.

Tying It All Together

Jeff Buchhalter, MD, PhD, *Alberta Children's Hospital*; Gardiner Lapham, RN, MPH, *CURE*

Discussion: 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?

11:20 - 11:30 a.m.

Final Remarks and Farewell

PARTNERS

Organizations leading the Partners Against Mortality in Epilepsy (PAME) partnership are the American Epilepsy Society (AES), Citizens United for Research in Epilepsy (CURE), and Epilepsy Foundation (EF). A complete list of partners is listed below (as of April 21, 2016.)

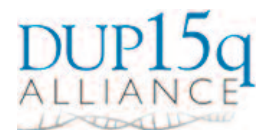


AMERICAN
EPILEPSY
SOCIETY

CURE
Citizens United for Research in
EPILEPSY



SUDEP Action
Making every epilepsy death count



WE'LL GIVE
EVERYTHING.
BUT UP.



pame.AESnet.org

PARTNERS

ADDITIONAL SUPPORT PROVIDED BY:

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

WITH APPRECIATION TO:

National Institute of Neurological Disorders and Stroke
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)



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