

2023

pame

Partners Against Mortality in Epilepsy

11.29 - 11.30.2023 | ORLANDO | FLORIDA

FAMILY DAY & CONFERENCE

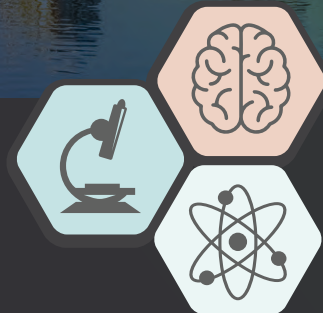


SPECIAL PRE-CONFERENCE AFTERNOON
SESSION FOR FAMILIES

WEDNESDAY / 11.29

2:30 PM - 5:30 PM

Families affected by epilepsy and advocates are invited to attend a special advocacy and family-focused afternoon session Wednesday, November 29th.



SCIENTIFIC CONFERENCE SESSIONS

THURSDAY / 11.30

8:00 AM - 6:30 PM

The program for the 2023 PAME meeting will be scientifically rigorous and informed by the experiences of people impacted and bereaved by epilepsy.

WELCOME

Dear friends,

Welcome to the 2023 Partners Against Mortality in Epilepsy (PAME) Conference in Orlando, Florida!

Ironically, we find ourselves steps away from the Magic Kingdom, yet we know the issue of epilepsy mortality is no fairy tale. However, we come together today and always to advance the power of research and the magic of partnerships in realizing a better world for people with epilepsy.

PAME's mission is to unite epilepsy researchers, healthcare providers, non-profit professionals, and people affected by epilepsy, including those who have so tragically lost a loved one. We believe that by working together we will more quickly advance research, awareness, and prevention of epilepsy related mortality. This conference plays a central role in this effort.

This year's meeting will be dynamic and exciting with more than 40 diverse presenters. On Wednesday we host our second annual special session for bereaved family members and advocates so they can meet and support one another and discuss ways to turn grief in to positive action. Thursday welcomes all stakeholders, and we are especially honored to host Professor Helen Cross as our keynote speaker. Dr. Cross is an outstanding leader in the field of epilepsy care and research. As president of the International League Against Epilepsy, she is the driving force behind the implementation of the recently adopted World Health Organization's (WHO) Intersectoral

Global Action Plan (IGAP) on epilepsy and other neurological disorders. She will discuss this landslide agreement and its significance towards driving prevention of premature epilepsy mortality across the world.

After a day of plenaries and breakouts covering a range of topics from progress in basic science to effective communication, we hope you will join us at the end of the day to celebrate the nearly 50 abstract authors by attending the robust poster session and cocktail reception. It is always wonderful to meet new people in our community and acknowledge the young investigators that remain our brightest light.

We want to thank the volunteers who gave their time and talent to plan this conference; the AES management team for their support; the PAME Governance Committee for its guidance; and the PAME faculty for their invaluable insights and contributions. We owe special thanks to the partner organizations, foundations, individuals, and corporate partners whose financial support made this meeting possible.

Finally, we are always grateful to the families who find the strength to be at this meeting and serve as the inspiration behind the PAME initiative. With heavy hearts for those who have been lost, we remain hopeful for the future and firmly resolved to see our collective dreams come true.

Most sincerely, PAME Conference Planning Committee



ELIZABETH J. DONNER, MD, MSc, FRCPC
Assoc Professor, Univ of Toronto Faculty of Medicine
Pediatric Neurologist, Hospital for Sick Children



GARDINER LAPHAM, RN, MPH
Family advocate
BAND Foundation



GEORGE B. RICHERSON, MD, PHD, FAES
Chair, Department of Neurology
Carver College of Medicine,
University of Iowa



JEFFREY BUCHHALTER MD, PhD, FAAN, FAES
Epilepsy Learning Healthcare System
Pediatric Epilepsy Learning
Healthcare System



TOM STANTON
President,
Danny Did Foundation



ANNE GRAMIAK, MPH, MSLOC
Senior Manager, ELC and Partnerships
American Epilepsy Society

GRATITUDE

PAME remains grateful to the American Epilepsy Society for providing fiscal and administrative oversight, and generous in-kind assistance.

Thank you to members of the Governance Committee for providing overall direction, planning, partnership engagement, and fiscal health of the collaborative. Members are representative of PAME constituencies and founding partners and include: Jeff Buchhalter, Elizabeth Donner, Alison Kukla, Eileen Murray, Tom Stanton, Anne Gramiak, Gardiner Lapham, George Richerson, Hannah Whitten and Beth Dean.

Thank you to the 2023 Abstract Review Committee chaired by Gordon Buchanan with members Lauren Harte-Hargrove and Franck Kalume.

Thank you to the SUDEP Research & Prevention Committee for championing implementation of the 2020 SUDEP Summit priorities. Its members include: Dan Atherton, Beth Dean, Cyndi Wright, David S. Auerbach, Elizabeth Donner, Dan Friedman (Co-Chair), Brandy Fureman, Gordon Buchanan, Heather MacLeod, Shelley Hutchison, Lori Isom (Co-Chair), Kukla, Alison, Laura Lubbers, Kristina Simeone, Kristina, Niu Tian, Tom Stanton, Vicky Whittemore, and Bill Nobis. We also want to recognize Alison Kukla, Jeff Buchhalter, Dan Friedman, Hannah Whitten, Kevin Chapman, Laura Lubbers, Laura Weidner and Tom Stanton for their participation in PAME's SUDEP legislative working group.

We are grateful to all partners who made this meeting possible. A full listing of organizations can be found on the back cover. A portion of the 2023 education program is supported by medical education grants from UCB, and Jazz Pharmaceuticals.

ABOUT THIS CONFERENCE & PAME

ABOUT PAME

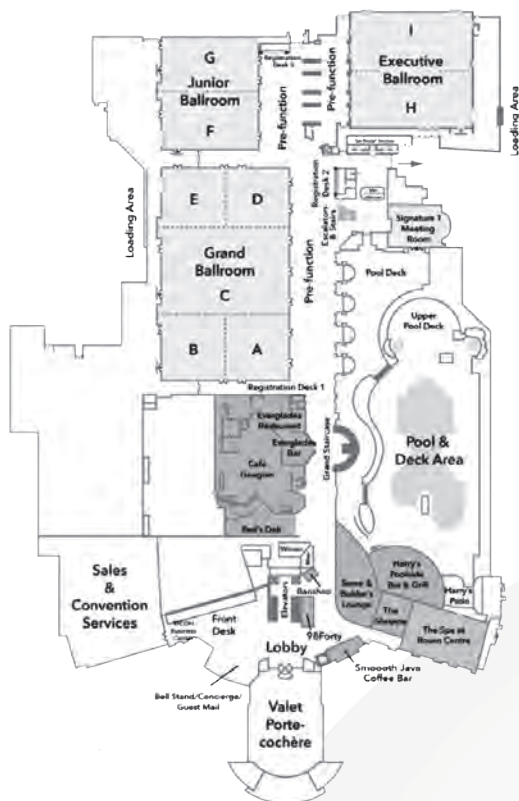
PAME is a community of people and organizations with diverse skills and experiences that come together to raise awareness and promote the prevention of premature death related to epilepsy. The PAME collaborative provides year-round educational opportunities, including the flagship PAME Conference, and encourages a better coordinated response to the urgent problem of epilepsy related mortality.

PAME's mission is to convene, educate and inspire all stakeholders - from the bereaved to those living with epilepsy, to health care professionals, advocates, clinical and basic scientists, and death investigators - to promote understanding and drive prevention of epilepsy-related mortality.

PAME is proud to convene this year's Conference whose goals are 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
- Provide opportunities for networking and collaboration among stakeholders, including people with epilepsy, researchers, families, clinicians, and advocates
- To be a welcoming gathering place of comfort and information for those who have lost a loved one
- Gain skills in advocacy to build public awareness and impact public policy regarding epilepsy mortality
- Encourage early-career investigators to study causes of mortality in epilepsy

ROSEN CENTRE HOTEL MAP



CONFERENCE EVALUATION

Please take a moment to complete the conference evaluation. Your feedback will help the planning committee in creating a great meeting for next year.

EVALUATION LINK

<https://www.surveymonkey.com/r/PAME2023>



Find us on Facebook

<https://www.facebook.com/PAMEOnline>

WEDNESDAY, NOVEMBER 29, 2023

2:30 pm

WELCOME REMARKS + FAMILY STORY

GRAND BALLROOM A

Speaker: Stephanie Mingel, Bereaved Parent, Advocate

Moderators:

Alison Kukla,
Epilepsy
Foundation of
America and
Mary Duffy,
Danny Did
Foundation

2:40 pm

PANEL DISCUSSION | Current SUDEP Research Updates

Dr. Maney and Dr. Nair will present on their current SUDEP research focused on SUDEP communication and understanding the caregiver perspective and the experience of traumatic loss and growth after SUDEP.

Moderator:

Alison Kukla,
MPH, Epilepsy
Foundation of
America

Panelists:

- Kayli Maney, MD, Duke University Hospital
- Rajesh Ramachandran Nair, MD, DM, DNB, FRCPC, FRCP, FRCPC, FAES, CSCN(EEG), McMaster Children's Hospital, Hamilton, Canada

3:30 pm

BREAK

3:40 pm

KEYNOTE REMARKS

Kelly Cervantes lost her medically complex daughter, Adelaide, in 2019 just before her 4th birthday. After losing her daughter to epilepsy, she knows that grief is many things. It's all-encompassing and something everyone will have to deal with, but it's never linear. Just as what we are grieving varies, so do our journeys to process it. She will share and discuss the themes in her new book, *Normal Broken: The Grief Companion for When it's Time to Heal But You're Not Sure You Want To*.

Moderator:

Mary Duffy,
Danny Did
Foundation

Faculty

- Kelly Cervantes, Advocate, Author, and CURE Epilepsy Board Member

4:20 pm

PANEL DISCUSSION | Turning Grief into Action

This interactive panel discussion will be an opportunity to learn from individuals who have lost loved ones to epilepsy, while they share their stories and the work they've been doing to raise awareness about SUDEP in their memory.

Moderator:

Alison Kukla,
MPH, Epilepsy
Foundation of
America

Panelists:

- Colleen Hosbach, Bereaved Parent, Advocate
- Allison Hurt, Bereaved Parent, Advocate
- David Schlobohm, Bereaved Parent, Advocate

5:20 pm

CLOSING REMARKS

5:30 pm

ADJOURN

6:30-8 pm

WELCOME RECEPTION FOR ALL CONFERENCE ATTENDEES

Cuba Libre Restaurant & Rum Bar • 9101 International Drive

THURSDAY, NOVEMBER 30, 2023

7–8 am	BREAKFAST & REGISTRATION
8–8:30 am	WELCOME – PAME CO-CHAIRS
8:30–9 am Grand Ballroom C <hr/>	KEYNOTE SPEAKER <p>Professor J Helen Cross is an outstanding leader in the field of epilepsy care and research. As president of the International League Against Epilepsy, Dr. Cross is a driving force behind implementation of the recently adopted World Health Organization’s (WHO) Intersectoral Global Action Plan (IGAP) on epilepsy and other neurological disorders. She will discuss this landslide agreement and its significance towards driving prevention of premature epilepsy mortality across the world.</p> <p>Faculty</p> <ul style="list-style-type: none"> • Professor J Helen Cross, President ILAE
9–10:30 am Grand Ballroom C <hr/> <p>Moderator: <i>Daniel Friedman, MD, NYU Grossman School of Medicine</i></p>	PLENARY 1 All-Cause Epilepsy Mortality <p>Understanding all-cause mortality in epilepsy is crucial because it extends our focus beyond SUDEP and highlights the various preventable factors contributing to premature deaths in individuals with epilepsy, such as accidents and comorbid conditions. This broader perspective allows us to develop more comprehensive strategies for improving outcomes for people with epilepsy. In this session, we’ll explore a comprehensive spectrum of preventable deaths associated with seizures and epilepsy.</p> <p>Faculty</p> <ul style="list-style-type: none"> • Kelly Cervantes, Advocate, Author, and CURE Epilepsy Board Member • Elizabeth Donner, MD, MSc, FRCPC, The Hospital for Sick Children, Toronto • Colin Josephson, MD, MSc, FRCPC, CSCN (EEG), University of Calgary • Leah Blank, MD, MPH, Icahn School of Medicine at Mount Sinai
10:30–10:45 am	BREAK
10:45 am–12:15 pm Grand Ballroom A <hr/> <p>Moderators: <i>Franck Kalume, PhD, University of Washington/Seattle Children’s and Erica Levitt, PhD, University of Michigan</i></p>	BREAKOUT #1 The Brainstem’s Role in Breathing and Death <p>In the past decade, converging lines of evidence from preclinical and clinical studies of the pathophysiological mechanisms of sudden unexpected death in epilepsy (SUDEP) have shown that this devastating outcome of epilepsy occurs when a seizure travels from the forebrain to the brainstem where it subsequently disrupts or interrupts the normal function of the cardiac, respiratory, or arousal centers. However, the neural pathways through which seizures travel to reach the vital control centers in the brainstem and the mechanisms of seizure-induced disruptions in these sites are not clearly elucidated. This session will explore recent advances that shed light on forebrain-brainstem connectivity networks that are involved in modulation of cardiac and respiratory functions and their potential roles in SUDEP mechanisms.</p> <p>Faculty</p> <ul style="list-style-type: none"> • Nathan Baertsch, PhD, University of Washington and Seattle Children’s Research Institute • Brian Dlouhy, MD, University of Iowa • Nuria Lacuey Lecumberri, MD, PhD, McGovern Medical School • Kyle Pattinson, DPhil FRCA, University of Oxford

(continued on page 6)

Grand Ballroom C

Moderator:

Tom Stanton,
Danny Did
Foundation

BREAKOUT #2 | Tackling Hard Conversations – Caregiver & Health Provider Perspectives

Too many epilepsy families have experienced the loss of a loved without ever being informed that sudden death was possible. This breakout examines the topic of communication between healthcare providers and patients/caregivers about risks that accompany epilepsy. Panelists will overview the state of SUDEP disclosure, provide the perspectives of caregivers, and discuss the role that nurses can play in these sensitive but critical conversations.

Faculty

- Lou Brossard, Bereaved Parent and Advocate
- Robyn Whitney, MD, FRCPC, CSCN (EEG), McMaster University, Ontario
- Erin Fecske, DNP, APRN, CNRN, CPNP-PC, FAES, Children’s Mercy Kansas City
- Kayli Maney, MD, Duke University Hospital

12:15-1:15 pm

LUNCH & SCIENTIST NETWORKING

- Networking session for young investigators

1:15-2:45 pm

Grand Ballroom A

Moderator:

Ilene Penn Miller, JD,
Rare Epilepsy Network

BREAKOUT #3 | Mortality in the Rare Epilepsies

People with epilepsy are at higher risk for premature death. The rare epilepsies represent a cohort of patients often with the most severe and complex presentations, increasing their risk that much more. This session will explore what is known about mortality and increased risk across the rare epilepsies and additional research and surveillance needed. We will hear from family members and organizational leaders about best practices in SUDEP education and grief support. And we will look at tools, like diaries, aimed at aiding in prevention.

Faculty

- Jeff Buchhalter, MD, PhD
- Tracy Dixon-Salazar, PhD, LGS Foundation
- Mary Ann Meskis, Dravet Syndrome Foundation
- Robert Moss, Seizure Tracker LLC

Grand Ballroom C

Moderator:

Heather MacLeod,
MS CGC,
Data Coordinating
Center for the SUID
and SDY Case
Registry

BREAKOUT #4 | Identifying Genetics and Cardiac Variants in Epilepsy

This session will share the genomic research findings from the genomes studied by the SUID & SDY Case Registry. It will provide an update on the importance of comprehensive care for epilepsy patients to include cardiology. Finally we will discuss opportunities for earlier identification and better care of patients through newborn screening.

Faculty

- Megan J Roy-Puckelwartz, PhD, Northwestern University Feinberg School of Medicine
- Martin Tristani-Firouzi, MD, University of Utah School of Medicine
- Ingrid Holm, MD, MPH, Boston Children’s Hospital and Harvard Medical School

2:45-3:00 pm

BREAK

3:15-4:45 pm

Grand Ballroom C

Moderator:

Elizabeth Donner,
MD, MSc, FRCPC,
The Hospital for Sick
Children, Toronto

PLENARY 2 | Moving Towards Prevention of SUDEP

Over the past 15 years, our understanding of SUDEP has shifted. Where we once thought of SUDEP as a rare & incurable phenomenon, we now understand it as a key driver of premature epilepsy mortality with opportunities for prevention. This session will explore a range of opportunities and interventions - from clinical & basic science approaches to advanced use of technology - that seek to drive the prevention of sudden death in epilepsy.

Faculty

- Iris-Maria Killinger, Dr. iur, Oskar Killinger Foundation
- Kristina Simeone, PhD, Creighton University School of Medicine
- Shobi Sivathamboo, PhD, Monash University and Alfred Health
- Ingo Helbig, MD, Children’s Hospital of Philadelphia
- Daniel Goldenholz, MD, PhD, FAES, Harvard Beth Israel Deaconess Medical Center

4:45-5 pm

CLOSING SESSION

5-6:30 pm

POSTER TOUR & RECEPTION

Grand Ballroom B



AMERICAN EPILEPSY SOCIETY

To Eradicate Epilepsy and its Consequences

This is the vision of the **American Epilepsy Society**.

AES is a community of physicians, scientists, advanced practice providers, nurses, psychiatrists, psychologists, engineers, pharmacists, advocates, and other professionals engaged in the understanding, diagnosis, study, prevention, treatment, and cure of epilepsy.

We are dedicated to advancing knowledge and supporting evidence-based clinical practice to improve outcomes for persons with epilepsy and their families.

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 partnerships

Learn more at
www.aesnet.org

PAME FACULTY BIOS



NATHAN BAERTSCH, PHD
Assistant Professor / University of Washington and Seattle Children's Research Institute

Research conducted in Dr. Baertsch's lab aims to understand the neural circuits and cellular properties that control breathing. This is done using neuronal recording and manipulation approaches in mice to characterize how brainstem regions produce respiratory rhythm, how they are regulated by other areas of the brain, and how disruption of these circuits leads to pathology.

LEAH J. BLANK, MD, MPH



Assistant Professor / Icahn School of Medicine at Mount Sinai

Leah Blank is an Assistant Professor of Neurology and Population Health Science and Policy at the Icahn School of Medicine at Mount Sinai in New York City. She is an adult epilepsy physician and health services researcher who is particularly interested in how to design health systems that improve outcomes, reduce premature mortality and reduce care disparities by delivering high quality epilepsy care.



LOU BROSSARD
SUDEP Awareness Advocate / PAME

Since losing their daughter, Brenna, to SUDEP on January 30th, 2022, the Brossard family has worked tirelessly at the local, state and national levels to ensure that other families that are living with epilepsy are properly informed about the potential risk of SUDEP occurring. Between their son, Nicholas, and daughter, Brenna, the Brossard family had 26 years of doctor appointments with their epilepsy caregivers. Not once in those 26 years were they ever informed about SUDEP, its risk factors, and the steps that could have been taken to mitigate the risk. They only learned about SUDEP by chance, a week after Brenna's funeral.

JEFF BUCHHALTER, MD, PHD



Adjunct Professor of Pediatrics / University of Calgary

Jeffrey Buchhalter MD, PHD is Adjunct Professor of Pediatrics at the University of Calgary and former director of the pediatric epilepsy programs at Alberta Children's Hospital, Phoenix Children's Hospital and the Mayo Clinic, Rochester. His current efforts involve clinical informatics approaches to improving outcomes for children with epilepsy and adults with epilepsy Quality Improvement (QI) methodology. Dr. Buchhalter leads the QI Core and pediatric epilepsy sites of the Epilepsy Learning Healthcare System network, a multi-site, QI-based project administered by the Epilepsy Foundation and serves on the leadership team for the Pediatric Epilepsy Learning Healthcare System. He has participated as co-founder of the Partners Against Mortality in Epilepsy conferences, former chair and member of the American Epilepsy SUDEP Task Force and was a member American Academy of Neurology workgroup that produced a practice guideline for Sudden Unexpected Death in Epilepsy. He co-leads the work group that is revising Quality Measures for Child Neurology. Dr. Buchhalter lives in Phoenix, Arizona, USA, from where he is involved several efforts with the Epilepsy Foundation including the SUDEP Summit and Rescue Medications for seizures.

KELLY CERVANTES

Author, Advocate, and CURE Epilepsy Board Member



Kelly Cervantes is an award-winning writer, speaker, and advocate best known for her blog *Inchstones*. She has been published in the *Chicago Tribune*, the *Chicago Sun-Times*, and *Cosmopolitan*, as well as quoted in the *New York Times*, *CNN*, and *People*. She is the immediate past board chair for the nonprofit CURE Epilepsy and also hosts their biweekly podcast, *Seizing Life*, where she interviews scientists, doctors, and individuals affected by epilepsy. Kelly currently resides in Maplewood, NJ, with her husband, Miguel Cervantes currently starring in Hamilton on Broadway, their children, and two dogs, Tabasco and Sriracha.

J HELEN CROSS

Professor / UCL Great Ormond Street Institute of Child Health



Professor Cross is the Prince of Wales's Chair of Childhood Epilepsy at UCL Great Ormond Street Institute of Child Health, Great Ormond Street Hospital for Children & Young Epilepsy. She is currently President of the International League Against Epilepsy, 2021-2025.

TRACY DIXON-SALAZAR, PHD

Executive Director / Lennox-Gastaut Syndrome (LGS) Foundation



Dr. Dixon-Salazar serves as the Executive Director of the Lennox-Gastaut Syndrome (LGS) Foundation and is an accomplished neuroscientist, geneticist, and decades-long epilepsy and rare disease patient advocate. Driven by her daughter's diagnosis of LGS, and the life-long challenges that ensued, Tracy obtained her bachelor's degree and then pursued a Ph.D. in neuroscience. She went on to conduct post-doctoral work in neurogenetics at the University of California, San Diego. After leaving the research lab to help translate her findings to the clinic, and following her tenure as Associate Research Director at CURE Epilepsy, Dr. Dixon-Salazar joined the LGS Foundation in 2017. As the Executive Director, Tracy implements the strategic research vision, builds collaboration, and pushes for more LGS research.

BRIAN J. DLOUHY, M.D.

Associated Professor, Department of Neurosurgery / University of Iowa



Dr. Brian J. Dlouhy is a neurosurgeon-scientist at the University of Iowa who specializes in the treatment of epilepsy. In addition to his clinical activities, Dr. Dlouhy leads a human brain research lab that focuses on human forebrain control of breathing, seizure induced loss of breathing, and sudden unexpected death in epilepsy (SUDEP). This research has led to novel insights into how seizures cause loss of breathing and SUDEP. Dr. Dlouhy's goal is to use this knowledge to develop a preventative treatment strategy for the millions of people with epilepsy who are at high risk for SUDEP.

ELIZABETH DONNER, MD, MSC, FRCPC



Co-Chair, Partners Against Mortality in Epilepsy / The Hospital for Sick Children and the University of Toronto

Dr. Elizabeth Donner is the Director of the Comprehensive Epilepsy Program at the Hospital for Sick Children and Michael Bahen Chair in Epilepsy Research and Professor in the Faculty of Medicine at University of Toronto. Elizabeth leads a research program focused on identifying those most at risk of Sudden Unexpected Death in Epilepsy (SUDEP). In addition, she has had a strong commitment to epilepsy advocacy in the professional and lay communities. She is a Co-Chair of Partners Against Mortality in Epilepsy, Co-Lead of ECHO Ontario: Epilepsy across the Lifespan and Board Member and Scientific Committee Chair for Epilepsy Canada.



MARY DUFFY
Executive Director / Danny Did Foundation

Mary Duffy serves as the Executive Director of the Danny Did Foundation, a Chicago-based nonprofit that holds the mission to prevent deaths caused by seizures. She began her service in the epilepsy community after her dear friend lost her son, Danny Stanton, to Sudden Unexpected Death in Epilepsy, or SUDEP. Mary believes that families who face seizures deserve honest and open communication from medical providers about the various treatments and risks within epilepsy. Among her specialties at Danny Did, she has helped thousands of caregivers and adult patients to gain seizure alerting devices. Mary is motivated by Danny and all those who have been lost too soon to epilepsy.

ERIN FECSKE, DNP, APRN, CNRN, CPNP-PC, FAES



Epilepsy Nurse Practitioner / Children's Mercy Kansas City

Erin Fecske, pronouns she/her, is a pediatric nurse practitioner in the Comprehensive Epilepsy Center at Children's Mercy Kansas City where she has worked for the last 10 years. In this role, Erin manages the care of patients with complex and refractory epilepsy. Erin is certified as a Clinical Neuroscience Registered Nurse (CNRN) and has specialized in the care of the neuroscience patient for much of her career. She is also recognized as a Fellow of the American Epilepsy Society for her contributions to the care of children and youth with epilepsy.



DANIEL FRIEDMAN, MD, MSC

Professor of Neurology / NYU Grossman School of Medicine

Daniel Friedman, MD, MSc is the Associate Director of the NYU Comprehensive Epilepsy Center and co-director of the Video-EEG laboratory at NYU Langone Medical Center. He received his medical degree from Case Western Reserve University School of Medicine, completed his neurology residency training at the Hospital of the University of Pennsylvania and his epilepsy/clinical neurophysiology fellowship at the Neurological Institute/Columbia University Medical Center. He specializes in the treatment of teenagers and adults with difficult to control epilepsy. He also performs research to better understand the causes of morbidity and mortality of epilepsy and test interventions to improve outcomes.

DANIEL GOLDENHOLZ, MD, PHD, FAES



Assistant Professor / Harvard Beth Israel Deaconess Medical Center

Daniel has expertise in electrical and biomedical engineering, biostatistics, neuroradiology and epilepsy. His lab, the Epilepsy + Data Science Lab works to leverage advanced tools to help people with epilepsy. Daniel also has a family member with epilepsy and therefore hates the disease from the depths of his being.



INGRID A. HOLM, MD, MPH
Professor of Pediatrics /

Boston Children's Hospital and Harvard Medical School

Dr. Holm is Professor of Pediatrics at Harvard Medical School, faculty in the Division of Genetics and Genomics at Boston Children's Hospital, and teaching faculty at the HMS Center for Bioethics. Dr. Holm's areas of research are the Ethical, Legal, and Social Implications (ELSI) of genomics and rare genetic disease research. She is Associate Director of Robert's Program in Sudden Unexpected Death in Pediatrics (SUDP), which takes an innovative approach to SUDP as a group of rare genetic diseases.

COLLEEN HOSBACH



Bereaved Mother and Advocate, Director / Morgan Rose Hosbach Foundation

Colleen's daughter Morgan passed away from SUDEP June 13, 2022. Morgan was living a normal life as a 23 year old woman, took an afternoon nap before work and never woke up. I'm here to tell Morgan's story for her.



ALLISON HURT
Bereaved Mother and Advocate

Allison is a bereaved parent and advocate. Her daughter Erin passed from SUDEP (sudden unexpected death from Epilepsy) in April of 2019, only one month after being diagnosed with Epilepsy. Allison is a board member of the Epilepsy Foundation Nebraska since 2019 and recently began working with the Danny Did Foundation as an Ambassador.

COLIN JOSEPHSON, MD MSC FRCPC CSCN (EEG)



Associate Professor of Neurology / University of Calgary

Colin Josephson MD, MSc (physiology), MSc (epidemiology), FRCPC, CSCN (EEG) is an Associate Professor of Neurology and clinician-scientist in the Department of Clinical Neurosciences and a member of the Centre for Health Informatics, O'Brien Institute for Public Health, and Hotchkiss Brain Institute at the University of Calgary. He completed his medical school and neurology residency at Dalhousie University and has completed fellowships in intracranial vascular malformations (University of Edinburgh) and epilepsy and EEG (University of Calgary). His major research interest has been the application of 'Big Data' and advanced analytics to better understand epidemiology and prediction problems in epilepsy.

PAME FACULTY BIOS



FRANCK KALUME, PhD

Associate Professor / University of Washington/ Seattle Children's

Franck Kalume, Ph.D. is an Associate Professor in the Departments of Neurological Surgery, Pharmacology, and Global Health at the University of Washington. He is also a Principal Investigator in the Center for Integrative Brain Research (CIBR) at Seattle Children's Research Institute. His research interests are focused on understanding the pathophysiological mechanisms of epilepsy and comorbid conditions in genetic refractory epilepsies.

IRIS-MARIA KILLINGER, DR. IUR

Oskar Killingier Foundation

Dr. Killinger is a criminal defense lawyer with a PhD in penal law. In 2019 she lost her son Oskar to SUDEP. Before, she had never been informed about this risk and his loss left her feeling illiterate. The Oskar Killingier Foundation was founded in 2020. The stopSUDEP campaign is fighting to raise SUDEP awareness and public education about epilepsy in Germany, Austria, and Switzerland.



ALISON KUKLA, MPH

Senior Manager, Programs and Partnerships / Epilepsy Foundation of America

Alison Kukla, MPH, is the Senior Manager for Programs and Partnerships at the Epilepsy Foundation where she provides leadership for the Foundation's SUDEP activities and bereavement support services. She is a public health professional and former staff in President Barack Obama's White House and United States Environmental Protection Agency. Alison has a Master of Public Health from Rollins School of Public Health at Emory University, and she is also a person with epilepsy having lived with active seizures since her diagnosis in 2006.

GARDINER LAPHAM, RN, MPH

BAND Foundation

Gardiner Lapham (RN/MPH) became a passionate epilepsy advocate after losing her 4-year-old son to SUDEP. She is former Board Chair of Citizens United for Research in Epilepsy (CURE Epilepsy) and a co-founder and current Chair of Partners Against Mortality in Epilepsy (PAME). Gardiner serves as a Trustee of the BAND Foundation where she oversees their epilepsy grants program.



NURIA LACUEY, MD, PHD, FAES

Associate Professor / University of Texas Health Science Center, Houston

Dr Nuria Lacuey Lecumberri received her medical training from the University of Navarra in Spain in 2007. She completed her residency in Neurology at Vall d'Hebron University Hospital in Barcelona in 2012. Subsequently, she trained in epilepsy and neurophysiology with a two year fellowship at Case Western Reserve University and joined the faculty there in 2016. She received her PhD (cum laude) at Autonomous University of Barcelona in 2018 for a thesis on sudden unexpected death in epilepsy. She was successfully

recruited July 2019 to McGovern Medical School as Assistant Professor with the Department of Neurology. Dr Lacuey's research is mainly SUDEP. In particular, her lab investigates brain respiratory control with the goal of using neuromodulation to enhance respiration after generalized convulsive seizures.

ERICA LEVITT, PHD

Associate Professor / University of Michigan

Dr. Levitt is an Associate Professor in the Department of Pharmacology and Department of Anesthesiology at the University of Michigan Medical School. She received a PhD in Pharmacology from the University of Michigan and a PharmD from Ohio Northern University. Her research is focused on how neural circuits that control breathing are impacted by drugs and disease.



HEATHER M. MACLEOD, MS CGC

Senior Project Manager / Data Coordinating Center for the SUID & SDY Case Registry

Heather MacLeod graduated from the Northwestern Genetic Counseling Program in 2001. She was one of the first genetic counselors to specialize in cardiovascular genetics. She is the Senior Project Manager for the Data Coordinating Center for the SUID and SDY Registry where she has been helping to develop and implement the registry since 2013. Heather is an active mentor and participant in many professional societies including the National Society of Genetic Counselors (NSGC), National Association of Medical Examiners (NAME), Heart Rhythm Society (HRS) and serves as a scientific advisor to the Sudden Arrhythmia Death Syndromes (SADS) Foundation.

KAYLI MANEY, MD

Third Year Neurology Resident / Duke University Hospital

Kayli obtained her Bachelor's and Medical degree from Florida State University. She then completed residency in Pediatric Neurology at Duke University. She is now completing a Clinical Neurophysiology Fellowship at Duke University. Her professional goal is to improve outcomes in patients with epilepsy, with a primary focus on medically refractory epilepsy and epilepsy surgery.

MARY ANNE MESKIS

Executive Director / Dravet Syndrome Foundation

Mary Anne is a founding member and the Executive Director of the Dravet Syndrome Foundation. She is a passionate advocate for the Dravet syndrome and rare epilepsy communities and has served on various working groups and industry advisory panels since her son was first diagnosed in 2004. While under her direction, DSF has placed a focus on research, as well as patient community engagement and education. She currently resides in western North Carolina with her husband and the youngest of her three children, Elliot, who has Dravet syndrome.

ILENE PENN MILLER, JD LLM

Director / Rare Epilepsy Network

Ilene Penn Miller is an epilepsy caregiver and thought leader with 20+ years' experience in nonprofit strategic planning, program execution and operations. Ilene Penn Miller serves as the Director for the Rare Epilepsy Network (REN) - 100+ rare epilepsy organizations working urgently to improve outcomes for patients through collaborative research. She served as Epilepsy Leadership Council Advocacy Co-Chair on the NIH National Institute for Neurological Disorders and Stroke (NINDS) Curing the Epilepsies Conference (2017-2021). Ilene is a former Advisor on the NIH NINDS Advisory Council (2013-2017). Ilene earned a B.S. in communications from Boston University; a J.D. from the Columbus School of Law (Washington, D.C.); an LLM in advocacy from Georgetown University Law Center (Washington, D.C.) and a Nonprofit Management Certificate from Georgetown University (Washington, DC). Publications include: Epilepsy Community at an Inflection Point: Translating Research Toward Curing the Epilepsies and Improving Patient Outcomes (Epilepsy Currents, June 2021); Rare Epilepsy Landscape Analysis & Appendix (RELA), and an editorial Raring For Change (Epilepsy & Behavior, 2020).



STEFANIE MINGEL

Family Advocate / Danny Did Foundation

Stefanie Mingel is a passionate epilepsy advocate. After losing her 21-month old daughter Emmy to SUDEP in 2013, Mingel became actively involved in the epilepsy community. She serves as an ambassador for the Danny Did Foundation, and has worked to raise awareness in her community both individually and through the Epilepsy Foundation of Florida, of which her husband is a former Board member. Mingel is passionate about raising SUDEP awareness, preventing seizure-related deaths and funding seizure detection devices for those who cannot afford them. She lives in Hollywood, Florida with her husband and three living daughters.

ROBERT MOSS

Co-Founder/President / Seizure Tracker LLC

As a parent of a child with Tuberos Sclerosis Complex and refractory Epilepsy, Robert is very aware of the importance of quality patient reported data in care provider and clinician communication. In 2007 he co-founded SeizureTracker.com, a web and mobile resource which empowers patients and care providers to collect personal seizure, treatment and lifestyle data and then easily share it with their clinicians. Reports created and shared through Seizure Tracker include a variety of data visualization tools allowing for longitudinal evaluation of therapy efficacy and its impact on seizure activity. Seizure Tracker has grown to be the largest collection of patient reported seizure activity in the world. Robert has been instrumental in establishing relationships within the epilepsy research community that facilitate the use of Seizure Tracker data to further our understanding of epilepsy and ultimately improve clinical outcomes.



KYLE PATTINSON DPHIL FRCA

Senior Clinical Research Fellow and Associate Professor / University of Oxford

Kyle Pattinson is a Senior Clinical Research Fellow and Associate Professor at the University of Oxford. He is also an Honorary Consultant anaesthetist at Oxford University Hospitals NHS Foundation Trust. His research centres upon investigating mechanisms of respiratory control using functional magnetic resonance imaging. This has mainly focused upon mechanistic and clinical studies of breathlessness,



RAJESH RAMACHANDRAN NAIR

Associate Professor, Pediatrics / McMaster Children's Hospital

Dr Rajesh Ramachandran Nair is pediatric epileptologist & neurologist at the McMaster Children's Hospital since 2006. He was the founding medical director of the Comprehensive Pediatric Epilepsy Program. His clinical care focus is medically refractory epilepsy, Ketogenic Diet and DEE/EE with Sleep Activation of Spike & Wave (SASW). Dr Ramachandran Nair is a program director for the International Child Neurology Teaching Network (ICNTN) by the International Child Neurology Association (ICNA), and the Canadian Epilepsy Teaching Network (CETN) by the Canadian League Against Epilepsy (CLAE). He is a member of the Adapt and Implementation Task Force of the International League Against Epilepsy (ILAE) Standards and Best Practice Council. He was a member of the department tenure & promotion committee, and the coordinator of the Pediatric Neurology Rounds. He is the Project ECHO (Epilepsy across the lifespan) Co- Hub lead for the McMaster Children's Hospital.



GEORGE RICHERSON, MD, PHD

Chairman, Neurology / University of Iowa

George Richerson, MD, PhD is Professor & Chairman of Neurology, and The Roy J. Carver Chair in Neuroscience at the University of Iowa. Dr. Richerson performs research on serotonin neurons and their role in control of breathing and arousal. These neurons are involved in the pathophysiology of sudden unexpected death in epilepsy (SUDEP) and sudden infant death syndrome (SIDS).

MEGAN J ROY-PUCKELWARTZ, PHD

Assistant Professor / Northwestern University Feinberg School of Medicine

Megan J Roy-Puckelwartz, PhD, is an Assistant Professor of Pharmacology and the Center for Genetic Medicine at Northwestern University Feinberg School of Medicine. Dr. Puckelwartz received her PhD in human genetics from the University of Chicago in 2009 and joined the faculty at Northwestern in 2014. She is an active member of the eMERGE Network and is director of the NuGene Project, the medical biobank at Northwestern.

PAME FACULTY BIOS CONTINUED



DAVID SCHLOBOHM
Bereaved Parent
and Advocate

I have been blessed with my wife Evonne for over 40 years. Together we raised our two beautiful daughters, Melissa and Stacy. Melissa passed away from SUDEP in 2022 at the age of 37. It has been traumatic for my family since we were not aware of SUDEP. I have been in business management for 35 years and use many of those skills advocating for SUDEP awareness.

KRISTINA SIMEONE, PHD

Associate Professor of
Pharmacology and Neuroscience
/ Creighton University School of
Medicine

Dr. Simeone's research on identifying preventative biomarkers and strategies for SUDEP was chosen for the 2020 'Best Basic Science Study in Epilepsy' Award by the International League Against Epilepsy. Dr. Simeone has chaired several scientific workshops for the American Epilepsy Society and Society for Neuroscience, has served on the Scientific Advisory Board for AES, and has served on multiple NIH



study sections. Dr. Simeone is a member of Creighton University's Strategic Planning Committee. For her commitment to teaching in the undergraduate, nursing, dental, graduate, and medical schools at Creighton, Dr. Simeone's students nominated her for the Golden Apple Excellence in Teaching Award.

SHOBI SIVATHAMBOO, PHD

Clinical Researcher / Monash
University and Alfred Health

Dr. Shobi Sivathamboo is a clinical researcher based at Monash University in Melbourne, Australia where she leads the SUDEP research group. Her interests include studying the national incidence and risk factors for SUDEP in Australia, identifying biomarkers for predicting SUDEP risk, examining cardiac and respiratory disease in people with epilepsy, and developing out-of-hospital non-invasive seizure detection devices for SUDEP prevention. She is also a current member of the International League Against Epilepsy (ILAE) SUDEP Task Force.



TOM STANTON
Executive Director /
Danny Did Foundation

Tom Stanton is the executive director of the Danny Did Foundation (DDF), a Chicago-based nonprofit that holds the mission to prevent deaths caused by seizures. DDF was founded in 2010 after the Sudden Unexpected Death in Epilepsy (SUDEP) of his nephew Danny at age 4. Tom serves in various leadership roles within the epilepsy community, including as Co-Chair of the Partners Against Mortality in Epilepsy (PAME) collaborative. He is thankful to have the chance to keep Danny's spirit alive through service to Danny Did.



MARTIN TRISTANI-FIROUZI, MD

Professor / University
of Utah School of Medicine

Dr. Tristani is pediatric cardiologist and clinician-scientist, who currently serves as Co-Director of the Center for Genomic Medicine, the University of Utah's premiere center for genomic innovation, discovery and the translation of genomic medicine into improved clinical care. His research is dedicated to the study of precision



cardiovascular medicine, focusing on inherited arrhythmias, sudden death in the young and congenital heart defects.



ROBYN WHITNEY, MD, FRCPC, CSCN (EEG)

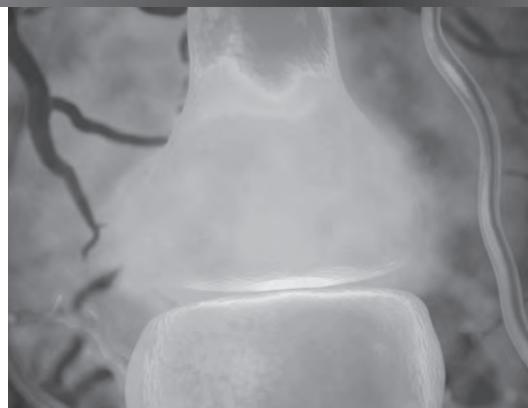
Pediatric Neurologist/Epileptologist
/ McMaster University, Hamilton,
Ontario, Canada

Dr. Robyn Whitney is a Pediatric Neurologist/Epileptologist and Assistant Professor in the Department of Pediatrics at McMaster University in Hamilton, Ontario, Canada. She obtained her medical degree and residency training in Pediatric Neurology at McMaster University and completed her fellowship in epilepsy at the Hospital for Sick Children in Toronto, Ontario. Dr. Whitney's clinical interests are in medically refractory epilepsy, developmental and epileptic encephalopathies, Tuberous Sclerosis Complex and epilepsy surgery. Dr. Whitney has an interest in medical education and her research interests are in epilepsy genetics, Tuberous Sclerosis Complex and SUDEP.

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Learn more about our many partnerships with epilepsy organizations to find the causes of SUDEP and to help and support the bereaved. Contact us at SUDEP@efa.org or epilepsy.com/SUDEP



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\$5.8M
AWARDED FOR SUDEP
PROJECTS TO DATE



40 SUDEP
PROJECTS
FUNDED



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YEAR WE LAUNCHED THE FIRST-EVER
PRIVATE RESEARCH PROGRAM TO
INVESTIGATE SUDEP AND ITS PREVENTION

CURE Epilepsy has been a leader in SUDEP research for almost 20 years.

We have funded research that showed a potential link between epilepsy and sudden death in children, established the first SUDEP registry, and demonstrated respiratory and cardiac risk factors may contribute to SUDEP.

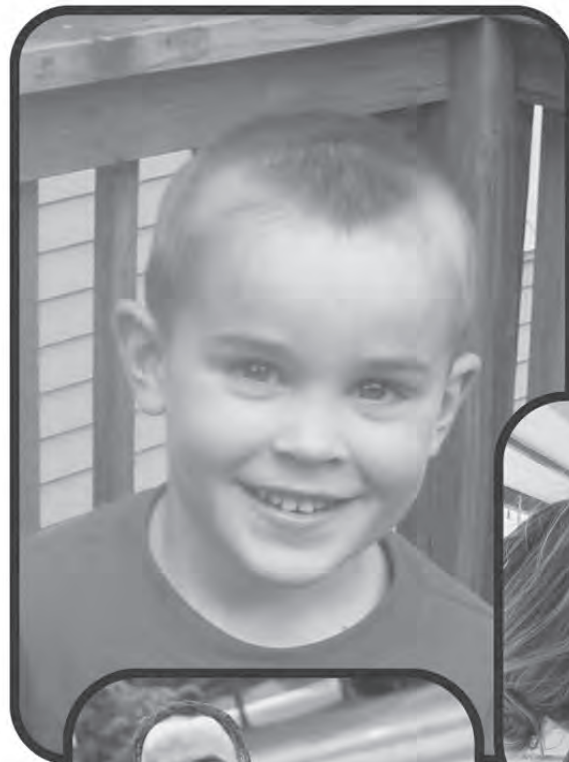
Our latest initiative focuses on SUDEP data standardization, which is intended to help increase the rigor, transparency, and translation of preclinical SUDEP research. SUDEP continues to be a priority area of focus for CURE Epilepsy, with new research initiatives in development for the coming year.

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memory, we work
to prevent
Sudden
Unexpected
Death in Epilepsy



Danny Did
FOUNDATION

Protecting People with Epilepsy



PAME ABSTRACTS

AWARD WINNERS

1. Impact of Comorbid Sleep Disorders on Mortality Risk in Patients with Epilepsy

M. Lazaj, MSc; G. Shukla, MBBS, MD, DM, FRCPC; L. Boissé Lomax, MD, MSc, FRCPC, CSCN; G. Winston, MD; A. Johnson, PhD; T. Derry, BScH

2. Disruption of Adenosine Metabolism in Mice Increases Risk of Seizure-Induced Death Despite Decreased Seizure Severity: Implications for SUDEP

B. Purnell, PhD; B. Rust, BS; J. Bhasin; T. Lu; S. George; K. Bah, BS; D. Fedele, PhD; D. Boison, PhD

3. Altered PI3K/mTOR Signaling Within the Forebrain Leads to Respiratory Deficits in a Mouse Model of SUDEP

P. Woller, BS; M. Rice, BS; D. Tiwari, PhD; C. Gross, PhD; S. Crone, PhD

BASIC MECHANISMS

4. Dysfunction of Central and Peripheral Circadian Clock Genes in Models of Absence and Temporal Lobe Epilepsy

P. Casillas-Espinosa, MD, PhD; G. Yamakawa, PhD; R. Lin, PhD; R. Mychasiuk, PhD; T. O'Brien, MD, PhD

5. Reduced GABA Uptake and Altered GABAergic Neurotransmission in Slc6a1(S295L) Knock-In Mouse Associated with Epileptic Encephalopathy

K. Zavalin, PhD; M. DeLeeuw, MS; K. Randhave, BS; J. Kang, MD

6. Abnormal Parvalbumin-Positive Interneuron Excitability in a Novel Mouse Model of Epileptic Encephalopathy Due to a Recurrent Kcnc1-p.A421V Variant

E. Wengert, PhD; M. Cheng, NA; E. Goldberg, MD, PhD

7. Effects of N-methyl D-aspartate (NMDA) Antagonists or an Angiotensin Receptor Blocker (ARB) on Seizure-Induced Respiratory Arrest (S-IRA) in the DBA/1 Mouse Model of SUDEP

C. Faingold, PhD; S. Louis, MS

8. Effects of Periaqueductal Gray (PAG) Stimulation on Respiration in the DBA/1 Mouse Model of SUDEP

C. Faingold, PhD; S. Louis, MS

9. Glycinergic Neurons Contribute to Features of Dravet Syndrome

B. Milla, MS; D. Mulkey, PhD

10. Altered Kcnh2/Kv11.1 Expression in the Brain and Heart, and Prolongation of Cardiac Repolarization in a Rabbit Model of Long QT Syndrome with Seizures

K. Wagner, BS; D. Auerbach, PhD; R. Ebrahimi, MS; K. Keller, MS; J. Ryan, PhD; R. Wojcikiewicz, PhD

11. Opto and Chemogenetic Dissection of Neural Circuitry Involved in Seizure-Induced Apnea

I. Wenker, PhD; M. Patel, PhD

12. Neuronal Plasticity Leads to Seizure-Induced Apnea

A. Brodovskaya, PhD; N. Adotevi, PhD; J. Kapur, MD, PhD

13. Genetic Mapping Using Collaborative Cross Mice Resource Identifies Novel Candidate Genes of SUDEP Susceptibility

B. Gu, PhD; J. Xenakis, PhD; T. Shannon, BS; T. Bell, PhD; B. Philpot, PhD; F. Pardo Manuel de Villena, PhD

14. Time-of-Day Dependent Mortality from Spontaneous Seizures Persists in Constant Darkness in the Scn1aR1407X/+ Mouse Model of Dravet Syndrome

B. Kreitlow, MS; A. Novella Maciel; A. Hernandez-Vasquez; G. Buchanan, MD, PhD

15. Apnoeas and Diaphragm EMG During Spontaneous Tonic-Clonic Seizures in a Rat Model of Temporal Lobe Epilepsy

K. Liska, PhD; A. Pant; B. Krajcovic, PhD; J. Jefferys, PhD, FAES, FMedSc

16. Brainstem "failure" and the window for resuscitation after respiratory arrest in rats

R. Gurevich; C. Joseph; A. Daniels; R. Kollmar, PhD; N. Cipriano; E. Cohen; S. Tominaga, MD; K. Sundaram, MD; J. Silverman, MD, PhD, and M. Stewart, MD, PhD

TRANSLATIONAL RESEARCH

17. Failure to Breathe Persists Without Air Hunger or Alarm Following Amygdala Seizures

A. Rhone, PhD; C. Kovach, PhD; S. Kumar, PhD; M. Mowla, PhD; G. Richerson, MD, PhD; J. Wemmie, MD, PhD; B. Dlouhy, MD

18. Stability of Hypercapnic Ventilatory Response on Repeated Measurements over Time in Patients with Epilepsy

R. Sainju, MBBS; D. Dragon, BS; J. Kuhn, RRT; J. Michelson, RRT; L. Wendt, MS; P. Ten Eyck, PhD; G. Richerson, MD, PhD; B. Gehlbach, MD

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Reference:

1. Data on file. Survey Report. LivaNova USA, Inc. Houston, TX. October 2021.



19. Cardiac Electrical Function Surrounding Seizures in Dravet and Lennox-Gastaut Syndromes

J. Ryan, PhD; A. Aschner, PhD; E. Donner, MD, MSc, FRCPC; D. Auerbach, PhD

20. Personalization of SUDEP Risk: A Survey of Transient Subclinical Comorbidities

K. Simeone, PhD; D. Martenz, BS; S. Iyer, MS; S. Matthews, MS; E. Donner, MD; S. Lhatoo, MD; T. Simeone, PhD

21. Reduced Epilepsy Morbidity and Mortality upon Gene Replacement Therapy in Succinic Semialdehyde Dehydrogenase Deficiency (SSADHD)

A. Liebhardt, BS; G. McGinty, BS; P. Pearl, MD; G. Gao, PhD; H. Lee, MPhil, PhD; A. Rotenberg, MD, PhD

22. Use of Pharmacokinetics to Establish an Optimal Dosing Regimen for a Triple-drug Therapy in a Mouse Model of Dravet Syndrome

J. Mensah, MS; K. Johnson, BS; C. Metcalf, PhD; C. Reilly, PhD; J. Rower, PhD; K. Wilcox, PhD

23. Spontaneous Epileptiform Discharges in a Genetic Rabbit Model of Kcnn2-Mediated Seizures, Long QT Syndrome, and Sudden Death

V. Singh, BS; K. Wagner, BS; J. Ryan, PhD; D. Auerbach, PhD

24. Beta-blocker Atenolol Reduces Cardiac-mediated Mortality in Preclinical Mouse Model of Sudden Unexpected Death in Epilepsy

M. Soh, PhD; E. Mohamed Syazwan, BSci (Hons); A. Kuanyshbek, MD; H. Lee, MD; C. McKenzie, BSci (Hons); M. Phillips, PhD; L. Bleakley, PhD; I. Scheffer, MD, PhD; S. Berkovic, MD; C. Semisarian, MD, PhD; C. Reid, PhD

25. Identifying Children with Febrile Seizures at Risk for Sudden Death

L. Gould, MSc, MA, PT; O. Devinsky, MD; T. Wisniewski, MD; E. Oermann, MD

26. Creation of Data Standardization Tools to Improve Translation of Preclinical Sudden Unexpected Death in Epilepsy (SUDEP) Research

L. Harte-Hargrove, PhD; L. Lubbers, PhD

27. Circadian Rhythm and Sleep in Focal Epilepsy

K. Ernst, MD; B. Erhard; J. Rémi, Reviewer

NEUROPHYSIOLOGY

28. Insights from Neuropixel Recording in the Respiratory Brainstem in Acute Kainate Rodent Seizing Deaths

R. Budde, BS; L. RoaFiore, BS, MS; P. Irazoqui, PhD

29. Increased GABAergic Neuronal Activity in the Lateral Septum Is Associated with Cortical Slow Waves and Impaired Consciousness in an Awake Mouse Model of Temporal Lobe Seizures

J. Liu, PhD; H. Blumenfeld, PhD, MD; S. Liu, BS; L. Sieu, PhD

CLINICAL EPILEPSY

30. Data Collection System for Seizure Monitoring with Wearable Sensors

M. Jackson, BA; J. Tang, PhD; X. Wang, MD, PhD; R. El Atrache, MD; T. Sheehan, BS; S. Cantley, BS; S. Yu, PhD; U. Asif, PhD; J. Rogers, PhD; I. Mareels, PhD; S. Harrer, PhD; T. Loddenkemper, MD

31. Ictal Asystole: Epilepsy, Arrhythmia, or Syncope?

J. Wiseman, MD; C. Richardson-Olivier, MD; A. Potash, MD; N. Medvinsky, NP; J. Bluvstein, MD; J. Paolicchi, MD

32. EMBRAVE: A Clinical Trial of PRAX-222, a Novel Antisense Oligonucleotide, in Pediatric Participants with Early Onset SCN2A Developmental and Epileptic Encephalopathy

S. Frizzo, MD; B. Spar, BS; K. Dalby, MEd; D. Patel, MBBS, MPH; H. Jacotin, MD; M. Souza, PharmD, MBA; S. Petrou, PhD

33. Exploring the Relationship Between Epilepsy and Epileptic Heart: A Cross-Sectional Analysis

C. Torres Romero, MD; P. Romaña Espíritu, MD; J. Macías de la Cruz, MD; V. Gómez Arias, MD; C. Ixcamparij Rosales, MD; C. González Gutiérrez, MD; L. Núñez Orozco, MD; I. Martínez Juárez, MD, MSc

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PAME ABSTRACTS

CONTINUED

NEUROIMAGING

34. Causal Connectivity of the Amygdala Inhibition of Respiration (AIR) Site to Whole Brain Using Concurrent Electrical Stimulation and fMRI (esfMRI)

S. Kumar, PhD; H. Oya, MD; A. Rhone, PhD; C. Kovach, PhD; M. Mowla, PhD; A. Chan, MD; J. Wemmie, MD; G. Richerson, MD; B. Dlouhy, MD

COMORBIDITY

35. Elevated Mortality Rate in Patients with Functional Seizures After Diagnosis and Referral

N. Robinson-Mayer, LMSW; E. Patterson, PhD; I. O'Sullivan, BA; f. Hobatch, BA; K. Darpel, MD; P. Patel, MD; G. Winder, MD; N. Beimer, MD; W. Kerr, MD

ANTI-SEIZURE MEDICATION

36. Stiripentol Efficacy Against SUDEP and SE-associated Mortality

A. Bacq, PhD; A. Robert, MS; P. Cloarec, MS; I. Heulard, MS; C. Lesueur, MS; E. Simon O'Brien, PhD; P. Girard, PhD; V. Castagné, PhD

37. Effect of Stiripentol on Lethal Audiogenic Seizures in the LAGS+ Selected Mouse Line Used as a Model of SUDEP

B. Martin, PhD; G. Dieuset, MS; A. Biraben, MD

38. EMBOLD: A Clinical Trial of PRAX-562 in Subjects with Developmental and Epileptic Encephalopathies Followed by an Open-Label Extension

B. Pfister, PhD, MBA; B. Spar, BS; K. Dalby, MEd; S. Frizzo, MD; D. Patel, MBBS, MPH; H. Jacotin, MD; S. Petrou, PhD; M. Souza, PharmD, MBA

39. Evaluation of Electrodermal and Cardiac Activity from Wearables Before and After Anti-Seizure Medication Intake

F. Mohammad Alizadeh Chafjiri, MD; E. Peter, BA; L. Voke, BS; S. Cantley, BA; M. Jackson, BA; S. Vieluf, PhD; T. Loddenkemper, MD

DIETARY THERAPY

40. Dietary Whey Reduces Mortality in a Dravet Syndrome Mouse Model of SUDEP by Promoting Recovery from Apnea

E. Bravo, PhD; F. Teran, MD, PhD; Y. Kim, PhD; A. Kelley; M. Crotts; C. Enyart; J. Kasuya, PhD; T. Kitamoto, PhD; G. Richerson, MD, PhD

HEALTH SERVICES

41. Communication About Sudden Unexplained Death in Epilepsy

K. Maney, MD; I. Pallotto, MPH; S. Bansal, BS; R. Shellhaas, MD, MS; S. Patel, MD; Z. Grinspan, MD; J. Buchhalter, MD, PhD; E. Donner, MD, MSc, FRCPC; G. Lapham, MPH, RN; T. Stanton, MPP; M. Lemmon, MD

42. Bridging the Gap Between Neurologists and People with Epilepsy/Caregivers: Systematic Literature Review About SUDEP Conversations

J. Luker, BA (Hons); P. Rylvlin, MD; T. Stanton, MPS; S. Shaw, PhD; K. Mearns, MBiochem

EPIDEMIOLOGY

43. The Incidence of Sudden Unexpected Death in Epilepsy (SUDEP) in Ireland

Y. Langan, MD, MRCPI; E. Lynn, PhD

44. Impact of Day of Admission on Mortality and Other Outcomes in Status Epilepticus: A Nationwide Analysis

A. Sawalha, MD; K. Sawalha, MD

PUBLIC HEALTH

45. SUDEP in Historically Minoritized Patient Groups: Using Lessons Learned from the COVID-19 Crisis to Develop a Proactive Prevention Model

H. Bender, PhD; R. Beattie, JD, PhD; G. Meli, BS; A. Sacks-Zimmerman, PhD; K. Katsman, MA; J. Spat-Lemus, PhD

ACCEPTED AND NOT ABLE TO ATTEND PAME

- **Sex-based Effects on Mitochondrial Function in a Mouse Model of Dravet Syndrome**
J. Aldridge, BS; A. Franklin, BS; C. Frasier, PhD

- **Mitochondrial Deficits May Support SUDEP in a Murine Pilocarpine Model of Temporal Lobe Epilepsy**
C. Frasier, PhD; J. Aldridge, BS; A. Franklin, BS

- **Eavesdropping on Thalamo-Cardiac Interactions During Seizures and Sleep for Biomarker Discovery of SUDEP Vulnerable Periods**
A. Kachhvah, PhD; Y. Vakilna, MS; O. Alamoudi, PhD; S. Suresh, MBBS; S. Pati, MD

- **Decreased Cholinergic Neuronal Activity in a Mouse Model of Impaired Consciousness in Temporal Lobe Seizures**
S. Liu, BS; P. Paszkowski; L. Sieu, PhD; J. Liu, PhD; M. Valcarce-Aspegren, MD; W. Khan, MD; S. Mcgill, PhD; D. Lee; A. Duque, MD; H. Blumenfeld, MD, PhD

- **Prediction of Sudden Unexpected Death in Epilepsy in Dravet Syndrome Mice by Non-Invasive Behavioral Monitoring at a Pre-Epileptic Age**
Y. Niibori, PhD; D. Hampson, PhD

- **Functional Connectivity of Arousal Structures Across Vigilance States: Relationship to Impaired Neurocognition in Epilepsy**
H. Pourmotabbed, MS; C. Martin, BS; S. Goodale, BS; D. Doss, BS; J. Shless, BS; S. Wang, MS; V. Morgan, PhD; D. Englot, MD, PhD; C. Chang, PhD

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PAME ABSTRACTS

- **Short-term Effects of Auricular Vagus Nerve Stimulation on T-Wave Alternans in People with Epilepsy**
J. Pukropski, MD; J. Baumann, PhD; A. Jordan, MD; R. von Wrede, MD; R. Surges, Prof

- **Kv3.1 Potentiation Mitigates Seizures in a Mouse Dravet Syndrome Model**
S. Vermudez, PhD; R. Lin, MS; G. McGinty, BS; A. Liebhardt, BS; B. Hui, BS; H. Lee, PhD; M. Sahin, MD, PhD; A. Rotenberg, MD, PhD

- **Age-Related Arousal Network Connectivity Changes in Temporal Lobe Epilepsy**
A. Gummadavelli, MD; D. Doss, BS; G. Johnson, PhD; J. Shless, BS; M. Jacobs, PsyD; K. Haas, MD, PhD; S. Bick, MD; D. Terry, PhD; C. Chang, PhD; V. Morgan, PhD; D. Englot, MD, PhD

- **Complicated Effects of Selective Serotonin Reuptake Inhibitors on Spontaneous Seizure-induced Mortality in Dravet Mice**
D. Min, BS; Y. Zhou, BS; E. Farrell, BS; H. Feng, PhD

- **Unique Autonomic Circuit Contributions to Seizures, Cardiorespiratory Dysfunction, and Premature Mortality in the Kv1.1 Knockout Mouse Model of SUDEP**
K. Paulhus, BS, MS; E. Glasscock, PhD; F. Kizek, BS; M. Parkinson, BS

- **A Brazilian SCN8A-related Epilepsy Cohort**
C. Cukiert, MD, MSc; V. Lessa, MD; J. Vieira, MD; J. Oliveira, MD; J. Burattini, MD; R. Guimaraes, MD; A. Cukiert, PhD, MSc, MD

- **5-HT2A/C Receptor Located in the Basolateral Amygdala Is Involved in Seizure-induced Respiratory Arrest in DBA/1 Mice SUDEP Models**
Y. Wang, BS; Q. Xu, BS; Y. Shen, BS; L. Gu, PhD; H. Zhang, PhD

- **The Contribution of 5-HT2c Receptor in Non-fatal Ventilatory Alterations in Model of Temporal Lobe Epilepsy in Rat**
H. Kouchi, PhD; J. Smith, PhD; B. Georges; L. Bezin, PhD; S. Rheims, MD, PhD

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CONGRATULATIONS to PAME 2023 Abstract Award Winners



MARION LAZAJ, MSc | Queen's University

Impact of Comorbid Sleep Disorders on Mortality Risk in Patients with Epilepsy

M. Lazaj, MSc; G. Shukla, MBBS, MD, DM, FRCPC; L. Boissé Lomax, MD, MSc, FRCPC, CSCN; G. Winston, MD; A. Johnson, PhD; T. Derry, BScH

BENTON PURNELL, PHD | Rutgers University

Disruption of Adenosine Metabolism in Mice Increases Risk of Seizure-Induced Death Despite Decreased Seizure Severity: Implications for SUDEP

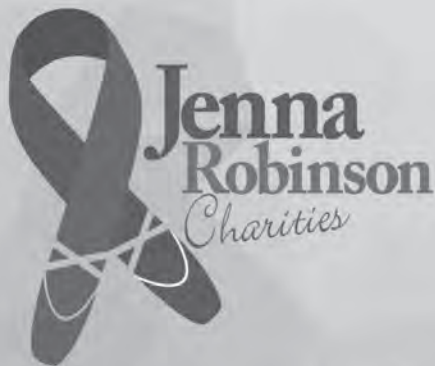
B. Purnell, PhD; B. Rust, BS; J. Bhasin; T. Lu; S. George; K. Bah, BS; D. Fedele, PhD; D. Boison, PhD

PATRICK WOLLER, BS | University of Cincinnati

Altered PI3K/mTOR Signaling Within the Forebrain Leads to Respiratory Deficits in a Mouse Model of SUDEP

P. Woller, BS; M. Rice, BS; D. Tiwari, PhD; C. Gross, PhD; S. Crone, PhD

Jenna Robinson Charities operates to raise awareness and funding for Epilepsy and SUDEP research.



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2023 PAME Conference

www.jennarobinsoncharities.org
info@jennarobinsoncharities.org



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Partners Against Mortality in Epilepsy

AES

AMERICAN EPILEPSY SOCIETY

EARLY CAREER GRANTS PROGRAM

PAME is partnering with the American Epilepsy Society to fund ideas that advance SUDEP Summit priorities through the AES Early Career Grants program. Trainees, fellows, and newly independent investigators are encouraged to apply through one of the AES Early Career Grant Programs:

Predocctoral Research Fellowships | up to \$30,000
Postdoctoral Research Fellowships | up to \$50,000
Research and Training Fellowship for Clinicians | up to \$50,000
Junior Investigator Awards | up to \$50,000
Epilepsy Study Consortium Mini-Grant | up to \$22,000 (for epilepsy fellows)

Specifically, PAME is interested in funding projects to advance priorities that will impact SUDEP prevention in the next 5 years. These priorities include:

- 1. Use of seizure detection devices in clinic:** How can devices be leveraged for SUDEP prevention in the clinic? How can technology design better meet the identified needs of patients and caregivers?
- 2. Leverage EHR to guide clinician actions:** Where are opportunities to maximize electronic health records (EHR) to guide clinical actions around SUDEP risk mitigation?
- 3. Projects which include understanding the mechanism of death in a proposed animal model of SUDEP**

Applications due January 12, 2023
Go to aesnet.org/early-career for more information

PAME WEBINARS



WEBINARS ON WEBSITE :

- **Devices For Epilepsy:** Current Options and the Future Pipeline
- **SUDEP Biomarkers:** How Close Are We?
- **Key Learnings and Next Steps From the NIH funded Center for SUDEP Research**
- **Sleep, Night, and SUDEP**
- **Understanding Disparities in Epilepsy Mortality:** Global and national perspectives
- **Grief and Death in Epilepsy:** Learning From Loss
- **Speaking About SUDEP:** Arming the Rare Epilepsy Community with the Latest Research
- **SUDEP Biomarker Challenge:** What Did We Learn?
- **SUDEP Communication:** Understanding the caregiver perspective and developing a SUDEP conversation guide

<https://pameonline.org/past-webinars/>

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<https://www.facebook.com/PAMEOnline>

PAME is a proud partner of the Epilepsy Foundation Seizure Safe Nation Campaign



Join the online conversation on SUDEP using #StarttheSUDEPConvo

We are doing our part to help
#StartTheSUDEPConvo

Learn about seizure first aid at <https://learn.epilepsy.com/>

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info@hopeforhh.org

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