

**Family Day Program 2026:
Wednesday, December 2nd, 1:30 – 5:30 PM MT**

1:30 PM	Welcome Remarks Mary Duffy, The Danny Did Foundation
1:50 - 2:20 PM	Understanding the Past & Present for a Better Tomorrow Jeff Buchhalter, MD, PhD, PAME Co-Chair
2:20 - 2:30 PM	BREAK
2:30 - 2:40 PM	Local Family Story Granting Comfort & Hope Julie Hutchison, Chelsea's Mom
2:40 – 3:25 PM Moderator: Mary Duffy, The Danny Did Foundation	Keynote Holding Grief, Honoring Love: Finding Compassion, Connection, and Care After Loss Grief changes us because love changes us. Yet we don't often recognize that connection. Instead, our fast-paced society may pressure us to "move on" or "let go," when in reality grief is not something to get over. Grief is something to be witnessed and given space. In this keynote, we'll explore how to make room for both the pain and the beauty of grief while learning to care for ourselves with compassion as we continue honoring the love that remains. Speaker: Laura Vargas, MSW, LCSW, Peer Support Community Partners
3:25 – 4:10 PM Moderator: Alison Kukla, MPH, Partners Against Mortality in Epilepsy	Panel Discussion Turning Grief into Action This interactive panel discussion includes individuals who have lost loved ones to epilepsy. They will share their personal stories of loss and their unique efforts to raise SUDEP and epilepsy awareness in memory of their loved ones. Panelists: - Corey Widman and Kelly Sweeney-Widman, Widdy's Work - Luis de la Rosa and Gladys Garzon, FightLikeTania - Brian and Traci Abeyta, Lincoln's Law
4:10 – 4:15 PM	BREAK

4:15 – 5:20 PM	Community Connection Tables These interactive networking roundtables will allow individuals to share their stories, discuss their grief, and learn about available resources. Moderator: • Sarah Waters, MSW, ASW, Epilepsy Foundation of San Diego County
5:20 – 5:30 PM	Closing Remarks • Alison Kukla, MPH, Partners Against Mortality in Epilepsy
5:30 – 6:00 PM	BREAK
6:00 – 7:30 PM	Welcome Reception Open to All PAME Conference Attendees Sponsored by Neurelis

Draft PAME Conference Program 2026
Thursday, December 3rd, 8:00 AM – 5:00 PM MT

8:00 – 8:15 AM	Welcome and Overview of the Day Gardiner Lapham, RN, MPH, Partners Against Mortality in Epilepsy
8:15 – 9:00 AM	KEYNOTE PLENARY Honoring NINDS's Transformational Leadership in SUDEP Research <i>Opening Remarks: Jeff Buchhalter, MD, PAME Co-Chair</i> <i>Keynote Address: Walter Koroshetz, MD, Former NINDS Director</i> For nearly two decades, the National Institute for Neurological Disorders and Stroke (NINDS) has helped transform SUDEP from an overlooked phenomenon into a major area of scientific inquiry through visionary leadership and sustained investment in epilepsy research. This opening plenary honors NINDS's lasting impact with a special award presentation, followed by keynote remarks from former NINDS Director Dr. Walter Koroshetz, reflecting on the evolution of epilepsy and SUDEP research, progress to date, and opportunities to further reduce epilepsy-related mortality.
9:00 – 10:30 AM Moderators: Lisa Bateman, MD, Cedars-Sinai and Laura Lubbers, PhD, CURE Epilepsy	PLENARY 1 SUDEP Research: Progress and the Path Forward The scientific community has made strong strides in understanding SUDEP, one of the most devastating consequences of epilepsy and the leading cause of epilepsy-related mortality. While much work remains to be done, the field has built an important foundation of scientific knowledge. In this session, pioneers who helped establish the field, alongside voices shaping its future, will examine the progress achieved to date and the priorities and opportunities that will drive the path forward for SUDEP research and prevention. Faculty: - Matthew Summerfield, University of Iowa - Lina Nashef, Kings College Hospital London - George Richerson MD, PhD, University of Iowa - Vicky Whittemore, PhD, NIH / NINDS
10:30 – 10:45 AM	BREAK
10:45 AM – 12:15 PM Moderators: Elizabeth Donner, MD, MSc, FRCPC, The	BREAKOUT #1 The Epileptic Heart This session will examine the bidirectional relationship between epilepsy and cardiovascular health, focusing on the emerging concept of the epileptic heart. Speakers will discuss the cardiac effects of recurrent seizures and anti-seizure medications (ASMs), as well as current insights into the mechanisms underlying sudden unexpected death in epilepsy (SUDEP). Through

Hospital for Sick Children, Toronto	clinical and translational perspectives, the session will highlight advances in understanding heart–brain interactions and their implications for improving patient care and reducing SUDEP risk.
10:45 AM – 12:15 PM Moderators: Tom Stanton, The Danny Did Foundation & Dominique Brown, Epilepsy Foundation of America	BREAKOUT #2 Policy, Practice, and Implementation: Aligning Partners to Reduce Epilepsy Mortality This breakout session will explore the growing movement to improve awareness, communication, and public health responses surrounding epilepsy-related mortality, with a particular focus on the successful passage of Colorado SB26-077. Through perspectives from families, clinicians, advocates, lawmakers, and community stakeholders, we will examine the importance of SUDEP disclosure, accurate death certification practices, and multidisciplinary collaboration in advancing epilepsy safety. The session will conclude with an interactive panel discussion and audience Q&A designed to foster shared learning and actionable ideas for improving care, communication, and prevention efforts nationwide.
12:15 – 1:15 PM	LUNCH Science Networking Lunch sponsored by Care & Cure Institute
1:15 – 2:45 PM Moderators: Gordon Buchanan, MD, PhD, University of Iowa and William Nobis, MD, PhD, Vanderbilt University	BREAKOUT #3 SUDEP and Breathing: State of the Science in Respiratory and Arousal Mechanisms This session explores the physiological mechanisms linking seizures to respiratory dysfunction and SUDEP. Speakers will present recent findings on the neural circuitry underlying seizure-induced respiratory arrest, the role of failed autoresuscitation, and how seizures impair hypercapnic ventilatory responses and arousal. By highlighting the latest basic science, the panel aims to identify novel pathways and future directions for understanding and preventing SUDEP. Faculty: • Amanda Gardland, Bereaved Parent • William Nobis, MD, PhD, Vanderbilt University • Ryan Budde, PhD, University Washington / Seattle Children's • Frida Teran, MD, PhD, University of Iowa
1:15 – 2:45 PM Moderators: Robyn Whitney, MD, McMaster Children's Hospital and Caitlin Grzeskowiak, PhD, Epilepsy Foundation of America	BREAKOUT #4 Preventing death in epilepsy: Communication, Technology & Targeted Interventions Despite recommendations from several clinical guidelines, SUDEP is still not routinely discussed with persons with epilepsy (PWE) and their caregivers. Globally, there is a pressing need to educate health care providers on SUDEP communication and disclosure, so that PWE and their caregivers are properly informed about the potential risks of SUDEP and SUDEP prevention. Artificial intelligence (AI) based SUDEP simulators provide a novel and potentially large-scale training tool for health care providers to learn about SUDEP communication and disclosure, which will be reviewed in this session. Communication around the use of wearable devices and monitors will also be discussed, with a review of current guidelines and position statements. Both caregiver and health care providers' experiences with seizure detection devices will further be explored. Finally, we will

	conclude with a discussion on mental health screening in PWE and review current support models and tools for intervention for both anxiety and depression. Faculty: ● Andy Baskerville, Epilepsy Advocate ● Daniel Friedman, MD, NYU Langone Health ● Itay Tokatly Latzer, MD, Tel Aviv Medical Center ● Heidi Munger Clary, MD, MPH, Wake Forest University
2:45 – 3:00 PM	BREAK
3:00 – 4:30 PM Moderators: Elaine O’Loughlin, PhD, CURE Epilepsy, Lindsey Morgan, MD, Seattle Children’s Hospital, & Maureen Slotnick, MSW, MBA, Epilepsy Foundation of America	PLENARY #2 Different Ages, Different Risks: Mortality Across the Epilepsy Lifespan The session will explore mortality through the lifespan. Speakers will focus on children, young and middle-aged adults, and older adults, with considerations of the unique aspects of social determinants of health and mortality risks in each age group. Faculty: ● Jason Raether, Nurse and Epilepsy Advocate ● Lindsey Morgan, MD, Seattle Children’s Hospital ● Rebecca Garcia-Sosa, MD, Lurie Children’s Hospital of Chicago ● Emily Johnson, MD, MPH, Johns Hopkins School of Medicine
4:30 – 5:00 PM	Abstract Winners & Closing Audience Reflections
5:00 – 6:30 PM	Poster Session and Reception