



Partners Against Mortality in Epilepsy

# 2024 SPONSORSHIP PACKAGE



**Family Day – December 4, 2024**  
**PAME Conference – December 5, 2024**

Los Angeles, CA

## BACKGROUND & STRUCTURE

Partners Against Mortality in Epilepsy (PAME) was created in 2012 to respond to the urgent public health problem that people living with epilepsy are three times more likely to die prematurely than the general population. PAME started as a multi-stakeholder conference focused on raising awareness and understanding of all forms of preventable epilepsy-related mortality, including suicide, accidents, status epilepticus, and Sudden Unexpected Death in Epilepsy (SUDEP). PAME represents a diverse and growing group of individuals - those impacted by epilepsy, medical professionals, nonprofit champions, pharma representatives and government leaders - who come together to advance awareness and prevention of mortality.

PAME is a coalition, originally founded by the American Epilepsy Society, the Danny Did Foundation, CURE Epilepsy, and the Epilepsy Foundation. The American Epilepsy Society serves as PAME's fiscal agent and provides in-kind program assistance. The Leadership Committee is made up of representatives from PAME's founding partners and key constituents (families, researchers, clinicians). PAME is led by a mother who lost her son to epilepsy.



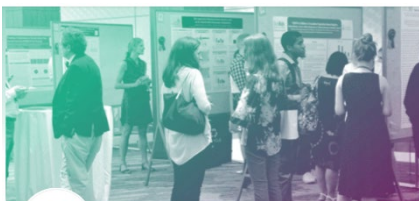
## MISSION & ACTIVITIES

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 mortality.

In 2021, after coordinating six successful meetings and growing a strong and diverse community, PAME's stakeholders decided to evolve the effort beyond a biennial conference. The newly energized partnership, **PAME 2.0, now amplifies its reach in the following ways:**

- Hosting an annual 1-day multi-stakeholder conference in advance of AES
- Offering an annual family day focused on supporting bereaved families
- Providing educational opportunities throughout the year – webinars & SUDEP Day
- Convening committees around specific opportunities that address gaps in the field
- Partnering with AES on a SUDEP research grant award

## PARTNERSHIPS & OUTREACH



PAME is made up of more than 12 nonprofit/advocacy groups from within the epilepsy community along with many physicians, researchers and bereaved families. With the recent expansion of programming beyond the biennial conference, we are rapidly building our email and social platforms. As our community grows, partnering with PAME offers an impactful way to educate and inform.

- Email distribution list: 886 people
- Facebook followers: 393
- Unique website visitors last 30 days: nearly 1,000
- Average webinar registration: 100 people

## WHY SUPPORT PAME?

PAME is the only effort in the US whose sole focus is on mortality and its prevention. A partnership approach to understanding and preventing mortality is critical to accelerating change, creating urgency, and demonstrating ownership in a problem that all people with epilepsy share in.

PAME is very proud of the broad and diverse support it has grown over the years and is interested in developing deeper relationships with new and old sponsors so that we can work together to more quickly advance understanding and prevention. As always, we welcome a range of support and in 2024 offer the following opportunities for our industry partners.



## 2024 PAME CONFERENCE PARTNER– Los Angeles, CA

The **PAME Conference** is the partnership's flagship event and occurs in advance of the Annual AES meeting each year. PAME partners play an important role in its planning and in dissemination of conference proceedings to patients, families, researchers, clinicians, and others. PAME meetings are scientifically rigorous and informed by the experiences of people impacted and bereaved by epilepsy. They are cross-sectoral in nature and include updates and discussion on the latest basic and clinical research, as well as directions in awareness and education. While SUDEP remains a thrust of the conference, other causes of mortality continue to be elevated. PAME maintains a special focus on younger investigators and highlights their work through a competitive abstract selection process. In 2023, PAME accepted 50 abstracts for presentation at the post-conference reception. Additionally, PAME hosted its first ever science networking lunch for young investigators to meet more established researchers and physicians.

The goals of the conference include:

- Critically evaluate mortality incidence, risk factors, and prevention strategies
- Describe the progress made and future directions for research
- Provide opportunities for networking and collaborations among stakeholders, including people with epilepsy, researchers, families, clinicians, and advocates
- Serve as a source of comfort and information for those who are bereaved
- Promote advocacy skills to build public awareness and impact public policy
- Encourage early career investigators to study causes of mortality in epilepsy



In 2023, more than 250 registered for the Conference, including 100 advocates/families and more than 150 medical professionals. Over 75 people registered for the Family Day meeting, held the day before the conference.

## 2024 Conference Support Opportunities and Benefits

Support Level	Support Amount	Conference Comp Registrations	Program book ad size	Logo on promo emails	6-foot tabletop exhibit on 12/5	Dedicated social media thank you	Logo on meeting signage	Logo on website
Breakthrough	\$20,000	10	1 page	X	X	X	X	X
Visionary	\$15,000	6	1 page	X	X	X	X	X
Discovery	\$10,000	3	½ page	X	X	X	X	X
Innovator	\$5,000	2	¼ page			X	X	X
Insight	Up to \$2,500	2					X	X

## 2024 WEBINAR PARTNER

As part of its mission to educate, PAME is planning at least 4 webinars in 2024. Webinars are free to join and are geared toward PAME's multiple audiences. While some content might be technical, PAME strives to educate all who are interested. Examples of past webinar topics include:

- *International Epilepsy Awareness Day 2023: Understanding the Global Burden of epilepsy mortality and the importance of reducing stigma in low-income countries.*
- *SUDEP: Common misconceptions*
- *How family led organizations are changing the face of SUDEP prevention.*
- *Epilepsy surgery and long-term survival in children with epilepsy.*



The 2023 webinars averaged 100 live participants with an additional 75 views of the recording on the website. The SUDEP misconceptions webinar stands at over 650 views, showing the desire for this type of education. Webinar audiences included professionals and the lay public.

## Webinar Sponsorship Opportunities and Benefits

### Webinar Sponsor - \$2,500

- Exclusive sponsor for a single webinar
- Recognition and logo in promotion of webinar (emails and social media)
- Recognition at beginning and end of webinar
- Recognition on the PAME website where the webinar will live as an enduring asset

### Webinar Series Sponsor - \$15,000

- Sponsor for 2023 PAME webinar series
- Minimum of 4 webinars
- Recognition and logo in promotion of all webinars (emails and social media)

**Thank you for your consideration!** Please contact Gardiner Lapham ([gardinerlapham@gmail.com](mailto:gardinerlapham@gmail.com)) and Anne Gramiak ([agramiak@aesnet.org](mailto:agramiak@aesnet.org)) for more information.