

2025 SUDEP Action Day Communications Toolkit

Each year, PAME and its partners recognize SUDEP Action Day, a day devoted to raising awareness around the world about sudden unexpected death in epilepsy (SUDEP) and inspiring action to save lives. On Wednesday, October 15, 2025, join PAME and some of its partners — American Epilepsy Society, The Addison Hutchinson Foundation, The Anita Kaufmann Foundation, The Cameron Boyce Foundation, Canadian Epilepsy Alliance, The Child Neurology Foundation, CURE Epilepsy, The Danny Did Foundation, Dravet Syndrome Foundation, Epilepsy Alliance America, Epilepsy Foundation, Epilepsy Canada, FUNDHEMI, HOPE for HIE, Kayven's Helping Hands, Landon's Legacy Foundation, Oskar Killinger Foundation, Pediatric Epilepsy Surgery Alliance, Rare Epilepsy Network, SUDEP Action, and TSC Alliance — by continuing the conversation about SUDEP and risk prevention. Only by talking about SUDEP, what it is, and how to prevent it, can we reduce the risk.

This year's theme, *"Hope Begins with a Conversation"*, empowers all to talk openly about SUDEP risks and prevention because every conversation can be a step toward safety, understanding, and hope. Many who have lost loved ones to epilepsy wish a conversation had taken place.



Below you will find a few assets you can use to recognize SUDEP Action Day. This year we'll be doing a week of messaging, and the toolkit is broken into daily themes. Please share with your community and on your social media channels.

Social Media Sample Posts

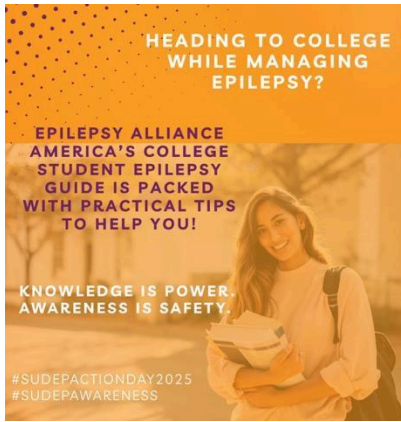
Thursday, October 9th: Awareness: The First Step Towards Prevention


 <p>AWARENESS IS THE FIRST STEP TOWARDS PREVENTION.</p> <p>EMPOWER ALL TO TALK OPENLY ABOUT SUDEP RISKS AND PREVENTION BECAUSE EVERY CONVERSATION CAN BE A STEP TOWARD SAFETY, UNDERSTANDING, AND HOPE.</p> <p>#SUDEPACTIONDAY2025 #SUDEPAWARENESS</p> <p> HTTPS://PURPLEDAYEVERYDAY.ORG/WP-CONTENT/UPLOADS/2022/05/SUDEP-FLYER-2022-WEB.PDF</p>	<p>FB/IG/LinkedIn: When communities openly discuss SUDEP, stigma fades, and more support, resources, and research follow. That's how awareness becomes the first step toward prevention. Together, let's raise awareness. Learn more about SUDEP @Anita Kaufman Fnd https://purpledayeveryday.org/wp-content/uploads/2022/05/SUDEP-Flyer-2022-WEB.pdf</p> <p>#SUDEPACTIONDay2025 #SUDEPAwareness</p>
	<p>X: Awareness is more than knowing it's a bridge to action and safety. Understanding SUDEP helps families, individuals, and clinicians work together toward prevention. Learn more about SUDEP from @Anita Kaufman Fnd: https://purpledayeveryday.org/wp-content/uploads/2022/05/SUDEP-Flyer-2022-WEB.pdf</p>

 <p>HAVING A SURGICAL EVALUATION ISN'T A DECISION: IT'S A STEP TOWARD UNDERSTANDING EVERY OPTION.</p> <p>Does Epilepsy Surgery Extend Life? Sudeep J. Patel, MD, FAHA, FAHA Associate Professor of Neurological Surgery and Biomechanics Chief, Pediatric Neurosurgery University of Pittsburgh School of Medicine UPMC Children's Hospital of Pittsburgh</p> <p>#SUDEPACTIONDAY2025 #SUDEPAWARENESS</p> <p> WWW.YOUTUBE.COM/WATCH?V=6OYSSRY_RWE</p>	<p>FB/IG/LinkedIn: Too many families never hear that epilepsy surgery can save their child's life. Having a surgical evaluation isn't a decision; it's a step toward understanding EVERY option. Start by watching this important webinar by @Pediatric Epilepsy Surgery Alliance and @DEE-P. https://www.youtube.com/watch?v=6OysSry_RwE</p> <p>#SUDEPACTIONDay2025 #SUDEPAwareness</p>
	<p>X: Too many families never hear that epilepsy surgery can save their child's life. Having a surgical evaluation isn't a decision; it's a step toward understanding EVERY option. Start by watching this important webinar by @Pediatric Epilepsy Surgery Alliance and @DEE-P. https://www.youtube.com/watch?v=6OysSry_RwE</p>


<p>EPILEPSY SURGERY IMPROVES SURVIVAL IN CHILDREN WITH DRUG-RESISTANT SEIZURES.</p>  <p>#SUDEPACTIONDAY2025 #SUDEPAWARENESS</p> <p>pediatric epilepsy surgery alliance  HTTPS://EPILEPSYSURGERYALLIANCE.ORG/2023/06/15/EPILEPSY-SURGERY-IMPROVES-SURVIVAL/</p>	<p>FB/IG/LinkedIn: Epilepsy surgery can dramatically improve survival for children with drug-resistant epilepsy. Research shows that children with drug-resistant seizures have a 10-year survival rate of 98% with surgery, compared to 89% without it. Our advocacy partners at the @Pediatric Epilepsy Surgery Alliance explain the research in this important blog post: https://epilepsysurgeryalliance.org/2023/06/15/epilepsy-surgery-improves-survival/</p> <p>#SUDEPAActionDay2025 #SUDEPAwareness</p>
	<p>X: Epilepsy surgery can dramatically improve survival for children with drug-resistant epilepsy. Research shows a 10-year survival rate of 98% with surgery vs. 89% without. Learn more from our partners at the @Pediatric Epilepsy Surgery Alliance: https://epilepsysurgeryalliance.org/2023/06/15/epilepsy-surgery-improves-survival/</p>

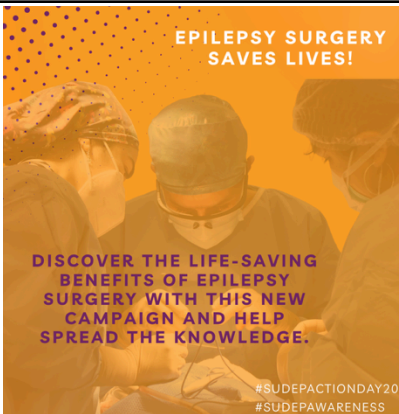
Friday, October 10th: Safety: Empowering People with Knowledge and Tools

 <p>HEADING TO COLLEGE WHILE MANAGING EPILEPSY?</p> <p>EPILEPSY ALLIANCE AMERICA'S COLLEGE STUDENT EPILEPSY GUIDE IS PACKED WITH PRACTICAL TIPS TO HELP YOU!</p> <p>KNOWLEDGE IS POWER. AWARENESS IS SAFETY.</p> <p>#SUDEPACTIONDAY2025 #SUDEPAWARENESS</p>	<p>FB/IG/LinkedIn: Heading to college while managing epilepsy? You're not alone, and you don't have to figure it all out yourself.</p> <p>@Epilepsy Alliance America's free College Student Epilepsy Guide is packed with practical tips to help you:</p> <ul style="list-style-type: none">• A seizure-safe dorm room checklist• Tips for better sleep & seizure monitoring• Reduce SUDEP risks• Prioritize your mental health• How to talk to roommates, professors, and RAs about safety <p>Knowledge is power. Awareness is safety. Download the guide today. https://epilepsyallianceamerica.org/wp-content/uploads/2025/08/Epilepsy-College-Student-E-Book.pdf</p> <p>#SUDEPAActionDay2025 #SUDEPAwareness</p>
	<p>X: Starting college with epilepsy? @Epilepsy Alliance America's free guide covers everything from creating a seizure-safe dorm to managing meds, mental health, and SUDEP risk reduction. Download now: https://epilepsyallianceamerica.org/wp-content/uploads/2025/08/Epilepsy-College-Student-E-Book.pdf</p>

 <p>HONORING KAYVEN: EMPOWERING PEOPLE WITH KNOWLEDGE AND TOOLS TO TALK ABOUT SUDEP.</p> <p>#SUDEPACTIONDAY2025 #SUDEPAWARENESS</p>	<p>FB/IG/LinkedIn: Kayven Hopper was an adventurous, imaginative, and loving soul who filled every space with laughter and light. Though he passed away from epilepsy in November 2023, his memory lives on through @Kayven's Helping Hands Foundation.</p> <p>Through three powerful pillars - Literacy, Enrichment, Epilepsy Empowerment - the foundation is creating opportunities for kids to explore, imagine, and thrive. By honoring Kayven's passion for adventure and discovery, we're helping children everywhere experience the magic he embodied.</p> <p>Together, we can make sure every child has the chance to dream big, just like Kayven. kayvenshelpinghands.org Learn more & get involved!</p> <p>#SUDEPAActionDay2025 #SUDEPAwareness</p>
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	<p>X: Honoring Kayven's spirit through @Kayven's Helping Hands Foundation, empowering kids to explore, imagine & thrive!</p> <p>Literacy Enrichment Epilepsy Empowerment</p> <p>Join us: sponsor a Little Free Library, support the Enrichment Fund & Raise Epilepsy Awareness. Learn more: kayvenshelpinghands.org</p>
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	<p>FB/IG/LinkedIn: Living with epilepsy means living with risks — but knowledge changes everything. Katja (41) shows how health literacy can turn fear into safety and treatment into partnership. Understanding the type of epilepsy — genetic, structural, immune, or metabolic — is key to finding the right therapy. Each cause carries its own risks and determines which treatment will work — and which will fail. Knowing whether seizures are focal or generalized can open doors to surgery, targeted medication, stimulation devices, or dietary approaches. Katja's story proves: when doctors share openly and patients ask informed questions, treatment becomes teamwork — and real choices for the future emerge. Learn more: https://sudep.de/</p> <p>#SUDEPAActionDay2025 #SUDEPAwareness</p>
	<p>X: Living with epilepsy means living with risks — but knowledge changes everything. Katja (41) shows how understanding your epilepsy type + asking informed questions turns fear into safety & treatment into partnership. Knowledge = choices. Choices = better futures. Learn more: https://stopsudep.de/</p>

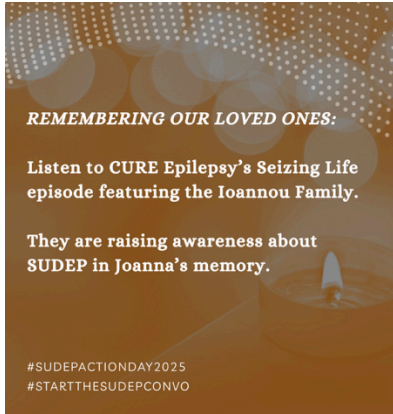
	<p>FB/IG/LinkedIn: Did you know that the likelihood of a person with epilepsy dying due to SUDEP is 1 in 1,000, and the risk increases significantly if the person has drug-resistant epilepsy. For someone with drug-resistant epilepsy, the chances of dying due to SUDEP rises to 1 in 150. Epilepsy surgery can reduce that risk by 300%! Explore the life-saving nature of epilepsy surgery here from @Pediatric Epilepsy Surgery Alliance: https://epilepsysurgeryalliance.org/about/epilepsy-surgery-saves-lives/</p> <p>#SUDEPAActionDay2025 #SUDEPAwareness</p>
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X: Did you know? The risk of SUDEP is 1 in 1,000 for people with epilepsy — but rises to 1 in 150 for those with drug-resistant epilepsy. Epilepsy surgery can reduce that risk by 300%!


Learn more about this life-saving option @Pediatric Epilepsy Surgery Alliance:

<https://epilepsysurgeryalliance.org/about/epilepsy-surgery-saves-lives/>



Saturday, October 11th: Stories: Voices of Loss, Love, and Hope

 <p>REMEMBERING OUR LOVED ONES:</p> <p>Listen to CURE Epilepsy's Seizing Life episode featuring the Ioannou Family.</p> <p>They are raising awareness about SUDEP in Joanna's memory.</p> <p>#SUDEPACTIONDAY2025 #STARTTHESUDEPCONVO</p>	<p>FB/IG/LinkedIn: On October 1st: @CURE Epilepsy released a Seizing Life episode on SUDEP, featuring the Ioannou Family of the @Joanna Sophia Foundation.</p> <p>Through courage and advocacy, the Ioannou Family shares their story to honor Joanna's memory and raise critical awareness about SUDEP and epilepsy.</p> <p>Save the date and tune in to hear their journey, learn more, and discover how we can all work together to prevent SUDEP.</p> <p>Learn more about the Joanna Sophia Foundation: https://joannasophiafoundation.org/</p> <p>Watch Seizing Life: https://www.cureepilepsy.org/seizing-life/</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo</p>
	<p>X: On October 1: @CURE Epilepsy released a powerful Seizing Life episode on SUDEP, featuring the Ioannou Family of the @Joanna Sophia Foundation.</p> <p>Don't miss their moving story and advocacy for epilepsy awareness.</p> <p>https://joannasophiafoundation.org/ https://www.cureepilepsy.org/seizing-life/</p>

 <p>REMEMBERING OUR LOVED ONES:</p> <p>We honor JaCorey, a kind-hearted soul whose laughter filled every room.</p> <p>#SUDEPACTIONDAY2025 #STARTTHESUDEPCONVO</p>	<p>FB/IG/LinkedIn: We honor JaCorey, a kind-hearted soul, photographer, USPS mail carrier, and someone whose laughter filled every room. His life ended too soon due to SUDEP, but his story shines on. Let's talk openly about epilepsy and SUDEP so more families aren't left unprepared. Share, learn, and advocate.</p> <p>https://www.epilepsy.com/stories/honoring-jacorey-life-joy-strength-and-love</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo</p>
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	<p>X: We honor JaCorey, a kind-hearted soul, talented photographer, dedicated USPS mail carrier, and someone whose laughter lit up every room. His life was tragically cut short by SUDEP. Let's break the silence on epilepsy & SUDEP so more families are informed and supported.</p> <p>https://www.epilepsy.com/stories/honoring-jacorey-life-joy-strength-and-love</p>
	<p>FB/IG/LinkedIn: If a risk is not known, it cannot be managed. This is especially true for SUDEP – Sudden Death in Epilepsy. Oskar died in 2019, unaware of this risk – as were we, his family. A fate shared by so many families around the world. Talking about SUDEP is not about creating fear, but about creating support. Awareness builds confidence to act – at school, at work, in sports, and in everyday life. The more SUDEP is acknowledged, the more people with epilepsy can rely on understanding, preparedness, and care. A community becomes a safety net when people know what to look for, how to respond, and why awareness matters. -Iris, Oskar's mum</p> <p>Learn more: https://sudep.de/</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo</p>
	<p>X: “If a risk isn't known, it can't be managed.” Oskar died in 2019, unaware of SUDEP, and so was his family. Talking about SUDEP isn't about fear; it's about support, awareness & action. Knowledge saves lives. Awareness builds safety. -Iris, Oskar's mum</p> <p>Learn more: https://stopsudep.de/</p>

Sunday, October 12th: Stories: Voices of Loss, Love, and Hope

	<p>FB/IG/LinkedIn: Family members are invited to share a memory of their loved one on the @Partners Against Mortality in Epilepsy (PAME) conference digital memory wall and virtual memory wall on Facebook. Please use this form http://bit.ly/4fVll9j to submit a picture and share a short memory of your loved one. If you submitted a picture for a prior conference, we will continue to use it until we hear from you again. Please email questions to pame@aesnet.org</p> <p>#SUDEPACTIONDAY2025 #StartTheSUDEPConvo</p>
	<p>X: Families are invited to honor their loved ones on the PAME Conference Memory Wall & the Virtual Memory Wall on Facebook. Share a photo + short memory using this form: http://bit.ly/4fVll9j</p> <p>Questions? Email pame@aesnet.org</p>
	<p>FB/IG/LinkedIn: Every child deserves the joy of learning, the thrill of play, and the strength of faith. @The Addison Hutchison Foundation honors Addison's beautiful spirit by providing children with educational, athletic, and spiritual support. Because when we nurture the whole child - their mind, body, and heart - those 'Happy Days' truly are the best days. Learn more, get involved, and share the love. https://www.theaddisonhutchisonfoundation.org/</p> <p>#SUDEPACTIONDAY2025 #StartTheSUDEPConvo</p>
	<p>X: Every child deserves the joy of learning, the thrill of play & the strength of faith.</p> <p>The Addison Hutchison Foundation honors Addison's spirit by supporting kids' education, athletics & faith. Learn more & get involved: https://www.theaddisonhutchisonfoundation.org/</p>





FB/IG/LinkedIn: If you've lost a loved one due to epilepsy, please know you're not alone. Join the @Epilepsy Foundation's Virtual Bereavement Support Groups to connect with others who understand and have experienced a similar loss. Available for both adults and young adults. For more information and to register, please email sudep@efa.org.




#SUDEPActionDay2025 #StartTheSUDEPConvo

X: Join the @Epilepsy Foundation's Virtual Bereavement Support Groups to connect with others who understand. Sessions are available for adults & young adults. Email sudep@efa.org to learn more & register.

Monday, October 13th: Health Care Providers: Their Role in Risk Reduction

 <p>#SUDEPACTIONDAY2025 #STARTTHESUDEPCONVO #SUDEPAWARENESS</p>	<p>FB/IG/LinkedIn: People living with epilepsy and their families deserve clear, compassionate information about SUDEP and epilepsy-related risks. Awareness leads to informed choices and safer lives.</p> <p>@The Danny Did Foundation urges healthcare professionals to talk about SUDEP early in the care journey and follow up at future appointments as circumstances and risks evolve.</p> <p>Talking about SUDEP isn't frightening; it's a vital step toward safety and understanding.</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness #DannyDid</p>
	<p>X: People with epilepsy & their families deserve clear, compassionate info about SUDEP. Awareness = informed choices & safer lives. @The Danny Did Foundation urges healthcare providers: talk about SUDEP early & often as risks evolve. It's not frightening, it's life-saving.</p>

 <p>#SUDEPACTIONDAY2025 #STARTTHESUDEPCONVO #SUDEPAWARENESS</p>	<p>FB/IG/LinkedIn: In a recent quality improvement survey asking healthcare providers about SUDEP, 36% of healthcare providers said they worry discussing SUDEP might cause extra stress or anxiety for patients and families.</p> <p>But many individuals affected by epilepsy say they want honest, early conversations. Finding the right balance matters. Thank you, @TSC Alliance, for this research. http://bit.ly/47BjSDh</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness</p>
	<p>X: In a recent survey, 36% of providers said they worry that discussing SUDEP may cause extra stress for patients & families. But many people with epilepsy want honest, early conversations. Finding the right balance matters. Thank you, @TSC Alliance, for this research. http://bit.ly/47BjSDh</p>

 <p>HEALTH CARE PROVIDERS: THEIR ROLE IN RISK REDUCTION</p> <p>AN IMPORTANT STEP IN YOUR CARE IS MAKING SURE YOU GET THE BEST QUALITY CARE POSSIBLE.</p> <p>FIND AN EPILEPSY SPECIALIST IN YOUR AREA.</p> <p>#SUDEPACTIONDAY2025 #STARTTHESUDEPCONVO #SUDEPAWARENESS</p> <p>  HTTPS://MY.AESNET.ORG/FINDADOCTOR</p>	<p>FB/IG/LinkedIn: Safety is a top priority when managing your epilepsy. Building your healthcare team can help reduce your risk for SUDEP. Visit the @American Epilepsy Society website to find specialty care and discuss how to reduce risks for SUDEP: https://my.aesnet.org/findadoctor</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness</p>
	<p>X: Safety is a top priority when managing your epilepsy. Building your healthcare team can help reduce your risk for SUDEP. Visit the @American Epilepsy Society website to find specialty care and discuss how to reduce risks for SUDEP: https://my.aesnet.org/findadoctor</p>


Tuesday, October 14th: Research: Driving Innovation to Understand and Prevent SUDEP

	<p>FB/IG/LinkedIn: You have the right to life-saving information. Seizure detection devices can help keep you safe by notifying your loved ones during a seizure. Learn more about SUDEP and explore devices with resources from @DannyDidOrg: https://www.dannydid.org/devices-technology/. Stay informed and take steps to protect yourself and those you love.</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness #DannyDid</p>
	<p>X: You have the right to life-saving info. Seizure detection devices can alert loved ones during a seizure. Learn more via @DannyDidOrg: https://www.dannydid.org/devices-technology/</p>
	<p>FB/IG/LinkedIn: Sudden Unexpected Death in Epilepsy (SUDEP) research has been slowed by inconsistent data collection across studies. That's why @CURE Epilepsy launched the Preclinical SUDEP Common Data Elements (CDEs), a framework designed to standardize SUDEP data across animal model studies.</p> <p>By unifying the way researchers collect and report information—such as seizure activity, posture at time of death, physiological measures, and neurological findings—these tools make studies more comparable, transparent, and impactful.</p> <p>https://www.cureepilepsy.org/for-researchers/research-resources/sudden-unexpected-death-in-epilepsy-sudep-cdes/</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness</p>
	<p>X: @CURE Epilepsy's Preclinical SUDEP CDEs standardize data across studies, making research more consistent, comparable, and collaborative. Together, we can accelerate progress toward prevention.</p> <p>https://www.cureepilepsy.org/for-researchers/research-resources/sudden-unexpected-death-in-epilepsy-sudep-cdes/</p>

	<p>FB/IG/LinkedIn: @CURE Epilepsy research reveals that generalized tonic-clonic seizures at night, particularly for individuals sleeping alone, greatly increase SUDEP risk. Ongoing data analysis and a recent expert workshop are driving progress in risk assessment. This is how science brings prevention within reach. Learn more: https://www.cureepilepsy.org/research-discoveries/sorting-out-sudep-seeking-the-causes-finding-those-at-risk/</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness</p>
	<p>X: @CURE Epilepsy research shows nighttime generalized tonic-clonic seizures, especially when sleeping alone, greatly increase SUDEP risk. Ongoing analysis and expert insights are bringing prevention closer. Learn more: https://www.cureepilepsy.org/research-discoveries/sorting-out-sudep-seeking-the-causes-finding-those-at-risk/</p>
	<p>FB/IG/LinkedIn: In a quality improvement survey, 27% of caregivers and individuals with @TSC reported learning about SUDEP more than five years after diagnosis. Yet, 40% said they would have preferred to hear about SUDEP at the time of diagnosis.</p> <p>Early conversations matter. Let's bridge the gap in epilepsy education. http://bit.ly/47BjSDh</p> <p>#SUDEPActionDay2025 #StartTheSUDEPConvo #SUDEPAwareness</p>
	<p>X: In a recent survey, 27% of people with @TSC & caregivers learned about SUDEP 5+ years after diagnosis, yet 40% said they wanted to know at diagnosis. Early conversations matter. Let's close the gap in epilepsy education. http://bit.ly/47BjSDh</p>

Wednesday, October 15th: Community: Working Together to Talk Openly about SUDEP

[illegible]

<p>#SUDEPACTIONDAY2025 #SUDEPAWARENESS</p>  <p>→ https://pameonline.org/event/2025-pame-conference</p>	<p>FB/IG/LinkedIn: The 2025 @PAME meeting will be held at the Omni Atlanta Hotel at Centennial Park in Atlanta, GA, on December 4th, 2025, with the family session occurring the day before on December 3rd. The meeting will be held ahead of the annual @American Epilepsy Society Conference (December 5th - 9th, 2025). Check out the program! https://pameonline.org/event/2025-pame-conference/</p> <p>#SUDEPActionDay2025 #SUDEPAwareness #StartTheSUDEPConvo #HopeStartsNow</p>
	<p>X: The 2025 PAME Conference is set for Dec 4 at the Omni Atlanta Hotel, with a special family session on Dec 3.</p> <p>Held just before the @American Epilepsy Society Conference (Dec 5–9). Check out the program & join us!</p> <p>https://pameonline.org/event/2025-pame-conference/</p> <p>-AES</p>

Social Media Graphics:

SUDEP Action Day 2025 Social Media Graphics Can Be Found [HERE](#).

*If you have any problems accessing the files, please contact Alison Kukla (alison.kukla@outlook.com).

Partner Resources:

- American Epilepsy Society: <https://my.aesnet.org/findadoctor>
- The Addison Hutchison Foundation: <https://www.theaddisonhutchisonfoundation.org/>
- The Anita Kaufmann Foundation: <https://purpledayeveryday.org/>
- The Cameron Boyce Foundation: <https://www.thecameronboycefoundation.org/>
- Canadian Epilepsy Alliance: <https://www.canadianepilepsyalliance.org/>
- The Child Neurology Foundation: <https://www.childneurologyfoundation.org/>
- CURE Epilepsy: <https://www.cureepilepsy.org/>
- The Danny Did Foundation: <https://www.dannydid.org/>
- Dravet Syndrome Foundation: <https://dravetfoundation.org/>
- Epilepsy Alliance America: <https://epilepsyallianceamerica.org/>
- Epilepsy Foundation: <https://www.epilepsy.com/>
- Epilepsy Canada: <https://www.epilepsy.ca/>
- FUNDHEMI: <https://fundhemi.org/>
- HOPE for HIE: <https://hopeforhie.org/>
- Kayven's Helping Hands: <https://www.kayvenshelpinghands.org/>
- Landon's Legacy Foundation: <https://www.landonslegacyfoundation.org/>
- Oskar Killinger Stiftung: <https://sudep.de/>
- PAME: <https://pameonline.org/>
- Pediatric Epilepsy Surgery Alliance: <https://epilepsysurgeryalliance.org/>
- Rare Epilepsy Network: <https://www.rareepilepsynetwork.org/>
- SUDEP Action: <https://sudep.org/>
- TSC Alliance: <https://www.tscalliance.org/>

SUDEP Action Day Events and Offerings:

Wednesday, October 1st: CURE Epilepsy Seizing Life Episode

- Seizing Life is a CURE Epilepsy podcast and videocast aiming to inspire empathy, offer helpful stories, and give hope as we search for a cure for epilepsy. Listen as guests share stories and insights on living with epilepsy in conversation with our host, Kelly Cervantes. The October 1st Seizing Life episode will be on SUDEP, featuring the Ioannou Family of the Joanna Sophia Foundation.

Sunday, October 5th, 9AM - 12PM MST | Scottsdale, AZ: Landon's Legacy at Butterfly Wonderland

- Join Landon's Legacy Foundation for a free and exclusive gathering at Butterfly Wonderland, a place that now holds a deeply personal tribute to their son Landon, whose life continues to inspire every act of service through the foundation. Open to the community!
- Sign up here: <https://givebutter.com/ra0CBS>

Wednesday, October 15th, 10AM PST | 1PM EST: Pediatric Epilepsy Surgery Alliance Webinar

Sharing the Sibling Experience: Insights from Adult Siblings

- Join Emily Holl, Director of the Sibling Support Project, along with adult siblings who grew up in families shaped by drug-resistant epilepsy and epilepsy surgery. We'll explore the emotional impact of growing up with a medically complex sibling, how roles evolve into adulthood, and strategies to support all children in the family. (For teen or adult siblings and caregivers. Please note: discussion will include SUDEP.)
- Register here:
<https://us02web.zoom.us/meeting/register/AWrw-RlKSqeYDcz7Jd5trw#/registration>

CNF's New Grief Community: Willow and Wind

- This November, CNF is launching *Willow and Wind*, a grief community for families who have lost children of all ages. The group will meet during the first three weeks of November. The sessions are completely free. Additional information on the program is below. Beginning in January, they'll expand the program to include an online community, podcast, and monthly meetup. Over time, this space will grow to support families experiencing all types of grief. CNF will continue to keep the community updated as it develops.
- Use this link to sign up and share it with people who may be interested in joining:

<https://www.surveymonkey.com/r/BN2DY2Z>

2025 PAME Family Day and Conference:

Wednesday, December 3rd: Family Day

- Family Day is an afternoon session designed to support bereaved members through building community, providing education, and identifying engagement opportunities. Participants can expect to hear personal stories and learn about advocacy initiatives aimed at bringing about positive changes. Bereaved adults, professionals, and advocates are welcome to join us as we hear from those who have researched, studied, or experienced loss in their own lives. Due to the sensitive nature of the content and other considerations, it is encouraged that participants be over the age of 18.

Thursday, December 4th: Scientific Conference

- 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 the planning and 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 discussions 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.
- More information:
<https://pameonline.org/event/2025-pame-conference/>

Hashtags:

- #SUDEPAwareness
- #StartTheSUDEPConvo
- #HopeStartsNow
- #BreakDownBarriers
- #SUDEPActionDay2025

CNF's New Grief Community: Willow and Wind



Willow and Wind- A Grief Community Program



Willow and Wind is a grief support program that honors both the tenderness of loss and the strength found in remembrance. The willow symbolizes resilience, flexibility, and grace—able to bend in sorrow without breaking. The wind represents the forces of change, the unseen currents of memory, emotion, and healing. Together, Willow and Wind reflects the journey through grief: unpredictable yet survivable, painful yet filled with moments of quiet strength, love, and transformation.

The Willow and Wind Grief Course is a three-week program where families come together to share, learn, and heal in a safe and supportive space. Each meeting is guided by our certified counselor, Brad.

Goals of the Willow and Wind course

- Provides professional, compassionate grief support when families need it most
- Breaks isolation by creating connection and shared healing
- Expands understanding of grief—including invisible and anticipatory grief
- Builds a lasting resource that grows with families and honors their lived experiences

When does it start?

The first group begins **November 2025**. You will receive an email with the meeting link one week before each session.

What happens during the sessions?

Together, we will explore:

- Introductions and setting expectations
 - The unique and personal nature of grief
 - Two rails of grief:
 - *Missing and Remembering*
 - *Writing New, Honoring Chapters*
 - The emotions of grief
 - Stages of adapting to a life we didn't choose
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Do I have to share?

No. This group is here for whatever you need—listening, sharing, or simply being present.

What if I want private support?

Brad has set aside time outside of group sessions for one-on-one conversations.

What else is part of the program?

This grief course is just the beginning. Our broader grief support community includes:

- An **online community** for parents and caregivers (January 2026)
 - A **grief podcast** with stories, expert perspectives, and tools (January 2026)
 - **Community education** on topics such as SUDEP and seizure detection (Ongoing)
 - Future offerings, including **anticipatory grief courses** and support for non-bereavement grief
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How do I sign up for the Willow and Wind Grief Course?

- You can register via the link accompanying the invitation email. You can also reach out to programs@childneurologyfoundation.org.

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