

Seizing Life, episode 85
Addressing and Reducing Epilepsy-Related Deaths
Guest: Gardiner Lapham
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

Kelly Cervantes: 00:18 Today on Seizing Life, I'm happy to welcome back to the show, Gardiner Lapham. Gardiner is a longtime advocate for epilepsy awareness and research, and the recipient of the American Epilepsy Society's 2021 Extraordinary Contributions to the Field of Epilepsy Award. She is a former CURE Epilepsy board chair, and a trustee of the BAND Foundation, which supports SUDEP prevention and education work. As well as efforts to reduce the treatment gap in low-income countries.

Kelly Cervantes: 00:46 Gardiner is also a co-founder and three-time chair of PAME, a collaboration of epilepsy organizations, providers, patients, and families, that she is here to tell us about today. Gardiner, thank you so much for joining us today. You are truly one of the original pioneers in SUDEP awareness and research, and I'm just so thrilled to have you here today. To start, why don't you tell us a little bit about PAME and what it stands for?

Gardiner Lapham: 01:16 Well, first of all, just thanks, Kelly, for having me here. You're amazing and what you've done and all the awareness you've created. So, you and CURE are a force and I am so happy to be here, and I'm really happy that you all are having me on to talk about PAME and to shine a light on its work, because it's a really exciting initiative. So, PAME, stands for Partners Against Mortality in Epilepsy, and it is a multi-stakeholder collaborative. It's not its own organization, but it's housed within the American Epilepsy Society.

Gardiner Lapham: 01:55 And it was created to bring professionals together with people with epilepsy and the bereaved, to come around a common agenda. So, PAME's mission is to convene, educate, and inspire all stakeholders, from people living with epilepsy, to bereaved, to researchers, healthcare providers, medical examiners, to bring them all together, to promote understanding and drive prevention around epilepsy related mortality.

Kelly Cervantes: 02:28 I want to get into some of the specifics of what PAME does, but before that, I want to discuss your personal connection to PAME. What drove you to found it and your personal connection to epilepsy?

Gardiner Lapham: 02:44 Well, I didn't found it alone. PAME was founded by a group of individuals and organizations who wanted to come together to

advance this work. CURE was a founding partner along with the Epilepsy Foundation, American Epilepsy Society, and Danny Did. But I was drawn to this effort, because as you know, I lost my son, as you lost your daughter to epilepsy, both of them just little ones. Henry died when he was four, unexpectedly and suddenly. And it was only a very short time after his epilepsy diagnosis.

- Gardiner Lapham: 03:26 And this was about almost 14 years ago, Kelly, when not a lot was going on in the SUDEP research and awareness world. Actually, CURE was really the only one out there providing research grants in the space. So, I started to search for answers and was frustrated that there wasn't enough going on. So, in PAME, I saw the promise of bringing people with epilepsy and the bereaved together with professionals, to be part of the solution, to work in partnership with these professionals. I knew that together, we could really make a difference and that the family voice and experience was an important part of making change.
- Kelly Cervantes: 04:16 I couldn't agree with you more, that patient-driven awareness that we have seen be so impactful, both in the epilepsy community and beyond. So, getting specifically into what it is that PAME, what are the initiatives? What are PAME's goals and what has it accomplished over ... I mean, I guess PAME's actually been around for a little while now.
- Gardiner Lapham: 04:42 Yeah, it actually, it has. It's hard to believe PAME's first meeting was 12 years ago. So, PAME started out as a conference that was held every two years. It was two and a half days long. And its goal then was to create awareness and understanding around these issues. And in recent years, we have evolved to provide more educational and ongoing content. So, we're still doing the conferences, and there will be one this year on December first, in Nashville, the day before the AES annual meeting.
- Gardiner Lapham: 05:17 But then, we are going to continue to roll out more webinars. We started that effort last year and this year we'll have a number of other webinars. So, please check out our website, pameonline.org, to find out more information about the conference and the webinars. And then, in addition to educational content, PAME wants to evolve to convene partners and individuals to identify, where are the gaps in the field and how can we work collaboratively to make progress on areas that are currently being overlooked?

Kelly Cervantes: 05:55 And for those who may not be aware, AES is the American Epilepsy Society. And they have a big meeting once a year with researchers and clinicians and presenting science and different studies. And it is a brilliant bringing together of epilepsy minds, to really push that science forward. So, it makes so much sense that PAME would be housed within AES and would have their meeting in conjunction with that larger meeting.

Kelly Cervantes: 06:25 We've talked a lot about SUDEP, unfortunately, on this podcast. It's not a comfortable topic, but I think those of us who have lived within this space for quite some time, feel the urgency and the need for us to speak about it. But that is not the only way that someone can lose their life to epilepsy. What are the other ways that we see mortality in epilepsy?

Gardiner Lapham: 06:55 Okay. That is very true. So, overall, people with epilepsy have a three times greater risk of dying prematurely than the general population. And PAME really tries to focus on the preventable causes or the possibly preventable causes of mortality. And those are, as you say, SUDEP, but it's also suicide, status epilepticus, and then accidents. And so, people with epilepsy very often suffer from co-occurring psychiatric conditions, and the most common are depression and anxiety.

Gardiner Lapham: 07:38 And this is a horrible statistic, but attempted and completed suicides are estimated to be between five and 14% of people with epilepsy. So, that's pretty significant and preventable often. And then, there are accidents such as burns and car collisions and falls, that put people with epilepsy at risk. And then of course, there's status epilepticus, which is not common, but when it happens, it's a medical emergency that requires attention. It can lead to a brain death. So, that definition of status is a seizure that lasts longer than five minutes.

Gardiner Lapham: 08:26 And then as you mentioned, SUDEP, which is the leading cause of epilepsy related mortality. But I think what we've learned in SUDEP is a community has been created around this one area of mortality, and that is really meaningful, has been meaningful in advancing awareness and research and understanding. And so, PAME wants to shine a light on all of these mortalities and create a community for all of it. So often we just talk about pieces, but it's really important to look at all the mortalities.

Kelly Cervantes: 09:02 Well, and to that point, we recently had Dr. Elizabeth Donner on the podcast and she was talking, the statistic that one out of every 1,000 people with epilepsy will die of SUDEP each year. Do we have statistics for these other types of mortalities in epilepsy?

- Gardiner Lapham: 09:20 Yeah, sure. I mean, there've been some studies that give us an idea of prevalence and give us an idea of risk, but really, the gold standard is population-based surveillance, and that just doesn't exist for SUDEP or for other causes of mortality. So, when these deaths aren't counted, when they're under-reported, they don't get the attention or resources needed to really make a difference in the burden that they are. So, we really need to improve these reporting systems and make deaths accurately counted.
- Kelly Cervantes: 10:05 Well, and I can imagine how easily it is for those statistics to be skewed. You think about someone who has a seizure and drowns, does it get recorded as a drowning? Does it get recorded as drowning due to seizure? I'm not even sure what those categories are. I know that when I was finally able to look at my daughter's death certificate, even though she didn't die from a seizure, it gave me some peace to know that epilepsy was listed on her death certificate as one of the ultimate causes of her death.
- Kelly Cervantes: 10:43 And I know that sounds bizarre, but there was comfort in me to know that she was being counted among that mortality in epilepsy in those statistics, because they do matter, to your point, it's important to have those statistics. It's important to have that accountability.
- Gardiner Lapham: 11:02 No, that's absolutely right. Every death matters, right? And like you say, it's important for research purposes, for us to understand the scope of the problem, so you can match up the resources to deal with the problem. But I think what you and I have experienced, and I have a hard time articulating it too. It's like, you also want to know for yourself, you want to understand why your loved one died. On Henry's death certificate, it was not SUDEP, and it really upset me. I felt like his death didn't matter or it was in vain. It had to be counted the right way and named the right way. And I have heard many families, over the years, say the same exact thing.
- Gardiner Lapham: 11:50 And there's a lot of work we need to do in developing stronger partnerships with the medical examiner community and the death investigator community, to work together to figure out, how do we address the barriers to their ability to accurately identify these deaths and then report these deaths? It's a real problem.
- Brandon: 12:17 Hi, this is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide, currently live with epilepsy. For more than 20 years, CURE Epilepsy has funded

cutting-edge, patient-focused research. Learn what you can do to support epilepsy research, by going to cureepilepsy.org. Now, back to Seizing Life.

- Kelly Cervantes: 12:40 In his address at the most recent PAME conference, Dr. Buchhalter said, "Premature mortality is common, not rare in epilepsy." And while the recording of the statistics and these numbers is so important, ideally, no one is dying from the mortality and epilepsy at all. To know that these deaths are common, not rare, can be very unsettling and anxiety inducing for patients and for families. I think one of the million dollar questions in this space is, how do we get this information to the patients and their families without unnecessarily scaring them? Or, is it necessary?
- Gardiner Lapham: 13:31 Yeah. I mean, it's all really good questions. So, I think that the thing is, knowledge is power, right? That's why you're doing these podcasts. You are trying to inform people. And so, yeah, this is a scary topic. It's hard for a lot of doctors to talk about this topic. I mean, we're all human, right? But knowledge is power. And now there are a lot of resources and support services out there, so that people can better manage their epilepsy and make better decisions, so that they can mitigate these risks.
- Gardiner Lapham: 14:10 So, there are the websites, right? CURE's got a lot of great information, Epilepsy Foundation, Danny Did. Danny Did has some great information on seizure detection devices, and they offer patient support. And then, there are all sorts of materials that providers have access to. But I think, it's important to be empowered, right? And to ask questions. So, I think where people need to start is, they need to ask questions, ideally know their seizure triggers, take medication as prescribed, know their risks and have seizure action plans.
- Gardiner Lapham: 14:53 So, I think when we're armed with information, it might not be as scary and you can put your own risk, once you better understand it, into context. And yes, these aren't as rare as we may have once thought, but most people with epilepsy are also going to do really well.
- Kelly Cervantes: 15:15 Right. Absolutely true. So, what can be done, because the best person to relay this knowledge, this information to patients and families, is their doctors. Right? So, how do we make sure that the physicians are relaying this information?
- Gardiner Lapham: 15:33 Yeah, it's another really good question. So, it's interesting, research has been done to understand, what do people want to

know and when do they want to know it? And most individuals with epilepsy, families, caregivers, want to know about these risks, either at the time of diagnosis or shortly thereafter. So, I think it's important for clinicians to know that.

- Gardiner Lapham: 15:58 And now there are practice and counseling guidelines available to help providers walk their patients through this information. How do you counsel people on this? What are the important points? How do you assess risk? So, there's a lot of information and there are resources available to help providers do this well. And I think too, we're going to see over time, that SUDEP and mortality risk education or counseling, become quality measures.
- Kelly Cervantes: 16:33 What does that mean?
- Gardiner Lapham: 16:35 So, a quality measure is like, how well is this practice doing around all sorts of pieces related to treating someone with epilepsy? So, you can go in and see, oh, what percent of providers in this practice actually counseled their patients on SUDEP risk or mortality risk. And if the practice didn't do well as a whole, or the individual provider didn't do well on that, then there are systems in place to improve the care, to circle back with that team or that provider and say, "Hey, you missed this. Let's start doing this counseling better." So, it's a very common way to assess how well medical teams are doing and taking care of their patients. So, I think it's super exciting that this is going to be an indicator that people will be watching over time.
- Kelly Cervantes: 17:31 That's incredible. I would love to see that awareness of SUDEP and the various mortalities trickle down to primary care physicians as well, or to pediatricians. I always think about how little our epileptologists understand epilepsy. The further away from the specialty that you get, even less is known.
- Gardiner Lapham: 17:55 I know. You're so right. And at the end of the day, not as many people may get to the specialists as they should. And so, it's incumbent on all these providers to be able to point people towards the right information and educate them. So, we've got a long way to go.
- Kelly Cervantes: 18:15 [inaudible 00:18:15]. Leading me right into my next question. What are your goals for PAME? What would you love to see the organization accomplish in the near future and the distant future?

- Gardiner Lapham: 18:27 So, PAME's goals are to continue to provide relevant, state-of-the-art content, so people continue to learn about these issues and become aware, but PAME is also about fostering collaborations. And I love PAME, because it's the perfect example of how none of us can do this alone, right? We all have to come together to do this. CURE does one thing really well. EF does another thing really well. Danny Did. I mean, there's so many organizations, but we're much stronger when we work together.
- Gardiner Lapham: 19:01 And it's very humbling to work in this space, because there are lots of really good people that see that it's hard to work together sometimes, but it just really feels like now more than ever, these walls have come down and people want to be efficient with time and resources. So, right now, PAME's very much focused on educational content, but over time, I hoped that PAME can help drive more solutions around all causes of mortality.
- Kelly Cervantes: 19:37 Now, having been working in the SUDEP and mortality and epilepsy space for as long as you have, you have your finger on the pulse of a lot of the research that is going on. And while PAME does not fund research, I wonder if you personally have a sense, are there certain pieces of research on the horizon that excite you? Or focuses that you wish organizations like CURE Epilepsy would look into funding more closely?
- Gardiner Lapham: 20:11 Generally speaking, we need a lot more focus just on awareness. That is still a challenge, right? And the stigma of epilepsy. So, raising awareness of the public health importance of all of these causes of mortality is just really important, right? And then, back to doctors need to talk about this. Patients need to be educated. It sounds really simple, but that's a significant challenge and there's actually a lot of research that needs to go in to drive that.
- Gardiner Lapham: 20:43 But then as we were talking about earlier, we need to develop better surveillance systems. And then what CURE knows so well is basic and translational research. That is key to understanding a lot of this, and we need to advance that work, so that we can test some of these prevention strategies. And then, we need to accelerate our search for a biomarker, so we can really be more specific about who is at risk and how do you understand how to change that risk?
- Kelly Cervantes: 21:17 Absolutely. I'm seeing so much exciting progress being made on biomarkers. And I really feel like that's going to be an interesting space to watch, as science continues to push

forward. Within the epilepsy community, we're talking about such heavy topics, I want to try and close this out on a slightly lighter note, what within this community gives you hope?

- Gardiner Lapham: 21:49 That's such an easy question. I mean, so what gives me hope is that I've actually seen a lot of progress in the relative amount of time that I've been in this space, 10, 15 years, a lot has changed. And it's the people ... I mean, it sounds so corny, but it's the people that keep me here, because I really love this community and I think the professionals and the families working together, it's inspiring to me that families can have such a voice in this space and make such a difference. And I've found such meaning in my loss, by doing this work. And so, it gives me a lot of hope.
- Kelly Cervantes: 22:38 I am just so grateful for you. If I can follow in your footsteps, I will just be one happy woman. You are incredible and so grateful for your time today. Thank you for all that you do.
- Gardiner Lapham: 22:53 Oh, thank you, Kelly, for all you do, and for all that CURE does.
- Kelly Cervantes: 23:00 Thank you, Gardiner, for sharing your experience, knowledge and insights with us, and thank you for your efforts to raise awareness and improve understanding of epilepsy related mortality through the creation of PAME. CURE Epilepsy has been at the forefront of research into epilepsy related mortality since pioneering its SUDEP initiative in 2002. We continue to fund cutting-edge research to identify the underlying mechanisms of SUDEP, while pushing for innovative solutions that will ultimately lead to SUDEP prevention. We hope you'll support this important research by visiting cureepilepsy.org/donate. Through research there is hope. Thank you.
- Legal Disclaimer: 23:46 The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. The information contained herein is provided for general information only, and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals, who are familiar with individual medical conditions and needs. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions, be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.