Our epilepsy story: SUDEP Aware

*Tamzin C. Jeffs and *†Elizabeth J. Donner

Epilepsia, 56(1):9–11, 2015
doi: 10.1111/epi.12599

OUR STORY

Tamzin Jeffs and Elizabeth Donner formed an alliance in 2008 to spearhead and promote the discussion of sudden unexpected death in epilepsy (SUDEP). They cofounded the Canadian nonprofit organization SUDEP Aware, and they have spent the last 6 years working together to improve understanding of SUDEP and bring support to families that are affected by it.

Dr. Elizabeth Donner (left) and Tamzin Jeffs cofounded the Canadian nonprofit organization, SUDEP Aware, in 2008.
Epilepsia © ILAE

Dr. Donner is a child neurologist, at Toronto's Hospital for Sick Children, specializing in epilepsy. Ms. Jeffs has lived with epilepsy for 13 years. She lost her 31-year-old sister to SUDEP in 2007. Donner and Jeffs create a united front for an issue that, historically, has caused much dissension between families and doctors. Affecting one per 1,000 people with epilepsy per year, SUDEP is a very real and devastating risk. The pair's shared passion and volunteer work break conventional barriers to information collaboration. This has led to major advances in Canada and internationally, raising awareness for SUDEP in patients, families, clinicians, and the wider community.

KNOWLEDGE IS PREVENTION

Tamzin: "When Elizabeth and I first met, on a local epilepsy organization board in 2007, we soon realized the value of combining our different experiences and distinct perspectives on SUDEP. What I found alarming was that in the 20 years my sister lived with epilepsy and during the 6 years I'd had epilepsy, the term SUDEP was never mentioned. Worse still, there was so little public information. There were only a handful of documents online—most of them scientific articles that required paid subscription to access. Why was no one talking about SUDEP?"

Elizabeth: "As a member of the medical community, I initially experienced SUDEP very differently from Tamzin. I was a resident assisting with an autopsy on a child, when the pathologist suggested SUDEP as a cause of death. I had not even heard of SUDEP, and as I read more, I thought, 'How can this be?' It was astonishing that people were dying and no one knew why. I dug deeper and coauthored a review of SUDEP cases in children. It was only later in my clinical career that I experienced, first-hand, the grief and anger caused by SUDEP, through the families: The loss and sadness that they experience over the question, 'Why?' It was discouraging that physicians were not sharing the reality of SUDEP with patients and families. The evidence, that reducing the frequency of generalized tonic colonic seizures reduces the likelihood of SUDEP, is well understood."

BRIDGING DIVIDES (AND OCEANS)

Tamzin: "One of the first things I did after my sister died was to collate information about SUDEP on a Website, which exists today as <sudepaware.org>, and makes it easier to find SUDEP-related news, research, events, and contacts.

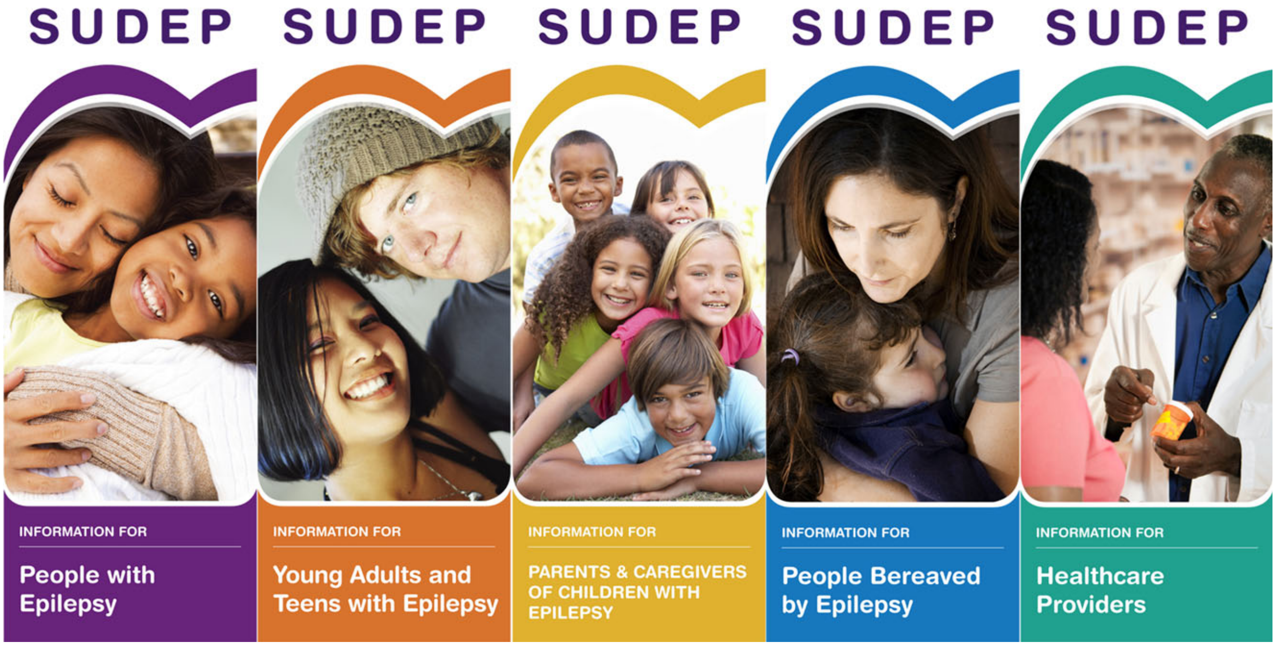
"The main mission of SUDEP Aware has been to encourage people with epilepsy, and their doctors, to talk about SUDEP. Our attention has also focused on epilepsy support agency staff, coroners, and nurses, all of whom play an important role in disseminating accurate and consistent facts regarding SUDEP.

Accepted February 17, 2014; Early View publication April 22, 2014.

*SUDEP Aware, Toronto, Ontario, Canada; and †Division of Neurology, Department of Paediatrics, The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada

Address correspondence to Tamzin Jeffs, Executive Director, SUDEP Aware, Suite 350, 283 Danforth Avenue, Toronto, ON M4K 1N2, Canada. E-mail: tcjeffs@sudepaware.org

Wiley Periodicals, Inc.



"We present at grand rounds, have information booths at scientific conferences, and provide a toll-free line to help raise awareness and understanding of SUDEP. The vast majority of our time, though, is spent working on projects with other organizations within the SUDEP community. This has made initiatives like our SUDEP Professional Development Day and creating standardized SUDEP reference materials a possibility. Collaboration on five SUDEP information brochures, each targeting a different audience and available in three languages, launched our global 'Making Sense of SUDEP' communication campaign in 2011.

"We hugely admire the 18-year work and dedication of SUDEP Action (formerly Epilepsy Bereaved UK) and consider them an invaluable leader in the international call for greater openness on SUDEP. In 2010, we joined the editorial teams of SUDEP Action and Epilepsy Australia to contribute toward the latest edition of 'SUDEP– Continuing the Global Conversation'—an all-encompassing book filled with a supportive combination of scientific research and family stories."

Elizabeth: "As an unpaid volunteer, Tamzin does an amazing job managing all the day-to-day activities of SUDEP Aware. With doctors cautious to mention SUDEP to their patients and bereaved families frustrated by the lack of prior discussion of SUDEP, it became clear that the two of us needed to bring the different parties together. In one of the biggest SUDEP initiatives to date, Tamzin and I worked with the American Epilepsy Society, Epilepsy Foundation, and five other organizations to initiate a first-of-its-kind conference in 2012—Partners Against Mortality in Epilepsy (PAME). More than 250 practitioners, scientists, doctors, patients, and family members participated in open-floor, information-building sessions. The conference was so successful that it has grown into a biennial event.

"Another way SUDEP Aware brings stakeholders together is through research. Families reach out to Tamzin, and when they are ready she connects them with SUDEP researchers who are in need of study participants. To support this, a portion of the funds raised by SUDEP Aware supporters goes into the research community."

FUTURE PLANS

Tamzin: "Our support services have mainly focused on families bereaved by epilepsy: people looking for answers, to connect with others, to get involved and help make something positive come from their tragedy.

"We are now also receiving communications from concerned relatives and people living with epilepsy. They want to learn more about SUDEP and how to reduce the risk. This is a strong indication that word *is* getting out, but still not enough, as the majority of bereaved families continue to cite the death of their loved one as their first encounter with SUDEP.

"Speaking personally, do I feel that my sister would have been here today if she'd known about SUDEP? No. But, I do feel that she was denied the crucial information that would have influenced her *own* decision-making about her *own* health. This is every person's right and SUDEP Aware will continue to focus on empowering as many people as possible.

"We are proud to be one of the very first organizations in North America to tackle SUDEP openly and vigorously. Now, as larger organizations join the cause, we consider that to be a good measure of our success. Obviously, there is still much that needs to be done. We invite you to join us and embrace being part of a SUDEP-aware community dedicated to preventing SUDEP."

You can learn more about making research connections through <sudepaware.org> or by contacting Tamzin Jeffs at 1-855-85-SUDEP (78337).

SUDEP
Aware
www.sudepaware.org

DISCLOSURE

The authors declare no conflicts of interest. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

DISCLAIMER

Editor's Note: *Epilepsia*'s Epilepsy Stories is a venue for nonprofit organizations to educate our professional readership about their mission for people with epilepsy from around the world. Many organizations raise awareness about epilepsy including ILAE's sister organization, the IBE and its chapters. *Epilepsia* does not endorse one organization over another. If you would like your nonprofit organization recognized, contact us at epilepsia@epilepsia.com.