Living with the loss of a loved one is hard, especially when it is an unexplained death. Words can never express what this journey is like. The shock. The disbelief and the never-ending grief.

When my daughter, Lydia, didn’t wake up on Mother’s Day morning, 2014, I truly thought I had lost my purpose. I had been my daughter’s voice, advocate and champion with her medical and educational needs. With her now gone, I felt…well, incomplete.

But, since starting as the new Director of the SUDEP Institute this year, I have found a renewed spirit and peace. Yes…peace. I have found that continuing to advocate, educate, create awareness and helping others has given me purpose again.

Making a difference for others has always been a driver and passion for me. Now, as the Director, I can take my passion and make it my new purpose. Driving research to find a cure for SUDEP so no other loved one suffers from this loss. Bringing awareness to the community. Educating and empowering those with epilepsy to have the tough conversations with their medical professionals. The list of possibilities is infinite.

“Tell the story of the mountain you climbed. Your words could become a page in someone else’s survival guide.” Isn’t this the truth? I plan to tell anyone and everyone who will listen to my journey, my goals, and share all the stories I continue to hear because it WILL make a difference. I look forward to my continued path with the SUDEP Institute.

Sally, Director, SUDEP Institute
sschaeffer@efa.org
Committed and moving forward…

The mission of the SUDEP Institute is to eradicate SUDEP and support those affected by it.

**Goals**

**PROMOTE RESEARCH:** Support and promote current biomarker challenge, registry programs along with coordinating partnerships and grants for additional research.

**PROVIDE EDUCATION & AWARENESS:** Increase awareness, education, and advocacy efforts with medical professionals, those living with epilepsy and their caregivers.

**BEREAVEMENT SUPPORT:** Create awareness and enhance bereavement support services to offer comfort to individuals affected by SUDEP.

As the SUDEP Institute gears up in 2018, re-evaluating the mission statement, setting goals and planning for the year ahead is essential. There are several key focus areas in which to grow to gain traction to accomplish the mission of eradicating SUDEP.

We are thankful to the SUDEP leadership, Steve Wulchin, John Popovich, and Brandy Fureman along with the team of professionals that have committed to being on our advisory board. We look forward to meeting soon to share our vision in greater depth.

“A goal without a plan is just a wish.”

Antoine de Saint-Exupery
Partner Brainstorming

Leaders from CURE: Citizens United for Research in Epilepsy, American Epilepsy Society, Danny Did and the SUDEP Institute met in Chicago to discuss collaboration and partnering to better help and serve those living with epilepsy.

SUDEP Resource Collaboration

The Child Neurology Foundation, Danny Did and the SUDEP Institute worked together to create resources for a pilot program launching in Indiana. The materials are also available to both parents and medical professionals: Understanding your child’s SUDEP risk (high and lower); Seizure Action plans as well as one for school. These documents can be downloaded from the Child Neurology site.

Hill Visit

Sally Schaeffer and her family met with their Congressman and Speaker of the House of Representatives, Paul Ryan. Speaker Ryan, already familiar with the Schaeffer family and their daughter Lydia, learned more about Sally’s new role as the SUDEP Director and the efforts to create additional awareness and the need for more research.
2018 is off to a great start creating awareness and providing education around SUDEP.

**Pipeline Conference**

Sally Schaeffer attended the Pipeline Conference held in San Francisco, CA from February 22-23rd. The SUDEP Institute, and The Danny Did Foundation met with the professional community to educate and create awareness around SUDEP. A Community Day also gave the opportunity to empower individuals living with epilepsy by providing information about SUDEP.

**Epilepsy Foundation National Walk**

Individuals from all over the country came to the Epilepsy Foundation’s National walk held in Washington, DC on April 14th. A remembrance wall, co-sponsored by the Danny Did Foundation, was available for individuals to place a flag to remember someone who had passed from SUDEP or epilepsy. The SUDEP Institute’s tent offered educational materials, flag decorating and a space for conversations with our SUDEP support coordinator, Kellie Jankowski or Director, Sally Schaeffer.

**American Academy of Neurology**

Sally Schaeffer attended the American Academy of Neurology in Los Angeles, CA in to talk with medical professionals about the risk of SUDEP. Productive conversations were held with Neurologists, Residents and Nurse Practitioners encouraging them to actively and openly discuss SUDEP with their patients.
InnoCentive Biomarker Challenge

Among individuals living with epilepsy, nearly one-third has ongoing seizures despite existing therapies. The lack of seizure control is the primary risk factor for SUDEP which kills more than 1000 people with epilepsy each year.

Determined to bring an end to SUDEP and help people with seizures live to their fullest potential, the Epilepsy Foundation’s SUDEP Institute is challenging Solvers worldwide to identify specific and sensitive biomarkers of SUDEP to facilitate the development of intervention for people at high risk.

Identifying biomarkers to predict and prevent SUDEP represents a major unmet medical need. Although there are several suggested causes of SUDEP, who is at risk of mortality and how to prevent it remains a mystery. The Challenge allows the Epilepsy Foundation’s SUDEP Institute to take advantage of interdisciplinary approaches and alternative perspectives.

There are 4 challenges as part of this initiative:

1) The first challenge was to create an advocacy campaign to inform and educate people with epilepsy, their families and the healthcare community about SUDEP.

2) The second challenge asked solvers to develop an intervention to help people with epilepsy comply with treatments plans, reducing their risk of seizures.

3) In the third challenge, solvers proposed a predictive biomarker or panel of biomarkers to identify people at risk for SUDEP.

4) The fourth and final challenge has 3 milestones to identify a detailed plan for the proposed solution to finding a predictive biomarker or panel of biomarkers to identify people at risk for SUDEP or seizures that compromise, cardiac or respiratory function to show proof of concept data, and finally to show evidence of the predictive validity of the biomarker.

**Milestone 1** required a detailed Project Plan of the proposed solution. **Closed October 10, 2016**

**Milestone 2** required the production of proof-of-concept data. **Closed October 10, 2017**

**Milestone 3** requires results that demonstrate the predictive efficacy of the biomarker(s). **Milestone 3 is a race to the finish and submissions will be accepted between October 17, 2017, and October 10, 2020.** Submissions will be reviewed as they are received, and, at the discretion of the SUDEP Institute, the first submission that meets all challenge criteria will be awarded the prize. The SUDEP Institute intends to make a final award of at least $800,000 for successful completion of Milestone 3.
PAME

The 4th Partners Against Mortality in Epilepsy (PAME) conference took place June 14-16 in Alexandria, VA.

People living with epilepsy, the bereaved, researchers, medical professionals and others came together to discuss research, advocacy and clinical practice related to SUDEP and other death from epilepsy. Individuals from across the country also had 40 visits with legislators. They discussed issues of early mortality from epilepsy and requested funding for research programs.

Conference topics included advocacy, an update on the Centers for SUDEP Research,

The conference was supported by contributions from organizations in the epilepsy community including American Epilepsy Society and SUDEP Institute/ Epilepsy Foundation, CURE: Citizens United for Research in Epilepsy and the Danny Did Foundation.

National Association of Medical Examiners Recommendation Paper

As most deaths from epilepsy aren’t witnessed, it makes the job of the medical examiner a bit harder. The common characteristics of a seizure can vary or be absent in SUDEP making it hard to conclude epilepsy was the cause of death. Medical examiners may also not be aware of SUDEP. Thus, it is suspected that death certificates under represent the number of people that have died due to epilepsy.

The members of the National Association of Medical Examiners, North American SUDEP Registry (NASR), Epilepsy Foundation’s SUDEP Institute, American Epilepsy Society (AES), and the Center for Disease Control and Prevention created an expert panel to generate evidence-based recommendations for the practice of the death investigation and autopsy, toxicological analysis, interpretation of autopsy and toxicology findings, and death certification to improve the precision of death certificate data available for public health surveillance of epilepsy related deaths.

Read more information to assist medical examiners, coroners, and death investigators when a sudden unexpected death in a person with epilepsy occurs.

The SUDEP Institute will be traveling with NASR to the National Medical Examiners Conference in October to support the presentation of the recommendations and educate medical examiners on epilepsy and SUDEP.
Charlie Read had a few generalized tonic-clonic seizures during the first three years of his life, but they came under easy control with a low dose of medication, and he appeared to be seizure-free between ages 3 - 15.

He lived life as fully as a kid can. Born into a family that loved bicycle trips, Charlie rode every year on the back of his dad’s bike on the annual 70-mile trip around the Quabbin Reservoir in Massachusetts. Then just before he turned 12, he completed the full ride on his own bike—the youngest person to do so in the 30-year history of the event. Later he said, “When I finished that ride, I felt like I could do anything.” He carried that attitude into all that he did.

Charlie had some challenges with motor skills and learning disabilities, but he rarely missed a day of school and he played on the school hockey and baseball teams. At his beloved summer camp, he tackled high-ropes and challenge courses with gusto. On the rare occasion when a fellow camper or teammate even hinted at making fun of him, Charlie’s confident and smiling demeanor just quietly put a stop to it.

Charlie spent the summer of 2016 training to be a counselor at this same camp, volunteering with his youth group doing home repairs in Appalachia, and sailing with his cousins on Cape Cod. He grew up before our eyes that summer, emerging as a fine young man with a huge heart. Then one day in the middle of August, he just didn’t wake up. Our hearts are shattered and our loss immeasurable.

The summer after Charlie’s death, we formed the team C2C4Charlie (Coast to Coast for Charlie) and bicycled across the US and Canada, raising more than $43,000 for the SUDEP Institute via the Epilepsy Foundation’s “Gear Up for Epilepsy” event. May it be part of Charlie’s legacy that we learn more about the causes and the prevention of this terrible phenomenon of SUDEP.

If you have a bike, you can ride too! Join Athletes vs. Epilepsy Gear up for Epilepsy and create your own cycling trek to contribute to the miles ridden and funds raised in support of the 3.4 million living with the challenges of epilepsy and those that die every year from SUDEP. Sign up today!

Charlie Read

May 31, 2000 – August 15, 2016
The SUDEP Institute is here to help. We provide

- Information to help empower those living with epilepsy to help begin conversations with their medical professionals.
- Individual or family support from a bereavement support facilitator
- Secure, safe, online bereavement support group to help families connect with others
- Remembrance pages where families can create a memorial
- Advocacy, as needed on a case-by-case basis, including coordination and assistance with the death investigation process.
- Access and assistance in enrolling and participating in SUDEP-related opportunities.

Call our Epilepsy & Seizures 24/7 Helpline at

1-800-332-1000

Email SUDEP@efa.org for more information or how to become a SUDEP Institute volunteer

website: www.epilepsy.com/sudep for more information.

We are now on social media!

Check out our Facebook SUDEP Institute /Epilepsy Foundation

Make a donation to the SUDEP Institute in memory of someone special.