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North American SUDEP Registry Newsletter - Summer 2018



Studying Epilepsy-Related Mortality to Help Save Lives

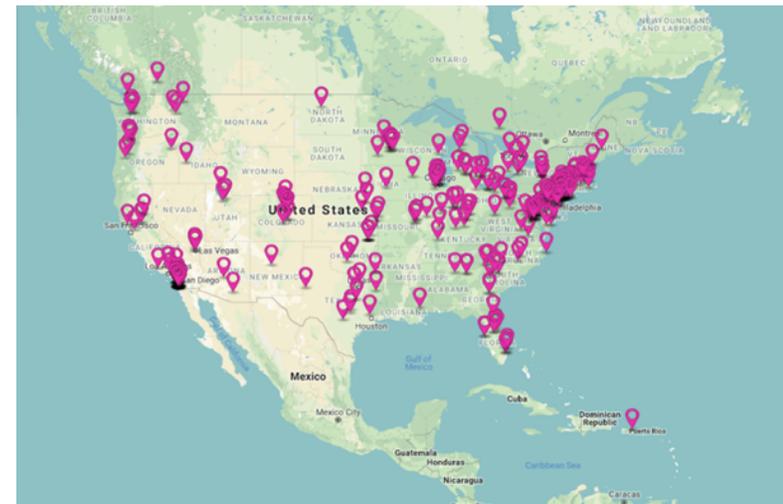
NASR is a privately-funded, collaborative effort among medical professionals, advocacy organizations and bereaved family members dedicated to better understanding and preventing Sudden Unexpected Death in Epilepsy (SUDEP) – the most common cause of epilepsy-related deaths. We facilitate the donation of brain tissue, DNA, and medical records from those who have suffered from SUDEP and promote their use to advance understanding and prevention.

Welcome, Sally Schaeffer!



Sally Schaeffer is the new Director of the SUDEP Institute with the Epilepsy Foundation. Beyond the professional realm, Sally's advocacy for therapeutic treatments for epilepsy have extended nationwide. Sally's special needs daughter, Lydia, was diagnosed with electrical status epilepticus in Sleep (ESES) in June of 2013. Unfortunately, Lydia succumbed to epilepsy when she died in her sleep on Mother's Day, May 11, 2014. Since Lydia's passing, Sally has continued advocating for additional treatment options as well as providing education and

awareness surrounding epilepsy, SUDEP, grief and bereavement. As the new SUDEP Director, Sally will continue drive the Institute's mission and vision as well as implementing the strategy to eradicate SUDEP. She will cultivate and continue to build relationships promoting research, education and awareness around SUDEP with the goal of eliminating it.



Distribution of NASR Cases 2011-2018 (Only North American cases reported here)

Research Update: Preliminary SUDEP Analysis

By Fizza Hussain and Chloe Verducci

Among all 490 enrolled NASR cases, we have 263 SUDEP cases, 86 living controls, 56 non-SUDEP controls, and 20 enrolled family members. In reaching our enrollment milestone for 250 adjudicated SUDEP cases, we are pleased to report our preliminary research findings. This progress would not be possible without the continued support of the NASR community, and the generous family members of loved ones who have unfortunately succumbed to SUDEP.

Presentations and Conferences

Partners Against Mortality in Epilepsy (PAME), June 2018



We report on initial demographic findings for the first 250 SUDEP cases enrolled. The median age at death for these SUDEP cases was 26 years, and 96 (38.4%) are female. Of cases with sufficient seizure history, 24.5% had no prior history of generalized tonic-clonic

seizures (GTCs). Death was witnessed in only 9% of cases. Tissue and/or DNA was donated for 235 of the 250 cases.

National Association for Medical Examiners (NAME), October 2018



Here, we compile preliminary investigative and pathological findings for SUDEP cases enrolled in NASR. GTCs precede most SUDEPs, and post-GTC state is associated with decreased arousal, as well as autonomic disorders including apnea and arrhythmia. We found that among unwitnessed deaths, 50.4% were found face down, and 51.2% showed evidence of a terminal seizure (including tongue/cheek bite, incontinence, etc.). Of the 28

cases with whole-brain NYU neuropathological exams performed so far, 89% exhibit epilepsy-related changes. Among autopsied SUDEP cases, 34% demonstrated pulmonary edema, or fluid swelling in the lungs.

American Epilepsy Society (AES), December 2018



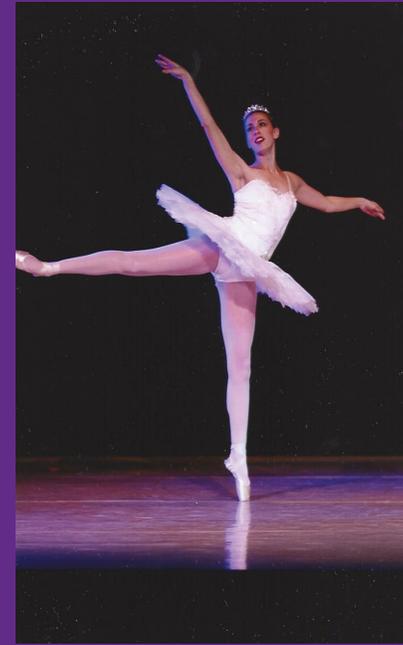
Of our enrolled SUDEP cases, 39% had a history of generalized seizures, and 57% had focal seizures. 27% of SUDEPs had less than 10 GTCs in their entire life prior to death, and only 12% had more

than 500 in their life. 56% of these cases had their last confirmed GTC more than 30 days prior to death. 46% took their anti-seizure medication as directed, but only 26% were confirmed to have taken their last dose.

For more information on our research, please contact the NASR team at 855-432-8555 or info@sudep-registry.org

Our Stories

Emily Redosh



Emily Redosh was born in Philadelphia in 1989 and grew up in the Denver metropolitan area. Although her parents tried to instill in her a love of the great Colorado outdoors, their mountain pursuits always took a back seat for Emily – her real passion, from a very early age, was dance. Emily began taking a “pre-ballet” class while in preschool, which grew to daily after school classes and regular performances. Over the years, she danced almost every part in the Nutcracker, earning the coveted role of Clara when she was 15, and the Sugarplum Fairy as a young adult.

Emily attended the University of Arizona where she traded her pointe shoes for ballroom heels. She won numerous medals for the U of A ballroom team at competitions around the country. When she returned to Colorado after receiving a Bachelor of Science degree in 2012, she balanced work at Colorado Physicians Health Program with her love of ballet and ballroom dance, along with a busy social schedule and an eagerness to see the world. And yes, she even began to appreciate the beautiful Colorado mountains as she joined friends and family on hiking and camping trips.

Emily passed away suddenly on December 2, 2017 from SUDEP. She had been diagnosed with epilepsy when she was 7 and her seizures were well-controlled with medication. She rarely spoke of her ailment, as she was determined that it wouldn't define her. She was a compassionate young woman who always had a kind word to say and an open and loving heart. Emily's family is honored to be able to pay Emily's short life forward through participation in the SUDEP Registry. Emily would be deeply touched to know she has had some part in advancing our knowledge of SUDEP and epilepsy. In that small way, Emily dances on.

~The Redoshes

What the Epilepsy Community Can Do to Support NASR's Mission:

For any SUDEP or other epilepsy-related mortality, please refer the family to NASR. They can register through the toll free number (855-432-8555), by email (info@sudep-registry.org), or via a survey on our website (www.sudepregistry.org). If the death was within the last 72 hours, we may be able to coordinate fresh-frozen brain donation. Even if it has been some years, we may still be able to obtain DNA, slides, and/or fixed tissue. We can link families with the SUDEP Institute for bereavement resources.

For those epileptologists interested in partnering in research, we have several mechanisms open for collaboration and welcome participation. Please contact Dr. Devinsky (od4@nyu.edu) or Dr. Friedman (Daniel.friedman@nyumc.org).

A Message to Our Families, by Fizza Hussain

“As the registry coordinator for NASR, I obtained the opportunity to speak at length with more than a hundred families enrolled in the study, serving as the initial contact for coroners, medical examiners, primary care doctors, neurologists, nurses, and of course - those affected by SUDEP more personally – close relatives expressing grief, confusion, and frustration after experiencing their loved one succumb to SUDEP (without warning) few hours ago, few days ago, or even years ago - inquiring how they can make a difference in the lives of those living with epilepsy. None of them wanted this to happen to another person’s child, sibling, friend, or spouse. Most unfortunately, calling after only finding out about SUDEP from an internet search. This needed to change.

Most people understand research as studies involving finding a cure for patients living with a certain disease, but for us, we had to work backwards. This dynamic of clinical research involving an outcome that starts with the end [death] which is a mystery to begin with, is a difficult one, starting from a sudden death (most unwitnessed, unknown cause, otherwise healthy individuals) and go back to figure out what could have led to these seemingly ‘fatal seizures’.

There were 2 key foundational steps to help kick start research in this area: one was to spread awareness about SUDEP among patients, families, and physicians – to help with precautionary steps for prevention, and second, was to identify and code SUDEP deaths accurately among medical examiners/coroners – to help make studying this phenomenon possible (if we could find SUDEP listed as a cause of death, then we could identify cases – hence find real data to study)

We are beginning to achieve this goal – we’re enrolling cases from across the country and abroad. We are gathering a diverse group of population, which is data that is incredibly valuable. We have made progress in classifying SUDEP accurately as well as providing guidelines to help certify SUDEP deaths correctly. In this newsletter we summarize some of our recent publications, some of the ongoing work happening in the NASR, and how your participation is helping to advance our understanding of SUDEP. Some projects under development include studying the genetics of SUDEP, and to identify biomarkers and other factors for risk assessment and further education.

I am transferring from NYU to work on other research, but I will remain dedicated to the goals of this public health issue. I couldn’t express enough appreciation for this organization and its team of brilliant researchers with aims to reduce epilepsy-related mortality. On behalf of the entire team, I would like to thank you again for your continued support of our program. You’ve served as the key resource for this project, and provided a wealth of information to the medical community, to apply perpetually. Not only have you dedicated your time and energy in helping us gather medical history and tissue donations to help the registry grow, but you’ve also provided monetary donations to our organization, you’ve held fundraisers in the name of our research, and you’ve held memorials to support and raise awareness of SUDEP and our SUDEP research. For this we are very grateful. Thank you again. It is through our collaboration that we will reach our goal of preventing SUDEP from affecting any more patients.”

Sincerely,
Fizza

Published Findings:

Devinsky O, Bundock E, Hesdorffer D, et al. **Resolving ambiguities in SUDEP classification.** *Epilepsia*. 2018;00:1–14. <https://doi.org/10.1111/epi.14195>

SUDEP Significance:

→ “[Standardizes] criteria among epilepsy researchers, medical examiners, and epidemiologists to determine cause and classify death will lead to more accurate tracking of SUDEP and other epilepsy-related mortalities.”

Middleton O, Atherton D, Bundock E, et al. **National Association of Medical Examiners position paper: Recommendations for the investigation and certification of deaths in people with epilepsy.** *Epilepsia*. 2018;59:530-543. <https://doi.org/10.1111/epi.4030>

SUDEP Significance:

→ “[To] generate evidence-based recommendations for the practice of death investigation and autopsy, toxicological analysis, interpretation of autopsy and toxicology findings, and death certification to improve the precision of death certificate data available”

Doumlele K, Friedman D, Buchhalter J, Donner EJ, Louik J, Devinsky O. **Sudden Unexpected Death in Epilepsy Among Patients With Benign Childhood Epilepsy With Centrotemporal Spikes.** *JAMA Neurology*. 2017;74(6):645-649.

doi:10.1001/jamaneurol.2016.6126.

SUDEP Significance:

→ “Sudden unexpected death in epilepsy is a very rare outcome in BECTS that clinicians should consider discussing in appropriate circumstances and possibly factoring into treatment decisions.”

Louik J, Doumlele K, Hussain F, Crandall L, Buchhalter J, Hesdorffer D, Donner E, Devinsky O, Friedman D. **Experiences with premorbid SUDEP discussion among participants in the North American SUDEP Registry.** *Epilepsy and Behavior*. 2017;70(A):131-134.

doi:10.1016/j.yebeh.2017.02.027

SUDEP Significance:

→ “Our study suggests that SUDEP remains infrequently discussed with family members of persons with epilepsy. Nearly three-quarters of family members wished they had known of SUDEP before the death.”

