Understanding and Coping with the Risks of SUDEP

Epilepsy-Pralid, Inc. was honored to co-host two workshops on Sudden Unexpected Death in Patients with Epilepsy (SUDEP) with the University of Rochester Medical Center on Thursday, November 15, 2018.

Historically, SUDEP has not been part of the conversation when a person is diagnosed with epilepsy. As a consequence, when SUDEP happens, families are completely blindsided - they had no idea that there was even a small risk of death associated with epilepsy.

The workshops were designed to respond to this need by increasing medical professionals’ comfort level with discussing SUDEP with their patients. We invited families who are living with epilepsy to advance their knowledge of SUDEP so that they may have productive conversations with their medical providers about managing their risk.

Credit for the workshops goes to Dr. David Auerbach, who secured a CURE Foundation grant to bring in Dr. Cynthia Harden to discuss the recently created SUDEP Guidelines. Dr. Auerbach approached EPI with the idea of turning a single talk about SUDEP into a day of SUDEP education and we are so thankful that he did. Dr. Auerbach put together an impressive array of speakers and his own research into cardiac causes of SUDEP is very exciting!

Over 70 people were in attendance. We also owe a big thank you to Tanya’s Trot and LivaNova as their financial support made this event possible.

SUDEP Information

If you or a loved one has questions about Sudden Unexpected Death in Epilepsy Patients, please contact us to speak with one of our epilepsy educators at (585) 442-4430 or (315) 477-9777.

For more resources on the web:
EPI epiny.org/epilepsy-resources.php
North American SUDEP Registry sudepregistry.org/
CDC SUDEP cdc.gov/epilepsy/about/sudep/index.htm

David Auerbach, PhD, pictured left, was the workshop organizer and is an Assistant Professor in the Aab Cardiovascular Research Institute at the University of Rochester Medical Center.
From the President
Jeff Sinsebox

New Alliance, Same Focus

2018 has brought changes to the way we connect with other epilepsy organizations and how we think about service delivery. EPI has made changes on the state and national level that will allow us the opportunity to improve and expand upon what we do for people impacted by epilepsy.

EPI has been a longtime member of the Epilepsy Coalition of New York. The Coalition has operated for many years under the same strategies of serving people with epilepsy. The Coalition is undergoing leadership change and it seemed like a great opportunity to update our services provided through the coalition.

In examining the social determinants of health as they relate to people with epilepsy, there are untapped opportunities for EPI. Instead of operating in a business-as-usual format, we are reinvigorating our approach and seeking new service paths to reflect the changing healthcare landscape of today.

Another significant change this year came in July. EPI has ended its long-term relationship with the Epilepsy Foundation of America (EFA) and has joined the newly formed Epilepsy Alliance America. Over the past several years EFA has shifted its focus towards funding research to cure epilepsy. It has also been working towards centralizing ownership and control of local affiliates. While we are grateful to have organizations working towards a better tomorrow, there are also people whose needs must be met today.

Leveraging our size and geographic reach, EPI will continue to focus on meeting the service needs of those in our local communities. We are a human service organization whose aim is to improve the quality of life for people now. We want people impacted by epilepsy to have support, advocacy, education, respite, effective housing, and good healthcare. Our top priority is the people who live in Central and Western New York.

Epilepsy Alliance America was formed to promote not only local service in local communities but the sharing of best practices with people in other areas of the country to improve upon that service. The Alliance wants to be good partner with other national and international epilepsy organizations to create a community of learning whose efforts have synergy. I am excited to see how this new organization develops over time. The collaborative spirit at our first meeting was infectious, and I have been energized by the possibilities.

More to come…

Epilepsy Alliance of America

Epilepsy Alliance America is a new, national organization dedicated to providing support, care, and service to those with epilepsy.

Officially launched on July 23, Epilepsy Alliance America has state-based partners in eight states, serving hundreds of thousands of people with epilepsy, their families, caregivers, and communities.

Out of the Shadows 2019: Renae Taylor, Jeff Sinsebox, Cathy Sculley, Emma Taylor
Visit www.epiny.org/events for all event details – including registration and ticket purchases!
Follow us on Facebook to stay connected with these and other events.
For more information, contact the Development Department at events@epiny.org.

**Saturday, February 2, 2019**

**Chocolate Ball**

**Hyatt Regency Downtown, Rochester | 5:30pm - 12am**

Join us for Rochester’s premier gala event for Chocolate and Cake and the Difference We’ll Make in the lives of people with epilepsy.

**1st Thursday of the month**

**Rochester Epilepsy Networking Group**

**Al Sigl Center, Door #1 Conference Center | 6pm - 7:30pm**

Join us for dinner and discussion at this monthly meeting for individuals, families, and friends who are affected by epilepsy and seizures. No meetings July & August.


**2nd Tuesday of the month**

**Syracuse Epilepsy Networking Group**

**CNY Philanthropy Center, 431 E Fayette St., Syracuse | 6pm - 8pm**

Join us for dinner and discussion at this monthly meeting for individuals, families, and friends who are affected by epilepsy and seizures. No meetings July & August.

2019 meeting dates: Jan 8, Feb 14, March 14, April 11, May 9, June 13, Sept 12, Oct 10, Nov 14, Dec 12

**3rd Thursday of the month**

**Broome County Epilepsy Networking Group**

**23 Jackson Ave, Endicott | 6pm - 8pm**

Join us for dinner and discussion at this monthly meeting for individuals, families, and friends who are affected by epilepsy and seizures. No meetings July & August.

2019 meeting dates: Jan 17, Feb 21, March 21, April 18, May 16, June 20, Sept 19, Oct 17, Nov 21, Dec 19

**Sat & Sun, March 9 & 10**

**Teen Epilepsy Weekend**

**Hampton Inn & Suites Rochester/Henrietta |**

Living with epilepsy can be hard! Teens are invited to this weekend retreat to have fun, meet other teens and young adults who understand epilepsy and seizures, find out ways to stay healthy, and ask questions and get answers from neurologists and other experts.

**Dinner with the Doctor**

EPI would like to thank Dr. Robert Gross of the University of Rochester Medical Center and Dr. Robert Beach of Upstate University Hospital for participating in our 2018 Dinner with the Doctor series. These dinners are a great way to talk to a neurologist and ask questions outside of a formal office visit.

2019 will see not only more Dinner with the Doctor style events, but also more epilepsy support programs - details are coming soon! Be sure to follow us on Facebook or sign up for our eNewsletter to stay informed about upcoming events and new programs.
The phrase “above and beyond” doesn’t really do justice to the support that Dr. Inna Hughes provides for her patients and families. She has an incredible workload – she has a robust pediatric epilepsy practice, is a Board Member at EPI, and last, but most certainly not least, she is a mom to a young child. In addition to all of this, she has organized several patient support programs in partnership with EPI.

As a pediatric neurologist, Dr. Hughes sees many patients on the Ketogenic Diet - an effective, but extremely difficult dietary therapy for seizures. Part of the difficulty is the specialized food that a caregiver needs to prepare for the child. To help families beginning the diet, Dr. Hughes partnered with EPI to provide Keto Starter Kits so that families could leave the hospital with everything they needed to have a successful start to the diet.

Armed with Dr. Hughes’ idea and data, in 2013, EPI successfully secured a start-up grant from the Greater Rochester Health Foundation. However, Dr. Hughes didn’t stop there. In 2014, she approached EPI with another patient support idea - this time for teens with epilepsy.

In her teen patient population, Dr. Hughes noticed increased signs of depression, varying levels of family support, and many teens reported a lack of peer support and positive interactions with people who understand epilepsy.

Dr. Hughes, along with staff from EPI, developed a “weekend away” retreat filled with meaningful educational sessions given by experts from the Strong Epilepsy Center at the University of Rochester Medical Center and having fun with their peers.

The transitional period between late teens and early young adults is a critical time for everyone - and even more critical for people with a chronic condition such as epilepsy. Learning how to advocate for your own health is a hugely important skill and a big focus of the teen weekend. The opportunity to have open dialogue with many different experts is an invaluable experience for these teens as they transition from their parents managing their medical care to managing epilepsy on their own.

Over the past four years, over 25 teens have attended at least one weekend, and many attended more than one, enabling them to deepen their peer networks and build skills year over year.

For 2019, we are excited to announce that we will be hosting two teen weekends – one on March 9 & 10 and a second on November 9 & 10. Learn more at epiny.org

Dr. Hughes - we cannot thank you enough for all that you do - for your patients and for the people that EPI supports. Thank you!

Dr. Hughes at the 2014 Al Sigl Community Walkabout, dressed as a minion, where her team raised over $1,000 for the first Teen Weekend.

Dr. Jennifer Kwon! Dr. Kwon has volunteered her time as one of our camp neurologists for the past several years. She recently relocated out of the area to be closer to family and we will miss her at camp! Before she left, Dr. Kwon donated a significant gift to EPI in support of the Teen Epilepsy Weekend! We are so grateful for her generosity.

Thank you Dr. Jennifer Kwon!
Epilepsy Scholarship

Overcoming Epilepsy

Each year, Epilepsy-Pralid, Inc. awards scholarships to students who demonstrate courage in the face of adversity. This year, we recognized two amazing individuals: Jillian Hopkins and Destinee Sobles.

Jillian Hopkins, a freshman at the University of Delaware is described as a self-motivated, natural leader with a huge heart. Her life changed forever at age 12 when after having a grand mal seizure, she was diagnosed with epilepsy. Initially, Jillian felt like an outcast and kept her epilepsy a secret from friends. For years, Jillian felt embarrassed about her epilepsy until one experience changed her perspective.

In 2016 Jillian began volunteering with Syracuse Challenger Baseball, an organization that makes baseball possible for children with disabilities. As she watched a child in a wheelchair hit a home run, she realized that no matter the circumstances, any goal can be achieved. Jillian believes that epilepsy is a blessing in disguise as it inspired her to help others.

Destinee Sobles’ life was also turned upside down at the age of 12. When Destinee was diagnosed with epilepsy, she was restricted from many things that once were normal due to the unpredictable nature of her epilepsy. After years of being in and out of the hospital and testing different medications, Destinee’s seizures were finally under control.

Destinee feels that epilepsy has made her a stronger and more compassionate person. Currently, Destinee is enrolled in Mohawk Valley Community College’s Radiology Technician program to become a sonographer.

Both young women volunteered their time at Camp EAGR this past summer.

EPI is elated to award this year’s EPI Scholarship to such service-minded young women. We know they will continue to keep on following their dreams and not let anything hold them back.
Chocolate and Cake and the Difference We'll Make!

Make a difference at EPI's 33rd Annual Chocolate Ball with a corporate sponsorship or an in-kind donation to our silent auction.

Learn more at epiny.org/events or contact Denise Ester at (585) 442-6420 x2263 or dester@epiny.org

February 2, 2019
5:30–11:00 pm
HYATT REGENCY DOWNTOWN

Your gift makes partnerships and new programs possible! Set up a recurring gift at www.epiny.org or simply return the enclosed envelope.