From the Director:

Thank you everyone who attended our Iowa Epilepsy Advocacy Day in March and for educating your legislators about how your journey with epilepsy impacts your quality of life. We have completed both our Studio E Epilepsy Art Therapy Programs this spring and will be displaying the artwork the night before the Iowa Walks for Epilepsy in West Des Moines and Iowa City. We are holding our Iowa Walks for Epilepsy in West Des Moines, Dubuque and Iowa City this spring. Our Epilepsy Education Seminar Series is also underway, with one already held in Clinton and two more coming up in May in Fort Dodge and Marshalltown.

We are going strong educating a variety of groups across the state with the Seizure Recognition and First Aid programs. School nurses are working with their administrators now to line us up on a professional development day prior to school starting in the Fall with all school staff. There were 430 police officers in Polk County who completed the online training for Seizure Training for Law Enforcement program in the month of March. We are also assembling newly diagnosed epilepsy folders for adults and pediatrics who are newly diagnosed with epilepsy and distributing these in neurology clinics across the state.

Don't forget that you can connect with others at one of our Epilepsy Empowerment Groups around the state, so check the flyer for a location near you. In the meantime, please call in and we will help guide you to resources to overcome challenges associated with your epilepsy.

Teens Speak Up! 2016
#TSU2016 in DC

Iowa delegates recently attended the Epilepsy Foundation’s 2016 Public Policy Institute and Teens Speak Up! Conference in Washington, DC! With more than 200 attendees, including Epilepsy Foundation affiliate staff, parents, teens, doctors and volunteers from across the nation, this year’s event gave families and affiliates an opportunity to share their personal stories and advocate in support of the Epilepsy Foundation’s legislative goals in more than 150 Congressional meetings.
The Epilepsy Foundation’s Iowa office sponsored two teen delegates and two parent delegates: Simon Clark, Des Moines, as a Teen Ambassador, returning in a leadership role and Kendall Maslak, Cedar Falls, who was our 2016 Iowa Teen delegate. Parent delegates were Sharon Clark of Des Moines and Ed Maslak of Cedar Falls. This event was held in conjunction with the National Walk for Epilepsy.

The Public Policy Institute included hearing from a research panel and hill day training, as well as networking sessions in order to prepare for the Capitol Hill day meetings with policymakers.

For the Capitol Hill meetings, our Iowa advocates met with Senator Grassley, Senator Ernst, Congressman Loebsack, Congressman Young and Congressman Blum, as well as Congressman King’s health staffer to educate about the needs of people with epilepsy.

We advocated for the following initiatives:

- **$9.5 million in funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC)**, which help build safer communities, end stigma associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions and disabilities.
- **$175 million in funding for epilepsy research at the National Institutes of Health (NIH) and $32 billion in overall funding for NIH**, to support funding for a cure and better treatments for epilepsy.
- **Compassionate Access Act (H.R. 1774), Compassionate Access, Research Expansion, and Respect States (CARERS) Act (S. 683, H.R. 1535), and Charlotte’s Web Medical Access Act of 2015 (H.R. 1635)**, bipartisan legislation that would lift federal barriers to research and ensure safe, legal access to medical cannabis and cannabidiol (CBD) safe, legal access to medical cannabis if a patient and their healthcare team feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks.
- **Advancing Research for Neurological Diseases Act (S. 849)**, bipartisan legislation that would create a system to gather data about neurological conditions and diseases.
- **Medicare Formulary Improvement Act (S. 648)**, bipartisan legislation that would protect timely access to lifesaving medications by ensuring that anticonvulsants and the other five classes of clinical concern remain protected under Medicare Part D.

Now that the conference is over, the real work begins! Our community of families, affiliates, and volunteers will all work together over the next year to share information on living with epilepsy and raising awareness. Each teen delegate is responsible for completing a Year of Service project in their respective state to help further the efforts of teen advocacy on epilepsy. More to come on the projects of our two Iowa teen delegates!
From the Maslaks:

The Teens Speak Up program proved to be an opportunity for my fourteen-year-old Kendall to experience a new level of independence, enjoy social activities with other kids from around the country and most importantly she expressed herself to leaders of our federal government. Socially, she was able to connect with so many people from the epilepsy community. Almost immediately she connected with an 11 year old named Hailey from Florida who is heading up Kids Crew. It is a program that connects kids who want to help support those with epilepsy.

Due to the effects of epilepsy Kendall’s articulation and cognitive ability has been impacted. When we met with legislators, I didn’t know how much or how well she would be able to explain a life with epilepsy. We met personally with three congressmen (Blum, Loebsack and Young) as well as both Senators Ernst and Grassley. Kendall did an amazing job of explaining that she sometimes feels dizzy before a seizure. She also expressed that because of her seizures she sometimes feels scared and has had to go to the hospital in an ambulance. When I asked Kendall what she liked most about the trip, she said “meeting people and talking”. I think that sums up well what the whole program is about.

From the Clarks:

“I’m so grateful to have had the chance to go back this year,” said Simon. “It felt more impactful being there in a leadership role and using my past experience to help others feel more comfortable and confident about talking to their legislators.”

Through TSU, Simon has learned how to speak effectively about his life with epilepsy and how to advocate for himself and for others. He has visited the State Capital in Des Moines several times to speak with his representative and senator about topics that impact his life and his future.

One of the biggest benefits of participating in the conference for Simon has been meeting other teens who live with epilepsy and who battle the same issues he does, quickly creating a strong bond and support system that teens with epilepsy may have trouble finding. He was able to share the Teen Connection website with all of the attendees and passed out wristbands for the site to Senator Ernst, Representatives Loebsack and Blum, and to staff members for Senator Grassley, Rep. King and Rep. Young. This program stresses the importance of letting lawmakers see the real people affected by the decisions they make and to hear how different legislation has helped or hindered their epilepsy treatment options and their quality of life.

Simon and his mother, Sharon, flew into Washington DC a little early, to be able to participate in the National Epilepsy Walk. For Simon’s mom, being part of the walk and talking to other parents of children with epilepsy is very emotional.

“Although Simon has been seizure-free for over 3 years, you never really get past the worry and the drive to do more for other parents and make the journey a little easier for other families.”
2016 Update

Studio E: The Epilepsy Art Therapy Program has wrapped up successful spring sessions in both Iowa City and Des Moines. Both groups met for six weeks with a certified art therapist to work on an art directive and explore feelings and emotions around the challenges that come with having epilepsy.

Each session began with a discussion on the activity that would take place during the session. The group also participated in a centering exercise to bring the focus on the art and emotions of the moment. The participants enjoyed each session very much, with many of the artists stating that they wished the group “had even more time” to meet and express through art.

Because the participants commit to attending all six sessions of Studio E, each group quickly becomes comfortable and familiar with one another. This is a crucial component for being able to share the feelings and symbolism that comes out in each participant’s artwork. One participant in the Iowa City group stated that she “didn’t know there were people out there that felt the same way I did about my epilepsy.” A true community is created within each Studio E art therapy group and many participants have plans to continue seeing one another long after Studio E has ended.

There is a Studio: E Art Gallery Show Friday, April 29th at the Courtyard Marriott in West Des Moines. This will be in conjunction with the pre-registration and t-shirt pick-up for the West Des Moines Walk occurring the very next day at Jordan Creek Center.

A big thanks to Lundbeck for the generous funding and support for the annual Studio E program. We hope to see you in 2017 for the next Studio E session!

#EFlowaWalks

Our biggest fundraiser of the year is wrapped up in a series of walks. We have three this year in April, May & June! Join us and make memories, friends and donations!

Iowa Walk for Epilepsy in West Des Moines: April 30, 2016
Iowa Walk for Epilepsy in Dubuque: May 14, 2016
Iowa Walk for Epilepsy & 5k Fun Run in Iowa City: June 4, 2016

Please pay attention to the sponsors listed on our walk registration sites and those featured on the walk page on our website! Also, check out the social media guides established for each walk that encourage you to share the news about the walks, build a team and encourage participation and support of the Epilepsy Foundation in Iowa which becomes support for Iowans impacted by Epilepsy!
EF-Iowa Intern Farewell

As the intern for the Epilepsy Foundation Iowa Office, I have taken part in several great events and had various opportunities throughout the semester. Some highlights of my time with the Foundation include coordinating and executing the Global Purple Day partnership with Scratch Cupcakery as well as representing the Foundation at both the Iowa Black Hawks Hockey game and the Iowa Barnstormers indoor football game. Another great opportunity in which I am so thankful to have taken part is the Studio E: Art Therapy series. I got to know several clients, take part in several wonderful art directives and learn more about how Art Therapy can help anyone and everyone.

I’ve had the opportunity learn about the communications side of working with the Foundation including making contributions to their website and all social media platforms which allowed me to then be able to create, edit and publish promotional announcements and content. I have also completed a few projects for the Foundation over the course of the semester which include a grant application, an educational handout, and a compilation of applicable grants for which the Epilepsy Foundation in Iowa might qualify for future projects.

This semester I have learned a great deal, grown both as a student and professional and am beyond grateful for each of the experiences, projects, events and opportunities I’ve been a part of as the Assistant Coordinator for Iowa Epilepsy Services.

-Kenzie Mertens

Side Effects is a special feature recognizing individuals who go above and beyond as a side to their day job or other roles in positively impacting individuals with Epilepsy. This edition’s Side Effects recognizes Amelia Heiden!

Amelia is a committed and compassionate volunteer for CamPossible! If you were at the 2015 Iowa Seizure Smart Conference in November, you saw a video of last year’s camp happenings. That video was her creation!

Aside from summer at camp, during the school year, she is also a student at the University of South Dakota where she is pursuing change to the way they handle disabilities.

She was recently featured in her University’s newspaper after presenting at IdeaFest. Find more of her story online from The Valonte.

A series of Epilepsy Education Seminars are being conducted in the spring. We have partnered with community hosts and area neurologists to provide epilepsy education in select communities across the state. Our goal is to offer epilepsy education and to assess the needs of the population of those impacted by epilepsy in those communities all in one evening. These seminars are provided at no charge, as they are part of our education and outreach efforts.

Fort Dodge, Iowa
Dr. Babak Rezaei, Best Western Starlite Village, May 10th at 5:30 PM Get registered!

Marshalltown, Iowa
Dr. David Moore, Best Western Regency Inn, May 19th at 5:30 PM Get registered!

Please share this information and invitation with anyone whom you feel would benefit from this opportunity!
Purple Day 2016

Iowa celebrated Global Purple Day with a bang this year! From cupcakes to body checks, we covered the day with education, fun and connections! We blew up social media all day long with epilepsy awareness and education. The morning kicked off at five Scratch Cupcakery locations throughout Iowa. Beautiful cupcakes were frosted with purple and adorned with the message: 1 in 26. Then, each location had information about the 1 in 26 statistic and others with which to educate their customers.

The evening didn’t disappoint either! Staff and friends of the Foundation gathered at Young Arena in Waterloo for the Blackhawks Hockey Game! A Cedar Valley family was blessed with the opportunity to drop the puck at the game opener. Pictured here: The Maslaks of Cedar Falls are on the ice while 14-year-old, Kendall, drops the puck just days after celebrating 1 year seizure free!

Several others came out in celebration with purple t-shirts galore! We were able to educate the public, spread the word about the walks, promoted EFI Teen Connection and connect with people who were interested in our services. We also captured pictures of the University of Iowa Neurology Department spreading awareness in celebration as well as supporters from Delta Phi Delta at Cornell College. We are grateful to these organizations who helped us spread awareness and education in celebration of Global Purple Day for Epilepsy Awareness 2016.
Taking Wells Fargo by Storm

Also in April, we were invited to Wells Fargo Arena to spread awareness at a game with the Iowa Barnstormers. The highlight of the night was when teens supporting teens with epilepsy were invited on the field as honorary team captains. This was an amazing experience for the kids involved and the families who were there to support them! This even is best shown in pictures! The first picture below shows the brainstormers behind the Barnstormers! Patrick O’Connor (right) is a leader within the Iowa Epilepsy Youth Council and a long-time friend of Andrew Godfrey (left), Account Executive with the Iowa Barnstormers. This beautiful friendship was the start of this awesome opportunity for Iowa teens impacted by Epilepsy as well as the outreach the Foundation was able to accomplish with presence on the concourse.

Thank you for your connection to & support of the Epilepsy Foundation-Iowa! Stay connected and reach us when you need!

1111 9th Street, Suite 370 Des Moines, Iowa 50314 515-238-7660 www.epilepsyiowa.org