

CREATING A COMMUNITY OF SUPPORT



Seeing your first seizure is memorable; seeing your child's first seizure is life changing. Taylor Roder still remembers every detail from her daughter's first seizure. Peyton was just 2 years old at the time, and until September 28th, 2015 had been a healthy little girl who met every developmental milestone and rarely got sick.

Peyton had gone through the day with no problems and was put to bed after her normal bedtime routine. Then the crying started, followed by screaming. Thinking it was just a nightmare, Taylor tried rubbing Peyton's belly to calm her down and wake her. It wasn't until noticing how stiff her body was that Taylor began to panic.

Once they arrived at the local hospital, Peyton suffered two more seizures that night and had to be transported to the Twin Cities for further testing. It was discovered there that Peyton had Tonic Nocturnal Frontal Lobe Epilepsy.

Six months after her diagnosis, Peyton reached status epilepticus and was rushed to the PICU after two days of uncontrolled seizures. This was the first Taylor heard of the condition, and now two and a half years later still remembers how close she was to losing her daughter.

"There are times that we don't even think of the fact that Peyton has epilepsy until it comes time for us to give her medication. Then, there are other times, where in the middle of the day reality hits and we're reminded that there are certain things she can't do that other kids her age can," says Taylor.

While Taylor received plenty of help and support from family and friends, Peyton's diagnosis left her frustrated and feeling alone. She knew of no other parents who had a child with epilepsy.

"A few months after Peyton's first seizure I began to feel frustrated because nobody knew what I was going through as a mother. However, around that same time, a couple that my mother knew reached out to me via Facebook. They had a little girl who was almost a year older than Peyton and had epilepsy as well."

Taylor also reached out to EFMN. Highlighting the challenges faced by those who live far from a regional city, Taylor learned the closest EFMN Connect Group was in St. Cloud – over 100 miles away. Determined to raise awareness and help others, Taylor has made frequent trips to the Twin Cities and has participated in the OneIn26 awareness campaign and the annual EFMN Advocacy Day at the Capitol. She also started her own Connect Group near home for other parents who couldn't make the drive to St. Cloud.

"I have received an immense amount of love and support since becoming so public about Peyton's epilepsy. I want Peyton to be proud and confident in her epilepsy because it's part of her. As she continues to grow, she will come to learn that not everybody is like her. I never want Peyton to question that it's okay to be different."



**2018-2020 STRATEGIC PLAN:
CONNECT WITH MORE
COMMUNITIES**

MAKING SCHOOLS SEIZURE SMART



EFMN has provided training to schools since 2006. The Seizure Smart Schools program has evolved and grown, educating over 15,000 people in 2017, but the mission of the program has never changed: to create a safe and supportive school environment for youth with epilepsy. We believe a student shouldn't have to worry about what will happen if they have a seizure at school or fear that they may be bullied because of their condition.

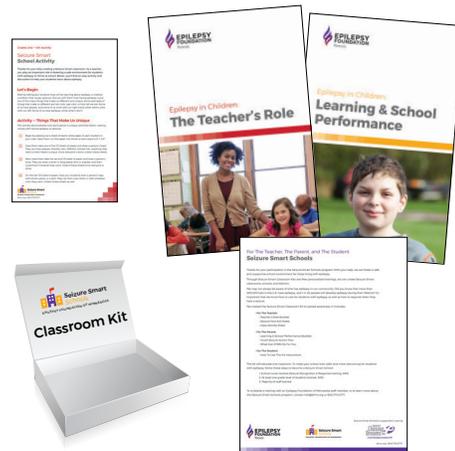
EFMN offers multiple ways for schools to support their students with epilepsy. An easy way to start is by ordering a Seizure Smart Schools Classroom Kit. These kits provide simple ways for a teacher (or parent) to help students understand epilepsy and know what to do if someone has a seizure. There are ideas for grade-appropriate activities and items to hand out to each of the students in the classroom. We've just updated the kits and they are ready to mail!

A Classroom Kit is just one way to get started. EFMN also provides training to school staff, seminars for school nurses, and online resources. In order for a school to be designated a Seizure Smart School, the school must have fulfilled these requirements:

1. The school nurse has participated in an EFMN Seizure Recognition & Response training, and
2. A minimum of one grade level of students has been trained, and
3. The majority of school staff has been trained.

254 schools are currently Seizure Smart. We are extremely grateful to our generous supporters for making sure this program is available to schools at no cost. At this year's annual Rise Above Seizures Gala, our supporters raised \$54,000 to help. It would take over \$250,000 more to make the materials available for every school in Minnesota and eastern North Dakota.

To get a free kit or learn more about becoming a Seizure Smart School, visit efmn.org/ssc or contact our Seizure Smart Schools Coordinator at jpickett@efmn.org or 651.287.2315.



Some of the materials included in the newly updated Classroom Kits that help train a classroom.

- 1 in 26 will develop epilepsy in their lifetime.
- Only 1 in 10 Minnesota schools are Seizure Smart.



THANK YOU WALKERS

On August 2 more than 1,000 walkers came together in four communities to raise \$87,000 as part of the Rise Above Seizures Walks. Thank you to everyone who helped raise awareness; your support is inspiring! Twin Cities Metro walk numbers will be released shortly.

EXPO TO FOCUS ON RESEARCH AND HEALTH

THIRD ANNUAL EPILEPSY & SEIZURES WELLNESS EXPO

Saturday, November 10, 2018

The third annual Epilepsy & Seizures Wellness Expo will take place on November 10. This event will present resources and information to people living with seizures no matter where they are on their epilepsy journey. From program staff to health care providers, this gathering of experts helps connect attendees of all ages with the information they need.

This year's Expo will feature keynote speaker, Dr. Brandy Fureman, Vice President of Research and New Therapies at the Epilepsy Foundation of America. Dr. Fureman will share insights on new research and therapies from the field. Attendees will also get to choose between breakout sessions on all aspects of research, therapy, and overall wellness.

Whether you are a participant in EFMN's programs, a supporter whose gifts make the Expo possible, or someone newly diagnosed with epilepsy, you will find the Expo to be a valuable resource.

The 2018 Expo will be held at the new Delta by Marriott Hotel in northeast Minneapolis. Register by October 26 for the chance to win a free overnight stay. Cost is \$10 for individuals and \$20 for the family. Financial assistance is available. Please contact apike@efmn.org for more information.

**To learn more and register visit
EFMN.ORG/EXPO.**

Epilepsy & Seizures Wellness Expo
Saturday, November 10, 8 AM - Noon
Delta by Marriott Hotel
1330 Industrial Blvd. NE.
Minneapolis, MN 55413

INTERESTED IN EXHIBITING?
Contact Amanda Pike at apike@efmn.org.



Thanks to your support, we're able to host the annual Epilepsy & Seizures Wellness Expo at minimal cost to attendees.



UPCOMING EDUCATION EVENTS

- Sep 27:** Employment Workshop - Accommodations
- Sep 29:** Parent Workshop - Seizure Medication & School Safety
- Oct 2:** Webinar - School Personnel Training
- Nov 8:** Employment Workshop - Hidden Job Market

To start receiving our monthly online Newsletter visit efmn.org/news

DONOR SPOTLIGHT: LEAVING A LEGACY



We recently learned of a donor who included EFMN in his estate plan with a gift totaling more than \$100,000. Unfortunately, we didn't know this generous donor personally. Instead, we met with a close friend who shared that he selected EFMN because it was an organization which makes a difference each day. The gift was designated as unrestricted, so we've decided to use it to support our programs and services as they have a direct benefit to individuals and families impacted by epilepsy.

Bequests and other planned gifts are important to the long-term sustainability of EFMN, and we'll be introducing a more robust planned giving program in 2019.

EFMN is incredibly grateful to this donor whose legacy will continue to live on through our mission.

To learn more on how you can make a lasting mark through a planned gift, please contact Rachelle Holm at rholm@efmn.org.

THANK YOU, DONORS!

ADVOCACY FOCUS: STEP THERAPY SUCCESS

As part of the Minnesota Step Therapy Coalition, EFMN is grateful for all of our epilepsy advocates who joined us on March 14 for our Advocacy Day at the Capitol and worked to pass this important legislation. The new law goes into effect January 1, 2019. It is estimated to cover just over half of Minnesota's population and includes all state regulated plans except Medicaid plans. Starting January 1, health care providers will have access to a patient-oriented procedure allowing them to override a health plan's step therapy protocol when they demonstrate one of the following:

- The required fail first drug is contraindicated, will likely cause an adverse reaction including physical or mental harm, or will decrease the ability of the patient to achieve or maintain reasonable functional ability in performing daily activities.
- The required drug is expected to be ineffective.
- The patient has previously tried and failed the required drug.
- The patient is currently receiving a positive therapeutic outcome on a prescription drug.

Similar legislation has been introduced on a national level – Restoring the Patient Voice Act. We are hopeful that Minnesota will again lead the way in getting a step therapy law passed.

BRIDGE TO INDEPENDENCE FUND RECIPIENT

We are proud to announce the first award from the Bridge to Independence Fund. Established in 2017, the Bridge Fund was formed to provide emergency assistance to individuals impacted by epilepsy. The first grant went to Steve Ireland, who recently learned he needed to find a new place to live because of rising housing costs. Steve received a \$1,000 grant to help with moving costs to a facility with support services. Steve shares, "The Epilepsy Foundation of Minnesota was very instrumental in helping my move go smoothly."

We are grateful to the Hubbard Foundation and our generous donors who made this fund possible. To learn more about the application process, contact Rachelle Holm at rholm@efmn.org.

To support the Bridge Fund, visit efmn.org/giving.



Epilepsy advocates meet with their representative John Marty at EFMN's annual Advocacy Day at the Capitol.

WHAT ARE SOME OF THE QUESTIONS YOU ARE FREQUENTLY ASKED?

FROM THE VIEWPOINT OF OUR PROGRAM STAFF

Fargo/Moorhead

Janice Tweet | jtweet@efmn.org

- How do I get help paying for travel costs to see my neurologist?
- Is there an Epilepsy Foundation that covers western North Dakota?
- What devices are available to help me monitor my child's seizures?

Duluth

Lisa Peterson | lpeterson@efmn.org

- Where can I learn more about the ketogenic diet?
- What are the different types of seizures and how should someone respond to a seizure?
- A family member of mine with epilepsy lives alone; how can I make sure they are safe?

St. Cloud

Lori Braegelmann
lbraelmann@efmn.org

- I am having issues finding or staying employed due to seizures; can you help me with this?
- I don't know anyone else with epilepsy; how do I meet others?
- Do you have resources for my child's teacher and school about epilepsy and what to do if they have a seizure?

Metro

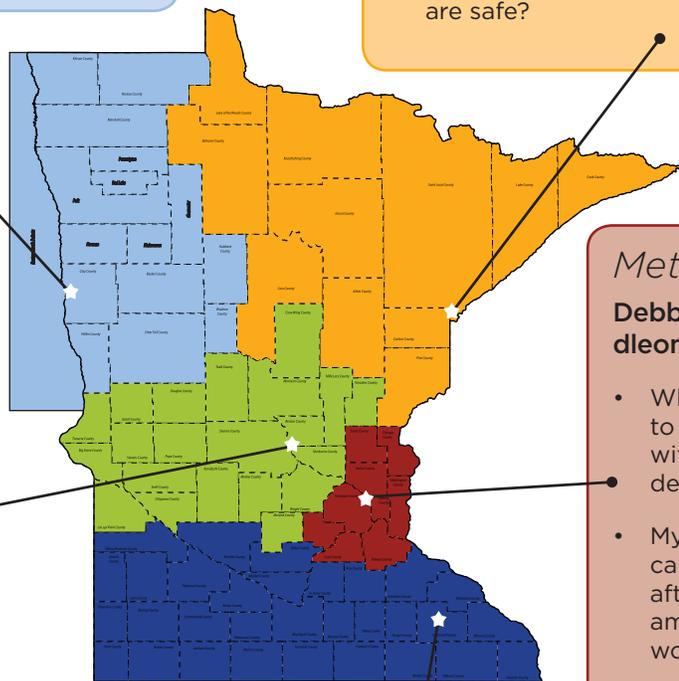
Debbie Leone
dleone@efmn.org

- What resources are available to help my family member with epilepsy who is feeling depressed and hopeless?
- My driver's license has been cancelled for three months after a recent seizure; how am I supposed to get to work?
- How do I go about getting a seizure assistance dog?

Rochester

Emily Gomez | egomez@efmn.org

- How do I get a medical cannabis prescription?
- I was just diagnosed with epilepsy, what do I do now?
- Are there any support groups in my area for people with epilepsy?



These and other epilepsy topics can be found at efmn.org/resources. For answers to your epilepsy-related questions, contact your regional coordinator or call our Information & Referral specialist at 800.779.0777.



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2018 UPCOMING EVENTS

- Oct 13:** Annual Shining Star Celebration
- Nov 10:** Epilepsy & Seizures Wellness Expo
- Nov:** Epilepsy Awareness Month

To have a list of quarterly events mailed to you, call 800.779.0777.

IMPORTANCE OF VOLUNTEERS



It takes a village of volunteers to pull off a successful Camp Oz! This year, 60 volunteers took time away from work and other commitments to make camp a memorable experience for our campers. The truth is, non-profit organizations like EFMN cannot fulfill their mission and achieve their goals without volunteers.

According to the Independent Sector Study (2017), one volunteer is worth an average of \$24.14 an hour to an organization. Over six days of camp, this becomes an enormous cost savings. We would like to give a huge thank you to all of the volunteers who invest in EFMN.

Thank you Upsher Smith Laboratories for being a valuable partner and allowing 30 of your employees to volunteer for the week!