

INVESTING IN EPILEPSY RESEARCH



In 2017 we came together as an organization, gathered feedback from those we serve, and developed a new strategic plan to guide us from 2018-2020. Two areas of focus were increasing the capacity of the organization, and investing in research. Due to the growth of the organization as a whole, we've been able to show strong financial results while expanding our programming to more people than ever.

Thanks in large part to the support of our donors, and the overall strength of the organization, we were able to increase our total financial support of epilepsy research to \$100,000 in 2018. This commitment to increased investment in research reflects the fact that when adjusted for prevalence, epilepsy is funded at much lower levels than other neurological conditions.

"As a leader in the epilepsy community, we need to continue promoting investment in innovation and research that will lead us to find cures and save lives," says Brandon Megal, EFMN Board of Directors President.

At the Epilepsy & Seizures Wellness Expo in November we heard from Brandy Fureman, PhD, VP of Research & New Therapies at the Epilepsy Foundation of America. Brandy has been an important partner in helping shape and direct our investment in research.

"I am most excited about the transformation we are seeing in epilepsy research to make sure that people living with

epilepsy are partners in the research process. More and more people are sharing their priorities and challenges, participating in research to find new therapies and solutions, and advocating for research funding. EFMN gives incredible support to epilepsy research, including the Human Epilepsy Project and the My Seizure Gauge project locally, and the Shark Tank competition open to U.S. and international entrepreneurs. These are great examples of what we can do together to accelerate epilepsy research and innovation," says Brandy.

We are happy to share that in 2018 we invested \$100,000 in two research projects, our single largest investment in research ever. Close to home, we gave \$50,000 to the HEP2 Clinical Trial, which has two sites in Minnesota. Nationally, we used our \$50,000 grant to leverage another \$50,000 in funding for the Epilepsy Foundation of America Shark Tank Competition. In total, our \$100,000 investment translates to \$150,000 in epilepsy researching funding.

Visit our website to learn more about our 2018-2020 Strategic Plan. Each newsletter will touch on the progress being made.

**2018-2020 STRATEGIC PLAN:
SUPPORT RESEARCH AND
INNOVATION**



ELAM BAER & JANIS CLAY EDUCATIONAL SCHOLARSHIP

Every year, ten \$1,000 scholarships are awarded to students with epilepsy thanks to the generosity of Elam Baer, Janis Clay, and family. Together, they established the Elam Baer & Janis Clay Educational Scholarship in 2006 to provide assistance to students living with epilepsy. This scholarship is a perfect extension of our vision, which is to work towards a world in which those with seizures realize their full potential.

“This scholarship shares the message that education and knowledge are important for everyone and we want to make it more accessible for those living with epilepsy,” says Elam Baer and Janis Clay.

Elam and Janis made clear they wanted the application process to be simple and straightforward. To be eligible for the scholarship, applicants must:

- Have a diagnosis of epilepsy.
- Be a high school senior or have a high school diploma.
- Provide proof of acceptance into a post-secondary academic or vocational program.
- Live in Minnesota or eastern North Dakota.
- Submit completed application and two letters of recommendation.

The application period is open until April 8 and recipients will be announced on May 22.

To apply visit EFMN.ORG/SCHOLARSHIP.



HAFSA YUSUF

Previous Scholarship Recipient

“I believe that I truly deserved to go to college. I’m the oldest of nine kids and have hopes to be the first family member to attend and graduate from college. The Elam Baer & Janis Clay Scholarship has significantly helped me with paying for my college education. It’s given me a chance to fulfill my dreams of someday becoming a pediatrician and rising above my seizures.”



Recipients of the 2018 Elam Baer & Janis Clay Educational Scholarship pose with Janis Clay (front row, second from left).

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

DONATED GOODS - SUPPORTING THE MISSION

As a friend and supporter of EFMN, you likely know about the broad array of programs and services we offer. However, for a majority of people, they only know us as the place with purple trucks that collect their used clothing. The social enterprise arm of our foundation, the Donated Goods division, provides a significant source of revenue that's generated by collecting and selling used clothing and small household items to Savers, a national corporation that operates a chain of second-hand stores.

Since 1997, this part of our organization has been recycling unwanted goods and generating revenue that supports people affected by epilepsy. In 20+ years the Donated Goods division has grown into an operation that employs 27 people and generates over \$1 million annually for programs and services. We collect items throughout the greater Twin Cities, Rochester, and St. Cloud areas through curbside pickups, donation bins, and clothing drives from partner organizations.

With Donated Goods revenue accounting for almost half our income, we are constantly looking for ways to keep the business strong. Recently, the Donated Goods division began investing in data-management tools to better analyze our operations and respond to market changes. Additionally, with 200,000 curbside pickups in 2018, we want to be sure these donors learn something about epilepsy even if their primary motive is cleaning the closet.

The quality and breadth of programs and services we're able to provide are due in large part to the people choosing to donate their used clothing and household goods. We take what people no longer want and convert it into services that support education about epilepsy, connections for those living with epilepsy, and resources to help people thrive.

With competition increasing for these types of goods, we count on your help by donating clothes and spreading the word.

Visit our website or call 800.779.0777 to schedule a pickup or find the donation bin nearest you.



Support Programs

One full truck of donations sends two kids to Camp Oz.

Make Space

We collected 7 million pounds of clothing in 2018.



Recycle & Reuse

One thrifted t-shirt saves 700 gallons of water.



2019 ADVOCACY FOCUS – SEIZURE SMART SCHOOLS LEGISLATION



EPILEPSY FOUNDATION OF MINNESOTA

There are 470,000 children living with epilepsy in the U.S. and it's estimated that 7,400 of those children live in Minnesota, a state which has just over 3,000 public, private, and charter schools. For students with epilepsy, it's important that school staff are well-equipped with the tools and knowledge to provide a safe and enriching environment.

This is why our top advocacy focus for 2019 is Seizure Smart Schools legislation (HF 1422) that makes sure identified school personnel are prepared to recognize and appropriately respond to someone having a seizure. Additionally, the legislation ensures that certain school personnel are trained and available to administer seizure rescue medications and medications prescribed to treat seizure disorder symptoms.

There are three components to this legislation:

- School personnel complete seizure recognition and first-aid response training; and
- Students have a Seizure Action Plan in place and available to school personnel responsible for the student; and
- Prescribed medication, including rescue medication, is administered to students with epilepsy by a trained nurse or staff member.

On February 27, epilepsy advocates from across Minnesota gathered at the State Capitol to meet with legislators and ask for their support. You can join our dedicated group of advocates by calling your legislators today and asking them to support and bring awareness of this legislation (HF 1422) to the education community. Together, we can raise awareness of epilepsy and ensure that when students have a seizure at school they're surrounded by people who can keep them safe.

This legislation expands the school personnel training portion of becoming a Seizure Smart School, but does not require schools to complete all criteria to be designated as Seizure Smart. While we provide programs and services throughout Minnesota and eastern North Dakota, our advocacy efforts are focused on Minnesota at this time.

Visit EFMN.ORG/ADVOCACY for more information.

RISE ABOVE SEIZURES GALA

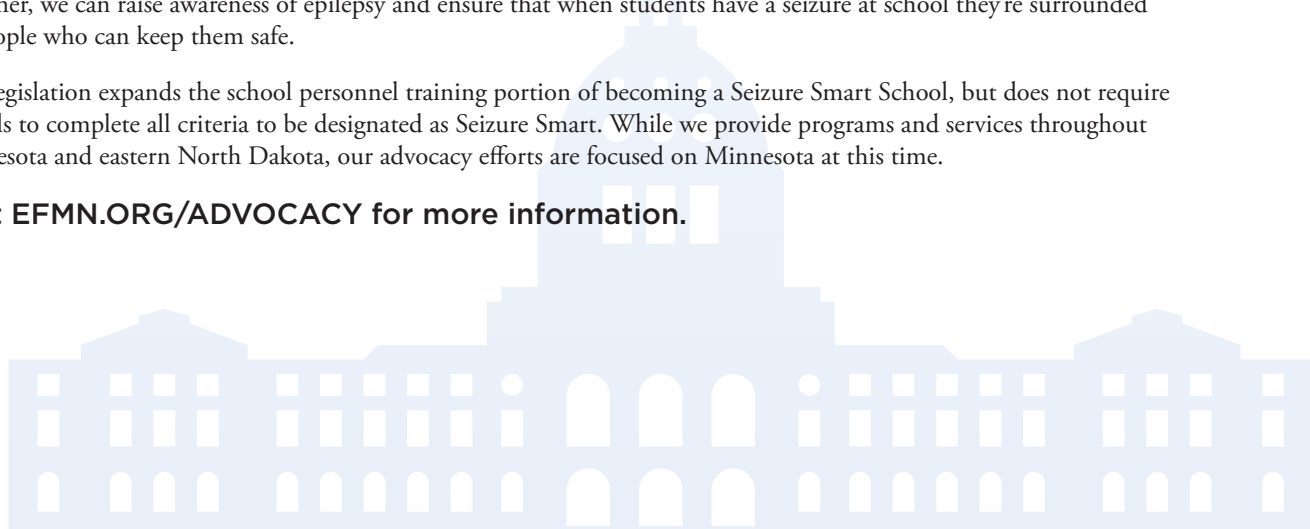
Saturday, April 27
McNamara Alumni Center

Tickets for the Rise Above Seizures Gala are now available for purchase at efmn.org/gala. Attendees enjoy a silent and live auction, dinner, program, and powerful personal stories centered on our theme of "Independence."

Can't attend? You can still participate in the silent auction via mobile bidding by creating an account at efmn.org/gala.



Keep track of your silent auction items with our mobile bidding system.



WHAT NEW OFFERINGS SHOULD PEOPLE IN YOUR REGION KNOW ABOUT?

FROM THE VIEWPOINT OF OUR PROGRAM STAFF

Fargo/Moorhead

Janice Tweet | jtweet@efmn.org

- **Family Connect Groups:** With on-site childcare and gym activities parents can connect while their kid(s) play.
- **Workshops:** These upcoming educational opportunities help inform and guide individuals and families affected by epilepsy.

Duluth

Lisa Peterson | lpeterson@efmn.org

- **Social Events:** For the first time we will offer social events outside the Duluth-Superior area.
- **Age-Specific Events:** These events help children, teens, and adults affected by epilepsy connect with others who are the same age.

St. Cloud

Amy Haugen
ahaugen@efmn.org

- **Meet Your New Regional Coordinator:** Amy Haugen, Senior Regional Coordinator for Central Minnesota, will host a meet and greet at the St. Cloud Donation Center office. Check the online calendar for more details.

Metro

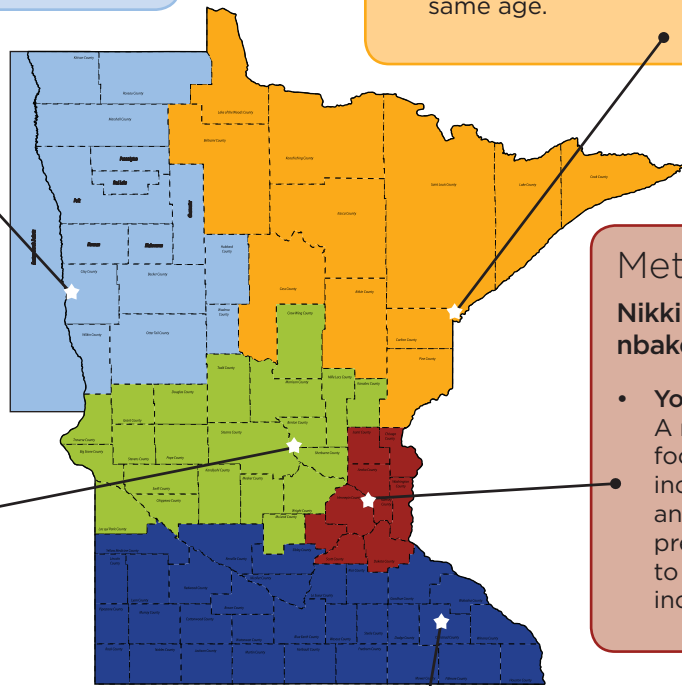
Nikki Baker
nbaker@efmn.org

- **Youth & Family Growth:** A new position at EFMN will focus on teen programming, increasing parent resources, and improving our clinic presence. This will translate to new social events and increased support services.

Rochester

Emily Gomez | egomez@efmn.org

- **Digital Trainings:** To better educate all of southern MN we'll be introducing online Seizure Recognition & Response trainings.
- **New Communities:** Open Houses and Connect Groups in new cities will help us reach more families and individuals.





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2019 UPCOMING EVENTS

Apr 27: Rise Above Seizures Gala

Jun 16: Camp Oz

Aug 1: Regional Rise Above Seizures Walks

Sep 21: Metro Rise Above Seizures Walk

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

COMING SOON: NEW EFMN WEBSITE

In our quest to better serve and educate our community, we are redesigning our website with plans to launch later this spring. Our goals were to make information easier to find, facilitate more connection with the people we serve, and help generate awareness and give you the tools to educate friends. Our content has been reorganized and refreshed, and we're serving up more stories about our community and promising research.

Take a moment to bookmark our site, sign up for the monthly e-newsletter, and send any feedback about tools or stories to nick.baker@efmn.org.

