



2018 Annual Report



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Mission

The Epilepsy Foundation of Minnesota (EFMN) leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures and save lives.

Vision

A world where people with seizures realize their full potential.

About Epilepsy

One in 10 people will have a seizure in their lifetime and 1 in 26 will develop epilepsy; an estimated 60,000 people with epilepsy live in Minnesota and eastern North Dakota. EFMN works to improve understanding of epilepsy through regional education programs and public awareness efforts. We work closely with individuals affected by epilepsy, supporting them through their personal journey with epilepsy, and connecting them to resources and to other people with similar experiences.



Dear Friends of EFMN,

In the words of Susan B. Anthony, "Independence is happiness." We recognize that independence looks different for each of us. For some living with epilepsy this means having the ability to drive a car, for others it is being seizure free, and yet for others, independence is being welcomed into a classroom in which the members know how to respond if a seizure occurs. At EFMN we strive to build independence for individuals and families impacted by epilepsy while building awareness in our communities.

Our organization has over 60 years of success supporting independence. This is done through our youth camps, Shining Stars, and Information Services programs, as well as our focus on building awareness and advancing our advocacy efforts.

Over the past year we reached more individuals while advancing our *Rise Beyond* strategic plan. We are proud to share that in 2018 we:

- Increased our investment in research and innovation, contributing over \$100,000 to promising innovations and therapies.
- Expanded camp offerings so that children of all abilities and regions can participate.
- Introduced an employment program focused on helping both employees and employers.
- Awarded our first Bridge to Independence Fund grant which helps individuals and families in a time of need.
- Continued to stay on the leading edge in programming; improving and expanding our offerings so that people living with epilepsy and their network of support can access them more easily.

In the following pages, you will read about some of our successes from the past year. We could not do our important work without the generosity of our financial donors and volunteers. We are fortunate to have you as one of the reasons that our community continues to thrive. Thank you for your continued and deep commitment to EFMN with a special focus on giving others the gift of independence.



Brandon Megal
Board President



Heidi L. Fisher
Executive Director



2018 PROGRAM SUMMARY AND IMPACT REPORT

EFMN programs are designed to benefit all people affected by epilepsy regardless of where they are in their journey. We measure our impact by how many people we educate, connect, and empower through programs like Seizure Smart Schools, Connect Groups, and the annual Advocacy Day at the Capitol, among others. Some highlights from 2018 include:

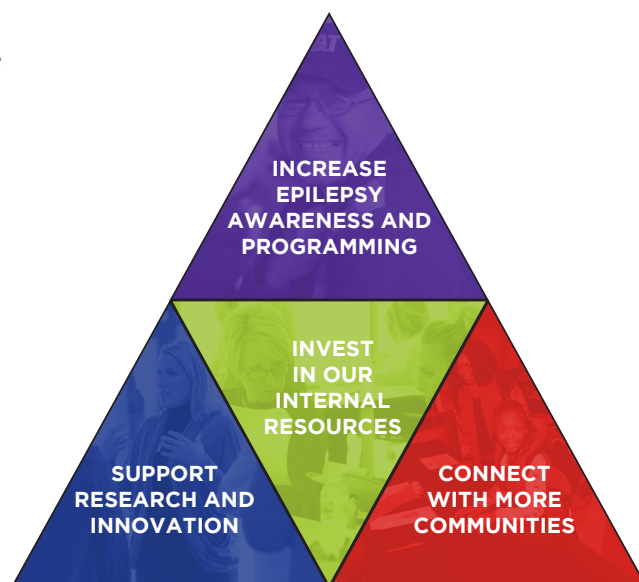
- **Educating** more than 52,000 people through trainings, workshops, and webinars. Additionally, over 125,000 people used our website as a resource.
- **Connecting** over 2,000 people through the Shining Stars program for youth with epilepsy and their parents, and social events like the annual adult picnic.
- **Empowering** more than 7,000 individuals by supplying them with the tools they need to take control of their epilepsy through advocacy efforts and our creative arts program.

2018-2020 STRATEGIC PLAN

During year one of the three-year *Rise Beyond* strategic plan, EFMN laid the foundation for growth in valuable services by implementing a new database system and launching a brand new website. These improvements allow us to better connect with and serve the people in our community while offering more resources than ever before.

Remaining consistent with our mission to accelerate therapies to stop seizures, find cures, and save lives, we invested a total of \$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, and on the national level used \$50,000 to leverage an additional \$50,000 for the Epilepsy Foundation of America Shark Tank Competition.

To connect our investment in research to the people we serve, the 2018 Epilepsy & Seizures Wellness Expo focused on new therapies and advancements in research. We were joined by Brandy Fureman, PhD, VP of Research & New Therapies at the Epilepsy Foundation of America, and held breakout sessions on topics such as treatments beyond medication and how new research can help us live healthier lives.



THE GIFT OF INDEPENDENCE

Independence looks different for everyone. For some, it means having the ability to go to work or school and be seizure free. For others, it's about being able to wake up and get out of bed without assistance. Wherever people are on the continuum, EFMN is here to offer support and programs that instill independence in the 60,000 individuals in our community living with epilepsy and seizures.

One of the new programs we've introduced that supports personal independence and provides emergency assistance is the **Bridge to Independence Fund**. Initially founded in late 2017 with a grant from Hubbard Broadcasting, this fund provides one-time financial assistance to individuals and families during a time of crisis or unanticipated expenses. The average grant is \$500, and to-date we have awarded over \$7,000 to people in need. Some recent examples of support are providing transportation to someone who can't drive to work due to a recent seizure, and paying for an additional EEG not covered by insurance.

"I have been lucky to be part of the committee that reviews applications for the EFMN Bridge Fund. We have always recognized the needs of those we serve, and sometimes that need is financial. Individuals with seizures and/or epilepsy face many hurdles in their everyday life, and when it comes to financial obligations related to doctor appointments, inability to work, or the need for transportation, EFMN is here to provide assistance. It is rewarding as a board member to witness the positive support provided for those we serve." – **Zack Frisk, EFMN Board Member**



"I think kids should go to camp because it's an outlet for creativity, and it's a chance for them to be themselves. Camp Oz taught me the only job I have is to be myself, and that's the best thing there is." –**Former Camp Oz Camper**

THANK YOU TO OUR EVENT CORPORATE PARTNERS



Your Partner
in Epilepsy



PARTNER HIGHLIGHT

Gillette Children's Specialty Healthcare has been a valuable EFMN partner for over 20 years. In addition to providing excellent care to families of children living with epilepsy, they have sponsored EFMN events such as the *Rise Above Seizures Gala* and *Epilepsy & Seizures Wellness Expo*. Tim Feyma, MD, a Pediatric Neurologist and board certified Epileptologist at Gillette, has a passion for helping children with epilepsy thrive and find independence in spite of their diagnosis. Tim currently serves on EFMN's Board of Directors and is chair of the Professional Advisory Board. His leadership, and the support of Gillette, is instrumental in EFMN's current success and future path. Thank you, Tim and Gillette Children's Specialty Healthcare for all your support.

"It is my joy and honor to advocate for the epilepsy community in tandem with the Epilepsy Foundation of Minnesota through education, legislation, and awareness efforts."

-Tim Feyma, MD



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Zogenix

2018 FINANCIAL SUMMARY

STATEMENT OF ACTIVITIES YEAR ENDING DECEMBER 31, 2018

Revenue:	2018	2017
Individuals, Foundations, and Corporations	765,345	672,788
Special Events, net	310,122	285,932
Program Fees & Other Income	45,256	32,461
Investments	(97,728)	153,776
Donated Goods, net income	1,476,247	1,593,987
Total Revenue	2,499,242	2,738,944
Expenses:		
Programs that Educate	753,795	677,066
Programs that Connect	662,776	507,046
Programs that Empower	323,513	283,759
Fundraising	412,189	482,825
Management and Administration	239,752	277,710
Total Expense	2,392,025	2,228,406
Total Change in Net Assets	107,217	510,538

STATEMENT OF FINANCIAL POSITION DECEMBER 31, 2018

	2018	2017
Cash and Cash Equivalents	1,053,147	1,709,034
Receivables	194,806	253,393
Prepaid Expenses	198,217	137,002
Investments	2,403,724	1,702,021
Property & Equipment	190,889	134,239
Net Investments		
Total Assets	4,040,783	3,935,689
Total Liabilities	204,184	206,307
Unrestricted Net Assets:		
Undesignated	1,199,290	1,394,322
Board Designated	2,274,934	1,616,458
Property & Equipment	190,889	134,239
Net Investments		
Donor Restricted Net Assets	171,486	584,363
Total Liabilities & Net Assets	4,040,783	3,935,689



COMMITMENT IN ACTION



Mike Marcotte and
Megan Newquist at the 2018
Rise Above Seizures Gala

Mike Marcotte is a producer at KSTP's Twin Cities Live, and spends his free time writing about food, travel, and entertainment for his website. However, for people in the epilepsy community, Mike is best known for using his position in the media to help bring awareness to the condition by sharing his personal story. In 2018, Mike was an integral part of the successful Rise Above Seizures Gala, both serving on the planning committee as well as emceeding the event with KSTP anchor, Megan Newquist. Mike also starred in a video about seizure first aid that was shared during Epilepsy Awareness Month.

"It's so rewarding to witness what the Epilepsy Foundation of Minnesota does for those who live in our communities. They are a beacon of light in some dark hours, especially for individuals and families just starting out on their journey with epilepsy. Those affected are reminded that they are not alone, and that with the Foundation's help, they can keep their independence. One in 10 people will have a seizure in their lifetime. 10 in 10 people need to know how to react. That's why the Epilepsy Foundation of Minnesota exists."

-Mike Marcotte

DONATED GOODS PROGRAM

Every year, thousands of Minnesotans generously donate used clothing and small household items by scheduling curbside pickups with EFMN. This helps reduce waste by reusing shirts, shoes, jackets, and more, while at the same time raising over \$1 million in annual revenue for our programs and services.

Make Space. Make a Difference.

Schedule a pickup at efmn.org or 800.779.0777

EPILEPSY FOUNDATION

THANK YOU, DONORS!

EPILEPSY CHAMPION CIRCLE

EFMN is pleased to recognize members of the Epilepsy Champion Circle for their annual gifts and commitments of \$1,000 or more. The extraordinary generosity of our donors enables us to make strides in the fight to overcome the challenges of living with epilepsy, accelerate therapies, find cures, and save lives.

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 Hans Zoerb

This list represents donations received during 2018. If you think you may have been listed incorrectly we are deeply sorry and ask that you reach out to Rachelle Holm at rholm@efmn.org or 651.287.2302 if you have any questions or suggested changes. Thank you!

ELAM BAER AND JANIS CLAY SCHOLARSHIP FUND

We are grateful for the continuing generosity of Elam Baer, Janis Clay, and several others, who make this fund possible.

2018 Scholarship Winners

Michael Blesi
University of Minnesota
Mechanical Engineering & Applied Mathematics

Hannah Enge
University of Minnesota
Physiology & Neuroscience

Alex Fischer
University of Iowa
Sociology

Sandra Johnson
Presentation College
Radiology Technology

Elizabeth McGraw
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Meghan Pryor
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Emma Tollefson
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Megan Winters
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IN HONOR OF

Gifts were received in 2018 in honor of the following:

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Betty Wheeler
Avan Wichelt
Max Witte
Cody Zbaren



ADVOCACY

A renewed focus on advocacy in 2018 led to EFMN's support of legislation impacting the epilepsy community, including step therapy reform. Thanks to the nearly 90 epilepsy advocates who joined us for our annual Advocacy Day at the Capitol, all those who called or emailed their representatives, and Professional Advisory Board Chair Tim Feyma for his testimony at a House Commerce committee hearing, step therapy reform was signed into law. Healthcare providers now have a transparent and accessible process to request an exception to a step therapy protocol when they believe it's in their patient's best interest.

2018 RISE ABOVE SEIZURES WALK

Walkers in five communities raised over \$200,000 for EFMN programs. We are especially grateful to our Walk Team Captains who encouraged their family, friends, and co-workers to participate.

2018 Walk Captains and Their Teams (\$250+)

Tamara Abers, Jordan's Jammers
Kim Albers, Rick's Warriors
Wendy Allen, Team Olivia
Bill Atwell, Team Stephanie Atwell
Anna Barber, Kayleigh's Shining Stars
Kathryn Barlow, Team Ella
Amy Bauer, G Squad
Clarissa Benitez, Team Miguel
Erik Bentley, Erik's Brainstorm Busters
Jennifer Beran, Team Tanner
Kayla Borman, Kayla's Krew 1 Seizure is 2 Many!
Lori Braegelmann, Braegelmann Brigade
Brian Britz, Hope for Isabella
Jenny Campos, Team Dysten
Korean Carr, Troopers for Treon!
Sarah Carver, Kayla's Krew
Dom Colasanti, Team Beastie
Laurie Colbeck, MN Epilepsy Group
John Conry, Team Marcus
Kristin Davis, Abby's Avengers
Lauren Denney, PMT Corporation
Melissa Devaraj, Team Devaraj
Nicole Doonan, Gillette SuperStrollers
Jeff Duncan, Team Gracie
Shanna Dunne, Guardians of the Galaxy
Rachel Dyrud, We Love the Welch Sisters
Kim Eastin, Team Eastin
Craig Edelbrock, Marccaylin's Memory
Danielle Ehresmann, Ehresmann End to Epilepsy
Stephanie Ferrari, TK's Travelers
Kacie Finley, Kacie's Crusaders
Mo Flynn, Team Flynn
Zachary Frisk, Sanford Neurology Fargo
Kelly Girgen, Seizure Destroyers
Ashley Grahek, Team L
Desiree Gregorich, Desiree's Dizzy Divas
Monica Gusa, Flushing the Stigmas
Hunter Haggberg, Hunters Hope
Erik Hassenstab, Adam's Superheroes
Jessica Hauser, Wyatt's Warriors
Jenny Henningsen, Seize The Day
Amanda Hernandez, Team Amanda
Alison Herseith, Mighty Maggie

Jennifer Hissam, Rachel's Ralliers
Erica Holzer, Team Joshua
Andrea Horsch, Just Horsch It
Jennifer Hover, Ronan's Rebels
Caitlin Hunstock-Jansson, Team Leah
Tom Huynh, Team MinnMed
Dustin Ihry, Team Ihry
Larissa Indrebo, Isaac's Minions
Nancy Johnson, Team Ryan J
Megan Jones, Team Landyn
Madeleine Karl, Students for Seizure Awareness
Ashley Kelner, Marsha's Memory Makers
Caleb Kern, Caleb's Courageous Course
Brad Kletzin, Ollie Tumba & The Electric Brains
Erica Klev, Gage's Gang
Krystal Koball, Team Kaya
Joanne Koenig, Mighty Mackenzie
Hope Kraay, Two Miracles Walking
Maira Kuepers, Team Finnegan
Krista Kujala, Team Hope
Anne Lampright, Team Anne
Heidi Larson, Brandt's Brigade
Emily Lewis, Always Lucky
Alison Lillegaard, Cranium Crackers
David Linder, Team Joe Hager
Jody Lindquist, The Survivors
Sarah Lundeen, Evelyn Epic Adventurers
Jennifer Madigan, Team Maddie
Patrick Marushin, Elena's Strollers
Angela Mattke, Team Graham
Michelle Maxwell, Team EFMN
Kat Metzger, Upsher-Smith Laboratories
Andrea Mialkowski, Team Andrea
Anna Milz, Team Milz
Ciana Murphy, Brynn's Backers
Britny Murphy, Murphy's Minions
Shana Nelson, Christian's Crusaders
Cindy Nelson, Spike & Wave
Rhea Nelson Rock, Nolan's Crew
Kristen Noll, Jude's Dudes
Maja Nord, We Go-pher Maja!
Gina Norris, Hope for Hazel
Rachael Oehlke, Team Hunter
Cheryl O'Fallon, Frandsen Fast Feet

Jessica Pack, The Pack Pacesetters
Greta Petersen, Amy and Trevor's Walk with Angels
Lisa Peterson, Seizure Stigma Stoppers
Chris Poshek, Team HH
Lindsay Pugh, Princess Aurora's Squad
Amy Purrington, EEPs PEEPs
Danielle Rehling, Jenna's Seizure Soldiers
Justin Reid, Iron Rangers
Kathleen Rieke, NeuronsUnite
Paul Ringstrom, Seizure the Day
Beth Ristow, Team Easton
Lynn Rodeghiero, Ary's Avengers
Taylor Roder, Peyton's Power
Chad Ruzek, Max's Marchers
Bethany Sandstad, Loving On Olivia
Nicole Schauer, Kadens Crew
Jason Schindler, Sauntering with Schindler Spirit
Candice Schintz, Team Rylan
Maria Schmidt, Team Abram
Sara Schmitz, Braden's Pit Crew
Ruth Schmitz, Ruth's Rockstars
Jackie Sharratt, Team Kellie
Anne Shosie, Ruth Rocks!
Jill Staloch, Fight Epilepsy
Analee Steffan, Team Mariah Klein
Cassandra Stoering, Team Silas
Michael Sund, Team Sund
Liz Thill, #SophiaStrong
Stacy Thompson, Purple Rain
Jennifer Tvrdy, Moovin for a Cure
Janice Tweet, Epilepsy Exponents
Peyton Vaden, Team Peyton
Emily Velure, Team Velure
Mike Vitali, Crystal D #1
Erik Weiss, Ellis And Friends
Stephanie Wendel, Purple Warriors
Faye Whited, Team Bear
Ashley Wilson, The Wilson's
Christy Woll, Holy Walkamolies!
Sydney Zeis, Team Sydney
Trisha Zeller, Team Rachel Roni

RISE ABOVE SEIZURES WALK - TEAM LEAH

Every year at the EFMN Rise Above Seizures Walk our community comes together to show support for those with seizures and take part in Minnesota's largest epilepsy awareness event. In 2018 we were joined by more than 2,500 walkers in five communities and raised over \$200,000 to support the programs and services our participants needs. Team Leah has attended the Twin Cities Metro walk since 2014, and last year they brought more than 50 walkers to support Leah, an eight-year-old with epilepsy.

"The walk is important because it allows all of Leah's supporters to get together in one place. Leah has two families, and so many friends that are like family. This is the one time of year we can all get together and support her as one." -Caitlin, Leah's mom



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