

2022

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ANNUAL  
REPORT



**EPILEPSY**  
FOUNDATION®

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**MICHIGAN**

**EPILEPSY FOUNDATION OF MICHIGAN**  
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(800) 377-6226 [WWW.EPILEPSYMICHIGAN.ORG](http://WWW.EPILEPSYMICHIGAN.ORG)

# WHAT ARE WE ALL ABOUT?

## FUELING TRANSFORMATION THROUGH ADVOCACY

By Brianna Romines, President-Epilepsy Foundation of Michigan

In 2022, the Epilepsy Foundation of Michigan stood at the crossroads of possibility, driven by a singular question that echoed in our hearts: "How can we amplify the voices of the epilepsy community and build advocates who will be heard?" This question propelled us to new heights, igniting a fire within us to elevate the cause we hold so dear.

One shining example of this incredible advocacy journey was Elleanna Waid's inspiring trip to Washington, DC, for Teen Speak Up! Elleanna's unwavering courage as she shared her journey with epilepsy and advocated for change on a national stage is a testament to the power of individual voices joining together to change. Her journey exemplifies the spirit of resilience that runs deep within our community.

But our advocacy journey didn't stop there. Through the Seizure Smart Mental Health Professional Network grant, we took monumental strides toward addressing a critical need in our community. We took the initiative to train over one hundred mental health professionals, equipping them with the knowledge and tools to understand epilepsy, functional seizures, and associated mental health conditions. This initiative was not only a response to your needs, but a testament to our commitment to listen and to act.

As we put the finishing touches on the 2022 Annual Report, we look back on these moments of triumph with immense pride. The pages are filled with stories of courage, resilience, and the unwavering dedication of our epilepsy community. The theme of the year, "Building Advocates, Being Heard," has been etched into the fabric of our Foundation, reminding us that our voices, our stories, and our determination are forces that can create lasting change.

Together, as we set our sights on the future, we do so with a sense of purpose that has been fortified by the challenges we've overcome. The road ahead may be filled with unexpected twists and turns. Yet we stride onward, firmly intertwined, comforted by the knowledge that together, we are not merely unstoppable but are the architects of an inspiring transformation that will shape the future of our community.

Here for you- Brianna



# HOW WE CHANGE LIVES

Epilepsy Foundation of Michigan strives to improve the lives of people affected by epilepsy; this happens through the more than 10,000 meaningful interactions we have with those we serve. This section illustrates how the mission is at work in people's lives.

- 1,493 client interactions were received on our **Here for You Helpline** for individualized education, consultation, and support.
- 26 contacts were made on behalf of 19 clients to help resolve conflicts related to employment, education, health care, or legal rights through our **Individual Advocacy** program.
- We relaunched a new organizational website ([www.epilepsymichigan.org](http://www.epilepsymichigan.org)) that was fully ADA accessible and compliant. It spotlights our programs and services, promotes opportunities to give to our mission, and provides resources to learn about epilepsy and seizures. In 2022, our website was visited 61,141 times.
- 39 campers (ages 7-15), including youth with epilepsy and their siblings, attended **Camp Discovery** at no cost through our partnership with North Star Reach. This partnership allowed campers to bond with one another and enjoy a variety of outdoor activities with safe medical supervision. Campers also attended an "Ask the Doc" session with an epileptologist which gave them an opportunity to voice questions and learn about epilepsy.
- 379 community members attended our **Epilepsy Innovation Conference, Back to School Conference, and Wellness & Epilepsy Conference**. Thanks to educational content from 39 expert speakers who volunteered to share their knowledge, the community received 18 hours of educational content and were provided opportunities to connect socially. For the Wellness & Epilepsy Conference, 99% of attendees agreed that "as a result of attending this conference, I intend to change at least one aspect of how I manage epilepsy or its consequences." For the Back-to-School Conference, 93% of attendees agreed that as a result of attendance, "I feel better equipped to support the health and school success of my student(s) with epilepsy."
- In partnership with the Greater Chicago, Minnesota, and Wisconsin Epilepsy Foundation Affiliates, the Foundation hosted the **Upper Midwest Rare Epilepsies Conference**. 125 unique individuals registered for discussions on research, new therapies, wellness, and planning for the future among those in the rare epilepsies community.
- Through 25 presentations, 1089 educators and other human service professionals received **Seizure Recognition and First Aid Training** and learned potentially life-saving skills to care for seizures.
- Over 800 hours were dedicated to the **Michigan Pediatric Epilepsy Project**, a collaborative grant with Children's Special Health Care Services that is focused on improving epilepsy care and outcomes for children and youth with epilepsy in rural and underserved areas.
- Two cohorts of teenagers completed **E-SMART (Epilepsy Self-Management, Advocacy, & Resilience for Teens)** in Summer and Fall offerings. This 6- week, Zoom-based program brought together 14 teens with epilepsy who focused on building knowledge, skills, and goal setting while providing peer support. 92% of the teens agreed that they are more confident in their ability to manage their epilepsy as a result of the program, and 100% agreed that their knowledge of epilepsy increased as a result of the program.

# HOW WE CHANGE LIVES

Epilepsy Foundation of Michigan strives to improve the lives of people affected by epilepsy; this happens through the more than 8,679 meaningful interactions we have with those we serve. This section illustrates how the mission is at work in people's lives.

- Through 24 phone sessions, 17 adults completed one of three Project UPLIFT sessions offered. After participating in **Project UPLIFT**, a phone-based, epilepsy self-management program focused on the management of depression, the large majority of participants experienced improvements on scored assessments for depression and anxiety.
- The **Call & Connect Network** provided opportunities to learn about epilepsy and connect in support. 31 Adults with Epilepsy, 33 Parents of People with Epilepsy, 24 Young Adults with Epilepsy, 15 Older Adults and Caregivers, and 5 teens with Epilepsy discussed epilepsy-related challenges and strategies for managing them through our weekly, bi-weekly, or monthly Call & Connect Network sessions.
- The **Seizure Smart Mental Health Professional Network** grant, a project funded by the Michigan Health Endowment Fund, was completed, resulting in 138 mental health professionals becoming trained in epilepsy, functional seizures, and associated mental health conditions. 24 mental health professionals then joined the Seizure Smart Mental Health Professional Network and are available for referrals for therapeutic care, and their contact information is listed on our website.
- **Optimizing Health Outcomes for Older Adults with Epilepsy**, a grant project funded by Michigan Health Endowment Fund entered its second year, and continued to focus upon the implementation of support, education, and outreach toward older adults with epilepsy and their caregivers.
- The **Big Brain**, an educational tool that teaches about epilepsy and brain health, was present at two Strolls for Epilepsy and an elementary school. Educational topics covered brain health, an overview of epilepsy and seizures, seizure safety and first aid, and celebrating differences.
- The **2022 Challenge of the Year** was entitled, "Building Advocates, Being Heard." Information about this topic was integrated into our existing programming (e.g., Conferences, Call & Connect Network, etc.), social media messaging, and website.
- The Foundation was able to harness the power of statewide, donated **Media Coverage** with 21 story placements on television, radio, print and electronic media in 8 major markets within Michigan as well as nationally.



# ELEVATING YOUR VOICE

Our mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

## **Here for You Helpline**

"Our conversation helped me feel understood and less alone. Having someone listen in a professional yet empathetic way was a missing piece I needed to heal."

## **Epilepsy Innovation Conference**

"This conference was great! I was very impressed with the way we got to learn about different medications and new topics that are being discussed in the field of epilepsy."

## **Back to School Conference**

"I am a care coordinator public health nurse for CSHCS, Oakland County, and this was a fabulous convention in every way. So informative with depth from the child, young adult, family and professional perspective."

"I appreciate your honest, clear approach to shared care. It helps me feel empowered to advocate more effectively and confidently on my child's behalf and realize that there really should be a dialogue initiated."

## **Wellness & Epilepsy Conference**

"This was my first conference by the Epilepsy Foundation of Michigan. The staff makes me feel like family. They are the most caring, compassionate, loving people. I will be back next year and for future events."

## **E-SMART**

"My favorite thing was learning how to advocate for myself better. I liked the program because it gives people ideas of what to do to make goals for yourself and how to help others."

## **Project UPLIFT**

"I feel more positive about me. I understand I must put myself first. I find time each day to reflect on myself and clear my mind. It helps so much with getting through health and social challenges."

## **Camp**

"100% confident that he would be safe. None of his other activities, including school, have the same level of protocols as epilepsy camp."

"I loved seeing him on departure day arm-in-arm with his new friends. I knew in that moment that he had an unforgettable experience. Thank you so very much."

## **Seizure Smart Mental Health Professional Network Grant Training**

"I really enjoyed this. As a new therapist, there is so much information to gain and this was neatly organized, and the content was great."

# BEING A GOOD STEWARD

Full Financial Summary and 990 available upon request and on our website: [www.epilepsymichigan.org](http://www.epilepsymichigan.org)

Statements of Financial Position As of December 31, 2021, and 2020			Statements of Activities For the years ended December 31, 2021 and 2020		
	2022	2021		2022	2021
Cash & cash equivalents	\$994,623	\$716,549	<b>Support &amp; Revenue</b>		
Investments	856,195	757,502	United Way designations	\$12,726	\$21,007
Contributions receivable	28,293	200,082	Revenue from governmental agencies	39,505	96,346
Prepaid expenses	21,405	31,093	Foundation & corporate grants	122,500	109,725
Property & equipment (net)	33,390	9,469	Special event revenues (net)	371,987	290,620
Operating right-of-use asset	173,712	0	Contributions & bequests	707,162	603,226
<b>Total assets</b>	<b>\$2,107,618</b>	<b>\$1,714,695</b>	Program service fees	1,935	750
Paycheck Protection Program Loan	\$0	\$101,815	Investment income (loss)	(97,732)	28,981
Trade payables	40,356	7,696	Paycheck Protection Program Income	101,815	101,812
Accruals – salaries & benefits	53,624	60,939	<b>Total revenue</b>	<b>\$1,259,898</b>	<b>\$1,252,467</b>
Accruals - other	334	743			
Deferred revenues	2,250	12,014	<b>Program Expenses</b>		
Deferred rent	0	10,303	Individual & family services	\$338,562	\$264,479
Operating lease liability current	64,334	0	Community services	463,343	411,809
Operating lease liability – net current	118,815	0	Advocacy & Public Policy	19,641	29,134
<b>Total liabilities</b>	<b>\$279,713</b>	<b>\$193,510</b>			
			<b>Support Services</b>		
Net assets without donor restrictions	\$1,750,951	\$1,383,759	Development	18,289	11,577
Net assets with donor restrictions	76,954	137,426	Management & general	113,343	104,500
<b>Total net assets</b>	<b>\$1,827,905</b>	<b>\$1,521,185</b>	<b>Total expenses</b>	<b>\$953,178</b>	<b>\$821,499</b>
<b>Total liabilities &amp; net assets</b>	<b>\$2,107,618</b>	<b>\$1,714,695</b>	<b>Change in net assets</b>	<b>\$306,720</b>	<b>\$430,968</b>



# 2022 ANNUAL REPORT

## CURRENT BOARD MEMBERS

**Angie May** – Board Chair

**Melissa Conway** - Vice Chair

**Stephen Kuehn, CPA** - Treasurer  
and Immediate Past Chairperson

**Kellie Jankowski** - Secretary

**Nadia Vann, Esq.** - Executive  
Committee

**Jeffrey Wilson** - Executive  
Committee

**Stephanie Bayma, RN**

**Carla Boyd**

**Mira Agrawal Cooper, MD**

**Jason M. Geisz, CFP**

**Sandy Gulick**

**Kelly Kiss**

**Michael Nanzer DPT, MBA, CSCS,  
FACHE**

**Robert Pulliam, CPA**

**Sarah Stempky-Kime**

**William Weatherston**

**Benjamin Worthington, III**

**Andrew Zillgitt, DO**

## CURRENT TEAM MEMBERS

**Brianna Romines, MPA**  
President

**Tori Allen, MPH**  
Program Contractor

**Pam Bird**  
Office Manager

**Heather Carr**  
Special Events Manager

**Nicole Fitzpatrick**  
Community Program Specialist

**Matt Montpas**  
Accountant

**Alyx Newton**  
Donor Relations Manager

**Renee Roederer**  
Community Care Director

**Crys Staffney**  
Development Director

**Shannon Waid**  
Education and Outreach Specialist





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