EPILEPSY FOUNDATION
Michigan

Epilepsy Foundation of Michigan
2018 ANNUAL REPORT

FROM THE PRESIDENT

BRIANNA ROMINES, MPA

We are here for you. It is a seemingly simple statement, right? It is a phrase that we repeat every day. You will find this phrase on almost every brochure, invite, and flyer. To us, this phrase is deeply rooted in our belief system that we are here to serve the epilepsy community. It is our role to lead the fight to stop seizures, search for a cure, combat stigma with education, make sure your voice is heard, reminding you that you are never alone, and to stand next to you, shoulder to shoulder as we battle epilepsy together.

Whether your connection to epilepsy is yourself, your child, a friend, parent, or someone you have lost … we are here for you. Because together *we* are the epilepsy community.

You see, our organization is relatively small and I can reassure you that every dollar is stretched as far as it could possibly go. This Annual Report illustrates that. But what it also means is that the next parent that learns their child has retractable epilepsy and is in desperate need of resources and support- we will be here. And the next adult that has a seizure and subsequently loses their driver's license and feels alone and isolated- we will be here. And the next child that has never met another person with epilepsy, let alone attend a camp where there is swimming, archery, boating, and lifelong friends- we will be here. This is what you make possible.

2018 PROGRAM IMPACT HIGHLIGHTS: HOW WE CHANGE LIVES

EPILEPSY FOUNDATION OF MICHIGAN STRIVES TO IMPROVE THE LIVES OF PEOPLE WITH EPILEPSY. THE FOUNDATION SERVED MORE THAN 7,100 PEOPLE IN 2018. THE FOLLOWING EXAMPLES ILLUSTRATE HOW THE MISSION IS AT WORK IN PEOPLE'S LIVES:

- 646 client calls were received on our ***Here for You*** **Helpline** with an average of 24 minutes per call of individualized education and consultation.
- 74 contacts were made on behalf of 40 clients to help resolve conflicts related to employment, education, insurance benefits, health care, or legal rights through our **Individual Advocacy** program.
- 68 children with epilepsy attended **Camp Discovery** through our new partnership with North Star Reach. This partnership also allowed an additional 10 teens with epilepsy to attend **Solstice Camp** with other teens who have chronic health conditions. As a result of attending camp, 92% of campers felt better about themselves and their epilepsy, and 85% felt more confident in themselves and their abilities.
- 19 teens with epilepsy attended our six-hour **Teen Transition Workshop**. As a result, 93% of participants felt they had a better idea of the things they need to work on and learn about to be ready for adulthood. As a follow up to the workshop, 5 families received individualized consultation on transition planning, and 11 families attended our Teen Mixer event.
- 94% of attendees at our first ever **Epilepsy Innovation Conference** indicated that their knowledge of epilepsy and epilepsy-related innovations increased as a result of attending. 100% of **Back to School Conference** attendees agreed that, by talking with other conference attendees, they learned something new about epilepsy or related issues. 90% of **Wellness & Epilepsy Conference** attendees agreed that, as a result of attendance, they intend to make at least one positive change in their behavior to promote improved health.
- Over 520 hours dedicated to the **Michigan Pediatric Epilepsy Project**, a collaborative grant with Children's Special Health Care Services, that is focused on improving access to quality epilepsy care for children and youth with epilepsy in rural and underserved areas.
- 640 participants in our Epilepsy Innovation Conference, Wellness & Epilepsy Conference, Back to School Conference, and monthly **Learn & Share Conference Calls** had access to over 34 hours of educational content provided by 60 expert speakers who volunteered to share their knowledge.
- 21 adults with epilepsy discussed epilepsy-related challenges and strategies for managing them through our weekly **Call & Connect Network** sessions.
- Through 180 phone sessions, 33 adults with epilepsy completed one of our phone-based epilepsy self-management programs (**PROGRESS Toward Wellness, PACES in Epilepsy, or Project UPLIFT**)
- 1,298 educators and other human service professionals learned potentially life-saving seizure recognition and first aid skills through our **Seizure Smart** Seizure Recognition and First Aid Training.
- Our 2018 **Challenge of the Year** program focused on "Life Transitions & Independence." Information about this topic was integrated into our existing programming (e.g. conferences, Learn & Share Conference Calls, etc.), social media messaging, and website. In addition, we created new programming focused on teen transition, conducted a survey on life transitions, and created and disseminated a report based on survey findings.
- **Education & Awareness** booths were staffed at 7 professional conferences, health fairs, or other community events.
- **Epilepsy Medical Center Outreach** was conducted through face-to-face meetings with the Foundation's President and Director of Education. The staff at 9 epilepsy programs were educated about our programs, events, partnership opportunities, and how we can work together to best serve epilepsy patients and their families.
- The Foundation was able to harness the power of statewide, donated **Media Coverage** with 32 story placements on television, radio, print and electronic media in seven major markets within Michigan.

2018 Financial Data: Being Good Stewards of your Support

Full Financial Summary and 990 available upon request and on our website:
www.epilepsymichigan.org

Statements of Financial Position
As of December 31, 2018 and 2017

	2018	**2017**
Cash & cash equivalents	$194,029	$202,794
Investments	282,068	199,646
Contributions receivable	43,820	32,745
Prepaid expenses & deposits	22,367	21,062
Property & equipment, net	4,263	3,751
Total assets	**$546,547**	**$459,998**
Trade payables	$1,694	$8,940
Accruals – salaries & benefits	59,827	59,351
Accruals - other	7,011	1,432
Deferred revenues	8,011	3,767
Deferred rent	12,276	18,267
Total liabilities	**$88,819**	**$91,757**
Net assets without donor restrictions	$439,731	$357,204
Net assets with donor restrictions	17,997	11,037
Total net assets	**$457,728**	**$368,241**
Total liabilities & net assets	**$546,547**	**$459,998**

Statements of Activities
For the years ended December 31, 2018 and 2017

Support & Revenue	**2018**	**2017**
United Way designations	$32,980	$27,809
Revenue from governmental agencies	40,933	58,048
Foundation & corporate grants	179,100	230,250
Special event revenues (net)	407,072	385,044
Contributions & bequests	217,359	209,517
Program service fees	12,741	43,080
Investment (loss) income	(12,748)	13,947
Total revenue	**$877,437**	**$967,695**
Program Expenses		
Individual & family services	$328,297	$356,750
Community services	287,016	294,081
Advocacy & Public Policy	68,293	82,501
Support Services		
Development	8,502	9,132
Administration & general	95,842	94,322
Total expenses	**$787,950**	**$836,786**
Change in net assets	**$89,487**	**$130,909**

In Your Words: Impact Quotes from 2018

Camp Discovery

“He had such a high from camp and I think him meeting other children with epilepsy really boosted his self-esteem. He told his neurologist about all the different kinds of epilepsy other kids had; watching him verbalize this to a doctor confirmed that ‘not being alone’ meant a lot to him.”

“She developed new relationships with other children who attended camp. She has been keeping correspondence with her new friends. Because of camp, she has been more accepting of trying new things and has shown that she is coming out of her shell a little more.”

Conferences

“Innovation and status of modern treatments is so important to patients and their families as we keep searching for relief and solutions.” (*Epilepsy Innovation Conference*)

“I really appreciate meeting and networking with other parents. I think this is one of the most valuable aspects of the conference.” (*Back to School Conference*)

“Wonderful speakers and topics at this conference. Enjoyed the in-depth scientific discussion regarding the use of cannabidiol in epilepsy & other disorders. Thank you for choosing to cover the topic of Cannabis for Epilepsy as this has been very stigmatized & taboo. Open discussion helps drive much needed research.” (*Wellness & Epilepsy Conference*)

Here for You Helpline

“Thank you for always, always being there. I just want you to know that it’s noticed, and you are appreciated. Thank you so very much!”

Individual Advocacy

“Thank you for helping us on Wednesday with the IEP Meeting. Words cannot express how grateful we are for you and your help. It was tough navigating through an unknown domain, and your support was awesome.”

PACES in Epilepsy (phone-based epilepsy self-management program)

“Having an instructor that has epilepsy was a good aspect of this program. I could use her examples to easily apply the session to myself. I thought this was a very helpful tool to have.”

OUR MISSION

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

. . . .

THANK YOU

Because of your support, another person with epilepsy can be filled with hope.

The Epilepsy Foundation of Michigan is leading the fight to stop seizures. We remain focused on our goals: to close the treatment gap between what is being done for people with epilepsy and what should be done, to improve how people with epilepsy are perceived, accepted, and valued in society and to ensure that people with epilepsy and their families have access to full life experiences. When our supporters demonstrate their commitment to the epilepsy community, our organization gets even stronger.

BOARD OF DIRECTORS

EPILEPSY FOUNDATION OF MICHIGAN
25200 Telegraph Road • Suite 110 • Southfield, MI • 48033
(800) 377-6226 • www.epilepsymichigan.org