

2020

ANNUAL
REPORT



EPILEPSY
FOUNDATION[®]

MICHIGAN

EPILEPSY FOUNDATION OF MICHIGAN
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COMBATING ISOLATION

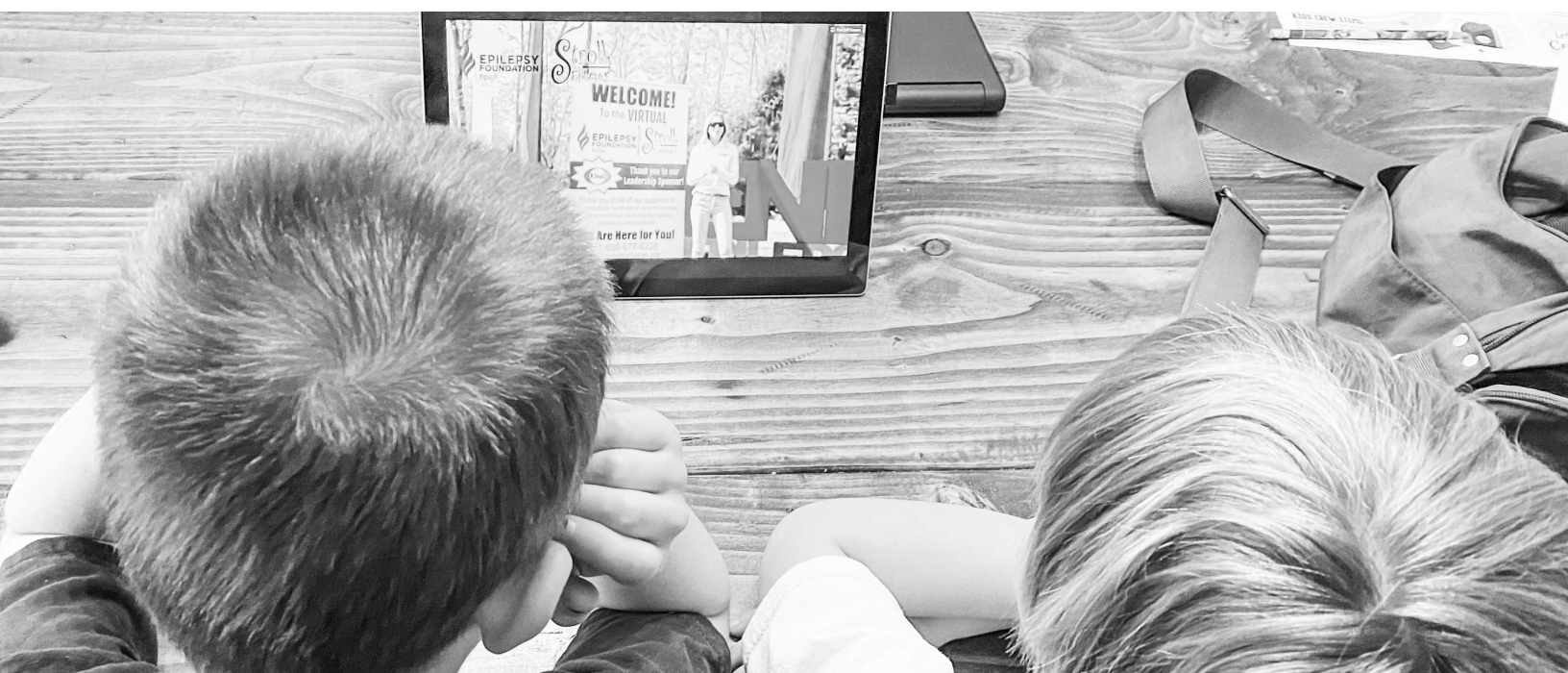
How 2020 taught the world something that the epilepsy community already knew
By Brianna Romines, President-Epilepsy Foundation of Michigan

Before each calendar year begins, we select our *Challenge of the Year* for the upcoming year. Through information gathered by our team and a network-wide survey, we select one big, epilepsy-related problem and do our best to help “move the needle.” And while we know that these challenges go far beyond our scope to be completely solved, we do believe that if we take a year to facilitate meaningful conversation, deepen education, and develop resources, that we can make an impact for those living with epilepsy. It wasn’t until March of 2020, that we realized just how important our *Challenge of the Year* would truly be.

The challenge that we had selected far before the pandemic ravaged our nation and the globe was Combating Isolation. This is something that has plagued the epilepsy community for far too long. Epilepsy has long possessed the power to make someone feel different, alone, and misunderstood. We must change that. 2020 taught us all what it feels like to be isolated and gave everyone a snapshot view into the life of someone living with epilepsy. But because being isolated is nothing new to us, we watched in awe as the epilepsy community rose up and became models to those that were new to this feeling.

You see, the epilepsy community is just that...a community. People that support and encourage those around them. And that’s where we come in. Our goal is to serve the epilepsy community so that this tenacious community grows, gains strength from their collective voice, and knows that they are never alone on this epilepsy journey. This report attempts to illustrate exactly that; how our mission is building and supporting a strong epilepsy community capable of changing the world...and capable of combating isolation in a year like no other.

Here for you- Brianna



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.

Camp Discovery at North Star Reach

"This has been a difficult time for everyone, but especially because we have to be so cautious given that our child has a compromised immune system. The opening campfire was an experience like no other. I have not seen my child that happy in months. The smile North Star Reach put on her face even through a computer made me cry tears of joy. It was the perfect experience during a difficult time."

Epilepsy Innovation Conference Week

"Insights into the new treatments and honest information about the pros and cons for these treatments. So valuable, thank you. I don't get this type of information anywhere else."

"I liked how there was a diverse range of perspectives during the meeting. It was great to hear from people who treat people with epilepsy, such as epileptologists and neuropsychologists, as well as people who have epilepsy themselves and who have family members with epilepsy as you can see how technology helps each of them in various ways, whether it is in their medical practice or in their everyday lives."

Back to School Conference

"It was amazing that all of these people spoke in "our language" – none of them were too smart, if you will, to help us!!! They gave advice and explained questions I have had for 6 years!!!! Without ever meeting my son!!!!"

Wellness & Epilepsy Conference

"She explained everything in down to earth terms for such a complex topic. Also it gives so much hope that you could find out what really is causing your seizures and possible better management."

"I think this was an outstanding way to bring this conference so easily to so many people! It was so well prepared and so much to learn!"

Project UPLIFT

"It gave me guidance because I felt lost. I have never felt more optimistic. This gave me hope, light, and people who understand me. I felt really lost and alone. I feel better now. UPLIFT is the right word because it uplifted me and gave me an outlook on life. I'm going to miss it. It's nice to be a part of something. You all are saving people's lives. People need connection, these exercises, and a way to laugh."

"You made the group not only a group but a mini-family for me."

Individual Advocacy

"After your conversation with our Superintendent, he went back to the school attorney and asked him to revisit the Epidiolex information. The attorney did his own research and reviewed what you had sent over and came back in agreement that the rules were grossly outdated. He drafted a letter to the Michigan Department of Education asking them to revisit this topic and change of their stance on Epidiolex. I'm not sure exactly what transpired but the school called this morning and said they are able to give [my daughter] her medication starting tomorrow!!! I am excited, not just for [my daughter], but for all the other students in Michigan that will benefit from these changes. Thank you, thank you, thank you for all of your work on this. It's nice to see changes being made without long legal battles."

HOW WE CHANGE LIVES

Epilepsy Foundation of Michigan strives to improve the lives of people affected by epilepsy; this happens through the more than 4,500 meaningful interactions we have with those we serve. This section illustrates how the mission is at work in people's lives.

- 881 client calls were received on our **Here for You Helpline** with an average of 22 minutes per call of individualized education and consultation. 60 contacts were made on behalf of 29 clients to help resolve conflicts related to employment, education, health care, or legal rights through our **Individual Advocacy** program.
- 34 children with epilepsy attended our **Camp Discovery at North Star Reach** at no cost through our 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. Both camp sessions were held virtually. The Epilepsy Foundation of Michigan participated in the planning and implementation of additional optional camp-at-home activities, including an improv session, a Doc Talk session, and a film festival.
- 85 - 96% of attendees at our virtual **Epilepsy Innovation Conference Week** indicated that the session taught them something new about epilepsy and epilepsy-related innovations. 93% of **Wellness & Epilepsy Conference** attendees agreed that they intended to make at least one positive change in their behavior to promote improved health, as a result of attendance. 93% of **Back to School Conference** attendees agreed that, as a result of attendance, they felt better equipped to support the health and school success of their student(s) with epilepsy. 586 participants in our Conferences and monthly Learn & Share Conference Calls had access to 24 hours of educational content provided by 46 expert speakers who volunteered to share their knowledge.
- The Foundation was able to harness the power of statewide, donated **Media Coverage** with 13 story placements on television, radio, print and electronic media in five major markets.



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- Over 846 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.
- Recorded conference presentations and **Learn & Share Conference Calls** on our YouTube channel were viewed 14,000 times.
- 85 Adults with Epilepsy, 5 Spouses and Partners, 32 Parents of Children with Epilepsy, 22 Young Adults discussed epilepsy-related challenges and strategies for managing them through our weekly or bi-weekly **Call & Connect Network** sessions.
- Through 24 phone sessions, 20 adults with epilepsy completed **Project UPLIFT** – our phone-based depression self-management program. 81% of participants experienced improved depression scores as a result of the program, and 43% had clinically significant improvements in depression scores.
- 617 educators and other human service professionals learned potentially life-saving seizure recognition and first aid skills through our **Seizure Recognition and First Aid Training**.
- Our 2020 **Challenge of the Year** program focused on "Combating Isolation." 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 conducted a survey on Epilepsy and Social Isolation, and created and disseminated a report based on survey findings.



BEING A GOOD STEWARD

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

Statements of Financial Position

As of December 31, 2020, and 2019

Statements of Activities

For the years ended December 31, 2020 and 2019

	2020	2019		2020	2019
Cash & cash equivalents	\$452,158	\$291,560	Support & Revenue		
Investments	576,038	524,878	United Way designations	\$20,454	\$17,081
Contributions receivable	17,131	17,324	Revenue from governmental agencies	34,583	36,396
Prepaid expenses	24,787	31,556	Foundation & corporate grants	104,650	114,775
Property & equipment (net)	5,472	4,453	Special event revenues (net)	302,065	393,967
Total assets	\$1,075,586	\$869,771	Contributions & bequests	397,286	583,016
			Program service fees	3,216	14,541
Paycheck Protection Program Loan	\$101,812	\$0	Investment income (loss)	59,779	40,843
Trade payables	2,966	6,521	Total revenue	\$922,033	\$1,200,619
Accruals – salaries & benefits	77,118	64,425			
Accruals - other	866	14,484	Program Expenses		
Deferred revenues	187	12,234	Individual & family services	\$263,734	\$323,914
Deferred rent	9,654	4,469	Community services	412,779	417,556
Total liabilities	\$192,603	\$102,133	Advocacy & Public Policy	21,233	40,045
			Support Services		
Net assets without donor restrictions	\$879,669	\$756,124	Development	9,851	10,715
Net assets with donor restrictions	3,314	11,514	Management & general	99,091	98,479
Total net assets	\$882,983	\$767,638	Total expenses	\$806,688	\$890,709
Total liabilities & net assets	\$1,075,586	\$869,771	Change in net assets	\$115,345	\$309,910



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