



EPILEPSY ASSOCIATION

# ANNUAL REPORT



2020



# Dear Donors and Friends,

First of all, thank you for your continued support of the Epilepsy Association. We are pleased to provide you with our 2020 Annual Report for your review. It shares the many challenges we faced this year and the perseverance, tenacity, and hope that we used to get through such a challenging year. The COVID-19 pandemic affected all aspects of the agency, including service delivery modes, staffing configurations, fundraising events, and Board member service. Swift and strategic responses to the quickly evolving situation allowed the EA to still experience many successes and, most importantly, provide a lifeline for many individuals living with epilepsy in our community. The pandemic reminded us how fragile we all are and how isolating epilepsy can be. Our achievements would not have been possible without our Board of Directors, Professional Advisory Board members, and agency staff, who continued to work hard to keep programming, services, and support available for those that we serve.

In 2020, we were able to host two in-person fundraising events before the COVID-19 pandemic hit in March. These early fundraisers gave our special event efforts a great head start for what lay ahead for the remainder of 2020. After March, all of our special events and much of our programming for the remainder of the year was shifted to remote participation. The agency integrated new software and technology to respond: our Seminars were held via Zoom, our Race the River 10K, 5K, and 1 Mile race was done virtually as a running challenge, and our Annual Gala was pre-recorded and premiered on YouTube in November, allowing guests to hold remote watch parties and participate in our silent auction and Fund-a-need online. Agency programming was done via telehealth and clients worked with case managers on the telephone or computer to address their needs.

It was very challenging not being allowed to provide community based, face-to-face service to our clients. As shelter-in-place and social distancing orders remained in effect, we continued to see an increased need for support by our local epilepsy population. Clients worked hard to cope with the stresses of their life with epilepsy and the weight of the pandemic. The 'silver lining' of the pandemic was that telehealth became a reality for us with the relaxing of some of the Medicaid rules. We all learned to think of new ways to advance the mission and vision of the Epilepsy Association in spite of the challenges—and we accomplished that.

Through connections to new community partners and the availability of COVID-19 government funds, we were able to secure increased dollars to help with service offerings related to COVID-19. We are proud to report we were able to maintain all of our services and programming, which made for another memorable year!

We thank you, our volunteers, and the greater Cleveland epilepsy community for your continued support of the Epilepsy Association. The generosity we saw from corporations and individuals was outstanding and is what allowed the Epilepsy Association to continue its work throughout Northeast Ohio, in a meaningful and impactful way. We look forward to a brighter 2021 and to your continued support and involvement.

Sincerely,

E. Sean Medina  
President, Board of Directors

Kelley S. Needham  
CEO

# 2020 Highlights—Our Impact

70

parents and families served

157

information and referral calls

382

individuals received case management and other adult social services

415

children and families served (students served thru school-based programming)

1,629

social service treatment hours provided

4,341

individuals reached through community programs

\$520,600

donated through private contributions, grants, and other special events

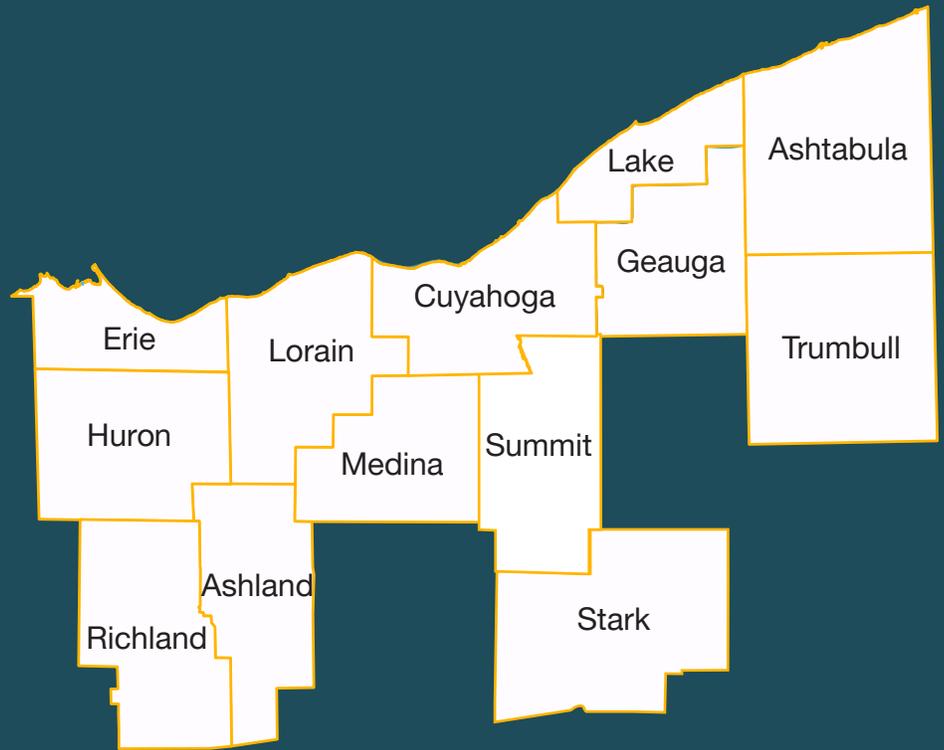
## About the Epilepsy Association:

The Epilepsy Association is a local, 501(c) (3) nonprofit organization, based in Cleveland, Ohio, that assists adults, children and families dealing with the challenges of epilepsy since 1953. The Epilepsy Association offers a wide range of services, including adult mental health case management, individualized support for children & families to increase quality of life, and community education to promote awareness. Our professionally trained staff is skilled in epilepsy and mental health management and recognizes the unique needs of individuals living with epilepsy. The agency is the sole provider of epilepsy specific community-based services in Northeast Ohio. The Epilepsy Association is nationally accredited and incorporates evidence-based practices into programming.

Today, the Epilepsy Association offers a wide range of services, including adult mental health case management, individualized support for children and families and community-based education. The agency is the is licensed by the Ohio Department of Mental Health and Addiction Services and is nationally accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). CARF is an international, independent, nonprofit accreditor of human service providers and certifies that providers meet the highest standards for quality. Our professionally trained staff of eight is skilled in epilepsy and mental health management and recognizes the unique needs of individuals living with epilepsy.

\*The 2020 figures were dramatically affected by the Coronavirus pandemic which for the majority of the year, staff were required to shelter in place, use social distancing, and limited all in person contact.

## Service Area



## Our Mission

To serve children, adults, and families in Northeast Ohio impacted by epilepsy; to raise awareness in the community, provide education, advocacy, and direct services that lead to an increased understanding of the disorder and better management of the condition; for affected individuals to build resilience, personal fulfillment, independence, and the ability to contribute meaningfully to the community.

## Our Purpose

We believe education and awareness are imperative to treatment, acceptance, equitable division of resources and the inherent right of every individual impacted by epilepsy to lead a happy, healthy and productive life.

The Epilepsy Association is not affiliated with any national organizations. The agency is a designated 501(c)(3) not-for-profit corporation. As a cost savings measure, the Epilepsy Association shares its office space with the Kidney Foundation of Ohio. All funds raised by the Association stay here in Northeast Ohio providing service in 13 counties which include: Cuyahoga, Geauga, Lake, Lorain, Summit, Stark and parts of Ashland, Ashtabula, Erie, Huron, Medina, Richland, and Trumbull.

# 2020 Client of the Year Award

## Living with Epilepsy

By: Sharon Irby



To hear more from Sharon, and to watch her video, search Epilepsy Association on YouTube to find our channel.

I was diagnosed with epilepsy in February of 2015. I went to bed one night and woke up 5 days later from being in an induced coma due to uncontrollable seizures. It was more life altering than I could have ever imagined. Epilepsy caused my life to do a complete turn and did not ask my permission, my opinion, or how I felt about it. My first turn, I asked when I could return to work. My doctors answered, “Ms. Irby with the amount of damage on your brain you’ll never be able to work again. I strongly suggest you apply for Social Security”. It was also no longer safe for me to live alone with my daughter, who at that time was 9 years old, and we had to move in with family.

I developed epilepsy due to having inflammation on my brain which has caused me to experience memory loss, depression, anxiety, and panic attacks. As you could probably imagine this was quite an emotional roller coaster ride. You would think the people who know what’s going on with you would be the most supportive, compassionate and understanding.

I felt alone until I was introduced to an organization that literally saved my life—the Epilepsy Association. I was able to meet people who were sympathetic and compassionate to that wonderful roller coaster ride I mentioned earlier. They gave me comfort while experiencing the most uncomfortable times in my life. I honestly believe that if I didn’t have my case manager and the other staff members at the Epilepsy Association that I would have given up on life.

Today my youngest daughter and I live in our own apartment. I’m finding out who I am with epilepsy. This fall I will be enrolling in college and I will be returning to my passion which is community engagement. I may have epilepsy, but epilepsy won’t stop me from reaching my goals and living a great life. My name is Sharon Irby, and I wasn’t built to break. I was built to last.

# Agency Services Included:

## Kids and Family Services

**One-on-one Resources**—Available for families who have a child with epilepsy. Our case managers are available to meet in the community to assess the needs of each family member and connect them with supportive community resources. Our case managers provide general support, epilepsy education, and advocacy.

**Epilepsy Education**—Our qualified staff and trained volunteers provide instructional presentations for students of all grade levels and school staff.

- ▶ **Kids on the Block puppet shows:** For children in preschool through 4th grade. The program features the puppet character, “Brian”, who has epilepsy. The goal of the program is to educate students in an age-appropriate way while focusing on dispelling myths surrounding epilepsy. Students have an opportunity to ask Brian questions about having epilepsy. The program also reviews head injury prevention.
- ▶ **Youth Education:** For children in 5th through 12th grade. Programming provides age appropriate epilepsy education, first aid for seizures, and a focus on understanding and acceptance of students with epilepsy.
- ▶ **School Staff Education:** School Staff Education: Presentation on epilepsy education, first aid for seizures, recognizing seizures in students, and considerations for having a child with epilepsy in the classroom.
- ▶ **Be SMART Manual:** An epilepsy education manual designed for school personnel.

Our Epilepsy Education program was able to be adapted to an online format during the 2020 year. This program was available to schools via Zoom online conferencing.

## Adult Social Services

**Mental Health Case Management**—A community-based service available for adults with epilepsy and a mental health condition. Individuals work one-on-one with a case manager who assists with increased access to community care, advocacy, and skill building. This is an evidence-based practice intended to help clients increase overall quality of life and succeed in the community.

**Support Group**—In 2020, the Epilepsy Association sponsored an adult group to provide support and education for those with epilepsy and their families and caregivers.

**Self-Management Group**—The Epilepsy Association now offers an online, 8-week self-management course for adults with epilepsy designed to help individuals learn strategies about how to best take care of their physical and emotional health. This is an evidence-based practice designed by Dr. Martha Sajatovic at Case Western Reserve University.

*Case Worker, André Buffington, does virtual puppet Show to educate students about epilepsy and seizure first aid*



## Community Services

**Information and Referral**—Information requests are answered by professionally trained staff who can provide additional information on epilepsy, advocacy, support, community resource referrals, and linkage to appropriate Epilepsy Association services.

**Seminar Series**—The Seminar Series is a series of four consumer-focused events that address issues and concerns voiced by the agency's clients and other individuals affected by epilepsy and their families. These seminars feature presentations by epileptologists on relevant epilepsy related topics.

**Public Awareness and Events**—The agency hosts five special events each year to help raise community awareness and funds for the Epilepsy Association. These events include:

- **Winter Walk for Epilepsy:** This community event is held annually at the SouthPark Mall in Strongsville and gathers over 500 community members, parents of children with epilepsy, and individuals affected by epilepsy. The Winter Walk is an indoor, 2-mile walk where participants form teams and collect pledges that support our programs and community services. Each year, the Winter Walk committee selects a featured family and highlights their story as a way to increase awareness about epilepsy throughout the community. The 2020 Feature Family award was presented to Claire Hardy and her family. The 2020 Winter Walk had 500 participants and raised over \$63,000.
- **Auto Show VIP Party:** In 2020, the Epilepsy Association teamed up with the Cleveland Auto Dealers Association to host a fun and casual, after-work VIP party on the opening night of the Cleveland Auto Show. This fundraiser helped raise money to fund agency programs. The 2020 AutoShow VIP Party had over 120 participants and raised over \$50,000.
- **Race the River:** The Annual Race the River Run is a family-oriented 10K, 5K and one-mile run/walk to benefit the Epilepsy Association. Although, the 2020 event was held virtually the 8th annual race included a self-timed 10K, 5K, and 1 Mile Family Fun Run, and included a challenge category to run the length of an Ohio river however you like to exercise: running, walking, hiking, biking, or cycling! The beauty of the virtual race is participants can take part anytime, anywhere while running the course of their choice! Nearly 100 participants logged their race miles and time while raising \$17,000 which helped support the Epilepsy Association programs and services.



Team members from Angelina's Army



Andre Wilson and Myah McDonald  
2020 Winter Walk Volunteers



Sara and Claire Hardy



2020 Winter Walk Participant



Dr. Lucyna Zawadzki  
2020 Legacy Award Honoree



Lucy Koslo  
2020 Youth Humanitarian Award Honoree



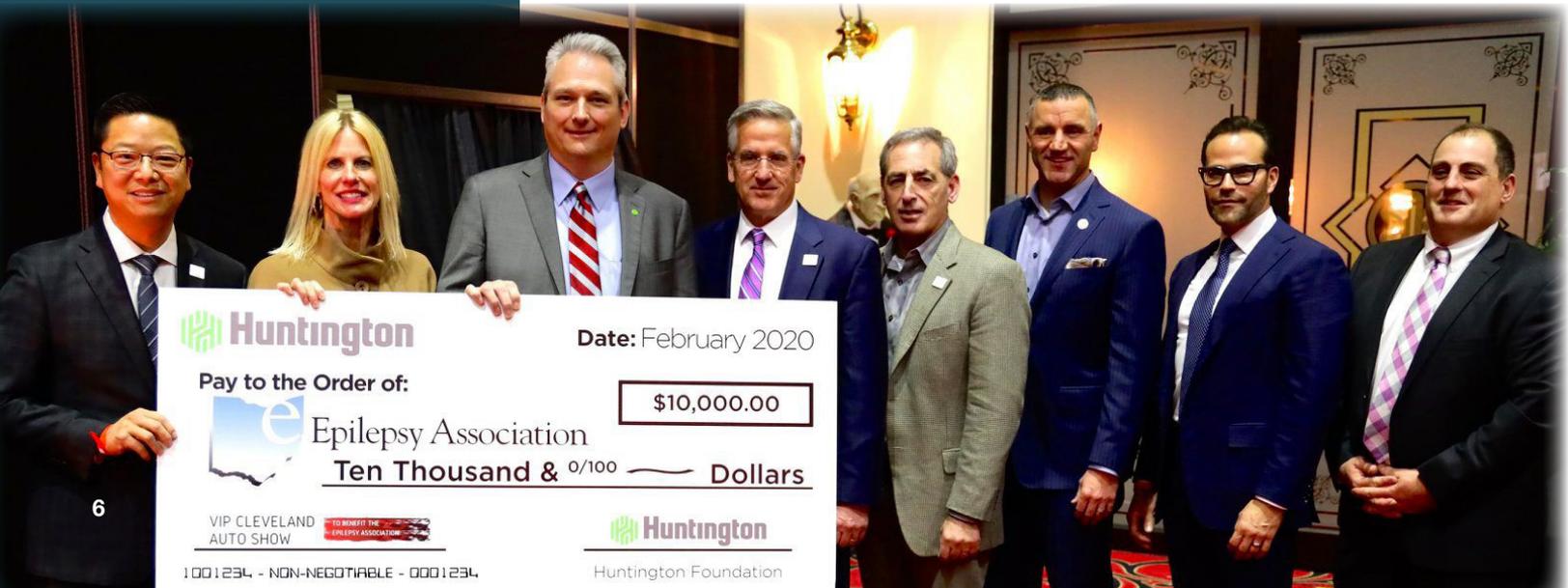
April K. Walsh and Sean Medina  
Board Member and Board President

## Community Services, continued

- ▶ **Purple Day® March 26:** Purple Day® is celebrated in 80 countries; the Global Epilepsy Awareness Day, or Purple Day®, focuses the world's attention on epilepsy. Purple Day was conceived by a young girl named Cassidy Megan of Nova Scotia, Canada and her goal was for people with epilepsy everywhere to know they are not alone. We celebrate Purple Day on March 26 and raise awareness in NEO by organizing a grass-roots campaign and supporters host mini-fundraisers throughout the city with a call to action being wear the color purple to show support and help raise epilepsy awareness.
- ▶ **Annual Gala:** Our annual event is held every year in November as part of the National Epilepsy Awareness month. The formal evening which is typically held at a downtown Cleveland hotel, shifted its program to be remote. The live program was broadcast live on YouTube where our Legacy Award was presented to Lucyna Zawadzki, MD Akron Children's Hospital Director, Pediatric Epileptology and our Youth Humanitarian Award honoree was Lucy Koslo, 10-year-old of Aurora Ohio. The 2020 Gala raised over \$115,000.

**Community Education**—The agency participated in several community health fairs throughout the year in an effort to increase community awareness of epilepsy and available agency services. The Epilepsy Association provided educational in-services on epilepsy and seizure first aid in the community.

*Huntington Bank check presentation to EA with other members of the Greater Cleveland Auto Dealers Association: Joey Huang, Kelley Needham, David Gibson, Kevin Joyce, Barry Axelrod, Paul Hrnchar Jr., Nathan Lancry, and Lou Vitantonio*



# Corporate Gifts

The Epilepsy Association wishes to thank our corporate sponsors for their gifts and event sponsorships.

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The Epilepsy Association wishes to thank all the individuals who supported the agency during 2020. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

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The Lubrizol Foundation

The Progressive Insurance Foundation

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The S.K. Wellman Foundation

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Charities Aid Foundation of America

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The Lubrizol Foundation

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***The Epilepsy Association thanks all the generous contributors who designated their gift through the United Way Campaign.***

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Bryan Maikut

Michelle Mayes

Marquettes Robinson

Michael Slama

Tiana Ware

*Listing supplied from United Way of Greater Cleveland. If your name is not listed, please call our Development office.*

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## Operating Support and Revenue:

2020 Audited

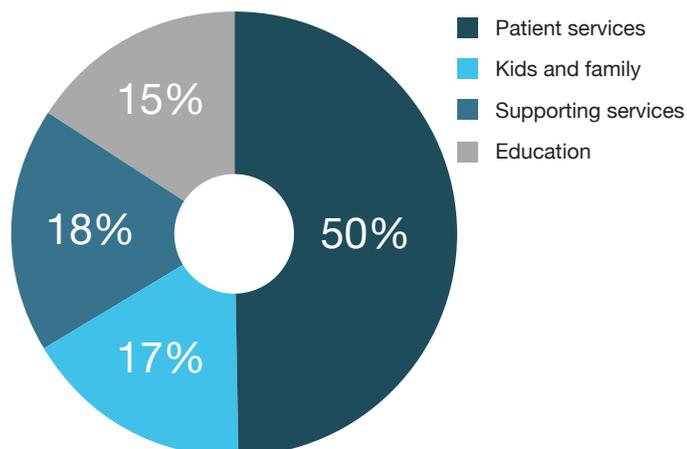
Contributions	\$186,951
Stimulus funds	\$37,954
Government grant	\$62,900
Program services fees	\$158,837
Special events	\$242,251
Less: Direct benefit to donor	\$(43,237)
Net gain on investments	\$7443
Interest income, checking	\$326
<b>Total support and revenue</b>	<b>\$653,425</b>

## Operating Expenses:

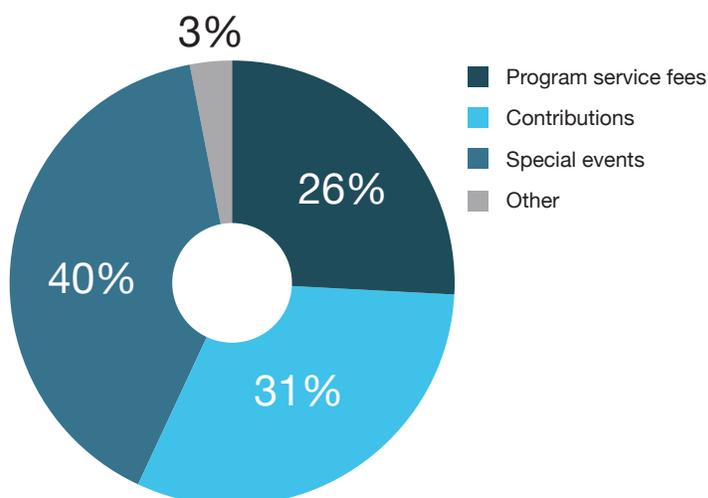
Program services	
Kids and family	\$102,230
Patient services	\$303,483
Public health education	\$95,853
<b>Total program services</b>	<b>\$501,566</b>
Supporting services	
Management and general	\$23,155
Fundraising	\$85,702
<b>Total support services</b>	<b>\$108,857</b>
<b>Total operating expenses</b>	<b>\$610,423</b>

Change in net assets from operations	\$43,002
Net gains on investments	\$94,340
Change in net assets	\$137,342
Net assets—Beginning of year	\$1,009,807
<b>Net assets—End of year</b>	<b>\$1,147,149</b>

## Use of Funds:



## Revenue Sources:





**Epilepsy Association**

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