

Epilepsy Association

Dear Friends and Supporters,

As the Board President and CEO of the Epilepsy Association, we are thrilled to present to you the 2022 Annual Report, which highlights the incredible achievements and progress of our organization over the past year.

2022 was truly a remarkable year for us as we continued our unwavering commitment to spreading awareness and providing support to the epilepsy community in Northeastern Ohio. Through our services and engaging community events, we were able to reach thousands of individuals and create a positive impact in their lives.

We are proud to share that we successfully renewed our CARF (Commission on Accreditation of Rehabilitation Facilities) accreditation in 2022. This involved a rigorous process where two surveyors from CARF conducted an intensive review of our organization from "top to bottom" assessing policies, leadership, fiscal, human resources to programing, client rights, outreach, and safety. We are thrilled to announce that our renewed accreditation will be valid for three years, which is the highest level of accreditation an organization can receive, and it reflects our commitment to excellence in providing excellent services to our clients.

In addition, we approved and launched our new three-year strategic plan (2022-2024), which is built upon the strong foundation of our past successes and the values that drive us. This strategic plan sets the direction for our organization's future and outlines our goals and initiatives to further enhance our impact in the community. More information on our strategic plan can be found on the next page in the Annual Report.

We also went through some changes in our staff in 2022. While we bid farewell to Colleen Saunier, our longtime Director of Development (12 years at the organization), and Nicole Richter, our Director of Community Programing (9 years at the organization), we are grateful for their invaluable contributions to the organization and their dedication to serving those living with epilepsy. We are pleased to announce the promotions of Nikki Johnson to Manager of Development and Public Relations, and Taylor Miller to Manager of Community Programing. We are confident that their expertise and passion will further strengthen our team and our ability to fulfill our mission.

None of our achievements would have been possible without the unwavering support of our Board of Directors, Professional Advisory Board members, donors, and agency staff. Your generosity and commitment have allowed us to continue our programming, services, and support for those we serve in Northeastern Ohio. We are deeply grateful for the overwhelming support from our community, which has enabled us to continue our work in a meaningful and impactful way.

As we look ahead to the future, we are excited to continue our efforts to inspire, serve, and sustain people in NEO to spread awareness, provide support, and advocate for the epilepsy community. We remain dedicated to our mission and are committed to making a positive difference in the lives of individuals living with epilepsy and their families.

We invite you to read our Annual Report for a detailed overview of our accomplishments in 2022 and our plans for the future. Once again, thank you for your continued support and partnership as we work towards a brighter future for individuals with epilepsy.

Sincerely,

Sue Stamberger Board President

Susan Stomberg

Kelley S. Needham

CEO

2022 – 2024 Epilepsy Association Strategic Plan

Every three years, we pause to reflect on our successes, challenges, opportunities, and community impact. We are driven to ensure that our actions are aligned with our organizational values and provide the greatest possible positive impact to the individuals we serve, our donors and our community. A Strategic Planning Committee was comprised of members of the Board of Directors and Professional Advisory Board.

We are proud to present our 2022 – 2024 Strategic Plan, which not only reflects our values but also builds upon the strong foundation of our past successes and deep ties to Northeast Ohio.

INSPIRE: The EA inspires the community with our passion and commitment to excellence in all we do. Our "inspire" goal allows us to focus on increasing awareness of epilepsy and the Epilepsy Association using traditional and social media and other marketing tools to tell the personal stories of our community. Telling these stories will establish new and strengthen existing connections between us, our clients, donors and health care partners.

In three years, we'll be able to mark our "inspire" success through web engagement analytics that will show increased new and unique visitors to our information and events websites, increased amounts raised in online donations, the numbers of new followers on social media including Facebook and Twitter, the number of online service request forms submitted and agency referrals.

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SERVE: The EA serves our community through diverse, compassionate, respectful and evidence-based programs that model science to service. Our "serve" goal allows us to focus on the quality of life and healthcare access of our current and future clients. We will expand the reach of our client service programming into a broader geographical footprint and expand virtual programming and technology to increase access to healthcare and other resources.

In three years, we'll be able to mark our success through the increased number of clients served; the expanded geographical footprint of our clients, referral sources, and donors; client satisfaction and other quality of life measures, and the amount of technology assisted visits.

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SUSTAIN: The EA sustains itself through resourceful management and collaborative efforts. Our "sustain" goal allows us to focus on being responsible stewards of client trust, donor funds, and stakeholder expectation. We do this by maintaining well qualified and engaged staff, offering evidence based, epilepsy-specific programs, and maintaining national accreditation. Key to these efforts is program service income, intelligent fund raising, from private and corporate donations and funds, supported by data management, and the continuous improvement and mix of special event offerings.

In three years, we'll be able to mark our success by the level of CARF accreditation, independent financial audit report results, dollars raised through special events, grants and private contributions and how we manage administrative costs without sacrificing client service or satisfaction levels.

2022 Highlights—Our Impact

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, SMART self-management programming, individualized support for children & families to increase quality of life, and community education to promote awareness. \$.82 cents of every dollar go back into community programming. 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.

413 individuals received case management and other social services

38 participants in collaborative SMART Self Management Program.

2,148 social service treatment hours provided

12,046 individuals reached through community programs

13,041 individuals received education about epilepsy

55,694 website visits

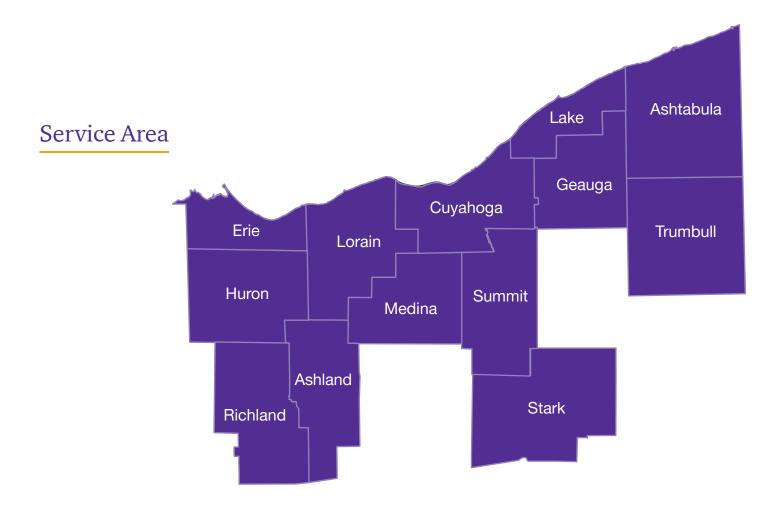
174 information and referral calls

6,214 Social Media followers across Facebook, Twitter, and Instagram

8 community fundraising events and educational seminars hosted

128 parents and families served

125 virtual visits provided to individuals and schools



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.

2022 Client of the Year Award: **Kim Hittle**



I was diagnosed with epilepsy in the spring of 1994 at the age of 16. The seriousness of my epilepsy came to light in 1996 during my freshman year at Mount Vernon Nazarene College when I began to have back-to-back seizures. I was having anywhere from 20-30 complex partial and petit mal seizures a day. At the end of the Fall semester, due to my seizures, I was faced with the decision to either stay in the Cleveland area or move to North Carolina to live with my father. So off to North Carolina I went and started receiving care at Duke University Hospital for epilepsy. Because of the many daily seizures, it was decided that surgery was necessary and the surgery

would be a lobectomy on my right temporal lobe. The surgery was not successful; therefore, I received the VNS implant which worked for two years. During this time, I was able to obtain my driver's license for the first time, but during a trip to Cleveland in September 2001 the VNS battery died and the seizures returned with a vengeance. I was having 40 seizures per day. At this time in my life, I had my associate degree in early childhood education and was already working as a preschool teacher for about 4 1/2 years. I was devastated, losing everything I worked so hard to achieve. I was then diagnosed with a major depressive disorder. I had no choice but to stay in the Cleveland area. I faced another brain surgery in April 2002 at the Cleveland Clinic. Right after that surgery was when I was referred to the Epilepsy Association.

The Epilepsy Association Case Management program supported me throughout my long process of rehabilitation. I had lost all memory of my past, my education, my teaching skills, driving skills, etc. Due to the memory loss I was no longer able to live an independent life. The EA was there during my years of struggling to make my way mentally, physically, and to try and regain independence. Because of EA's abundance of resources, assistance and giving and helping to build supports; they provided the help I needed to get to where I am today.

Today, I successfully live on my own and have a part-time job working for the YMCA of Greater Cleveland teaching water aerobics. I am fully involved in my church, I have a group of friends I really enjoy spending time with, and I take care of my fur babies. With the help of EA's Case Management services, not only am I living my best life since my surgery in 2002, I am learning that my epilepsy does not define who I am or who I'm going to be. For the past five years I am finally in control of my life since being seizure free. My name is Kim Hittle and I will not allow epilepsy to get in the way of me achieving my future goals and to independently live my daily life!

Congratulations Kim!

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.

Parent Support Group – Parents/guardians of children with epilepsy can connect with others and receive support and education. This group is offered virtually and discuses different topics related to having a child with epilepsy.

Epilepsy Education – Our qualified staff and trained volunteers provide instructional presentations for students of all grade levels and school staff. Programming is offered in-person or virtually.

- Puppet show: 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:** 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.





2022 Winter Walk - Spieth Family (The 2022 Winter Walk Featured Family) and Kelley Needham

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.

Self-Management Group – An 8-week virtual self-management program for adults with epilepsy designed to help individuals learn strategies about how to best take care of their physical and emotional health. A nurse educator and a peer educator (person with epilepsy) facilitate the program sessions. This program is offered virtually and is an evidence-based practice designed by Psychiatry and of Neurology at Case Western Reserve University School of Medicine.

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.

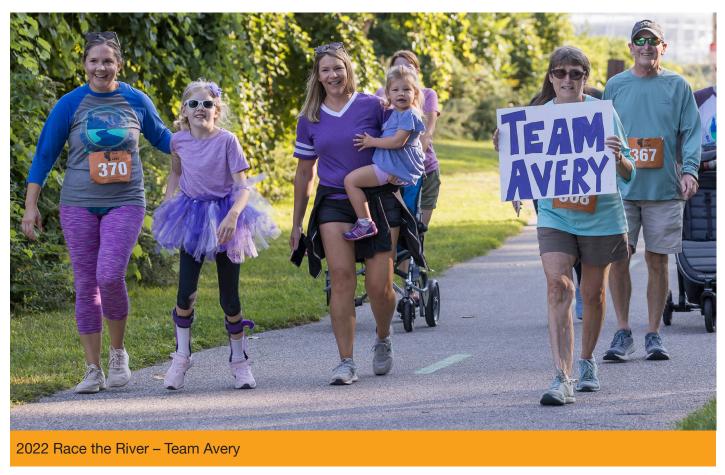
2022 presentations were made by:

Danielle Becker, MD Jennifer Waldron, DO Michael DiSano, MD Elizabeth N. Spurgeon, MD

Community Services, continued

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 was held at the SouthPark Mall in Strongsville and gathered over 230 of 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. The 2022 Winter Walk raised over \$51,000. 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 2022 Feature Family award was presented to Kevin Spieth and his family.
- Purple Day*: Purple Day* is the Global Epilepsy Awareness Day that is celebrated on March 26. Purple Day® focuses the world's attention on epilepsy. The 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. The Epilepsy Association celebrates 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.





2022 Golf Outing - April Walsh, Kelley Needham, Rick Lorentz, and Spirnak Family

Community Services, continued

- Annual Golf Outing: The 2022 Golf Outing was held in June at Sweetbriar Golf Club in Avon. In it's second year, each guest was treated to 18-holes of golf, a cart, lunch, and a post-round reception. The fundraiser helped raise money to fund the agency's program. The 2022 Outing had 88 golfers and raised over \$30,000.
- Race the River: The 10th Annual Race the River Run was held at Merwin's Wharf Restaurant and the course followed the Metroparks all-purpose trail and ran through out the Irish Bend and Tremont neighborhoods. This year's 10K, 5K, and one-mile run/walk raised over \$20,000 and had 200 participants.
- Annual Gala: The annual event was held every year in November as part of the National Epilepsy Awareness month. In 2022 we celebrated the 31st Anniversary of this event. The formal evening had over 250 people in attendance and our Legacy Award is presented to recognize a person/ medical professional and corporation who has made outstanding contributions in the field of epilepsy. The 2022 Legacy Award Honoree was Dr. Lara Jehi from the Cleveland Clinic. In addition, we recognize Team Avery with our Youth Humanitarian Award and Elizabeth Gedeon, LISW with our first ever Caregiver Award. The 2022 Gala was held at the Cleveland Marriott Downtown at Key Center and raised over \$147,000.

Community Education – The agency participates in several community health fairs throughout the year in an effort to increase community awareness of epilepsy and available agency services. The Epilepsy Association also provides educational in-services on epilepsy and seizure first aid in the community.



2022 Gala - Team Avery, and Sue Stamberger

CDC Grant Summary

2022 kicked off a significant collaboration between the Epilepsy Association of Western and Central PA, Epilepsy Association, and Epilepsy Alliance Ohio, made possible through a CDC Grant. The primary objectives of this collaboration were to increase the availability and accessibility of resources for individuals with epilepsy in Ohio, Pennsylvania, West Virginia, and Kentucky.

The collaborative project focused on two key goals: expanding outreach and delivery of an evidence-based self-management program for people with epilepsy and building, supporting, and sustaining local and regional multi-sector partnership networks to enhance access to underutilized community resources that cater to the social needs of people with epilepsy.

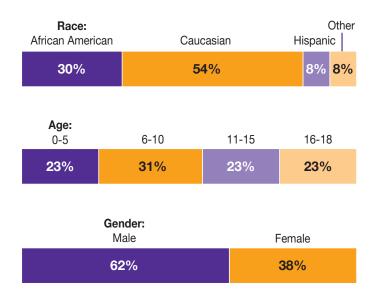
The evidence-based program, known as Self-Management for People with Epilepsy and a History of Negative Health Events (SMART), has demonstrated remarkable results in reducing epilepsy-related complications and improving the quality of life, as well as physical and mental health functioning of individuals with epilepsy. Notably, research has shown that these positive outcomes persist even after completing the program, with improved quality of life and reduced seizure count still maintained one year later.

To ensure the SMART program reaches its intended beneficiaries, the coalition focused its efforts on recruiting and enrolling individuals who often lack awareness and access to available resources. This includes transition-age young adults (18-24 years) with epilepsy and individuals residing in Appalachian and rural communities, where access to epilepsy-related resources may be limited.

Through this collaborative effort, the Epilepsy Association, Epilepsy Association of Western and Central PA, and Epilepsy Alliance Ohio aim to deepen the knowledge of self-management in people with epilepsy and make valuable contributions to the Centers for Disease Control and Prevention-funded Managing Epilepsy Well (MEW) Network.

Overall, this collaboration has been instrumental in expanding outreach, increasing access to evidencebased self-management programs, and establishing strong partnership networks, thereby improving the well-being and quality of life for individuals with epilepsy across Ohio, Pennsylvania, West Virginia, and Kentucky. As one participant said, "It's really nice to know that I'm not alone in this process."

Kids and Family Programming



Adult Case Management Programming Other 1% Race/Ethnicity: Hispanic African American Caucasian 3% 56% 40% This only totals 99% Age: 20-34 35-54 55-64 65-75 21% 44% 25% 10% This only totals 99% Gender: Male Female 36% 64% \$20,001 & above Income: \$10,501-\$15.001-None \$1-\$10,500 \$15,000 \$20,000 13% 14% 9%

26%

38%

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 2022. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

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The Lord Byron Society (\$250 to \$499)

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The Leo Tolstoy Society (\$100 to \$249)

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Ms. Diana Cipriani

Moira Clark

Pam Claxton

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Mr. Adam Zuccaro

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Sandra Reid

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Lubrizol Foundation

Nordson Corporation

Pella Rolscreen Foundation

Progressive Insurance Foundation

Total Quality Logistics

UHG

In Memory

The following 9 individuals passed away in 2022. Family members asked for donations to be made in their memory to the Epilepsy Association. These memorial gifts totaled \$30,622 and these gifts will remain in Northeast Ohio to be used to provide services to those who struggle with epilepsy in the Northeast Ohio community.

Brenna T. Brossard

Harry Carpenter Sr.

Janet Kaye George

Kristen J. Harper

Jeanne M. Lipton

Tayler Scott McDannel

Mary Lou Phillips

Dawn Riggle

Mary Jo Sonnenberg Schneider

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Nicole Richter

Director of Community

Programing*

Taylor Miller, QMHS

Manager of Community Program

Christine Spradling, LPCC

Contract Clinical Director

Delilah Toles, QMHS

Case Manager

Barbara Rutt, SWA

Case Manager

Stephen Love

Case Manager**

Colleen Saunier

Director of Development and

Public Relations*

Nicole Johnson

Manager of Development and

Public Relations

Ethan Miller

Development Associate**

*Left the Epilepsy Association

in 2022

**Joined the Epilepsy Association

in 2022

Partners and Accreditations

ADAMHS Board of Cuyahoga County



Ohio Department of Mental Health and Addiction Services



CARF



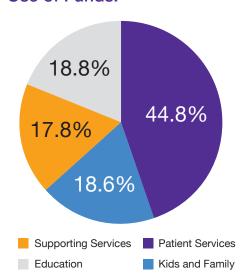
Financials

Statement of Activities and Changes in Net Assets

Operating Support

and Revenue:	2022 Audited
Contributions	\$245,915
Program services fees	\$289,423
Special events	\$256,829
Less: Direct benefit to donor	\$(70,914)
Net gain on investments	\$9,396
Total support and revenue	\$730,649

Use of Funds:



Total Support and Revenue

Operating Expenses:

Program services	
Kids and family	\$130,500
Patient services	\$314,553
Public health education	\$131,797
Total program services	\$576,850
Supporting services	
Management and general	\$25,070
Fundraising	\$99,931
Total support services	\$125,001
Total operating expenses	\$701,851
Change in net assets from operations	\$28,798
Net loss on investments	\$(172,128)
Change in net assets	\$(143,330)
Net assets—Beginning of year	\$1,325,490
Net assets – End of year	\$1,182,160

Revenue Sources:





Epilepsy Association

2831 Prospect Ave. Cleveland, Ohio 44115 (216) 579-1330 www.epilepsyinfo.org



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Instagram name is epilepsy_association

Special thanks to Jyll Presley for the layout and design of the annual report and to Daily Legal News for its printing.