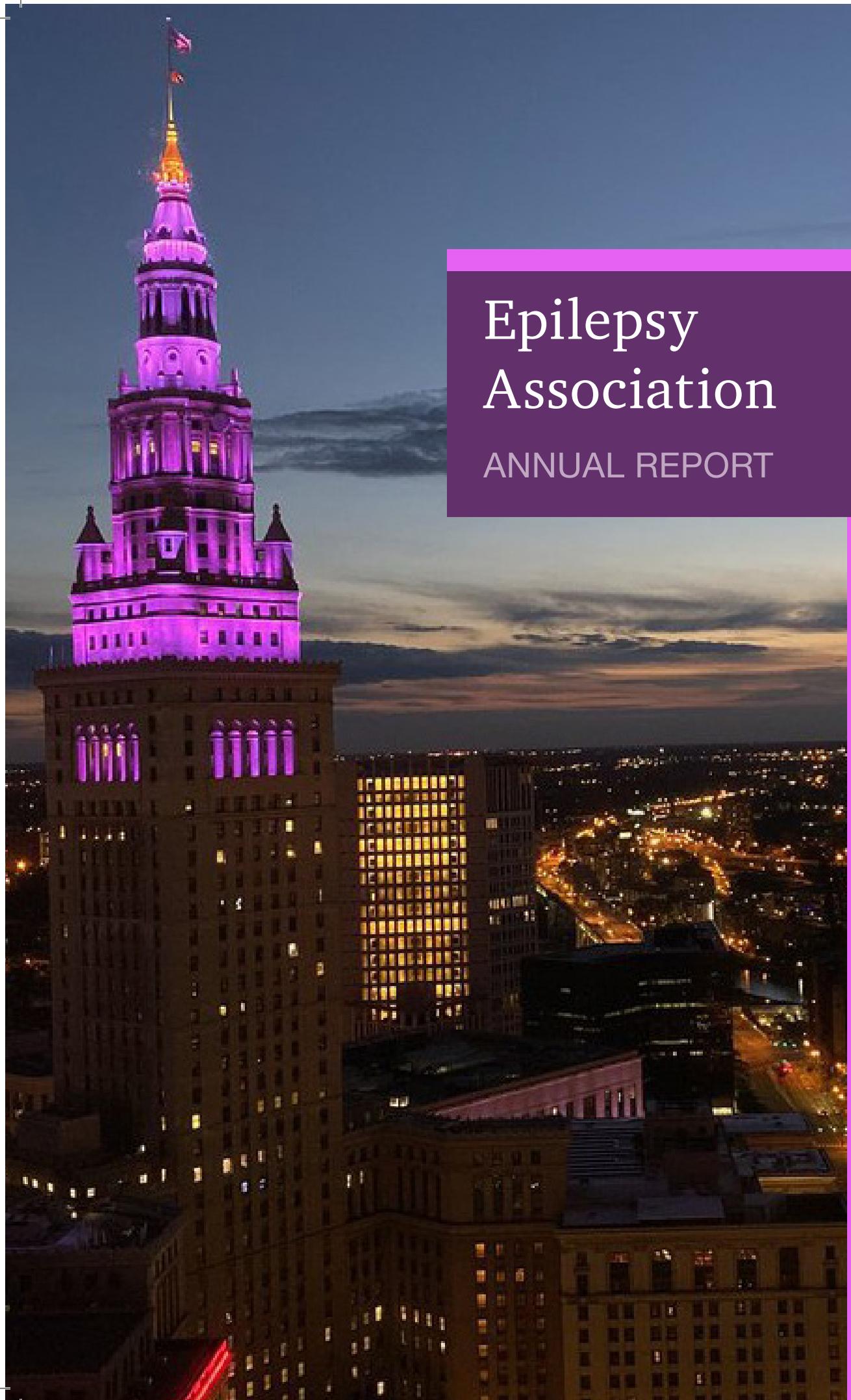




Epilepsy Association

ANNUAL REPORT

2021



Dear Donors and Friends,

We are excited to share our 2021 Annual Report for you to review which highlights the successes we had in 2021. The agency still faced challenges while navigating the second year of the COVID-19 pandemic, but through it all, we still were able to accomplish all our overall goals while serving those living with epilepsy and seizure disorders in NEO.

We went back to hosting fundraisers in person, but still making virtual components available for participants who wanted to support remotely. We added a new special event, a very successful Golf Outing held in June. The agency increased the use of technology with our special events and in our Adult Case Management program too through a grant funded program. Hotspots and iPads were purchased for our clients to be used through a loaner program for virtual appointments with healthcare providers to access other services and supports that will help to improve their quality of life with epilepsy.

In 2021, EA partnered with the Epilepsy Alliance of Ohio, the Epilepsy Association of Western & Central Pennsylvania, and CWRU to successfully secure 5-year funding through the CDC. The grant is to support the CDC Improving Epilepsy Education Systems of Care and Health Outcomes through National and Community Partnerships Initiatives by utilizing the combined resources and expertise of our multi region coalition partners. This opportunity provides EA with the chance to expand our reach into a broader geography and offer the SMART self-management program to individuals living with epilepsy who may be residing in areas where there is little to no access to specialized epilepsy support. It will also increase connections to other multi-system providers to insure better service access to clients.

Also, during 2021 the Epilepsy Association Planning Committee developed the 2022-24 strategic plan with input from a wide range of stakeholders. The committee reflected on successes, challenges, opportunities, and community impact. There was a drive to ensure that the actions of the committee would produce a plan that was aligned with our organizational values and would position us to provide the greatest possible positive impact to the individuals we serve, our donors, and our community. The plan reflects our values and also builds upon the strong foundation of our past successes and deep ties to Northeast Ohio. The plan has three main tenants: Inspire, Serve, and Sustain which will guide us over the next 3 years.

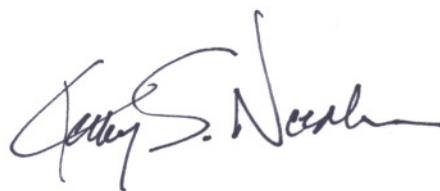
Our achievements would not have been possible without our Board of Directors, Professional Advisory Board members, donors, and agency staff, who continued to work hard to keep programming, services, and support available for those that we serve. The generosity we saw from the Northeast Ohio community has allowed the Epilepsy Association to continue its work in a meaningful and impactful way.

Thank you for your continued support of the Epilepsy Association, we look forward the challenges and new opportunities 2022 may bring!

Sincerely,



E. Sean Medina
President, Board of Directors



Kelley S. Needham
CEO

2021 Highlights—Our Impact



128 parents and families served

175 information and referral calls

445 individuals received case management and other social services

150 students received educational in-services in school on epilepsy and seizure first aid

1,824 social service treatment hours provided

5,352 individuals reached through community programs

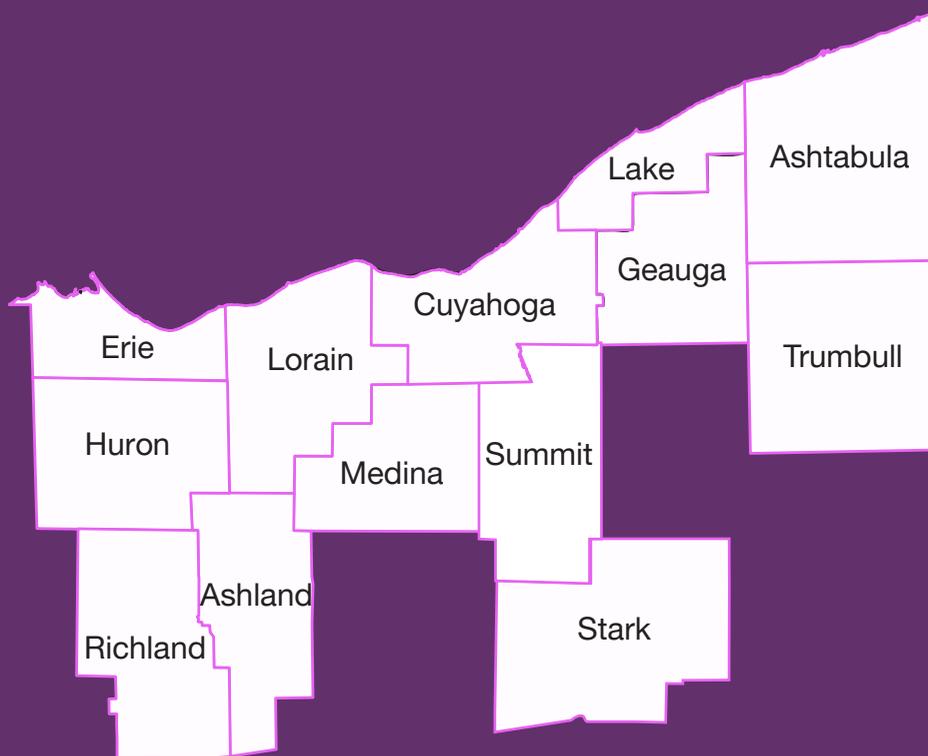
About the Epilepsy Association:

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 goes 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, SMART self management program, and community-based education. The agency 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 2021 figures were affected by the Coronavirus pandemic.

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.

2021 Client of the Year Award

Norene Van Leer

I can look back on my history with epilepsy with amazement. I was 14 when I began having seizures. After completing multiple tests, I was informed that my seizures were psychological and to seek therapy. At about age 25, I was treated and medicated for anxiety attacks; however, my seizures were still not managed. During this time, I was attending college, working full time and being a mom to my new baby. It was tough having multiple seizures while still managing to show up for work. I tried different medications and I would go through periods of stopping my medications which was quite dangerous. I was working overtime, going to school while still being a mom, but I was constantly stressed and felt exhausted. At age 37, I got into a car crash when I had a seizure at a red light.

I was finally diagnosed with epilepsy at age 42 and was informed that I would no longer be able to work. My life took a complete 180 turn. I completed multiple testing and was approved for surgery. At this moment I was introduced to the Epilepsy Association. From day one, I felt complete understanding from the Epilepsy Association, something I did not get at doctors' offices about my seizures for years. With the Association, I never felt like I had to fake it and they helped make me feel good when I didn't. I've never had a case manager who didn't try understanding me and what I was going through. Everyone has been great and I love the seminars and functions I am invited to participate in. I am so honored to say that my seizures are manageable, and I'm able to enjoy life again. I look back on my journey with the Epilepsy Association and I am so blessed that I have had them with me encouraging me, teaching me and pushing me forward for the last six years. Although I have made much progress, I am still learning new ways to cope and manage my seizure activity daily. Thank you, Epilepsy Association, for choosing me to be the client of the year. I am truly honored to receive this award.



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 discusses 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.

- ◆ **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.

The Epilepsy Education programs were offered both in-person and via Zoom during 2021 to meet the varying needs of schools throughout the pandemic.

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.

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 Dr. Martha Sajatovic at Case Western Reserve University.



2021 Winter Walk Feature Family
The Helmet Family—Bill, Carly, Nathan, Liam

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 hundreds 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. 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 2021 Feature Family award was presented to Nathan Helmet and his family. The 2021 Winter Walk had 225 participants and raised over \$55,000.
- ◆ **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 Golf Outing:** New for 2021, the Epilepsy Association brought back their golf outing fundraising. This scramble style outing was held in June at Sweetbriar Golf Club in Avon. Each guest is treated to 18-holes of golf, cart, lunch and a post-game reception. The fundraiser helped raise money to fund agency programs. The 2021 Golf Outing had 96 golfers and raised over \$35,000.



2021 Winter Walk Participants



2021 Golfer Foursome



2021 Golf Foursome
Daryl & Rose Sconyers and Jon & Sue Stamberger



Team Avery
2021 Race the River's Top Fundraising Team



2021 Race the River 10K & 5K runners



Annual Gala attendees

Community Services, continued

- ◆ **Race the River:** The 9th Annual Race the River Run is a family-oriented 10K, 5K and one-mile run/walk to benefit the Epilepsy Association. The Race had a new location for 2021 at Bur Oak Reservation in the Lorain County Metroparks. The 2021 Race the River event raised over \$20,000 and had 119 participants.
- ◆ **Annual Gala:** The annual event is held every year in November as part of the National Epilepsy Awareness month. In 2021 we celebrated the 30th Anniversary of this event. The formal evening has 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 2021 Legacy Award Honorees were Michael Devereaux, MD and Hans Lüders, MD, Professors of Neurology, University Hospitals Cleveland Medical Center. Both physicians were honored at our first ever Gala in 1992 and we were thrilled to be recognizing them again for the legacy they have continued to leave on the local and international epilepsy community. The 2021 Gala was held at the Cleveland Marriott Downtown at Key Center and raised over \$139,000.



Kelley Needham CEO; 2021 Legacy Award Honorees Michael Devereaux, MD & Hans Lüders, MD; E. Sean Medina, Board President

Corporate Gifts

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

\$10,000 and above

SK Life Science

\$5,000 to \$9,999

Franklyn Development Company
Greenwich Biosciences
Hahn Loeser & Parks LLP
Jay Auto Group
Parker Hannifin Corporation
Yourcause Pella Rolscreen Foundation
Summa Health
Supernus Pharmaceuticals, Inc.
Zogenix

\$1,000 to \$4,999

Ancora
BakerHostetler
BBG, Inc.
Boak & Sons, Inc Roofing & Insulation
Charities Aid Foundation of America

Cigna
Cleveland Clinic Epilepsy Center
Dollar Bank
Eisai Pharmaceuticals
Farmers National Bank
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Lincoln Electric Co.
LivaNova
The Lubrizol Corporation
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Terrace Construction Company
The Triad Engineering & Contracting Co.

Trucast, Inc.
U.S. Bank
United Way of Central Maryland
Westin Cleveland Downtown

\$100 to \$999

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Nature Stone Flooring
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Team Logic IT
United HeathCare
Vantage Solutions LLC



2021 Race the River 10K & 5K runners

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Donors

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The Edgar Allan Poe Society (\$5,000 to \$9,999)

John and Jean Hlay
Mr. & Mrs. Jeffrey and
Teresa Karlovec
Ms. Amy Kellogg
Mr. Sean Medina
Mr. & Mrs. Bryan and Sarah Salisbury
Mr. & Mrs. Michael and
Connie Scanlon
Dr. & Mrs. J. Patrick Spirnak

The Charles Dickens Society (\$1,000 to \$4,999)

Mr. & Mrs. Darrell and Louise Allen
Mr. & Mrs. Jesse and Mary Jo Baden
Mr. & Mrs. Richard and Debbie Bass
Ms. Jennifer Carlile
Anne Crawford
Dr. & Mrs. Michael and
Jan Devereaux
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Trish Vince
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Patrick Waide
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Jonathan Zande

The George Frederick Handel Society (\$500 to \$999)

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Michael Barrett
Dr. & Mrs. Mark Bej MD, FACNS
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Larry Flynn
Ms. Karyn Frederick
Ms. Elaine Hutchins
James Johns
Ms. Stephanie Kapcio
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Kelley Needham
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Reid Sheppard
Kristen Smith
Christopher Spirnak
Mr. Shaylor Steele
Ryan Tofte
Debra Yarwood
Mr. Ben Young
Dr. Lucyna Zawadzki

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

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Julie Baraona

Joseph Beatty Jr
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Mr. Michael Blake
Martin Booher
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Robert Scotta
Mike Slifka
Mr. & Mrs. Amy and Eric Spieth
Ms. Susan Stanton

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Donors

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Mr. & Mrs. Joseph H. Thomas
Kara Vandersommen
Maureen Waide
Amanda Whyte

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

Mr. Albert Adams
Mr. Rabon Allen
Mohmad Araman
Ms. Nancy Babel
Mr. Richard H. Bamberger
Carol Baptiste
Kaitlin Barnes
Angie Barnhizer
Lauren Bass
Terry Bennett
Michael Berthelot
Barbara Bestic
Ms. Marlene Biggs
Lisa Birkes
Mr. & Mrs. William and
Michelle Blood
Ms. Megan Bob
Josh Bobinger
Donald and Linda Bodner
Christopher Brandt
Deanna Bremer Fisher
Ms. Keionna Brown RN, CPNP
Gary Bryenton
Mr. & Mrs. Joseph and
Janice Bubnick
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Paul Butrey
Mr. Jeff Byce
Ms. Sarah Camden
Dr. & Mrs. Krishan Chandar
Ms. Allison Chapin
Diane Chapman
Mr. & Mrs. Lee and Tuni Chilcote
Mr. & Mrs. Homer and
Gertrude Chisholm

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Kevin McDonough
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Eric Patrick
Stacey Patrick
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Mr. Jeremy Peyton
Frank Pines
Michelle Polewan

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

John and Sharon Pope
Mr. & Mrs. Joseph and
Catherine Prion

Dave Pycraft

Sandra Reid

Audrey Ricciardi

Jennifer Richards

Marissa Ripp

Dave Roberts

Mrs. Lisa Roberts-Mamone

Gregg Rossi

Marvin Rossi

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Mary Scarberry

Ms. Patti Schaar

Benjamin, Emily, and Young
Peregrin Schenk

Mr. & Mrs. Mark and Joe Sciulli

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John Soppe

Liz Soppe

Ms. Janet Spreen

Alfred F. Stabilito

Dr. & Mrs. Thomas and
Kathleen Stellato

Gabrielle Stires

Sarah Tabeling

Mike Thompson

Jennifer Varanese

Steph Vidmar

Michelle Watkins

Mr. Fred Wheeler

Ms. Dianne Williamson

Mr. & Mrs. Steven and Leah Woytek

Yanshi Zha

Keren Zhou

Tracy Ziminski

Mr. Adam Zuccaro

Every effort is made to ensure the accuracy of our donor listings. If a mistake has been made, please call our Development office so we may correct our records.

In Memory

The following 12 individuals passed away in 2021. Family members asked for donations to be made in their memory to the Epilepsy Association. EA is extremely grateful for this support understanding the profound lost that proceeded it. These gifts remain in Northeast Ohio to be used to provide services to those who struggle with epilepsy in the Northeast Ohio community.

Elizabeth Ann Rowe Burke

Virginia "Gee Gee" Dipuccio

Sharon Irby

Matthew J. Jelenic

Clara Keim

Anna M. Levan

Jeremiah Mackim

Joseph Sims

Christopher Spirnak

Richard Sternagel

Marilyn H. Stewart

Gloria J. Zust

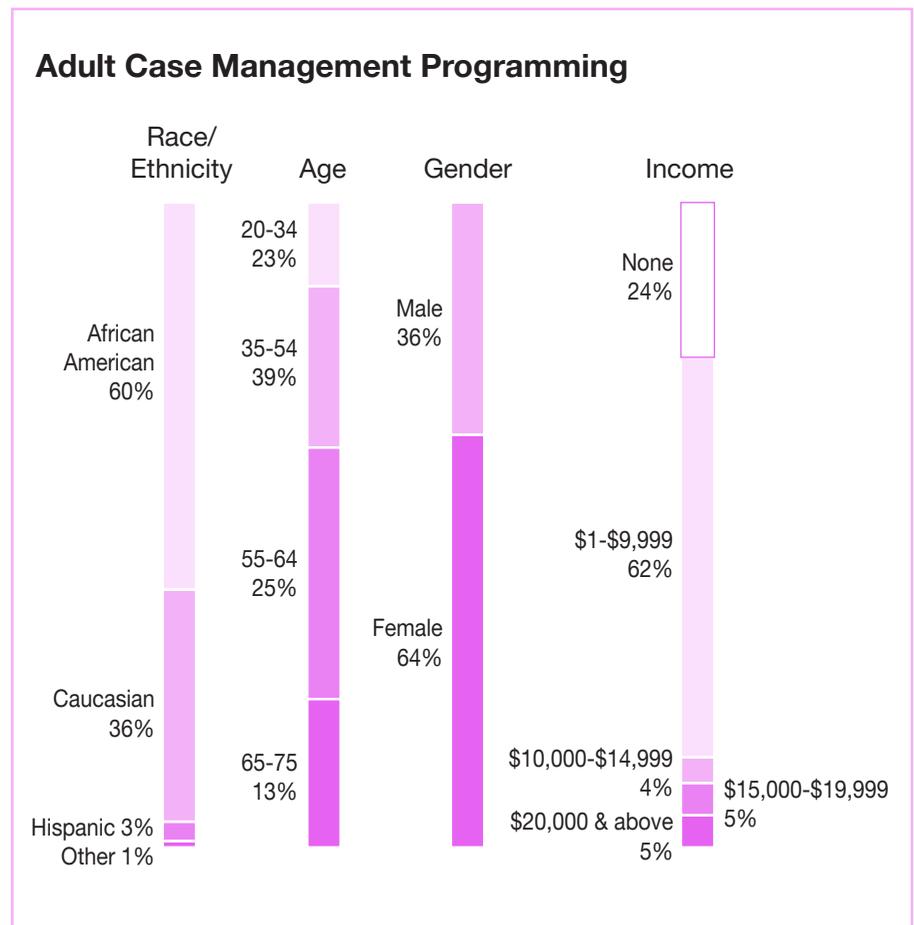
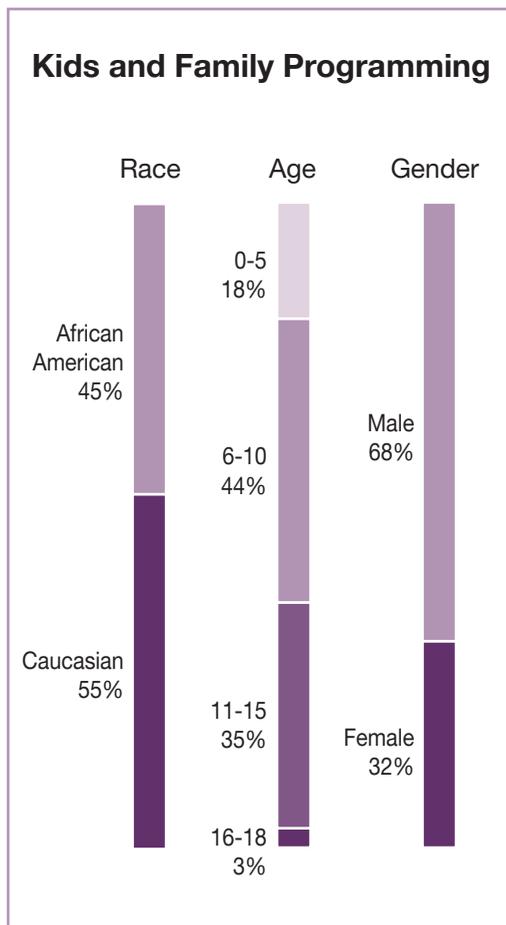
Foundation Gifts

- The Cleveland Foundation
- Eaton Foundation
- The Elisabeth Severance Prentiss Foundation
- The Murphy Family Foundation
- Reminger Foundation
- The Ridgecliff Foundation
- Rollin M. Gerstacker Foundation
- The S.K. Wellman Foundation
- Sisters of Charity Foundation of Cleveland

Matching Gifts

- Nordson Corporation
- GE Foundation
- Johnson & Johnson
- Pella Rolscreen Foundation
- Dollar Bank Foundation
- Progressive Insurance Foundation
- Lubrizol Foundation

Who We Serve:



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 Mark Holcomb, Treasurer
 Carole Barita, Secretary

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 Shaylor Steele
 Kierston Vaughn
 April K. Walsh
 Ben Young
 Adam Zuccaro

*Term expired in 2021

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Stephen Hantus, MD, Co-chair
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 Michael Devereaux, MD
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 Martha Sajatovic, MD
 Asim Shahid, MD
 Susan Stanton, PA
 Jennifer Waldron, DO
 Lucyna Z. Zawadzki, MD

*Term expired in 2021

Staff Listing

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 Colleen Saunier
 Director of Development
 Nicole Johnson
 Development Associate
 Nicole Richter, MS
 Director of Community
 Programming
 Christine Dessoify, LPCC
 Contract Clinical Director
 Taylor Miller
 Case Manager
 Delilah Toles
 Case Manager
 Barbara Rutt
 Case Manager

Partners and Accreditations

ADAMHS Board of Cuyahoga County



Ohio Department of Mental Health
 and Addiction Services



CARF



Financials

Operating Support and Revenue:

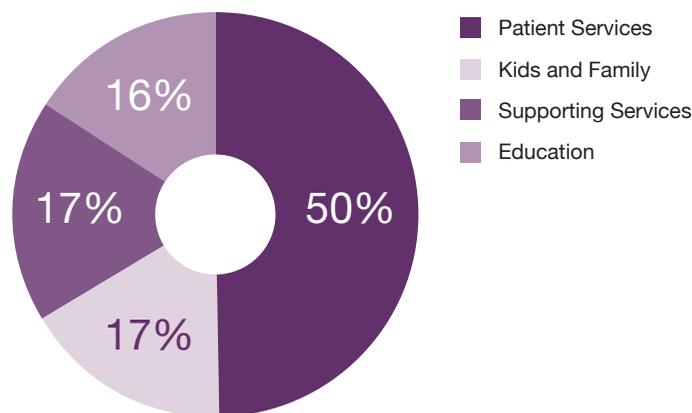
2021 Audited

| | |
|----------------------------------|------------------|
| Contributions | \$258,267 |
| Stimulus funds | |
| Government grant | \$62,900 |
| Program services fees | \$167,145 |
| Special events | \$252,210 |
| Less: Direct benefit to donor | \$(56,322) |
| Net gain on investments | \$9,142 |
| Total support and revenue | \$693,342 |

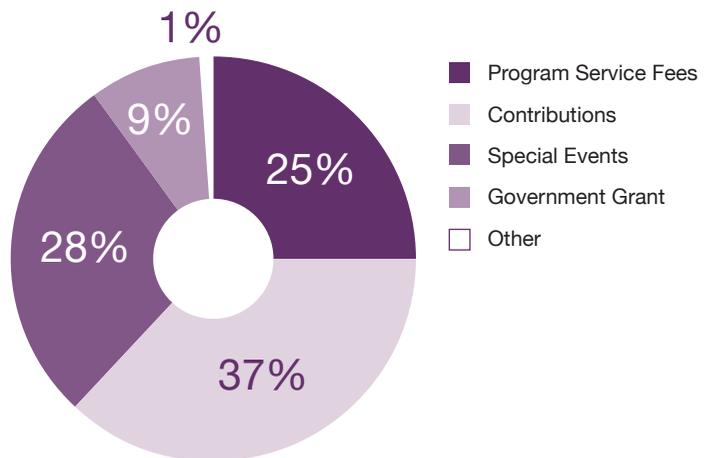
Operating Expenses:

| | |
|--------------------------------------|--------------------|
| Program services | |
| Kids and family | \$125,836 |
| Patient services | \$275,982 |
| Public health education | \$124,828 |
| Total program services | \$526,646 |
| Supporting services | |
| Management and general | \$24,547 |
| Fundraising | \$86,310 |
| Total support services | \$110,857 |
| Total operating expenses | \$637,503 |
| Change in net assets from operations | \$55,839 |
| Net gains on investments | \$122,502 |
| Change in net assets | \$178,341 |
| Net assets—Beginning of year | \$1,147,149 |
| Net assets—End of year | \$1,325,490 |

Use of Funds:



Revenue Sources:



2021 independent audit performed by HW&Co.



Epilepsy Association

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



Follow us on social media

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Twitter handle is @Epilepsy_Assn

Instagram name is epilepsy_association

Blog is at www.insightsintoepilepsy.org

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