

2023
ANNUAL REPORT



Hands United for Epilepsy Awareness

Epilepsy Association



Committee Chairman Lou Brossard and members of Fly High Sweet Brenna

Dear Friends and Supporters,

As the Board President and Executive Director of the Epilepsy Association, we are thrilled to present to you the 2023 Annual Report. This past year was a monumental one for us, marked by significant achievements and new initiatives that have deepened our commitment to raising awareness and providing support for individuals living with epilepsy.

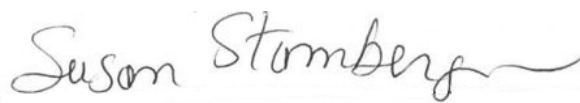
One of the most exciting developments of 2023 was the launch of our EA Ambassadors program. This program was designed to offer our sponsors an even greater opportunity to support our mission and raise awareness for epilepsy. In its inaugural year, we were fortunate to have three dedicated ambassadors who tirelessly championed our cause in the Northeast Ohio community. We extend our heartfelt thanks to our Leonardo Da Vinci Sponsor, Jazz Pharmaceuticals, our Vincent van Gogh Sponsor, SK Life Sciences, and our Sir Isaac Newton Sponsor, Dollar Bank, for their generous support and partnership in this initiative.

Another significant event in 2023 was the retirement of our beloved CEO, Kelley Needham. Kelley dedicated an incredible 32 years of her life to the Epilepsy Association, and her impact on our organization and the epilepsy community is immeasurable. Her compassion, dedication, and leadership have inspired us all, and we are deeply grateful for her years of service.

Following the announcement of Kelley's retirement, a thorough search was conducted, and we are delighted to announce that Patty Varanese has been appointed as our new Executive Director. Patty brings with her a wealth of experience and a passion for serving others, having served at esteemed organizations such as the Cuyahoga County Department of Jobs and Family Services, Catholic Charities, and Beech Brook. Patty's reputation as a vigorous client advocate precedes her, and we are confident that under her leadership, the Epilepsy Association will continue to thrive and grow.

As we look to the future, we are filled with excitement and optimism for what lies ahead. The Epilepsy Association remains steadfast in its commitment to providing resources and spreading awareness for those living with epilepsy. With your continued support and partnership, we are confident that we will achieve even greater success in the years to come.

We extend our heartfelt thanks to each and every one of you for your unwavering support and dedication to our cause. Together, we are making a tangible difference in the lives of individuals affected by epilepsy, and for that, we are profoundly grateful.



Sue Stamberger
Board President



Patty Varanese
Executive Director

2023 Highlights – Our Impact

300 parents and families served, an 134% increase from 2022

189 information and referral calls, an 8% increase from 2022

1,670 individuals received case management and other social services (Direct Client service)

114 students and teachers who received educational in-services in school on epilepsy and seizure first aid

2,238 social service treatment hours provided

14,130 individuals reached through community programs

\$400,000 raised from grants, special events, and private contributions

1,727 minutes on the phone with people calling for epilepsy resources

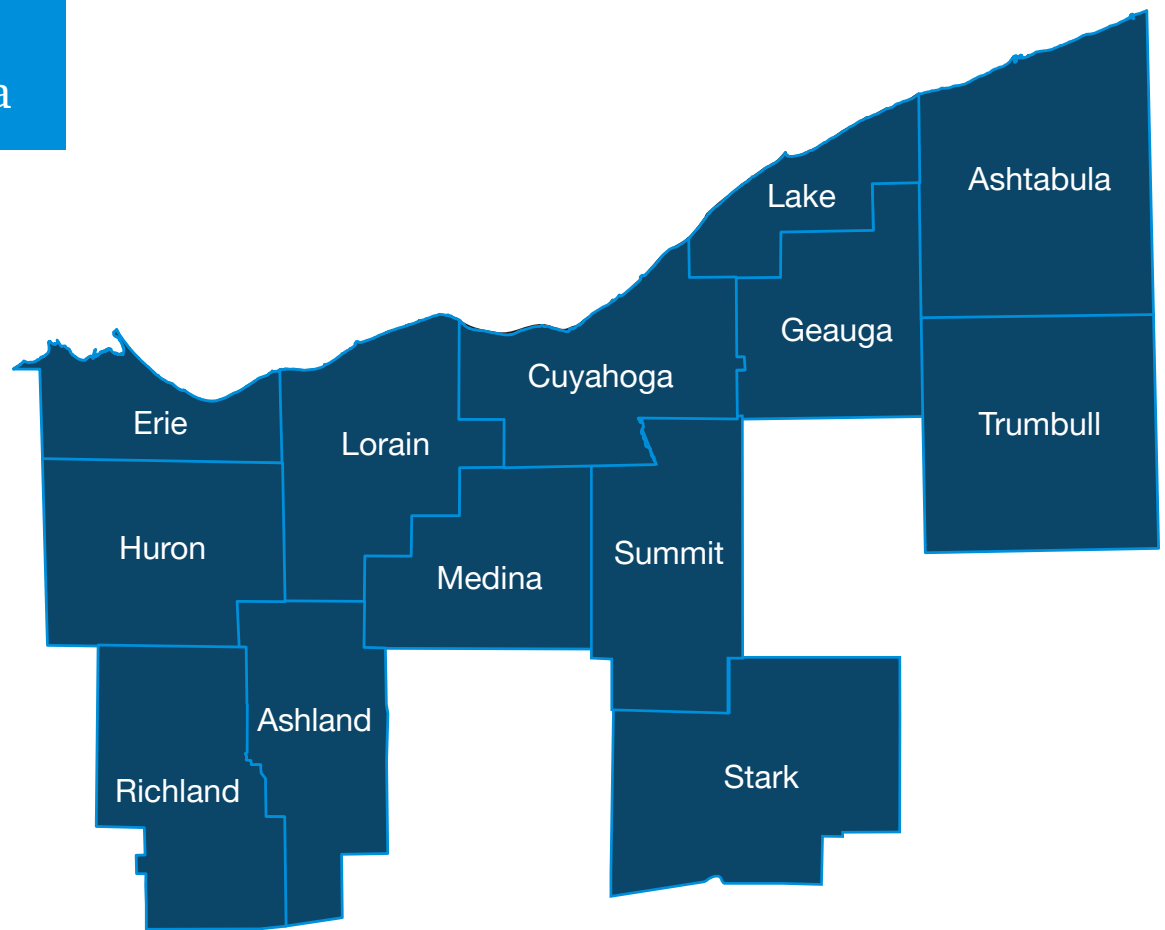
55 volunteers helped us bring our programs and special events to life

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 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.

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.

2023 Client of the Year Award:

Sharon Scott Brown



I have the privilege of sharing a story of resilience and triumph over adversity. My name is Sharon Sheppard-Scott and for over five decades, I have battled the challenging symptoms of Epilepsy. I was diagnosed at the age of 20 after a difficult time in my life. Epilepsy often leads to feelings of isolation, depression, and anxiety. But I made a choice to not let my condition define me or hold me back. Instead, I focused on raising my children, ensuring they had a valuable education and a bright future. Through my love of education, I dedicated myself to East Cleveland City School District for over 40 years, working alongside countless others who shared a passion for nurturing our youth.

Throughout my life, I have encountered several challenges. Yet, in the face of adversity, I held on to a mantra that became the guiding light in my life: “Don’t give up.”. My positive outlook became a beacon of hope not just for myself, but for those around me. I knew that in order to create a better world for my children and myself, I had to focus on the good and the possibilities that lay ahead. My unwavering belief in a higher power, in God, has been a guiding force that has carried me through the darkest moments. It is through this faith that I have found resilience, hope, and the strength to persevere.

In 2015, my daughter found the Epilepsy Association. Their team of case managers has provided me with much support, helping me to become more involved in programs and activities within my community. They also connected me with resources available to navigate the complexities of my condition.

After over 40 years with East Cleveland City School District, I retired this past December, which is a milestone that I consider a true blessing. Retirement granted me the freedom to prioritize my well-being and explore new interests in my community. I have held true to the saying, “Don’t give up.”

In closing, thank you for letting me share a testimony about the power of faith, determination, and community support (special shoutout to Ms. Taylor Miller and Dr. Jonathan Zande).

Remember, life’s challenges do not define us. We define ourselves by our response to those challenges. Let us embrace the mantra of “Don’t give up and don’t give in”.

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.

Coffee with Caregivers – 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. Programming is offered in-person or virtually.

- **Puppet show:** For children in preschool through 4th grade the program features the puppet characters, “Brian and Diane”, who have 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.



2023 Winter Walk



Volunteers Sue Loy and Carole Barita checking in runners at the 2023 Race the River

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, professor of Psychiatry and of Neurology at Case Western Reserve University School of Medicine.



Team Arena from 2023 Race the River

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.



2023 Youth Humanitarian Honoree Samuel Wigger



Hayden Grove – 2023 Gala Entertainment



Golfers at the 2023 Golf Outing

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 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. This year’s Winter Walk we highlighted a featured story to further epilepsy education. We promoted awareness for SUDEP (Sudden Unexpected Death in Epilepsy). The 2023 Winter Walk had 360 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.



Runners at the 2023 Race the River



Walkers at the 2023 Winter Walk



Team Avery at the Race the River



Client Susan Bradfield and Aubray Johnson at the 2023 Winter Walk

Community Services, continued

- **Annual Golf Outing:** This scramble style outing was held in June at Sweetbriar Golf Club in Avon for its second year. 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 2023 Golf Outing had 98 golfers and raised over \$40,000.
- **Race the River:** The 11th Annual Race the River Run is a family-oriented 10K, 5K and one-mile run/walk to benefit the Epilepsy Association. The Race was at Lakewood Park in Lakewood, OH. The 2023 Race the River event raised over \$20,000 and had 260 participants.
- **Annual Gala:** The annual event is held every year in November as part of the National Epilepsy Awareness month. In 2023 we celebrated the 32nd 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 2023 Legacy Award Honoree was Dr. Chinasa Nwankwo. In addition, we were able to recognize Samuel Wigger with our Youth Humanitarian Award and Sarah-Maria Riffle, LISW with our Caregiver award. The 2023 Gala was held at the Cleveland Marriott Downtown at Key Center and raised over \$130,000.

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.

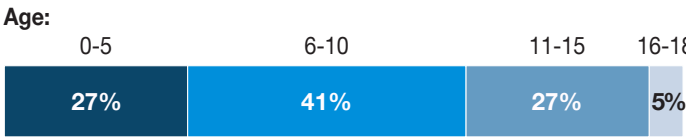
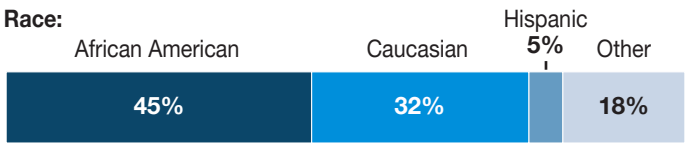


2023 Gala Sponsors

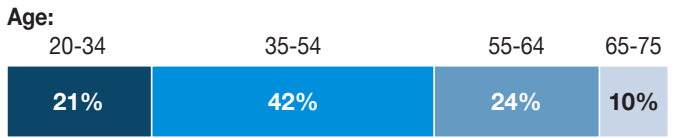


Runners at the 2023 Race the River

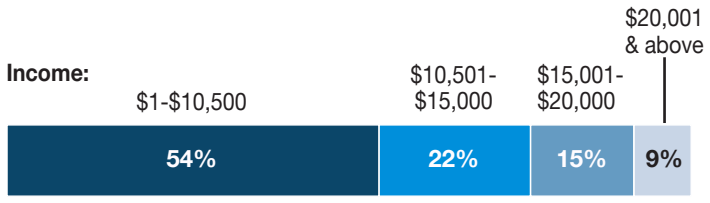
Kids and Family Programming



Adult Case Management Programming



This only totals 97%



Corporate Gifts

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



Lisa and Keith Behrendt

\$10,000 and above

Jazz Pharmaceuticals*
Marinus pharmaceuticals
SK Life Science*
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\$1,000 to \$4,999

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*We are thankful for our 2023-2024 EA Ambassadors and their dedication to our mission

\$100 to \$999

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Donors

The Epilepsy Association wishes to thank all the individuals who supported the agency during 2023. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

The Vincent Van Gogh Society \$10,000 and above

Mr. & Mrs. Richard and Debbie Bass

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

Mr. Sean Medina
Mr. & Mrs. Bryan and Sarah Salisbury
Ms. Amy Kellogg
Mr. & Mrs. John and Jean Hlay

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

Mr. & Mrs. Darrell and Louise Allen
Ms. Carole Barita
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Deanna Murlin
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Robin Nwankwo
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Linda Wieser
Alex Wolf
Bob & Brenda Yost
Mr. Ben Young
Dr. Lucyna Zawadzki

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Michael Barrett
Susana Bowlings
Don Davis
Mr. Rocco Dipuccio
James Dolbow
Ms. Takiyah Durham
Mr. & Mrs. Linda Glasser
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Curtis Harris
Mr. & Mrs. Bill and Carly Helmet
Ms. Susan Krantz
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Ms. Stephanie Moore
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Kelley Needham
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Sarah Pozek
Bob and Kathy Richards
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Lori and John Rowley
Dr. Martha Sajatovic MD
Mr. John R. Schloss
Susanne Schroer
Mr. & Mrs. Darryl and Rose Sconyers
Kent and Sharon Spieth
April Walsh
Laura & Justin Walter
Nancy Wiggers

Donors

The Epilepsy Association wishes to thank all the individuals who supported the agency during 2023. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

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

Joan Bannon
Tom Bernot
Sue Christy
Aaron Cook
Carol F. Crawford
Mr. Thomas Delaney
John & Vicky DePiere
Michael DiSano
Lijean Donovan
Ms. Karyn Frederick
Anthony Giampaolo
William Helmet
Josh Janszen
Cheryl Komora
Brian & Shanna Laraway
Bernadett Mamone
Tania Markarian
Jeremy Mayer
Mr. Scott McDannel
Justin McLoughlin

Chinasa Nwankwo
Genevieve Patrick
Stacey Patrick
Marvin Rossi
John Schroeck
Aasef Shaikh
Kevin Slivka
Kara Vandersommen
Trish Vince
Jennifer Waldron
Erin Whitford
Jerome Williams
Lindsey Wilson

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

Mr. Albert Adams
George and Michele Albertini
Sammy Assaf
Ms. Nancy Babel
Ms. Vicki Barone
Veronica Barrow
Brian Bash
Hillary Bashaw
Lisa Behrendt
Byron Berroteran
Ms. Meredith Berthelot
Michael Berthelot
Ms. Marlene Biggs
Rebecca Bittinger
Gracelyn Bogle
David Bowsher
Allison Bratko
Jaci Bucci
David Buchholtz
Elizabeth Burner
Brigid Burzanko
Denise Bussman
Paul Butrey
Amanda Cairns

John Cairns
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Mr. Irwin Frank
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Lori Galindo
Katie Gannon

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

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Emily Genetin
Mr. & Mrs. Paul Getch
Jim Gibson
Charles Gilbert
Michelle Gillcrist
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Evan Green
Alexis Gurganious
Mrs Sara Hardy
Karin Harper
Mr. & Mrs. Jeffery and
Susan Hastings
Nikki Heap
Nathan Helmet
Robin Henderhan
Jylene Henning
Kayla Hetrick
Michele Hoegler
Sherry Hofus

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Deborah Howe
Melissa Hughes
Dr. And Mrs. J. Patrick Spirnak
Steve Jackson
Cheryl and Jake
Suzanne Jambe
Shelby Johannsen
Fran and Mike Johnson
Kate Johnson
Gayle Jones
Sue Kasunick
Sara Kennedy
Mr. Anthony Kepley
Katherine Kerr
Shera Kile
Corey Kimble
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Iken Sans
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Mr. & Mrs. Brian and Shannon Tareshawty
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Hannah Wright
Maddie Wright
Taylor Wright
Tasha Yovetich
Ms. Katherine Zucca
Mr. Adam Zuccaro
Jeffrey Zucker

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

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Jennie Schmitz
Mr. & Mrs. Pete H. Schramm
Kim Schroeder Perry
Nicholas Scotese
Abby Seelie
Pete and Kathy Serio
Jennifer Shepard
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Ms. Susie Stanton
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Kaelin Sullivan
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Sarah Tabeling



Daryl Sconyers, Rose Sconyers, Board President Sue Stamberger, and Jon Stamberger at the 2023 Golf Outing



Representatives of Akron Children's Hospital at the 2023 Gala

Foundation Gifts

Eaton Corporation
Rollin M. Gerstacker Foundation
The Ridgecliff Foundation
The Elisabeth Severance Prentiss Foundation
Reminger Foundation
The S.K. Wellman Foundation

In Memory

The following 2 individuals passed away in 2023. Family members asked for donations to be made in their memory to the Epilepsy Association. These memorial gifts totaled \$3,945 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.

- Kathryn "Kate" McDannel
- D'Vere Armand Mays

Our Supporters

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Martha Sajatovic, MD
Susan Stanton, PA
Jennifer Waldron, DO
Jonathan Zande, MD
Lucyna Z. Zawadzki, MD

Staff Listing

Kelley S. Needham
CEO (Retired at the end of 2023)
Patty Varanese
Executive Director
Taylor Miller, QMHS
Manager of Community Program
Christine Spradling, LPCC
Contract Clinical Director
Delilah Toles, QMHS
Case Manager
Barbara Rutt, SWA
Case Manager
Nicole Johnson
Manager of Development
and Public Relations
Ethan Miller
Development Associate

Partners and Accreditations

ADAMHS Board of Cuyahoga County



Ohio Department of Mental Health and Addiction Services



CARF



The Spirnak Family, Delilah Toles (Honoree of the Humanitarian Award in Memory of Christopher Spirnak), Kelley Needham, and April Walsh

Financials

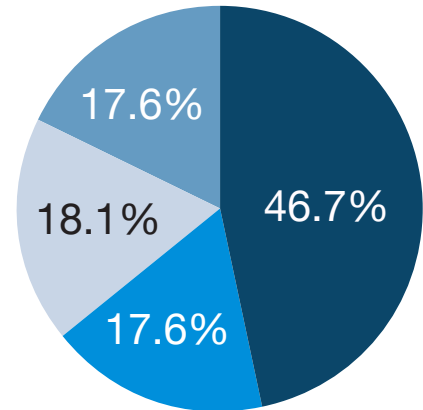
Statement of Activities and Changes in Net Assets

Operating Support and Revenue:

2023 Audited

Contributions	\$162,975
Program services fees	\$244,257
Special events	\$292,924
Less: Direct benefit to donor	\$(77,819)
Net gain on investments	\$23,960
Total support and revenue	\$646,297

Use of Funds:



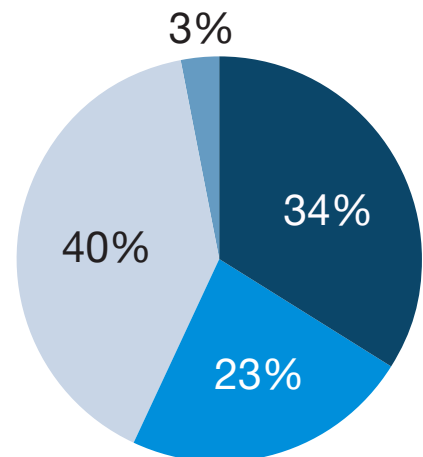
Supporting Services Patient Services
Education Kids and Family

Total Support and Revenue

Operating Expenses:

Program services	
Kids and family	\$123,446
Patient services	\$326,703
Public health education	\$122,849
Total program services	\$572,998
Supporting services	
Management and general	\$29,053
Fundraising	\$97,639
Total support services	\$126,692
Total operating expenses	\$699,690
Change in net assets from operations	\$(53,393)
Net loss on investments	\$121,099
Change in net assets	\$67,706
Net assets—Beginning of year	\$1,182,160
Net assets—End of year	\$1,249,866

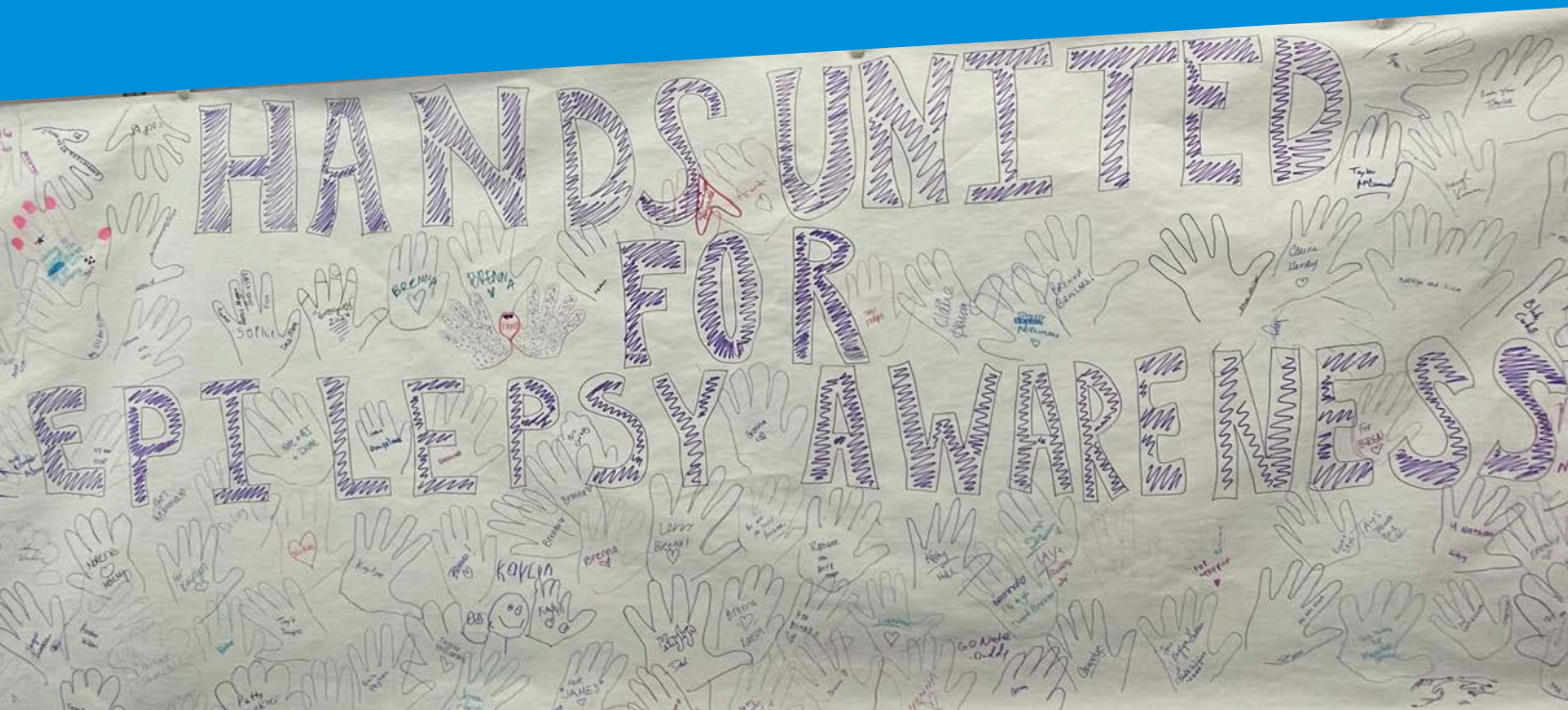
Revenue Sources:



Investments and Miscellaneous Income Program Service Fees
Special Events Contributions

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