



# EPILEPSY ASSOCIATION ANNUAL REPORT 2019

# DEAR DONORS AND FRIENDS,

First off, thank you for your continued support of the Epilepsy Association! We are excited to publish our 2019 Annual Report for you to review, which shares the many successes we had in 2019. Our achievements would not have been possible without our Board of Directors, Professional Advisory Board members and agency staff, who embrace the mission and purpose of our organization every day.

In 2019, we incorporated new awareness efforts, developed new donors, were funded by new foundations, and grew our Purple Your Year™ efforts by adding a Young Professional committee. Through our connections to new community partners, it has led to an increase in our service offerings, which has allowed us to continue to meet the needs of those living with epilepsy in our community. These efforts have further established our organization as the go-to local resource for those living with seizure disorders in Northeast Ohio.

Most notably in March of 2019, we were surveyed by The Commission on Accreditation of Rehabilitation Facilities (CARF). The CARF survey evaluates all aspects of agency operations and awards accreditation for programs that demonstrate excellence in conformance to best-practice standards. We are happy to report that the Epilepsy Association achieved the highest level of accreditation possible, which is a 3-year accreditation.

We are midway through our 2018-2020 Strategic Plan. We have now been able to dive in, take direction of the plan, and focus our efforts on providing relevant services to those children, adults, and families affected by epilepsy, raise awareness of epilepsy and the Epilepsy Association's services, and increase its funds to support agency services. Technology was a large focus for us, in regards to the Strategic Plan, as we incorporated new awareness efforts via social media and implemented new fundraising technologies, including mobile bidding, which help us raise additional funds faster than ever. The agency continued to succeed financially, insuring responsible management and stewardship of donor and vendor dollars. On our patient side, we moved to full implementation of electronic health records for all our client's files. Additionally, we further developed our Managing Life with Epilepsy, 8-week web-based course, that covers strategies on how to improve your quality of life with epilepsy—this online class has allowed us to reach more individuals in our local community and beyond.

Since expanding our service area to 13-counties we have been able to reach and serve more people than ever before. In fact, we reached more than 20,055 people during 2019, which is an 12% increase over 2018! With a staff of only eight employees, we are proud to report on our accomplishments throughout this memorable year!

We thank you, our volunteers, and the greater Cleveland epilepsy community for your continued support of the Epilepsy Association! Your generosity ensures that the Epilepsy Association can continue its important work throughout Northeast Ohio.

Sincerely,



Marquettes Robinson  
President, Board of Directors



Kelley S. Needham  
CEO

# 2019 HIGHLIGHTS

## Our Impact:



**84**  
parents and families served



**219**  
information and referral calls



**475**  
individuals received case management and other adult social services



**1,465**  
children and families served (students served thru school-based programming)



**2,482**  
social service treatment hours provided



**20,055**  
individuals reached through community programs



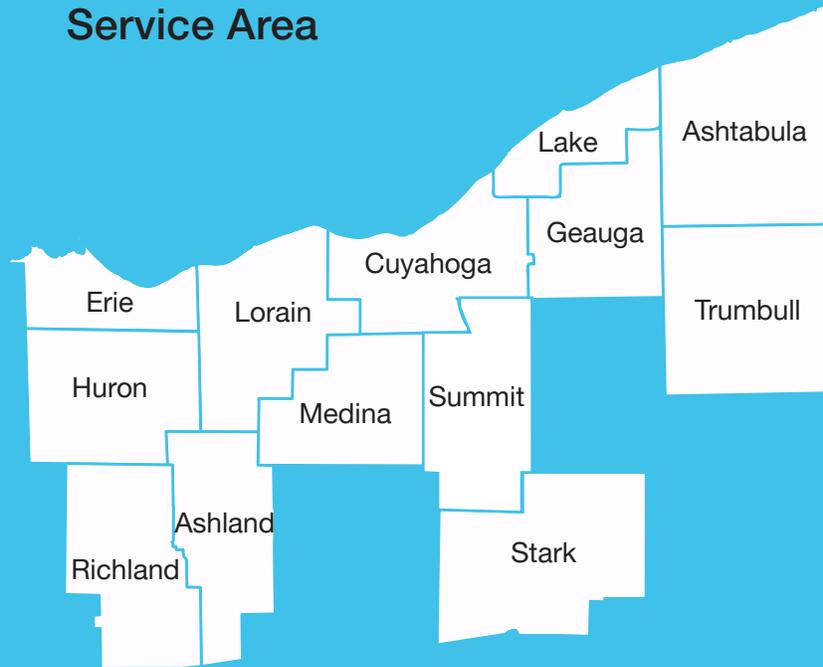
**\$439,745**  
donated through private contributions, grants, and other special events

## 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 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.

# 2019 CLIENT OF THE YEAR AWARD

## Jackie Spencer

Jackie first came to the Epilepsy Association in 2017 after being referred by a social worker at his neurologist's office, right before he was about to have another brain surgery. Jackie was feeling isolated, stuck in his current situation, and he was stressed about upcoming surgery. He became a client of the Epilepsy Association's Adult Mental Health Case Management program and began working with a case manager who helped provide him some support. Jackie had a successful surgery and began working on some goals he had for himself, which included joining the work force, driving again, managing his depression, finding more appropriate housing, and becoming seizure-free. Jackie has since been able to accomplish all of these goals and is also pursuing his passion for acting. He is working part-time and hopes to be able to someday have a full-time job and continue to be seizure-free.



(L to R) Marquettes Robinson, Board President, Kelley Needham, CEO and Jackie Spencer

*“Talking with people who understand exactly what I’m going through and supporting me every step of the way is such a great feeling. I no longer feel alone. The Epilepsy Association has given me confidence and support that I can achieve any goal that I set out for myself.”*  
– Jackie Spencer

# AGENCY SERVICES INCLUDE:

## 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:** 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.

## 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 Groups**—The Epilepsy Association sponsors an adult group that provides support and education for those with epilepsy and their families and caregivers. The group meets the second Wednesday of every other month from 6-7:30 PM at the Parma Branch of the Cuyahoga County Public Library. The group is led by our professionally trained case managers.

**Self-Management**—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.



## 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 and other medical professionals 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 2019 Feature Family award was presented to Chris Flannery. The 2019 Winter Walk had 500 participants and raised over \$52,000.

- **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 Northeast Ohio 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.
- **Rockin' the Keys for a Cause:** This is a fun and casual, after-work music themed event that helps raise money to fund agency programs. The 2019 Rockin' the Keys fundraiser had over 100 participants and raised nearly \$25,000.



## Community Services, continued

- **Race the River:** The Race the River Run is a family-oriented 10K, 5K and 1-mile run/walk to benefit the Epilepsy Association. In conjunction with the road race is our Family Fun Day. Families living with epilepsy are invited to attend the Epilepsy Association annual Family Fun Day that runs simultaneously with our race. The Family Fun Day is attended by parents of children with epilepsy and adults with epilepsy and consists of family-friendly activities allowing individuals and families to come together for support, networking, and fun! The 2019 Race the River event raised over \$35,000 and had 400 participants.
- **Annual Gala:** Our annual event is held every year in November as part of National Epilepsy Awareness month. 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 2019 Legacy Award Honoree was: Elia Pestana Knight, MD, Pediatric Epileptologist, Cleveland Clinic, and our Youth Humanitarian Award honoree was Justin Flamm of University Schools. The 2019 Gala raised over \$163,000.

**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.



## Corporate Gifts

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

# DONATIONS

### \$10,000 and above

Greenwich Biosciences  
Sunovion Pharmaceuticals  
Supernus Pharmaceuticals, Inc.  
University Hospitals

### \$5,000 to \$9,999

BakerHostetler  
Cleveland Clinic Epilepsy Center  
Covia  
Eisai Pharmaceuticals  
Rainbow Babies & Children's  
Hospital  
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### \$1,000 to \$4,999

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Alliance Data Systems

## Donors

# DONATIONS

The Epilepsy Association wishes to thank all the individuals who supported the agency during 2019. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

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

Mr. & Mrs. Richard Bass  
Mr. & Mrs. Chris and  
Michelle Counahan  
John and Jean Hlay  
Mr. & Mrs. Jeffrey and  
Teresa Karlovec  
Ms. Amy Kellogg  
E. Sean and Rebecca Medina  
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Dr. & Mrs. Pat and Diane Spirnak

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

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Mark and Jennifer Carlile  
Mr. Victor Cohn  
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Mike and Robin Kane

*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.*

## Donors

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Ms. Stephanie Kapcio  
Mr. & Mrs. Bryan Kingsbury  
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Amanda Valcanoff  
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### The Leo Tolstoy Society (\$100 to \$249)

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Tina Hobart  
Abigail E Hoovler

## Donors

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The Epilepsy Association wishes to thank all the individuals who supported the agency during 2018. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

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

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Dollar Bank Foundation  
Eaton Foundation  
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Kohl's National Giving Program  
Lubrizol Foundation  
The Murphy Family Foundation  
Reminger Foundation  
The Ridgecliff Foundation  
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GE Foundation  
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KeyBank Foundation  
Lubrizol Foundation  
Nordson Corporation  
Pella Rolscreen Foundation  
Progressive Insurance Foundation

# DONATIONS

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

Michael Dolsen  
Carolyn Fender  
Joel Forquer  
Michelle Frazier  
Amy Kellogg

Mark Knapp  
Cyndi Lehman  
Holly Lewis  
Hans Luders, MD  
James Lyle

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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# OUR SUPPORTERS

## 2019 Board of Directors

### Officers

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Vice President  
\*\*E. Sean Medina,  
Vice President  
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Treasurer  
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Courtney Schmidt  
Diane M. Spirnak  
Susan Stamberger  
Shaylor Steele  
Kierston Vaughn  
April K. Walsh  
Ben Young

\*We would like to remember Chad S. Davies, our late Board Vice President, who passed away suddenly in January of 2019. He was a dedicated member of the Board and generous supporter of our agency.

\*\*E. Sean Medina took over as Vice President in January 2019.

## 2019 Professional Advisory Board

Stephen Hantus, MD  
Co-Chair  
Jun T. Park, MD  
Co-Chair

Mark Bej, MD  
Keionna Brown, RN, CPNP  
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## 2019 Staff Listing

Kelley S. Needham—CEO  
Colleen Saunier—Director of Development  
Miranda Pflaum—Development Associate  
Nicole Richter, MS—Director of Community Programming

Christine Spradling, LPCC—Contract Clinical Director  
André Buffington—Case Manager  
Carly Sekerak—Case Manager  
Linda Ware—Case Manager

## Partners and Accreditations

ADAMHS Board of Cuyahoga County

Ohio Department of Mental Health  
and Addiction Services

CARF



# FINANCIALS

## Operating Support and Revenue:

Contributions and Grants	
Program Services Fees	
Special Events	
Less: Direct Benefit to Donor	
Interest	
<b>Total Operating Support and Revenue</b>	

## 2019 Audited

\$142,613
\$237,563
\$307,162
\$(66,881)
\$1,173
<b>\$621,630</b>

## 2018 Audited

\$170,301
\$214,155
\$303,817
\$(66,091)
\$240
<b>\$622,422</b>

## Operating Expenses:

Program Services	
Kids and Family	
Patient Services	
Public Health Education	
<b>Total Program Services</b>	

\$103,414
\$335,462
\$96,647
<b>\$535,523</b>

\$101,845
\$316,567
\$94,676
<b>\$513,088</b>

Supporting Services	
Management and General	
Fundraising	
<b>Total Support Services</b>	

\$23,034
\$85,647
<b>\$108,681</b>

\$39,412
\$60,563
<b>\$99,975</b>

**Total Operating Expenses**

**\$644,204**

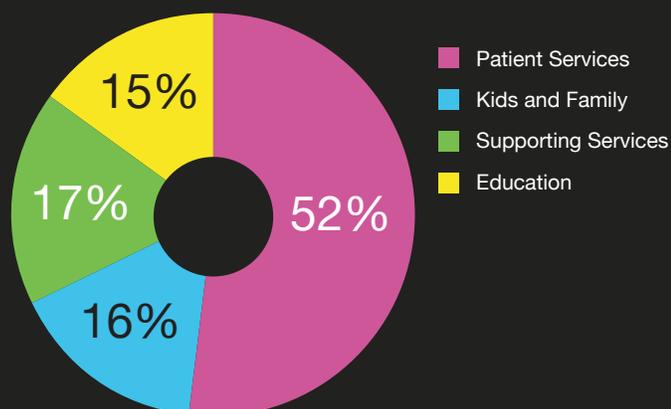
**\$613,063**

Change in Net Assets from Operations	
Net Gains on Investments	
Change in Net Assets	
Net Assets—Beginning of Year	
<b>Net Assets—End of Year</b>	

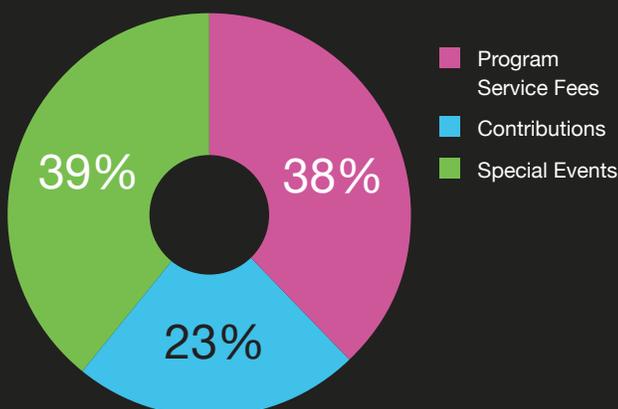
\$(22,574)
\$127,884
\$105,310
\$904,497
<b>\$1,009,807</b>

\$9,359
\$(50,144)
\$(40,785)
\$945,282
<b>\$904,497</b>

## Use of Funds:



## Revenue Sources:





**Epilepsy Association**

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(216) 579-1330  
[www.epilepsyinfo.org](http://www.epilepsyinfo.org)



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