ANNUAL REPORT
Epilepsy Association
Dear Donors and Friends,

We are excited to report it was another outstanding year for the Epilepsy Association! A big thank you goes to our loyal Board Members, Professional Advisory Board members and agency staff who embrace the mission and purpose of our organization every day.

2018 was a busy year; we incorporated a new service offering, expanded our service area, developed new donors, were funded by new foundations, helped raise awareness and further established our organization as the sole provider of epilepsy specific community-based services in Northeast Ohio.

Community SMART, our newest service offering, done in collaboration with Case Western Reserve University, was one of our major accomplishments. Launching this web-based class has allowed us to reach more in our local community and beyond by helping those with epilepsy learn strategies about how to best take care of their physical and emotional health. We saw there was a greater need for service in Stark and Summit Counties and expanded our service area to now cover 13 counties across the state. Through these efforts, additional marketing, and much more, we were able to reach more families, field more information and referral calls, and provide more direct service and social service treatment to our community. In fact, we reached more than 16,500 people during 2018, which is an 8% increase over 2017! With a staff of only eight employees, we are proud to report on our accomplishments and this memorable year!

The agency would not be where it is today without our volunteers and the larger epilepsy community assisting in our mission. We have witnessed tremendous accomplishments from those who are dealing with epilepsy and this makes us eager to look forward to more years of service as our job is far from complete. We thank you for your continued support of the Epilepsy Association!

Regards,

Jeffrey B. Karlovec
President, Board of Directors

Kelley S. Needham
CEO
2018 Highlights—Our Impact

The Epilepsy Association is a local, 501(c)(3) nonprofit organization, based in Cleveland, OH, 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.
Our Mission

For children, adults and families in Northeast Ohio impacted by epilepsy we will raise awareness in the community, provide education, advocacy and direct services that lead to an increased understanding of the disorder and to better management of the condition, 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.
At the Epilepsy Association, we see clients overcome obstacles in their lives on a daily basis, and this year we saw great improvements with one special client, Carolyn Updyke.

Carolyn has had a long and challenging struggle with epilepsy. Her diagnosis came in elementary school when she had her first seizure. Attending school as a child with frequent seizures was extremely difficult for Carolyn, and despite being on medication, she continued to struggle with the stress and anxiety of epilepsy.

As an adult, Carolyn was still struggling and it was challenging for her to independently manage her epilepsy and mental health concerns—this interfered with her ability to care for herself. She came to the Epilepsy Association for our Case Management program 15 years ago and she was seeking out services that would help her be able to learn some skills to better manage these issues and gain some stabilization in her life. Carolyn was homeless at the time and needed support in finding appropriate housing that addressed all of her needs. Carolyn worked with Case Manager, Linda Ware, who was able to help her find safe and stable housing while helping her build relationships that would be trusting, supportive and helpful.

In addition to being connected with permanent housing so many years ago, Carolyn has learned many new skills since opening as a client to the agency. She has received crucial assistance to help her manage her daily life such as advocacy with medical providers, assistance with carrying out daily tasks, occasional crisis management, epilepsy and mental health education, and learning important coping and self-management skills. Carolyn’s feelings of loneliness have also decreased as a result of her receiving agency services because she is able to feel supported and heard and can reach out to her case manager when she needs some guidance.

Recently, Carolyn has made some great strides in her ability to step outside her comfort zone and participate in some new programs as a result of her growing confidence in herself. She agreed to participate in the Community SMART program at Epilepsy Association and learned some new skills for epilepsy self-management and well-being. She also spoke with first year medical students from Case Western Reserve University who came to EA as a part of their first-year field experience. She shared valuable insight and information from a patient point-of-view as a person living with chronic conditions. Being able to speak as an advocate for herself and share her own experiences about her epilepsy and mental health is a huge step for Carolyn, and we are very proud of the progress she has made.

“Receiving services from the Epilepsy Association continues to help me feel supported and cared about. And having a case manager helps me to feel like I am able to do things I wouldn’t have been able to do before on my own.”

– Carolyn Updyke

(L-R) Linda Ware, EA Case Manager and Carolyn Updyke, EA Client
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 a self-management group 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 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 EA 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 2018 Feature Family award was presented to the Watson and Wilhelm Families. The 2018 Winter Walk had 500 participants and raised over $50,000.

◆ 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.

◆ Race the River: The Race the River Run is a family-oriented 10K, 5K and one 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 2018 Race the River event raised over $28,000 and had 300 participants.

◆ Annual Gala Our annual event is held every year in November as part of the 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 make outstanding contributions in the field of epilepsy. The 2018 honoree was: Martha Sajatovic, MD Professor of Psychiatry and of Neurology at Case Western Reserve University School of Medicine. The 2018 Gala raised over $167,000.

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. Epilepsy Association also provides educational in-services on epilepsy and seizure first aid in the community.
New program offering for 2018—Community SMART

Program Description:
Community SMART is a program for adults who are struggling to manage their epilepsy and is designed to teach self-management skills. The program offers eight weekly remote sessions which are co-led by a trained nurse educator and a trained peer educator. Educators use a written curriculum delivered online, and the interactive sessions last 60–90 minutes. Groups are limited to about 6–10 adult participants. Each session focuses on an area of wellness that, along with regular epilepsy care, can help participants become better self-managers of their epilepsy. The program is held remotely in an effort to address the barriers related to transportation for people with epilepsy. Additionally, since SMART is held remotely, participants from areas of Ohio and even outside of the state can participate in the group where previously they may have struggled to access epilepsy-specific support due to geographic location and lack of safe and reliable transportation.

Key Components:
The SMART program is intended to improve health outcomes in people with epilepsy. The program addresses challenges surrounding epilepsy stigma, stress, and limited social support.

Participants are given the opportunity to share information about their own experiences with epilepsy as related to the weekly topics which promotes social support and decreases feelings of isolation. Participants also receive a standardized manual and handouts that re-emphasize materials tailored to the needs of participants. At the conclusion of the weekly sessions, participants receive scheduled follow up phone calls from the nurse educator to encourage ongoing use of skills developed in the program.

Program Outcomes:
◆ SMART was found to be associated with improved health outcomes in individuals with epilepsy and mental health conditions.

◆ Participants demonstrated a reduction in depressive symptoms which was confirmed by significant reduction in depression scores at the time of follow up.

◆ 94% of participants agreed or strongly agreed that SMART was useful and that it covered all/most of the important issues relevant to their situation and that they would recommend it to other people with epilepsy.

◆ Participants across the sessions reported that they really enjoyed being a part of a group of people with similar concerns as many had never met someone else with epilepsy before.

◆ Participants especially felt like they could relate to the peer educator and felt comfortable asking questions and getting information from others in the group who have had success with different strategies.

◆ Participants shared things like “SMART gave me the confidence to share more about my epilepsy with family” and “SMART helped give me information I would not otherwise have after being recently diagnosed with epilepsy.”
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 2018. The Epilepsy Association named the giving levels after writers, artists, and composers who had epilepsy.

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($249 to $100)

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

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

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

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<th>Officers</th>
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<th>Karen P. Johnson</th>
<th>Mark A. Phillips</th>
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<td></td>
<td>Debra J. Horn</td>
<td>Jun T. Park, MD</td>
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<table>
<thead>
<tr>
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<th>Stephen Hantus, MD</th>
<th>Michael Devereaux, MD</th>
<th>Prakash Kotagal, MD</th>
<th>Asim Shahid, MD</th>
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<td>Co-Chair</td>
<td>Jun T. Park, MD</td>
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<td>Ajay Gupta, MD</td>
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<td>Martha Sajatovic, MD</td>
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## 2018 Staff Listing

- **Kelley S. Needham**—CEO
- **Colleen Saunier**—Director of Development
- **Miranda Pflaum**—Development Associate
- **Nicole Richter, MS**—Director of Community Programming
- **Janet Jones, LPCC-S**—Contract Clinical Director
- **André Buffington**—Case Manager
- **Carly Sekerak**—Case Manager
- **Linda Ware**—Case Manager

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**MENTAL HEALTH & ADDICTION SERVICES**

**Ohio**
## Financials

### Support and Revenue: 2018 Audited

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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<tr>
<td>Contributions and Grants</td>
<td>$170,301</td>
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<tr>
<td>Program Services Fees</td>
<td>$214,155</td>
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<td>Special Events</td>
<td>$303,817</td>
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<td>Less: Direct Benefit to Donor</td>
<td>$(66,091)</td>
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<td>Net Gain on Investments</td>
<td>$0</td>
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<td>Total Support and Revenue</td>
<td>$622,182</td>
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### Operating Expenses:

#### Program Services

- Kids and Family: $101,845
- Patient Services: $316,597
- Public Health Education: $94,676
- Total Program Services: $513,118

#### Supporting Services

- Management and General: $39,412
- Fundraising: $60,563
- Total Support Services: $99,975

Total Operating Expenses: $613,063

Change in Net Assets from Operations: $9,119
Net Loss on Investments: $(49,904)
Change in New Assets: $(40,785)
Net Assets—Beginning of Year: $945,282
**Net Assets—End of Year**: $904,497

### Use of Funds:

- Patient Services: 15%
- Kids and Family: 16%
- Supporting Services: 17%
- Education: 52%
- Program Service Fees: 31%
- Contributions: 25%
- Special Events: 44%

2018 independent audit performed by HW&Co.
Follow us on social media

Search Facebook for Epilepsy Association
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.