



Can one person make a difference?



Epilepsy Association 2012 Annual Report

177

Individuals Received Case Management and Other Social Services



2,389

Case Management Hours Were Provided

8,725

Community Epilepsy Awareness Education Participants



233

Information & Referral Requests Fulfilled



2,861

Students and Teachers were reached through Youth Epilepsy Awareness Programs

207,952

Dollars Donated by Private Contributions



202,532

Dollars donated through Special Events

= making a difference

In our role as the sole provider of community-based social services designed to meet the unique and complex needs of individuals living with epilepsy, the Epilepsy Association strives to reduce the historic medical and social disparities experienced by our community.

Letter From the President & CEO

Dear Friends,

We are pleased to share with you the Epilepsy Association 2012 Annual Report describing the agency's accomplishments during the year. Throughout the report we explore how the Association's many volunteers are working to improve the community's awareness of epilepsy. Our goals are to erase the ancient stigma attached to epilepsy, increase public and private funding for community-based support services, and achieve greater social acceptance and understanding of individuals living with seizure disorders.

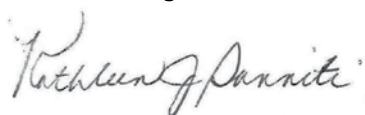
We begin by asking ourselves "Can one person make a difference?" We believe as you read this report you will conclude, that the answer is "yes". While the agency is a brick and mortar organization, the true essence of the Epilepsy Association lies with the hundreds of volunteers who understand the importance of contributing their time, talent and money in a common effort to address the social acceptance of epilepsy. Through their efforts, the Association is able to provide "state of the art" mental health case management and other vitally important social services.

In addition to the core services provided by the agency, this year volunteers organized the region's first Purple Day® Campaign. Purple Day® is the perfect illustration of how one person can change the world. In this instance, that person was a young girl named Cassidy Megan. With the help of the Epilepsy Association of Nova Scotia and the Anita Kaufman Foundation, Cassidy started a world-wide movement to end the social isolation she and many others with epilepsy commonly experience. Since the Day's inception in 2008, Purple Day® has grown to be celebrated in 132 countries. Purple Day® encourages everyone to wear purple and share the facts about epilepsy on March 26. Individuals in Northeast Ohio participated in many different ways including arranging to have the iconic Terminal Tower in Cleveland lit purple, asking their cities to declare March 26 as Epilepsy Awareness Day, and posting thousands of messages on social media declaring support for those facing the challenges of living with epilepsy. Purple Day® was the largest public awareness program in the Association's history.

In this report, we have also highlighted the 2012 Winter Walk for Epilepsy Featured Families. By sharing their stories the Fender family and Cheryl Bridges encouraged 600 walkers and event volunteers to rally in support of the Epilepsy Association. Community support for our annual mall walk/stroll continues to grow. Our 2012 event was the strongest ever.

As both volunteer and staff leadership of the organization, we have the pleasure of directing one of the most engaged and supportive Board of Trustees in the city, and we wish to express our gratitude for each member's individual commitment to providing support and leadership for the agency's many fundraising events and community programs. We also wish to thank the agency's staff for their excellent service provided to both the agency clients and volunteers. Finally, we wish to thank the corporate, philanthropic and individual donors for their generous contributions. We are grateful for all the support we have received during the year.

With warm regards,



Kathleen J. Sanniti
President, Board of Trustees



Kelley S. Needham
CEO



Kathleen J. Sanniti
President, Board of Trustees



Kelley S. Needham, CEO

About the Epilepsy Association

The Association began in the mid-1950s through the efforts of parents of children with epilepsy under the name the *Parents Crusade Against Epilepsy*, and later became the *Committee of Epilepsy of the Family Health Association*. In 1972, the Committee on Epilepsy became an independent agency supported through funding from the Cuyahoga County United Way Services. Today the Epilepsy Association is licensed by the Ohio Department of Mental Health, is a funded agency of United Way Services, and is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF). CARF is an international, independent, nonprofit accreditor of human service providers and CARF accredited service providers meet the highest national and international standards for quality. The agency has held this CARF distinction for 28 years. Epilepsy Association services are provided by its staff of 7 full-time and two part-time professionals, and many volunteers.

Agency services include:

- Information and referral services
- Mental health case management
- Support group
- Community and school-based epilepsy awareness education and advocacy

The Epilepsy Association is not affiliated with any national organizations. The agency is a 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 services in 11 northeast Ohio counties. This includes the following counties: Cuyahoga, Geauga, Lake, Lorain and parts of Ashland, Ashtabula, Erie, Huron, Medina, Richland and Trumbull.

2012 Annual Report Donations

Thanks to the following for their help with this Annual Report.

Mark Nuss - cover design

Studiothink - design layout

Medical Mutual - printing

Mission

The Epilepsy Association is a not-for-profit corporation dedicated to helping people cope with and manage seizure disorders by improving their quality of life, while empowering individuals to reach their full potential within the community.

Vision

Our vision is that all people with epilepsy and seizure disorders will be accepted in our community and have a measurably improved quality of life.

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Partnerships

ADAMHS Board of Cuyahoga County
United Way of Greater Cleveland
CARF Accredited
Licensed by the Ohio Department of Mental Health

“No one is useless in this world who lightens the burden of it to anyone else.”

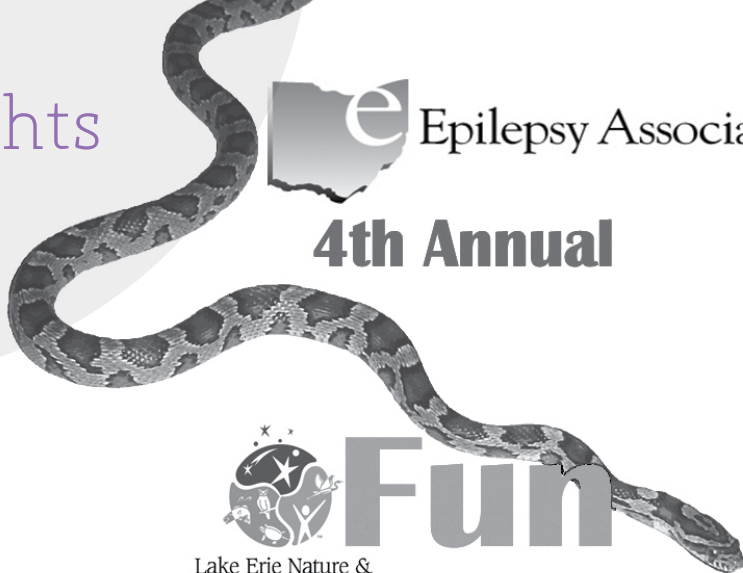
— *Charles Dickens*

Highlights

 Epilepsy Association

4th Annual

 **Fun**
Lake Erie Nature & Science Center



Family Fun Day at Lake Erie Nature & Science Center

The Family Fun Day was a relaxed, informal gathering allowing families affected by epilepsy to have a day dedicated to networking, support, and fun! There was no formal program, so families were free to tour Lake Erie Nature & Science Center at their leisure. Live wildlife demonstrations were the hit of the day. The 2012 Family Fun Day was sponsored by Cyberonics, Inc., Lundbeck, Inc., and Lubrizol Foundation.

2012 Client Recognition Award

At the Annual Meeting in June, the Epilepsy Association Board of Trustees recognized an agency client for their achievement in recovering from the consequences of severe epilepsy and mental illness. The 2012 award went to Ms. Dorthea Johnson. Dorthea's recovery included the re-discovery of her love for making art. Dorthea works in the medium of bones, which are easily obtainable from local restaurants. She chooses to work with bones because they remind her of pleasant times watching her mother cook as a child. Dorthea's family was with her when she received this award.



**2012 Client Recognition Award,
Ms. Dorthea Johnson**

Purple Day 2012

Purple Day is an example of how the efforts of one person can become a world-wide game changer. In 2008, 9 year old Cassidy Megan, of Nova Scotia, Canada came up with the idea of having one day each year devoted to epilepsy awareness. Cassidy has epilepsy and she chose the name Purple Day because lavender is the international color for epilepsy. The lavender flower is associated with solitude and feelings of isolation, which are emotions that she and so many others affected by epilepsy experience. With the help and support of the Anita Kaufman Foundation, Purple Day® has grown into an international day of epilepsy awareness and celebrated on March 26. In 2012 grassroots volunteers in 132 countries organized activities to show those with epilepsy they are not alone. Purple Day® is unique and as Cassidy says "anyone can support PurpleDay®, and no idea is too big or too small, and every idea to create awareness of epilepsy is just right."

In 2012, the Epilepsy Association promoted Purple Day® in Northeast Ohio. Marcia Columbro, M.D., led the agency's efforts by "challenging everyone to help raise epilepsy awareness by wearing purple on March 26th." We invited everyone to join in our efforts and the community response surpassed expectations. Mark Nuss designed a special Purple Day® awareness poster and we loaded the Epilepsy Association website and social media sites with Purple Day® resources such as sample proclamations, fact sheets, e-mail messages, and Mark's poster for anyone to download and use. Dozens of businesses and schools participated by wearing purple and sharing their pictures on Facebook and Twitter. The Terminal Tower was lit purple and local news channels picked up on the story. SouthPark Mall in Strongsville donated booth space and Britney Ferrigno, a student at Baldwin Wallace University, recruited sororities to staff the booth for three days. University Hospitals donated bill board space and promoted Purple Day® throughout the UH system. The cities of Cleveland and Elyria proclaimed March 26 as Epilepsy Awareness Day. Purple Day® resonates for individuals who live with epilepsy. It provides a voice for many who understand how isolated epilepsy can make someone feel. The Association thanks everyone who joined in raising awareness of epilepsy in Northeast Ohio.



Fundraising Highlights



2012 Gala Co-Chairs Jeffrey B. Karlovec and Susan D. Krantz seen here presenting the Legacy Awards



Legacy Award Winners from left to right: Dr. Dileep Nair, Thomas TS Kaung, accepting the Award on behalf of the Ridgecliff Foundation, Tom Herschel, accepting the Award on behalf of CBS Radio. Also pictured is Michael A. Minelli from the Ridgecliff Foundation.

Legacy Award & 21st Annual Gala

The Legacy Award recognizes outstanding work in the advancement of epilepsy treatment, public awareness of epilepsy and contributions to the Epilepsy Association. This year the Epilepsy Association recognized CBS Radio, the Ridgecliff Foundation, and Dileep Nair, M.D. from the Cleveland Clinic Foundation for their contributions on behalf of individuals with epilepsy. They were presented with their awards at the annual Gala held on November 9, 2012.

The Gala's fundraising effort surpassed its goal with contributions reaching \$93,000. The evening's success was due to its sell-out crowd of 250 guests, over 100 silent auction donors and the many corporate and individual sponsors who provided financial support.

Medical Mutual provided the event's Signature Sponsorship.

The Adcom Group and Cleveland Clinic Epilepsy Center provided Platinum Sponsorships.

Supporting the Gala at the Gold Sponsorship level was Alere, Baker & Hostetler, LLP, CCS Medical, Daily Legal News, Dollar Bank, Express Scripts, MetroHealth Medical Center, Rainbow Babies & Children's Hospital, Skoda, Minotti & Co., Technical Consumer Products, University Hospitals, University Hospitals Neurological Institute, and Zinner & Company, LLP.

Patron Sponsorships were received from Richard Bass, CBS Radio, The Lubrizol Corporation, Lundbeck, Inc., Nordson Corporation, and Thacker Martinsek, LPA.

Underwriting for the evenings activities was provided by U.S. Bank, Western Reserve Systems, Inc., The Adcom Group, DigiTrace – a division of SleepMed, Barb Shum, Rob and Holley Martens, and Daniel and Courtney Schmidt.

The event's organizing committee donated many man hours to ensure the evening's success. Co-Chairs for the 2012 Gala were Jeffrey B. Karlovec and Susan D. Krantz. They were assisted by committee members Deb Lawrence-Auten, Richard Bass, Jennifer Carlile, Lisa Cartellone, Michael Devereaux, M.D., Mary Jarachovic, Karen P. Johnson, Amy E. Kellogg, Jan Koch, Cynthia McHugh, Maureen Morreale, Mark Nuss, Marquettes Robinson, Paula Sauer, Courtney Schmidt, Diane Spirnak.





2012 Winter Walk

The 2012 Winter Walk, presented by the Cleveland Clinic raised over \$64,000. The seventh annual walk was held simultaneously at the Great Lakes Mall in Mentor and the SouthPark Mall in Strongsville, drawing more than 600 walkers and volunteers at both sites. Providing the starts for the walkers' annual mall stroll were Masters of Ceremonies and Fox8 personalities Tracy McCool and Bill Martin. Area businesses and corporate sponsors staffed information and activity tables along the route for children and their parents. The walk/stroll lasted about an hour and concluded with a raffle and door prize drawings. Winter Walk is a family event and proceeds support social services provided by the Epilepsy Association.

Two families were chosen as the *Walk's Featured Families*. *Featured Families* allow the use of their stories at the walk and in pre-event publicity as a way to understand epilepsy. The 2012 feature families were the Fender family and the Bridges family. We thank Duane and Carolyn Fender, and Christina Bridges and her mom Cheryl Bridges for contributing their stories.

Duane Fender's wife Carolyn submitted her husband's story in the hope that sharing their family's experiences the community will become more tolerant and accepting of seizure disorders. Duane and Carolyn are parents of four children. Duane's seizures were controlled until one day on a family camping trip he experienced a rare seizure type called gelastic or laughing seizure. Duane still experiences these seizures and his experience shows us that a strong family support system is essential in managing epilepsy.

Christina's mom nominated her because in her words "Christina is the most amazing person I know." Christina Bridges' story is about pursuing your dreams, even when the odds are not in your favor. Christina started having seizures as a young girl during a skating competition. At one point, Christina was having as many as 80 seizures a day. Despite all the medical tests, anti-seizure medications and even epilepsy surgery, Christina pursued her dreams to graduate from high school and go on to college. Christina is a wonderful role model for other young people struggling to manage the challenges of epilepsy. She is determined not to let epilepsy stop her from achieving her goals. Today, Christina is a student, a friend, and an advocate for epilepsy awareness.

The Cleveland Clinic was the 2012 presenting sponsor. The Walk also received sponsorship support from the following local companies: Rainbow Babies and Children's Hospital, Cyberonics, Lundbeck, Inc., Baker & Hostetler, LLP, Wickliffe Eagles, DigiTrace, Sahara Sales Inc., Rotary Club of Strongsville, and Willow Run Vet Clinic.

The Walk was co-chaired by Kathleen Sanniti and Jennifer Carlile. Serving on the committee were: Laketa Jackson-Burts, Rabon Allen, Halle Bishop, Kathy Bricker, Michelle Duggniero, Kia Durham, Dayna Stewart, Meggan Few, Ray Haseley, Sonal Mutatkar, Sheryl Nehamkin, Maria Podmore, Lisa Rock, Mark Ryland, Kim Vaughn, Keionna Walker, April K. Walsh and Barb Walsh.

The 2012 Winter Walk Award Winners for the most funds raised were:

Top Fundraiser over 18: Brian Frate
Top Fundraiser under 18: Julia Karlovec

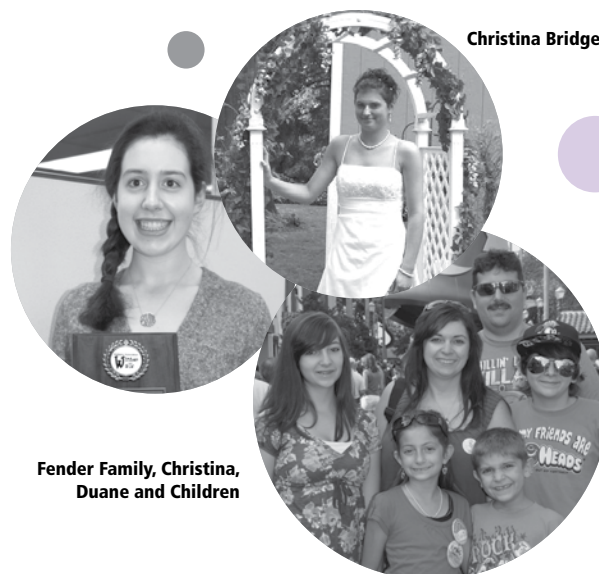
Top Corporate Fundraising Team was: The Cleveland Clinic
"Benny & the Jets" A special thanks to their Team Captain: Barb Walsh

Top Personal Fundraising Team:
"Team Paige"
A special thanks to their Team Captain: Brian Frate

Largest Team:
Team Fender Bender, their Team Captain was Carolyn Fender

Individual who sent the most emails:
Carolyn Holman

Julia Karlovec, Winner
most funds raised under 18



Christina Bridge

Fender Family, Christina,
Duane and Children



Reverse Raffle

For a chance at winning the \$2,000 grand prize, or the famous Epilepsy Association Bucket of Booze, the overflowing crowd at the annual Reverse Raffle had great fun hoping their number wouldn't be called! Emcee Paul Orlosky kept reminding everyone that the goal of the evening was to have your number pulled last! Event Chairperson April Kingsbury Walsh and her committee did an outstanding job organizing one of the Association's most popular fundraising events. Serving on the committee were Tony Biasiotta, Dan Calloway, Lisa Chesler, Ann Failing, M.D., Ray Haseley, Sam Misseri, Lisa Rock, Stefanie Shein, and Gary Snyder. These volunteers along with the event's sponsors raised \$26,000 for epilepsy awareness. Supporting the 2012 Reverse Raffle were Partner Donor, Ann Failing, M.D. in honor of her late husband Robert J. Maciunas, M.D., along with U.S. Bank as a Supporter Sponsor, and Friend Sponsors were Forest City Enterprises, Inc., Howard, Wershbaile & Co., Lundbeck, Inc., Melamed Riley Advertising LLC, Nordson Corporation, Nurenberg Paris Heller & McCarthy Co., L.P.A., and Studiothink.



Virtual Runner



Virtual Runner is a unique fundraiser that started in 2009. Runners choose to run in any races they like during the competition time period. Races can be held anywhere in the world. Virtual Runners come from all walks of life. Participants are serious or casual runners; youth and adults. Virtual Runners run for their friends, loved ones, and for themselves, but mostly they run because they share a common goal of dedicating 13 weeks each fall to bring about greater awareness of epilepsy.

Since its inception in 2009, Virtual Runners have raised \$70,062 and raced a total of 4,058 miles for greater epilepsy awareness.

This year there were 41 team members (our largest ever), \$18,255 was raised, and 1,010 miles were raced.

On behalf of all the Virtual Runners and the Epilepsy Association, we wish to express our gratitude to all those who donated and supported us during the 13 weeks of competition. Thanks to our corporate sponsors RPM, Meyers, Roman, Friedberg & Lewis, American Greetings, AdCom and Consolidated Graphics for contributing to the success of this year's competition.

Runners reaching elite team status (raising \$150 or more) and earning the Virtual Runner Team Racing Shirt were: Debra Horn, Julenne Chappell, Robin Kane, Bill Roddy, Lucy Johnson, Karen Johnson, Ben Johnson, Michael Kane, Peter Nelson, Shelby Kane, Linda Ware, Julia Johnson, Laurel Cox, Kristen Roenigk, Jane Burgett, Heath Grissinger, Gordon Johnson, Jan Babbit, Harold Babbit, Kathy Fenix, TJ Johnson, Courtney Schmidt, and Tyler Katz

The 2012 Virtual Runner Competition Winners are:

Most Funds Raised: Adult: Julenne Chappell who raised \$1,385 and Youth: Lucy Johnson who raised \$1,065

The most miles raced: Adult: Glenn Dumonthier, Jr. with 132 miles. This is the second time Glenn has won in this category
Youth: Sean Kane with 24.8 miles. This is the third year in a row that Sean has won in this category.

This year's competition organizing committee was Co-Chaired by Karen Johnson and Debra Horn. Serving on the committee were Pete Nelson, Robin Kane, Bill Roddy, Jan Roe and Debbi Langsdale. Thanks runners for your hard work and dedication to epilepsy awareness.



Virtual Runners (left to right) Debra Horn, Karen Johnson, Courtney Schmidt (with Baby Stella), April Walsh, in front is Julia Johnson



The Kane Family

Donations

Contributors through United Way of Greater Cleveland

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

John Adamich	Mark Devcic	Robin Kane	Theodore Noah	Arin Schur
Jane Alancheril	Tasheania Dismon	Amy Kellogg	Tracey O'Keefe	Andrea Segedi
Barbara Alliance	Danielle Engle	Bonnie Kern	Gardner Patterson	Deanne Sikora
Robert Antonelli	Daniel Enovitch	Brian Kimball	Danielle Pepi	Michael Slama
Michael Basich	Rita Enovitch	Mark Knapp	Britney Perkins	Anthony Smits
Eva Basquez	Enterprise Rent-A-Car	Kimberly Kruser	Christine Pfeifer	Ariane Spates
Jill Bavis	David Fagnilli	Megan Laney	Richard Pressler	Tara Spicer
Deborah Berardi	Robert Felty	Carla Laning	Deborah Prezelj	Julie Staveski
Vadim Berezowskiy	Carolyn Fender	Cynthia Lehman	Jodi Rich	Jennifer Tekancic
Margaret Bewie	Joel Forquer	Laura Lennerth	Anita Robinson	Dynda Thomas
Thomas Boltja	Donna Frimel	Holly Lewis	Marquettes Robinson	Teala Thomas
Sharon Bradley	Irene Frye	Jane Lisy	William Roddy	Wallace Thomas
Amy Brady	Amy Gasbarre	Joseph Lucchese	Kimberly Rose	Nancy Udovic
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Stephen Coolbaugh	Patricia Holmes	Kelley Needham	Colleen Saunier	Barbara Wolgamuth
Brenda Darkovich	Gregory Jelinek	Laura Nelson	Justina Saxby	Lacey Wood
Edward Dennis	Barbara Johnson	Peter Nelson	Gayle Schmuhl	Kendra Zusy

Corporate Gifts

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

\$10,000 and above

United Way of Greater Cleveland

\$5,000 - \$9,999

Rainbow Babies & Children's Hospital
Medical Mutual
Baker & Hostetler, LLP
University Hospitals
Cleveland Clinic Epilepsy Center

\$1,000-4,999

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CCS Medical
Medco Health Solutions, Inc.
MetroHealth System
Skoda, Minotti & Co.
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The Lubrizol Foundation
CBS Radio
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Sleepmed/Digitrace
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Western Reserve Systems, Inc.
Studiothink
KeyBank Foundation
Ford Motor Company
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USG Interiors, Inc.

Matching Gifts

Dollar Bank Foundation
GE Foundation
KeyBank Foundation
The Lubrizol Foundation
The Progressive Insurance Foundation

Foundation Gifts

- The Katherine and Lee Chilcote Foundation grant support for "Youth Epilepsy Education"
- Elisabeth Severance Prentiss Foundation grant support for "Health Home"
- The Frank Hadley Ginn and Cornelia Root Ginn Charitable Trust grant support for "Proactive Skill Building Program"
- Ridgecliff Foundation grant support for "Proactive Skill Building Program"
- Ronald McDonald House Charities of NE Ohio grant support for "Youth Epilepsy Education"
- Sisters of Charity Foundation of Cleveland grant support for "Emergency Assistance"
- William J. & Dorothy K. O'Neill Foundation grant support for new telephone system

Donors

The Epilepsy Association wishes to thank all the individuals who supported the agency during 2012. The Association named the giving levels listed below after historic writers, artists, and composers who had epilepsy.

\$1,000 and above

"The Charles Dickens Society"

Mr. Richard Bass
Mr. Michael Battaglia
Mr. Anthony Biasiotta
Ms. Jennifer Carlile
Dr. & Mrs. Michael Devereaux
Dr. Ann Failinger
Ms. Debra Horn
Mr. & Mrs. Jeffrey B. Karlovec
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Mrs. Courtney Schmidt
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Mr. Tom Tucker
Dr. Ingrid Tuxhorn

\$500 - \$999

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Dan and Kathy Golovan
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Mr. & Mrs. Mark Holcomb
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\$250-\$499

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Ms. Roberta E. Brown
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Ms. Ruth Cary
Ms. Julenne Chappell
Mr. & Mrs. Lee Chilcote
Ms. Paula Christ
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Ms. Sheila Strekal
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Mr. & Mrs. Guy Totino
Mr. & Mrs. Peter and Kathy Voitko
Ms. Carrie Wells
Ms. Cindy Zawadzki

\$100 - \$249

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Mr. Roger Avakian
Ms. Denice R. Baldanza
Mr. & Mrs. William Erv Ball
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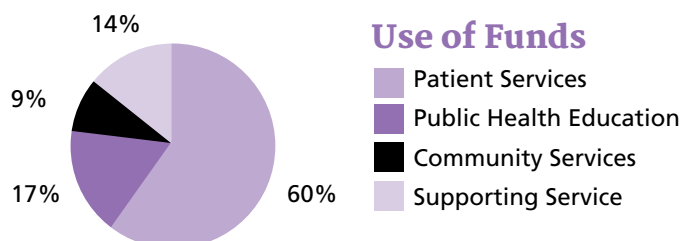
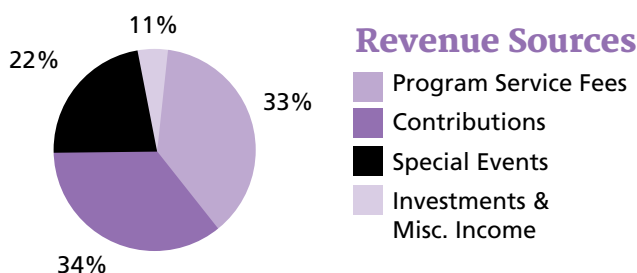
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Financials

Statement of Activities and Changes in Net Assets

Support and Revenue	2012 Audited	2011 Audited
Contributions	207,952	202,964
Program services fees	204,041	237,061
Special events	202,532	199,213
Less: Direct benefit to donor	(65,722)	(59,272)
Net gain on investments	64,662	18,985
Miscellaneous		
Total Support and Revenue	\$613,465	\$598,951
Expenses	2011 Audited	2010 Audited
Program services		
Community services	50,998	55,199
Patient service	356,992	386,428
Public health education	101,997	110,410
	\$509,987	\$552,037
Supporting services		
Management and General	23,478	25,414
Fundraising	57,481	62,220
	\$80,959	\$87,634
Total Expenses	\$590,946	\$639,671
CHANGE IN NET ASSETS	22,519	(40,720)
NET ASSETS – BEGINNING OF YEAR	920,683	961,403
NET ASSETS – END OF YEAR	\$943,202	\$920,683



2012 independent audit performed by Howard, Wershbae & Co.



Epilepsy Association

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