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Celebrating 35 Years!

In 1976, the mother of a child with epilepsy took a leave from Xerox in order to start an organization to support families dealing with the challenges of epilepsy. Pat Ladd-Thurston began her journey to create a community focused on providing support, information and education about epilepsy because she had concerns about her daughter's seizure disorder. Mrs. Ladd-Thurston feared that the seizures, medications and negative social response would affect her daughter's normal growth and learning.

The Epilepsy Association of Greater Rochester (EAGR) was formed in 1977 and hired its first paid staff to provide information and education about epilepsy, emotional support for parents and people with seizures as well as connection to community resources to help individuals with epilepsy live life to its fullest potential.

The 1980s

During the 1980's with grants from New York State, the Office of People with Developmental Disabilities (now known as OPWDD) and contracts with Monroe and Wayne counties, more services were developed—school programs, community information sessions, seizure first aid trainings, counseling, and recreational events.

In 1982, two special volunteers had a idea for a fund raiser. Elaine Michael and Ann Marie Scibetta decided to hold a gala and ask local pastry chefs to participate in a chocolate competition. The Chocolate Ball, Rochester's premier fund raising gala, was born. The Chocolate Ball is still going strong and has raised more than \$1.5 million for mission-related services. The 27th Chocolate Ball will be held on February 9, 2013.

In 1985, EAGR opened its first residential program – our Supportive Apartment Program which helps prepare individuals with developmental disabilities for independent living. Mrs. Ladd-Thurston's daughter, Sue, was one of the first residents.

continued on page 3...



Jeff Sinsebox, President & CEO

New CEO and New Direction

The Epilepsy Foundation is excited to announce our new President and CEO - Jeff Sinsebox. Jeff comes to us from People Rebuilding and Living In Dignity (PRALID) where he has been the CEO for seven years, leading PRALID into a period of growth and prosperity.

Jeff began as a direct care worker in a group home twenty years ago and worked in a number of different programs providing services to individuals with developmental disabilities before becoming the CEO of PRALID in 2005. He has extensive expertise in running high-quality and effective programs. Jeff resides in the Rochester area with his wife Maureen and his two daughters.

With his hiring comes a bold and courageous new path. The Epilepsy Foundation will be joining forces with PRALID in order to be able to better serve individuals with epilepsy and other neurological conditions. PRALID is a pioneer in creative and innovative brain injury services and by partnering with them, the Epilepsy Foundation's services will be enhanced and strengthened.

Message from Leadership: Our Promise to You

In New York State, the environment is changing for nonprofits – especially for nonprofits specializing in providing services to individuals with brain injuries, developmental disabilities, epilepsy and other neurological conditions. How this will ultimately impact nonprofits and those they serve remains uncertain.



Given the changing environment, PRALID and the Epilepsy Foundation of Rochester-Syracuse-Binghamton have agreed to come together to explore a new way of operating that will ensure that the mission-based services of both organizations are preserved for future generations.



The similarities between PRALID and the Epilepsy Foundation are striking. Both organizations were founded by parents who were concerned about the lack of appropriate services for their children. Both organizations also have a focus on neurological conditions, believe in person-centered services, and have similar missions and values. Through the blending of staff and services, we will realize greater administrative efficiencies and thus directing more of our collective resources where they are needed most – to the people we serve. The critical services that each organization provides will continue for many years to come.

As we move forward with this change, we make three promises to you today.

- The services provided by each organization will continue with minimal disruption to our clients as all of the critical services from both organizations will be preserved.
- The missions and values of both organizations will be preserved.
- Our gratitude for the tremendous support we have received is and will continue to be unwavering. Both organizations are fortunate to have incredibly dedicated and passionate supporters and we look forward to continuing these relationships.

As the leaders of the PRALID/Epilepsy Foundation board, we take our duty to the clients, donors, staff, volunteers, and friends of both organizations seriously. We sincerely believe that this process will result in a stronger organization for the future.

With sincere appreciation,

Lisa Bianchi
Co-Chair, Board of Directors

Jonathan Sacks
Co-Chair, Board of Directors

Watch for the Winter issue of
Epilepsy Foundation NEWS
for more details on this
exciting new direction.



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President & CEO: Jeff Sinsebox

Mission: To lead the fight to stop seizures, find a cure and overcome challenges created by epilepsy.

Vision: Remove stigma, be first-in-mind for innovative programs, provide fast response and high-quality services for people with epilepsy and related disabilities so they may reach their potential.

The Epilepsy Foundation is a nonprofit human services agency addressing the needs of area residents affected by epilepsy, seizure disorders, traumatic brain injuries, developmental disabilities and neurological conditions. The agency serves all individuals and families without regard to race, color, sex, age or national origin. Programs include information and referral, education programs, community services, family support services, residential services and Camp EAGR: a residential summer camp for children with epilepsy. Funding is provided by contracts with NYS Office for People with Developmental Disabilities (OPWDD), NYS Department of Health (DOH), Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR), National Epilepsy Foundation, Epilepsy Coalition of New York State, United Way, grants, special event fund raising, and gifts from individuals.

Newsletter editor: Sarah Korba

35 years of epilepsy services continued

The 1990s

Under the leadership of Sheila Appleby, who would be the third and longest executive director to date, EAGR saw significant growth in the 1990's. In 1992, kids with seizures were able to experience one of childhood's special rights of passage – summer camp and with the inaugural season of Camp EAGR, twenty-five kids with epilepsy got to be just kids for one week. This year, Camp EAGR welcomes over eighty children.

The opening of a new Syracuse office and the first of several name changes for EAGR occurred in 1997. EAGR became the Epilepsy Foundation of Rochester & Syracuse Regions. The Epilepsy Foundation also added a second residential program with the opening of Howitt House in 1996 and added what would become a critical service with the opening of our Employment Solutions program in 1994. The Epilepsy Foundation would continue to build upon its employment services and today, is able to offer a number of tailored employment options to the entire range of individuals with epilepsy, traumatic brain injuries, and other neurological conditions.

The 2000s

The year 2000 ushered in another name change as we opened an office in Binghamton. The Epilepsy Foundation of Rochester-Syracuse-Binghamton had finally arrived. Two more residential programs were added during this decade. Wagner House is named for long-time supporters Mr. & Mrs. Frederick Wagner and Sheila's House is dedicated in honor of Sheila Appleby, who retired in 2006 after a tenure of 15 years.

During the late 2000s, we expanded our educational outreach into new counties, formed a new support group in Ithaca, and established the Stephen A. Segar Scholarship Fund for high school and college students with epilepsy. A total of \$27,000 has been awarded to eighteen deserving young men and women with epilepsy since the fund's inception in 2007.

Today

As we move toward nearly four decades of service, the Epilepsy Foundation of Rochester-Syracuse-Binghamton has served more than 120,000 individuals affected by epilepsy.

Now, we are joining with People Rebuilding And Living In Dignity (PRALID) in order to provide better services to more individuals. Many of the changes will be behind-the-scenes process improvements. Some of the changes will be in communications like the format of this newsletter and the look of our website. As always, our commitment to providing high-quality and innovative services to people with epilepsy will not change.

As a friend of the Epilepsy Foundation, we thank you for your support. You have been a critical partner in our success. We look forward to your continuing support as we move into our brightest future.



2012 Chocolate Ball Honorary Chairs Corinna & Steven Ognibene. *Midnight in the Garden* was the theme for the 26th Annual Chocolate Ball which raised more than \$130,000 for epilepsy services.



Team SEC from the Strong Epilepsy Center in Rochester ran the Flower City Half-Marathon on April 29 in support of the Epilepsy Foundation. Thank you Team SEC!



On March 14, over 200 guests enjoyed wine tasting and other attractions at GardenScape's exclusive preview party *A Taste of Spring*, benefiting the Epilepsy Foundation.



The 2nd Annual Salt City 5k Walk for Epilepsy in beautiful Onondaga Lake Park was a huge success! On July 14, nearly 300 walkers joined us to raise awareness and more than \$18,500 for epilepsy services in Central NY.



Leaps and Hounds Towards Epilepsy on April 21 raised more than \$1,800 for our Emergency Medication Fund.



Team Gabby was the largest team at the 2012 Salt City Walk -- with 60 walkers and raising more than \$2,000!

6th Annual Scholarship Awards

“A pessimist sees the difficulty in every opportunity; an optimist sees the opportunity in every difficulty.”

Melissa Magee opens her winning scholarship application essay with this fitting quote from Winston Churchill. This statement exemplifies the philosophy behind the Stephen A. Segar Scholarship Awards. “Contrary to myth or stigma, people with epilepsy are intelligent, capable, and high-achieving,” says Stephen A. Segar, Esq. “Having epilepsy should never be looked upon as a limitation. It is my hope that this scholarship program, in some measure, encourages students with epilepsy to pursue their dreams.”

As the one of the founding partners of the successful law firm Segar & Sciortino, Mr. Segar knows a little something about not letting epilepsy get in the way of one’s dreams. Mr. Segar had his first seizure in his early 30’s and has struggled with seizures and medication side effects ever since. It was Mr. Segar’s personal experience with epilepsy that led him to create the Stephen A. Segar Scholarship Fund at the Epilepsy Foundation.

Each July, three extraordinary young adults with epilepsy are recognized for their academics and extracurricular activities, and, most importantly, for their achievement as an ambassador for epilepsy.

Tom Campagnola was the captain of his wrestling team at Auburn High School, and while being diagnosed with epilepsy was challenging, Tom continued to be a leader both on and off the mat. His coach, John Alberici, director of Auburn Wrestling, honored Tom with these words: “The remarkable thing about Tom is that although epilepsy has altered some of his plans and goals in life, it has not affected his outlook. Tom maintains a positive attitude while battling the day to day challenges with epilepsy.”

In 2006, when Matthew McKenna was fourteen years old, he underwent brain surgery in an attempt to stop his seizures that were increasing in frequency and no longer responding to medication. Matt’s surgery was a success and stopped his seizures, but what struck Matt’s neurologist, Dr. Giuseppe Erba, was not that the surgery was successful, but how fourteen-year-old Matt handled



2012 Stephen A. Segar Scholarship Winners
Left to Right: Thomas Campagnola, Melissa Magee,
Matthew McKenna, Stephen Segar, Esq.

himself and how Matt continues to handle himself today.

Dr. Erba states, “When I saw him last, I was struck by his crewcut, fully exposing the white line of the surgical scar on the left side of his head, standing out from his full dark hair. I asked why he did not let his hair grow longer. He replied there is no reason to hide it. He continued telling me that often people ask him what caused it: a car accident? a gun shot?...and he simply replies that he had brain surgery because he had epilepsy. This, invariably, leaves the person who asked quite impressed (...cool...!). Separately, his father told me that he had expressed the same concern about letting the scar be so visible. Matt replied: ‘Dad, this is me, the scar is what I am...’ I would add that the scar is the symbol of what he has done, the mark of the first big battle he had to fight, the testimony of his bravery, the “purple heart” he deserves to wear.”

Melissa Magee finishes her essay with “Fortunately what I once saw as a tragedy, I now see as a blessing. I appreciate that epilepsy has made me see life more vibrantly. After going through this experience [being diagnosed with epilepsy as a teenager], I know I can tackle anything that comes my way. I am ready to take on the world.”

Melissa -- we couldn’t agree more.

For more information on the Stephen A. Segar Scholarship, visit www.epilepsy-uny.org.

Thank you to the following donors who have made donations to the Epilepsy Foundation from January 1, 2012 to June 30, 2012.

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We care about our donors and friends!

We have made every effort to list names correctly. If there is an omission or error, please accept our apology and let us know by calling Sarah Korba at (585) 442-4430 x2703 or skorba@epilepsy-uny.org.

Ensuring the Future

The Epilepsy Foundation of Rochester-Syracuse-Binghamton is excited to announce that it has received an initial distribution of \$250,000 from a bequest. The estate wishes to remain anonymous.

“We are extremely grateful for the generosity and foresight of this donor. To include the Epilepsy Foundation in her will was incredibly thoughtful. This gift will help us make a real difference in the lives of people with epilepsy,” states Lisa Bianchi, chair of the Board of Directors for the Epilepsy Foundation.

The gift will be maintained in perpetuity in a board designated fund. Proceeds of which will enhance epilepsy education and service initiatives for years to come.

For more information on including the Epilepsy Foundation in your estate plans, please contact us at (800) 724-7930.



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Support Groups

Call (800) 724-7930 to confirm

Binghamton Teen & Adult Support Groups

Wilson Memorial Hospital, Johnson City, NY
Wilson Conference Room 5A, 4th Floor Piccano Bld.
7:00 pm - 8:00 pm
Sept 19, Oct 17, Nov 21, Dec 19

Ithaca Epilepsy Support Group

Tompkins Public Library, Ithaca, NY
6:00 pm - 8:00 pm
Sept 11, Oct 9, Nov 13, Dec 11

Rochester Adult Epilepsy Support Group

1650 South Ave, Suite 300, Rochester, NY 14620
6:00 pm pizza, 6:30 pm -7:30 pm meeting
Sept 6, Oct 4, Nov 1, Dec 6

Rochester Parent Family Network

1650 South Ave, Suite 300, Rochester, NY 14620
6:00 pm pizza, 6:30 pm - 7:30 pm meeting
Sept 13, Oct 11, Nov 8, Dec Holiday Party TBD

Syracuse PFN/Adult Support Group

1045 James Street, Suite 270, Syracuse, NY 13203
6:00 pm pizza, 6:30 pm -7:30 pm meeting
Sept 25, Oct 30, Nov 27, Dec Holiday Party TBD

Upcoming Events

Al Sigi Community of Agencies WalkAbout

Eastview Mall, Victor, NY (*new location*)
Walk for Epilepsy Awareness at the Al Sigi Community
WalkAbout. Register on the web at www.epilepsy-ny.org
October 28, 2012 at 9:30 am

November is Epilepsy Awareness Month

Details to be announced on our website.

ROC the Day

Choose the Epilepsy Foundation. Details on the web at
www.roctheday.org
December 12, 2012

27th Annual Chocolate Ball

Rochester Riverside Convention Center
February 9, 2013

Stay Connected

For more details about these events and much more,
find us online!

Website: www.epilepsy-ny.org

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