

Highlights

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Epilepsy: Like An Earthquake

“Epilepsy came into our lives like an earthquake,” explains Joe DiStefano when talking about his son’s first seizures and subsequent epilepsy diagnosis when he was 5 ½ months old. “We were completely unprepared and knew very little about epilepsy and seizures.”

Joe & Ellen’s son is now 12 years old and they are still learning new things about epilepsy. Michael has severe epilepsy with multiple different seizure types with only moderate control. Despite taking multiple medications, Michael still has weekly seizures and recently started experiencing a new type of seizure.

“We knew about Camp EAGR years ago,” states Joe, “But we weren’t ready. For many years, Michael’s seizures were so frequent and his needs were so great that we barely let him out of sight. We just couldn’t imagine letting him go to camp for an entire week.”

Camp director, Mike Radell, didn’t let that stop him and kept talking to the DiStefanos about camp and “gradually wore us down,” explains Ellen with a laugh. And so, in August of 2012, Michael DiStefano came to camp for the first time. Six months later, Michael’s parents are still amazed at the difference one week at Camp EAGR made in their child.

“I can’t tell you how surprised we were when on the last day of camp, Michael didn’t immediately run into our arms. We thought that maybe he didn’t see us. No, he saw us, but was having too much fun with his camp friends. We were so blown away at how independent he was at the end of camp” explains Ellen.

Michael came back from camp a more confident kid. He is willing to try things that he wouldn’t try before and he can’t wait to go back. “When Michael slips back into not trying new things, all I have to say is that ‘you’d be able to at Camp EAGR’. Just mentioning camp, even six months later boosts his ego.” explains Joe.

Michael talks about camp frequently, wears his camp t-shirt every week and can’t wait to go back.

This year camp runs from August 11-17. To register your child for camp or to find out how you can help this great program, call Mike Radell, our camp director at (800) 724-7930 x2741. More information about camp can be found on our website at www.epilepsy-uny.org.



Michael DiStefano

Opening Doors to Opportunities

The partnership of the Epilepsy Foundation of Rochester-Syracuse-Binghamton and PRALID has provided an unexpected opportunity. PRALID was looking to enrich their offerings in an already successful structured day program for individuals with traumatic brain injuries. The Epilepsy Foundation wanted to help individuals with traumatic brain injuries who want to work but need additional support to be ready for competitive employment.

Adding a pre-vocational track to PRALID’s structure day program meets the needs of both programs and creates a great opportunity for individuals with traumatic brain injuries.

“It’s a unique service that is not offered anywhere else in Rochester,” states Brigette Kuter, supervisor of PRALID’s structured day program. “We’ve been exploring ways to meet more of our participants’ needs and it has been wonderful working with the Epilepsy Foundation to create a custom pre-vocational track.”

“We are excited to be involved. We are able to use our collective experience with providing *continued on page 3...*

President's Message

Recently I went to see a basketball game. While watching the competition between the Lightning and the Sharks,



Jeff Sinnebox, President

I don't know if I could have told you the score or really even what happened. I was focused on what this basketball game meant.

This game was about work but it was also about much more than that. Four members of the Lightning currently live in the Monroe Developmental Center. When that building closes later this year, they will be moving into our new home, receiving employment assistance from us, and attending our day program.

I came to get to know the players better, support them, and introduce them to a handful of staff that would be working with them in the near future. Fourteen of our agency staff arrived. Several of them giving up their lunch break during a training just to meet these guys. Everyone was smiling and the mood was light but everyone there knew the importance of what we were doing. This game had a much greater meaning for me than I had anticipated.

I got to sit in the stands and watch the staff that just a year ago had worked at two separate agencies sitting side by side as if they had always worked together. I saw positive attitudes and enthusiasm towards the first major initiative undertaken by the combined agency. I saw people who care about what they do and have immediately invested in these new participants.

I take great pride in the work we do as an agency. I take great pride in having compassionate, creative, and involved staff dedicated to all they do. I am so impressed by the way in which our staff, supporters, our board, and our community have embraced the changes we have made over the past year and help build a stronger, more vibrant agency prepared for the future.

I recently attended my first Syracuse University basketball game. The size of the crowd, the unbelievable talent

of the players, the TV crews, and the energy in that dome can't hold a candle to the game in a little gymnasium I just saw. For myself and our staff, the game was fun and the opportunity to meet and interact with the guys was great.

After the game, the guys were excited about meeting our staff and sharing their individual stats with us. I'm not sure what the final score of the game was. I think the Lightning got beat pretty badly. But no one cared.

I heard one of our staff say, "Everybody wins."



Administrative Updates

Our Summer 2013 Issue will have a new look and will be a combined newsletter featuring participants, programs and staff from both the Epilepsy Foundation and PRALID.

The Epilepsy Foundation has reorganized office space in the Rochester area and consolidated operations with our partner PRALID. We now have two Rochester offices. All administrative staff including the President's office, Finance, Human Resources, Development and other administrative functions are located at:

2 Townline Circle
Rochester, NY 14623
(585) 442-6420

All program staff including Admissions, Quality Improvement, Epilepsy Education, Service Coordination, Employment, Community Habilitation and Traumatic Brain Injury services are located at:

1650 South Ave, Suite 300
Rochester, NY 14620
(585) 442-4430

If you are not sure where the staff person you are trying to reach is located, the reception desk at both offices will be happy to help. Just give us a call.

**Administration**

2 Townline Circle,
Rochester, NY 14623
(585) 442-6420
(585) 442-6964 fax

Programs

1650 South Ave, Suite 300
Rochester, NY 14620
(800) 724-7930 toll-free
(585) 442-6305 fax

Syracuse Office

1045 James Street, Suite 270
Syracuse, NY 13203
(877) 214-7715 toll-free
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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 individuals 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. Funding is provided by contracts with NYS Office for People with Developmental Disabilities, NYS Department of Health, Adult Career and Continuing Education Services-Vocational Rehabilitation, National Epilepsy Foundation, Epilepsy Coalition of New York State, United Way, grants, special events, and gifts from individuals.

Newsletter editor: Sarah Korba

Opportunities - continued from page 1

employment services to design a curriculum that will take individuals from a desire to work to being ready for success in competitive employment,” states Stephanie Bourne, director of employment services.

The pre-vocational track has four phases designed to support individuals with traumatic brain injuries who have the desire to work or volunteer learn the necessary skills at their own pace. This program will cover everything from basic job readiness and soft skill training such as appropriate attire, writing cover letters and resumes to supporting individuals in finding and applying for volunteer opportunities. The final step is completing an ACCES-VR application and transitioning into competitive employment.

PRALID’s Structured Day Program provides an adult learning setting where individuals with traumatic brain injuries are able to participate in meaningful activities and learn life-enhancing skills. This community-based program provides a fun, individualized, and structured therapeutic environment in which individuals work in small groups towards the outcomes of their choosing. Social and recreational opportunities are incorporated into all activities and are the main focus of the evening program which is held three nights a week. Monthly activity schedules can be found on PRALID’s website at www.pralid.org.

The pre-vocational track will officially begin April 1st and we are enrolling now! Call Brigitte at (585) 359-2112 to schedule your tour of our program today!

Connect with Others

Support Groups

One of the goals of the Epilepsy Foundation of Rochester-Syracuse-Binghamton is to help individuals and their families with epilepsy and related disabilities, and those dealing with traumatic brain injuries, reach their potential. Support groups provide opportunities for problem solving and for networking with individuals in similar circumstances. Currently, there are active epilepsy support groups in Broome, Monroe, Onondaga, and Tompkins counties. Check out the calendar on page 8 or on the web at www.epilepsy-uny.org. Are you interested in starting a support group near you? If so, let us know!

Youth Council

Are you 18-24 and affected by epilepsy? Join our Youth Council to make a difference in your community! Our Youth Council provides opportunities for leadership, mentoring, public speaking, outreach and awareness about epilepsy, raising funds, connecting with peers, and having fun! All youth, aged 18-24 are welcome to join - friends and family members of those with epilepsy are welcome. Also open to individuals across our service territory - come to our next meeting in person or call or Skype in!

Contact Mike Radell at (585) 442-4430 ext. 2741 or mradell@epilepsy-uny.org for more information about either of these great programs.



The summer of 2012 saw our most successful Camp EAGR ever - we had a record 80 campers attend a life-changing week. Registration for 2013 is now open - Camp EAGR will run from August 11-17, 2013 - visit www.epilepsy-uny.org for more details and registration forms.

Volunteer Camp EAGR Counselors needed!

Are you over 18, love kids and the outdoors? Experience a week of a lifetime by volunteering at Camp EAGR this year! If you are interested, please contact our camp director Mike Radell to schedule an interview. Application to be a counselor and more information can be found on our website at www.epilepsy-uny.org.



In September 2012, the inaugural Tanya's Trot for Epilepsy was held in honor of Tanya, a 25 year-old woman who passed away due to complications from epilepsy. \$14,000 was raised for epilepsy services. Save the date for 9.22.13!



The residents and staff of our Supportive Apartment Program had a good time, enjoyed a delicious meal and danced the night away at our annual Residential Holiday Party.



The 2012 Al Sigl Community WalkAbout was the best ever with 140 walkers raising almost \$23,000 for epilepsy! Julia's Warriors (pictured above) was our top team raising more than \$3,000 thanks to strong fund raising efforts by Julia's family and a matching gift from the Al Sigl Community of Agencies.



Joe Netti, Nicole Cliento, Maria Burgos, and Andy Yankanick were recognized at our staff holiday party for their years of service and dedication to the Epilepsy Foundation and PRALID.

Celebrating Outstanding Staff

The Epilepsy Foundation and PRALID held a joint staff holiday party this year on December 7 to celebrate the work of both agencies and to highlight a number of outstanding employees.

Two employees were selected by their peers as truly exceptional. Stephanie Bourne, director of employment services at the Epilepsy Foundation of Rochester-Syracuse-Binghamton and Anne Fantigrossi, IRA supervisor at PRALID's Woodruff IRA.



Anne Fantigrossi and Stephanie Bourne, our 2012 Employees of the Year

A number of other employees from both agencies were honored for their years of service and dedication to the individuals that we serve.

15 Year Awards

Maria Burgos, Nicole Cilento, Alicia DiSalvo, Andy Yankanick

10 Year Awards

Shermond Johnson, Joe Netti, Kathleen Smith

5 Year Awards

Rita Binion, Chad Boehnke, Cleola Brown, Alison Cresov, Latasha Decarlis, Ronald DeMun, Mary Farrow, Barbara Hart, Mark Leader, Alana Rucker, Mildred Santos, Shamiya Snowden, Patrice Taylor, William VanDeMortel

Congratulations to all our employees who work hard all year round providing excellent service to individuals with epilepsy, traumatic brain injuries, developmental disabilities and other neurological conditions.

New Epilepsy Services Director

A new position was created at the Epilepsy Foundation this fall - a director of epilepsy services.



Pamela Hunter, new director of epilepsy services

“We wanted to strengthen and grow our core epilepsy services -- creating this position and promoting Pamela Hunter -- was the best way to ensure this will happen. Pam brings a wealth of knowledge and passion for meeting the needs of people with epilepsy to this position and exciting things are in store for 2013.” states Jeff Sinsebox, president.

Pam Hunter, formerly the regional director of organizational development and education, now oversees all of our epilepsy services as well as our Syracuse office.

Pam and her team are already hard at work to enhance our existing epilepsy programs, develop new programs in response to the needs of people with epilepsy, and ultimately, serve more people with epilepsy better and more effectively.

Some of the highlights to look forward to in 2013 are an increased focus on legislative advocacy, growing our support groups and youth council to meet the needs of more families, a new ketogenic diet support program, educating 200 school nurses, streamlining our Intake & Case Management department so that individuals are connected to needed services faster, development of a pre-vocational structure day program in partnership with PRALID (see article on page 1 for more information) and increased awareness of epilepsy and our services in the Central and the Southern Tier regions of NY.

Feel free to contact Pam Hunter with any questions about our epilepsy services and our direction for 2013 at phunter@epilepsy-uny.org.

Thank you to the following donors who have made donations to the Epilepsy Foundation from July 1, 2012 to December 31, 2012.

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Support Groups

Call (800) 724-7930 to confirm

Binghamton Teen & Adult Support Groups

Wilson Memorial Hospital, Johnson City, NY
Cafeteria Conference Room, Piccano Bld.
6:30 pm - 8:00 pm, 3rd Thursday of the month
Mar 21, April 18, May 16, June 20

Ithaca Epilepsy Support Group

Tompkins Public Library, Ithaca, NY
6:00 pm - 8:00 pm, 2nd Tuesday of the month
Mar 12, April 9, May 14, June 11

Rochester PFN/Adult Support Group

1650 South Ave, Suite 300, Rochester, NY 14620
6:00 pm - 7:30 pm, 1st Thursday of the month
Mar 7, April 4, May 2, June 6

Syracuse PFN/Adult Support Group

1045 James Street, Suite 270, Syracuse, NY 13203
6:00 - 7:30 pm, last Tuesday of the month
Mar 26, April 30, May 28, June 25

Upcoming Events & Important Dates

Stephen A. Segar Scholarship

Application available on our website at www.epilepsy-uny.org
Deadline: **April 30, 2013**

3rd Annual Salt City Walk

Long Branch Park, Liverpool, NY
July 13, 2013

Camp EAGR

YMCA Camp Weona
August 11 - 17, 2013

Wine & Microbrew Tasting Cruise

Canandaigua Lady on Canandaigua Lake
August 24, 2013

Al Sigi Community WalkAbout

Eastview Mall, Victor, NY
October 27, 2013

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

Website: www.epilepsy-uny.org

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