Thank you to those who celebrated with us at the 30th Annual Chocolate Ball, helping to raise nearly $100,000 for epilepsy programs! Because of your generosity, we are able to continue providing education, training, scholarships, emergency medication funding, Camp EAGR/COAST, support groups, case management, and more to the thousands of individuals and families who rely on us for help. A special thank you to the participating chefs and judges from this year’s Cake Competition!

Guests browsed silent auction items using mobile bidding while tasting delicious cakes from participating chefs in and around Rochester. Cocktails and appetizers were enjoyed, then it was on to dinner followed by dancing to live music from The Swooners with Champagne Brown. Mayor Lovely A. Warren even stopped by to proclaim February 6, 2016 ‘Epilepsy-Pralid, Inc. Day of Chocolate.’

Educational conferences/partnerships – see inside for details
him family, his work, and the things that are important to him. It was a privilege to get to know him, see a part of his world and understand how we support him in his life.

Then it was time to eat. The food was delicious, the conversation interesting, and there were a few nice surprises at the end. Late in the dinner, the guys had prepared questions for me. They asked about the future direction of the agency, access to community events, and a host of other insightful topics. One man wrote me a poem and gave it to me. After dinner, I got to exchange jokes with guys and we topped the evening off with a performance to Michael Jackson’s “Bad.”

While I had a great time, the administrator in me was playing auditor and noticing everything. I was blown away by what I saw. I already knew our house supervisor, Dave Zambito, treats the people in our residential program and the kids at Camp EAGR with the utmost respect. I knew that his style is informal, real, and always person-centered. It was impactful to not only see it in action, but to see how he has influenced his team. The staff were on top of everything. While respecting choice and dignity, they navigated the tricky waters of dietary needs, behavior, medical issues, and socialization in a way that was natural and meaningful. These staff were so effective in the way they were supporting the guys that it would have been hard for the untrained person to understand all the work they were doing. Isn’t that the point? These staff weren’t the “professionals” addressing the “needs” of the guys—they were people quietly and competently living the mission of the agency.

The day of the dinner had been long and challenging. When heading to the house, I was tired and I wanted to go home. But as I drove home after the dinner, all I could do was smile. I was completely energized and I could not remember what was so challenging earlier in the day. The staff that work for us could make more money doing other things, but they have chosen us. The people that live here could be elsewhere, but they have chosen us. There is something special in the services we provide that makes it all worthwhile and I am grateful to be a part of it.

Clarification | For those who may have received the 2015 Fall Appeal, please note: two of the individuals were impacted by brain injuries, and one of the individuals was impacted by a traumatic brain injury.
Empowering Communities Through Educational Opportunities

In an effort to spread awareness about epilepsy, developmental disabilities, and brain injuries, Epilepsy-Pralid, Inc. (EPI) community educators are providing education and training to schools, businesses, community centers, etc. Additionally, EPI holds several conferences and educational programs throughout the year.

We host a Parent, Youth, and Young Adult Conference in order to empower these specific demographics affected by epilepsy. Doctors and community educators offer presentations on various subjects, depending on the demographic. Panel discussions and workshops ensure everyone is a part of the conversation. For the Young Adult Conference, topics include “Managing Medication Changes,” “Drugs and Alcohol Versus Medication,” “The Art of Advocacy,” SUDEP: Empowering You,” and more.


Running throughout June and into late July is the Studio E Art Therapy Program. The aim is to promote artistic expression, build autonomy, use art as empowerment, encourage emotional stability, provide connection with others, and more.

For Epilepsy Awareness Month in November, “Dinner with the Doctor” in Rochester, Syracuse, and Binghamton allows people to ask a doctor questions while enjoying a meal. This casual yet informative environment allows individuals to meet others facing the challenges of epilepsy, all while gaining knowledge about the issues that mean the most to them.

We are able to provide these events thanks to our educational partners, including Lundbeck, Nutricia North America, Sunovion, UCB, and the University of Rochester Medical Center.

Go to www.epiny.org for a full list of upcoming events.

If you are interested in having a community educator come out to your workplace, school, business, church, community center, conference, etc., please call Mike Radell at (585) 442-4430 x2741 or email mradell@epiny.org. We serve 22 counties in New York State and can provide general or extensive education regarding epilepsy or brain injuries; we also provide seizure first aid training.
Tanya's Trot for Epilepsy

Tanya Johannes was 25 years old when she passed away from Sudden Unexplained Death in Epilepsy (SUDEP) in November of 2010. She had experienced seizures for 11 years leading up to her death. Several years later, Tanya's family managed to keep her spirit alive with the creation of Tanya's Trot, a 5k run/walk for epilepsy.

Tammy Johannes, Tanya's mother, noted “There is a lack of awareness associated with epilepsy. People who do not have a loved one or have not had to experience the condition do not understand the impact it has on your life. The efforts that one has to go through to attempt to control the condition is long, difficult, and unclear.”

Epilepsy and its challenges vary from person to person, and each individual requires treatment specific to their personal situation. It's typically not as easy as going to the doctor and getting a magical pill to stop seizures. Oftentimes, a series of trial and error methods, approaches, and combinations are relentlessly attempted in an effort to achieve seizure control. Some individuals and families are luckier than others, but anyone involved in a circle of support understands the social, physical, mental, and emotional toll epilepsy can have.

After attending the National Walk for Epilepsy in Washington, D.C., Tammy Johannes decided she wanted to start a local 5k run/walk to help the three million people in the United States who have epilepsy, while simultaneously honoring her daughter. In 2012, Tanya's Trot was born. Nearly 500 people attended, and over $80,000 has since been raised.

Epilepsy-Pralid, Inc. is proud and honored to be the beneficiary for the 5th Annual Tanya's Trot 5k Run/Walk, held in Akron Falls Park, NY on September 18th. The money raised will go toward epilepsy services and supports, including education, first aid for seizures training, advocacy, case management, summer recreational and pre-vocational camps, scholarships, support groups, conferences, and more.

To join the Trot, log onto www.epiny.org/events.php.

How You Can Help!

We rely on your generosity in order to provide critical services to people in our community who turn to us for help. We appreciate your support in helping others live the lives of their choosing. Please consider making a gift today. Thank you!

Giving Has Never Been So Easy!

- Set up a recurring gift at www.epiny.org; just $10/month could fund a cultural excursion for adults with brain injuries. $20/month could sponsor a day at Camp EAGR for a child with epilepsy.
- Give directly through the newsletter by sending back the enclosed envelope with a gift.
- Double your contribution with a matching gift from your employer. Just complete the form at your participating employer’s office. It’s that easy!
- Hold a “Jeans Day” at your workplace in honor of Epilepsy-Pralid, Inc.
- Designate your United Way gift to Donor Option #2215.
- Register for the 6th Annual Salt City Walk for Epilepsy and create a team to help fundraise.
When you ask Steven Jacobs questions about his past, he can’t tell you all of the answers. Like millions of others who have suffered brain injuries, Steven faces the challenges of both short and long term memory loss each and every day. The ability to speak, the ability to walk, the ability to remember, impulse control, judgement challenges, and problem solving deficits were all new challenges Steven would face. However, there are plenty of “Steven” characteristics that remain, like his tenacity to learn and grow.

In April of 1991, Steven was a 32 year-old living in Arizona. An overdose of cocaine and lidocaine caused an anoxic brain injury, which typically occurs when there is a lack of oxygen to the brain. This landed him in a coma for four days, the hospital for three months, and then rehab where he was completely reliant on others, as a result of the brain injury. Veteran Affairs services helped get him through the subsequent years, but some of the major improvements began when Steven partnered with Epilepsy-Pralid, Inc. (EPI) back in November of 2005.

Prior to his brain injury, Steven had no indications of any developmental challenges. He had grown up with eight siblings and went through school without a hitch. He was a marine and a mason by trade, a skill which ran in his family.

Perhaps that inherent discipline has helped Steven achieve what he has today. He is now able to walk short distances entirely independently, without the assistance of a walker. When he started with EPI, he was wheelchair bound. A combination of factors has likely contributed to his success: access to EPI supports such as service coordination, the structured day program, home services and also the consistency in staff coupled with the pursuance of goals created with Steven’s determination to succeed.

When asked what improvements he has made and what obstacles he has overcome, Steven responded, “Before, I couldn’t talk at all.” With a lot of practice, he was able to speak and walk again, both of which he was unable to achieve prior to receiving services with EPI. Daily exercises and stretching with staff help Steven continue making progress, as well as his own personal resolve to continue improving both physically and mentally.

His current goals include making healthier food choices, becoming more integrated with the community, and continuing to respond verbally as opposed to using gestures. A very social man, Steven has always enjoyed being around others. From his days as a church-going motorcyclist and an avid reader, Stevens continues to lead the life of his choosing by reading his horoscope every day, volunteering twice a week (delivering Meals on Wheels and helping to sort food at Foodlink), and remaining an active community member.

Steven shared his story with us hoping that he could help others who may be facing the challenges of a drug addiction or brain injury.

Your gift to EPI helps Steven and many others facing the ongoing challenges of living with a brain injury, developmental disabilities, or epilepsy. Thank you for helping others live the lives of their choosing.
Sunday, August 7
Camp EAGR
25th Anniversary!
YMCA Camp Weona, Gainsville, NY

This year marks the 25th Anniversary of Camp EAGR, our summer camp for kids with epilepsy and their siblings! Camp COAST, our pre-vocational summer camp for young adults with epilepsy, is also scheduled for this week. Register for both camps at www.epiny.org!

Thursday, June 9
Studio E: The Epilepsy Art Therapy Program
107 Norris Drive, Rochester, NY 14610

This multi-week art therapy program is open to people with epilepsy and is made possible by partnership with Lundbeck. Studio E is open to artists of all talent levels, whether you are a professional artist or have never held a paint brush. To register or receive more information, please contact Mike Radell at mradell@epiny.org or 585-442-4430 ext. 2741.

Saturday, July 9
6th Annual Salt City Walk
Long Branch Park, Syracuse | 9-11am

Join us for this family-friendly event which supports epilepsy services in Central NY.

Some of last year’s fun included a DJ, face painting by Michael's, Otto the Orange, balloon twisting, inflatable skee ball, a team t-shirt contest, and more! Registration fee of $5/individual or $15/family of 3+ includes all activities, a t-shirt, snacks, and more! Register to walk at www.epiny.org.

Saturday, July 22
EPI Friends & Family Day
Frontier Field | 6:15pm

Take a moment to meet others who are, in some way, touched by Epilepsy-Pralid – whether it be through services, family, friends, or employees! All are welcome. Go to www.epiny.org to register.

August 7-13
Camp EAGR & Camp Coast
YMCA Camp Weona, Gainsville, NY

September 18
5th Annual Tanya’s Trot for Epilepsy 5k Run/Walk
Cummings Lodge, Akron Falls Park

Join the Trot! Epilepsy-Pralid, Inc. is honored to be the beneficiary of the 5th Annual Tanya’s Trot for Epilepsy. Sign up at www.epiny.org.

February 4, 2017
31st Annual Chocolate Ball

New venue! Hyatt Regency Rochester

We are already looking forward to another great year of Chocolate Ball! If you are interested in sponsoring this event, please contact Shaunta Collier-Santos at (585) 442-6420 x2227 or email scollier-santos@epiny.org.

Learn more at www.epiny.org

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