Over 300 people attended the 6th Annual Salt City Walk at Long Branch Park, Syracuse on July 9th. Together we walked and rolled, raising over $25,000 to support epilepsy services such as education & training, scholarships, Camp EAGR, Camp COAST, support groups, case management, and more! Amy Robbins of 93Q joined as the event emcee, and other special guests included Otto the Orange, Jeff the Magic Man, & Michaels’ face painters.

Camp EAGR/COAST: The week of August 7-13 marked a special occasion, as Camp EAGR celebrated its 25th Anniversary! Kids with epilepsy and their siblings, ages 8-17, enjoyed activities such as rock wall climbing, canoeing, horseback riding, swimming, archery, and more at the unique week-long residential camp. Campers build confidence, make new friends, and just have fun.

Camp COAST, a pre-vocational camp for young adults 18+ with epilepsy, was held alongside Camp EAGR.
In remembering the efforts and involvement of long time agency friend, Fred Wagner and his family, I think of not just him; but of all people whose ongoing efforts have opened doors, created meaning, enhanced the way we provide services, and ensured that the individuals we serve receive the best of what we do. They have helped the people we serve to believe that all things are possible. They have helped our staff to think outside of the box and challenged our organization to continuously improve the way it operates.

This summer marked the 25th anniversary of Camp EAGR. Every year it is a great success and this year was no exception. Camp is such an important program that impacts so many people, yet we sometimes forget how truly remarkable it is. Camp started as a desire to fill a need for normative recreational experiences for children with epilepsy and each year, a blend of creativity, staff support, volunteers, collaboration, the generosity of donors, and some government support comes together to make it happen. Camp isn’t just a great program to serve children with epilepsy; it is a blueprint for how we can make the best impact in the lives of people with disabilities.

The greatest effect we can make as an organization comes from partnering with the people we serve on their path to living the life of their choosing. Government funding supports much of what we do. It provides needed assistance for people to be safe, healthy, and develop needed skills in life. But government funding can’t meet all needs. The enhancements we make in people’s lives don’t come merely by accessing public funds; they come from mobilizing resources in our community. By connecting individuals, volunteers, and donors, we open a wellspring of resources.

This is where the magic happens.

Once people we serve have their basic needs met, the opportunity to explore our community is realized – they begin to develop skills and talents, make real connections, and in turn, we see them give back to their community.

At camp, the vast majority of our volunteer counselors are former campers. Camp could not run without them. The time and work they give us ensures that future campers will have the same unforgettable experience they did. We don’t just provide a nice experience for kids; we give them a platform upon which they will build a life of choice — from childhood camper, to young adult volunteer, to contributing community citizen.

Our best successes in serving people with brain injuries, developmental disabilities, and epilepsy are a result of individuals coming together with purpose and contributing time, money, effort or expertise to build a better tomorrow. To Fred and all the others that have given so much of themselves, thank you.
Sunday, October 30, 2016
Al Sigl Community WalkAbout
Eastview Mall | Registration 8:30am, Walk 9:30am
A family-friendly event that people of all ages and abilities will enjoy! Donate or raise $20 or more per adult or $40 per family and receive a t-shirt, breakfast, raffle entry, free entry into the costume contest and kid-friendly entertainment throughout the mall. Children participate for FREE with a parent or other adult. Once you’re registered, invite your friends and family to pledge their support and join the fun. Top fundraisers earn great prizes. Sign up today at www.crowdrise.com/epilepsy-pralid-incs-walkabout-2016.

November 29th  #GivingTuesday
ROC the Day
Choose donor option #2215 through United Way or give directly to EPI at www.epiny.org!

Rochester, November 3rd | Syracuse, November 15th | Binghamton, TBA
Join us for our Dinner with the Doctor Series 2016! As a part of National Epilepsy Awareness Month this November, Epilepsy-Pralid, Inc. in sponsorship with Lundbeck, is excited to bring three opportunities for Dinner with the Doctor — Rochester, Syracuse, and Binghamton.

These dinners present a unique opportunity for face time with local neurologists. Learn more about epilepsy, new research and treatment options, outside of the doctor’s office. Meet and connect with other individuals affected by epilepsy.

Sunday, November 13th
Cooking with KetoCal at the
New York Wine & Culinary Center
800 S Main St, Canandaigua | 4:00–6:00pm
Epilepsy-Pralid, Inc. is proud to partner with Nutricia North America, makers of KetoCal, to bring Cooking with KetoCal to Rochester and Upstate NY during National Epilepsy Awareness Month. Chef Rachel Finn will demonstrate the preparation of various dishes that include KetoCal. Sign up online at www.epiny.org.

Seating is limited to the first 50 people!

November 12th–13th
Talk About It: A Teen Epilepsy Weekend
Pittsford Hilton Garden Inn
Co-sponsored by Epilepsy-Pralid, Inc. and the Strong Epilepsy Center at URMC. Presentations, workshops, and more for teens with epilepsy ages 13-18.
$35 registration includes overnight stay, meals, presentations, and more. Sign up online at www.epiny.org!

NOVEMBER IS Epilepsy Awareness Month
Like us on Facebook at www.facebook.com/epilepsypralid to celebrate with us and share the ways you’re encouraging epilepsy awareness!

Mark Your Calendar!
July 15, 2017
Out of the Shadows 5K
See event details at www.outoftheshadows5k.org/

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with epilepsy dies suddenly and prematurely and no other cause of death is found. Not everyone with epilepsy is at risk of SUDEP and it is important that people with epilepsy discuss their individual risks and concerns with their health professionals.
#SUDEPAwarenessDay2016 #UnitedAgainstSUDEP
Fred Wagner’s Legacy of Giving

Around our agency, employees refer to one of the residential group homes simply as “Wagner.” The house is named after Fred Wagner, a longtime supporter who recently passed away.

Fred supported Epilepsy-Pralid, Inc. (EPI) and the individuals we partner with for 30 years. He also served on our Board, was an Al Sigl Board representative, was an extraordinarily generous donor, and remained active with EPI through our many events.

Another individual living at Wagner House said, “My favorite memory with him was when he would come over during the Christmas holiday time with his family and help us decorate the house.”

Patricia Pennella, Associate Director of Residential at EPI, described Fred as “Generous, kind, caring, down to earth.” She recalls, “Every time I saw him, he’d ask about the individuals living in the House, referring to them by name and inquiring with me about my own family and those personal details he managed to remember.”

Lance Thomas, Director of Finance, described Fred as “Such a jovial person, full of life – spirited.”

Fred’s passion for helping others with epilepsy was personal. His sister struggled with uncontrolled seizures as a result of her epilepsy. Years ago, there weren’t as many treatment options or services available. Even now, one-third of people with epilepsy live with uncontrollable seizures because no available treatment works for them.

Fred and the Wagner family have made a significant impact on the individuals receiving services from our agency, but also on the employees who have had the chance to interact with him or his family. We thank you, Fred, for your years of service on our Board, your unfailing inquisitive nature (which made for great conversations), and your generosity which touched the lives of so many. You will be missed and always remembered.

“Generous, kind, caring, down to earth. Every time I saw him, he’d ask about the individuals living in the house, referring to them by name and inquiring with me about my family and those personal details he managed to remember.” – Patricia Pennella
Jessica Nejeschleba received her Bachelor's degree from SUNY Binghamton in the spring of 2016. When she walked the stage to accept her diploma, she was sure to give a shout out to epilepsy by wearing a cap adorned with the words ‘Dear epilepsy, I did it!’

Her relationship with epilepsy has been complicated to say the least. She noted the complexity of the disorder as well as the overall lack of awareness, which can make the subject particularly uncomfortable to discuss with others. In fact, it was only in the spring of 2016 when Jessica really started opening up about her experience with epilepsy to others. A major reason for the initial hesitation was the fear of being seen differently by others – she didn't want special treatment.

At the age of seven, Jessica was diagnosed with absence seizures, which look a lot like staring spells lasting a few seconds. After a while, she was taken off medication. In 2007, a tonic-clonic seizure surfaced during a school trip in Hershey Park, Pennsylvania. Collapsing to the ground, Jessica remembers seeing the tops of trees, an ambulance, and then waking up in a hospital.

A seizure then occurred during her freshman year of high school, where students passing by in the hallway watched as she convulsed. After switching neurologists, things started to change for the better. Jessica has since been seizure free for eight years.

Jessica recently reached out to Epilepsy-Pralid, Inc. (EPI) to find out how she could help others with epilepsy. She recognized the need for increased education about the disorder, as well as the financial burden that can accompany epilepsy due to costly medical bills.

She set up shop in a few different areas of the Binghamton community – the college union, a local pizza joint favored by students enjoying a night out, and her place of employment – selling Gertrude Hawk candy bars for $1 each. She sold every single candy bar, 960 in total, for a profit of over $400 to go toward epilepsy programs and services. Along the way, she found the community was receptive to the cause and wanted to learn about epilepsy. She met people who had family members with epilepsy and were excited she was doing something to help others who face similar challenges.

It won’t stop there for Jessica. She has decided to go full force into activism, education, and fundraising for the cause. Jessica was a volunteer camp counselor at Camp EAGR during the week of August 7th-13th and also plans to partner with EPI to bring even more education and training to the Binghamton area, especially to the University. She also wants to get students involved in the Out of the Shadows 5K, a run/walk and clambake to be held at Mountain Top View in Binghamton, NY on July 15th of 2017, to benefit EPI. Her partnership with the agency is a great example of the kind of community leadership we rely on in order to help as many people as possible experiencing epilepsy in all different capacities.

Jessica hopes to send a message to others, especially the freshman in college who go through a particularly difficult transition, to let them know there are plenty of strong examples of people with epilepsy who persevere, and to let them know they aren't alone and it's okay to talk about it. “I am no longer afraid to say I have epilepsy… It's a forever disorder, you can't let it hold you back.”

Jessica will be attending Grad school at SUNY Binghamton to obtain a Master's degree in Public Administration with a Non-Profit Management Certificate.

If you or anyone you know is interested in volunteering or fundraising for EPI, please contact Shaunta Collier-Santos at (585) 442-6420 x2227 or email scollier-santos@epiny.org.
Expression Through Art

In the spring of 2016, Epilepsy-Pralid, Inc. (EPI) partnered with Nazareth College and the York Wellness and Rehabilitation Institute (YWRI) to create a special six-week art therapy program. Individuals from the Day Program and Structured Day Program at EPI, programs for adults with developmental disabilities and brain injuries, respectively, went through the wellness and art therapy initiative. Students training to be occupational and art therapists partnered with participants to provide the tools needed to encourage artistic and self-expression in the form of paintings, pottery, and drawings.

At the conclusion of the six-week session, the students presented at EPI and provided participants with their finished artwork. The students also facilitated a reflective in-depth discussion so that everyone could share and discover what was learned. The program was so popular that another will soon be held for others who hope to experience the program.

Your gift makes partnerships and new programs possible! Set up a recurring gift at www.epiny.org or simply return the enclosed envelope.