Thank you to all those who came out to support EPI’s 31st Annual Chocolate Ball! This year we raised over $100,000! As guests browsed through silent auction items and sampled from our collection of eight competing cakes, guests also sampled gourmet flavored cotton candy as well as gin and vodka from Tommyrotter Distillery. Emcees Scott Hetsko and Scott Spezzano kept the evening light and fun and guests were inspired to advocate for epilepsy by Emma Taylor, 15-year-old organizer of the Out of the Shadows 5K & Clambake (July 2017, visit epiny.org/events to learn more). Otto Harnischfeger kept up the energy and fun going with the live auction of our Signature Cakes. Dinner was followed by live music from Danielle Ponder and the Tomorrow People!

We are privileged at the Chocolate Ball to be able to honor our partners in the community who sustain EPI with their loyalty and support of our mission. This year we highlighted Jennifer Wallace of Key and Key Insurance & Benefits Services (formerly First Niagara), with the Outstanding Partnership Award. We also honored the Wagner Family with the inaugural presentation of the Wagner Award, posthumously given to Frederick and Marilyn Wagner – long time donors and supporters of EPI, beginning with Epilepsy Foundation of Rochester-Syracuse-Binghamton, and founders of Wagner House.

Our Grand Prize Winner from our Signature Cake Competition was Chef Tammy Fuchs from the Genesee Valley Club, with her cake “Gunfight at the O Cake Corral.” Chef Fuchs also took home 1st Place for Best Taste and 1st Place for Show Piece. Other winners include Chefs Melissa Savino and Tina Culhane, from The Cake Place, for Best Taste Runner Up with their cake, “Out of this World” and Chef Mina Rivazfar-Hoyt, of Something Delicious, with her cake, “Nightmare on Main Street”, took home Showpiece Runner Up and People’s Choice. Other competitors included Chefs Jill and Michael Zazzaro, from Chef’s Kitchen & Bakery, “Love in the Night”; Chef Evy O’Brien, from Sweet Tastes by Evy, “Wonder for Health & Freedom”; Chef Tammy DiCecca, from Special T Cakes, “Romancing the Cure”; and Chef Kelly Halligan, from Get Caked, Inc., “A Force to be Reckoned With”; Chef Haley Shuman, from Hegedorns Market, “A Mother’s Love is Forever”. An extra special thank you to our chef competitors and judges of our Signature Cake Competition. These cakes make our event truly unique!

We look forward to seeing everyone on February 3, 2018!!
We Never Close!

When I was a child my parents had an antique radio in our living room. If as much as a flake of snow was flying, I remember turning on that radio to listen for school closings. Sitting there eating breakfast with the that tiny old radio cranked just hoping for that day or two a year when they announced my school was closed. Those were great days. That excitement never faded for me. I remember getting classes canceled for weather one time in college and it made me feel just like I did when I was twelve. I imagine most people like a good snow day.

This March has brought some remarkable weather. Two powerful and significant storms wreaked havoc on our area in back-to-back weeks. It seemed like just about everything closed down — but not us. We provide 24/7 supports to many people scattered around Central and Western NY and those needs don’t just go away because mother nature decides to show us who’s boss.

During the recent windstorm in Rochester many people lost power and heat. Basements flooded and roads were impassible. The people we serve and our staff were thrown into chaos. But the staff were impressive. I saw many staff that overcame no heat, no hot water, closed schools, and dangerous conditions. They arrived to work and began the business of assisting our participants in their struggles with the exact same things. With our South Avenue office out of heat, phones, and internet, staff piled into the Townline office to keep operations going.

Before the dust had settled on the wind storm, the snow came. The 40” that hit Binghamton made our Rochester storm seem rather mild. Again, the staff rallied. Our residences were staffed, programs cooperated to ensure we continued to meet the needs of the people we serve. Management calmly got it done by adjusting, improvising, and even taxiing staff to work.

I am so proud of the staff that work for EPI. Any challenges this agency faces are met by employees ready to take them on. During those difficult seven days, no one we serve was harmed. Participants were inconvenienced by temporary relocations, operating under generator power, adjusted staffing schedules, and transportation woes. But they were also reminded of the commitment EPI and its staff made to assist them in overcoming whatever barriers come about. And while I didn’t get any snow days during these storms, I got to feel that excitement in a very different way.

In Memoriam:
Patricia Ladd-Thurston

In 1976, Pat Ladd-Thurston had concerns about her daughter’s seizure disorder. Sue’s seizures occurred frequently, without warning, and were very frightening to watch. Sue’s teachers found her epilepsy difficult to cope with in school. Mrs. Ladd-Thurston worried about both the physical and mental/social effects the seizures and the medications were having on her daughter. She felt very alone and wished she could have other parents to talk to.

Employed by Xerox, she applied for their Social Service Leave Program and received a year paid sabbatical during which she worked with neurologists at Strong Memorial Hospital to develop community resources for people with seizure disorders and their families.

Mrs. Ladd-Thurston put a notice for a public meeting for parents and families affected by epilepsy in the newspapers, and the response was significant. The resulting group of parents, led by Mrs. Ladd-Thurston, organized the first epilepsy-specific services in Rochester, NY. In late 1976, Mrs. Ladd-Thurston, with support from other parents and local neurologists, filed incorporation paperwork and the Epilepsy Association of Greater Rochester (EAGR) was born.

While we are called Epilepsy-Pralid, Inc. today and the scope of our agency is much larger, we still retain much of what Pat Ladd-Thurston instilled in that early organization – a focus on providing support to families who are struggling with the diagnosis of epilepsy.

EPI was truly saddened to hear of Mrs. Ladd-Thurston’s passing in December 2016. We will always be grateful for her work 40 years ago and will strive to honor her legacy by continuing to grow and strengthen our epilepsy services.
Saturday, May 20
**Live Out Loud: Concert Event**
The Historic German House, Rochester | 7pm

Join us for a benefit concert to rock out and knock out barriers effecting people with epilepsy, brain injury and other developmental disabilities. Scheduled to perform are Jimmie Highsmith, Jr. and Danielle Ponder & The Tomorrow People. Tickets are $30 for general admission and $75 VIP.

Saturday, July 8
**7th Annual Salt City Walk**
Long Branch Park, Syracuse | 9-11am

Join us for this family-friendly event which supports epilepsy services in Central NY. Last year's fun included a DJ, face painting, Otto the Orange, balloon twisting, inflatable skee ball, a team t-shirt contest, snacks and more! There is no registration fee.

Saturday, July 15
**Out of the Shadows 5K & Clambake**
Mountain Top View, Binghamton | 9am-5pm

Join us for a 5k run/walk & clambake to benefit Epilepsy-Pralid, Inc. The venue has a beautiful pavilion where there will be plenty of food and drinks available and places for kids to play.

Saturday, July 22, 2017
**Friends & Family Night**
Red Wings Stadium

Save the date for another evening of friends & family fun celebrating EPI!

August 13-19
**Camp EAGR & COAST**
Camp Weona, Gainsville

Come to Camp EAGR/COAST and enjoy a week of swimming, horseback riding, rock wall climbing, laughing and having fun with kids and their siblings who are affected by epilepsy.

Sunday, October 29
**Al Sigl Community WalkAbout**
Eastview Mall, Victor | 9:30am

A family-friendly event that people of all ages and abilities will enjoy! There is no registration fee for this event. Join us for a costume contest and kid-friendly entertainment throughout the mall. Once you register, invite your friends and family to pledge their support and join the fun. Top fundraisers earn great prizes.

Saturday, February 3, 2018
**32nd Annual Chocolate Ball**
Hyatt Regency Rochester | 5:30pm

The Chocolate Ball is a gala featuring elegant food, drink and music, and chance to sample and purchase award-winning chocolate cakes from our Signature Cake Chef Competition.
EPI is always looking for ways to be more person-centered; to promote independence and choice to the individuals we serve. It is great to see the real impact of the work of our care teams, especially when it happens right in our own corporate offices!

Rebecca, who attends our Day Program, also works at our front reception desk, helping to cover lunch breaks. Each day for about an hour, Rebecca leaves Day Program and enters the Administrative offices at 2 Townline Circle. “I love it,” Rebecca said about working at EPI, “I would do it for free if they let me!”

EPI offered Rebecca the opportunity to carry her own key fob when she wants to leave the Day Program to enter the administrative office side of the building. Previously, Rebecca would have to wait for a staff member in Day Program, which would delay her getting to the reception desk on time. Now, Rebecca carries a fob in her purse.

She says she loves it and why didn’t we think about this before! Rebecca states that she can now hang out more in the admin side as well, at times when she likes to escape “all the activity” of Day Program. A seemingly small thing but one can tell she has more of a sense of independence since receiving her own fob.

Tracy was invited to attend an open interview with Richard Anderson, Manager of Day Services. Tracy was the life of the party as he joked his way through. This helped loosen the atmosphere for all the interviewees. Tracy asked each of them what their name was, writing them down as the interviewees responded, and proceeded to ask them questions.

On their first break, Richard asked Tracy which of the applicants he felt would be a good fit for our Day Program. Tracy responded back with individual names of applicants. During their last break, Tracy and Richard huddled and he was given background packets to distribute to each of the applicants Tracy thought should be hired. He handed the packets to those he felt a connection with starting with his first choice zig zagging across the room in this wheelchair, with no input from Richard.

All of the applicants had a greater sense of appreciation since the decision to hire came straight from Tracy. Richard acknowledged to Tracy afterwards that he made all the same choices that Richard would have made himself.

Tracy has also assisted in other interviews with Josh Singletary, Day Program Supervisor at EPI. Josh states that Tracy is a big help; his attendance at these interviews adds a good touch to the process — by getting applicants connected from the very beginning with an individual they will be working with. According to Tracy the best part about the interviews is, “being able to talk about me,” he said joking.

When you ask Rebecca about EPI, she will tell you, “They gave me my life back.” Bringing Tracy into staff interviews and giving Rebecca a small, but important addition to her freedom, promotes the person-centered approach at EPI. It puts our individuals into the driver’s seat of their services, and enables them to contribute in a meaningful way to their community.
Emma Taylor is a 15-year-old freshman at Seton Catholic Central in Binghamton. Emma’s story with epilepsy began when she was 13 on a summer family vacation to Hawaii. While there visiting her aunt and uncle, Emma experienced her first tonic-clonic seizure, formerly called grand mal. After returning home, Emma not only had to adjust to being an 8th grader, she also had to adjust to the rigorous ups and downs of a new diagnosis of epilepsy. Although the news of Emma having epilepsy was devastating to her and her family, she was determined to keep being who she’s always been: a fun, athletic, and outgoing young lady. It wasn’t always easy. Seizures and medication side effect made school work and sports harder for Emma, but her resilience has allowed her to continue doing all the things she loves.

Emma soon connected with EPI. Emma attended EPI’s teen weekend which she says inspired her and energized her immensely. “I met a lot of great teens just like me,” Emma says. Since then Emma has told her story at the 31st annual Chocolate Ball and has gone on to speak at the Teen Summit to advocate for the Epilepsy Foundation in Washington, DC on Capital Hill to her elected officials. Emma will be attending Camp EAGR this summer: “I am so excited about camp. I can’t wait to go” she says.

Emma wanted to make a difference for people who are affected by epilepsy by bringing awareness to others. To do so, Emma has organized Out of the Shadows, a 5k and clambake being held at Mountain Top View in Binghamton on July 15, 2017 to benefit EPI. “I wanted to raise money to help people who can’t afford medications, camp tuition, or to get educated on epilepsy,” Emma shares. Emma has secured sponsorships from The Riordan Management Group Inc., and Megan Fals (just to name a few) and has even received donations to help towards her goal. “I will overcome,” says Emma.

To learn more about Emma’s story, become a sponsor, or register for Out of the Shadows 5k, visit: outoftheshadows5k.org or like Out of the Shadows on Facebook.

Registration is Open! outoftheshadows5k.org
Join us on July 15th
9am – 5pm
585-442-6420
Early Registration: $40;
After June 1st: $52;
Early Registration &
Clambake: $92;
Late Registration &
Clambake: $97
Salt City Walk 2017

EPI is very excited about our 7th Annual Salt City Walk on July 8th at Long Branch Park in Syracuse, NY.

This family fun walk will include activities, a t-shirt contest, raffles, a light breakfast, takeaways, and special guest appearances. The event raises awareness and funding for epilepsy services in Central NY provided by EPI.

Last year over 300 people joined together to support epilepsy awareness and services raising over $25,000. It is our hope that we can count you in to help us reach our goal of $30,000.

To register to walk, become a sponsor or make a donation please visit our website https://epiny.ejoinme.org/scw17reg.

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Overcoming the fear of seizures that causes you to set limits is the hallmark of the Epilepsy Scholarship. This annual scholarship is open to college-bound and enrolled college students in Western NY, Finger Lakes, and Central NY.

Applicants must demonstrate excellence in academics, extra-curricular or civic service activities, and most importantly, an ability to overcome obstacles and persevere in pursuit of their dreams. Deadline extended to May 20, 2017.

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