

EPI Matters

Providing support for all people with developmental or acquired brain conditions to live the life of their choosing.

Vol. VI Issue I Summer 2018



2018 Chocolate Ball Rochester's Adventures in Chocolate Land

Thank you to all those who supported Epilepsy-Pralid, Inc.'s, 32nd Annual Chocolate Ball! We raised more than \$120,000! We could not have achieved this without YOU - our sponsors, donors, and volunteers.

With this success, we can continue our work providing epilepsy education and tailored supports to the more than 6,000 people who rely on us for help. Guests browsed through silent auction items and sampled from our collection of seven competing cakes, themed after "Alice in Wonderland."

Guests were inspired to advocate for epilepsy by Lisa Noonan, event chairperson and mother of a child with epilepsy; Emma Taylor, organizer of the Out of the Shadows 5K; and EPI scholarship winner Christina Sculley.

We were also excited to honor community partners who sustain us with their loyalty. This year Delta Sonic received the **Outstanding Partnership Award**. We also honored Tammy Johannes, founder of Tanya's Trot, with the **Wagner Award**, given in memory of long-time supporter Fredrick J. Wagner.

We look forward to celebrating the 33rd Chocolate Ball on February 2, 2019!



Our **Grand Prize Winner** (pictured above) from our Signature Cake Competition was Chef Melissa Savino from The Cake Place, with her cake "Muchness." Chef Melissa Savino also took home 1st Place for Show Piece.



Chris Cebula, EPI Board Chair; Tammy Johannes, 2018 Wagner Award Winner; Jeff Sinsebox, EPI President

Thank you to our Chocolate Sponsors!



Controlling Destiny Through Self-Direction

Everybody has a story to tell. Our stories can be simple and bold. They can be subtle and complex. What has meaning and purpose to one person may seem absurd to another. Our stories are shaped by genetics, relationships, experiences, places, and events in our lives. At the center of each of our stories is us. We make decisions, we respond to people and our environments - we choose. Choice makes us who and what we are. When we exercise meaningful choice, we are self-determined.

Self-determination is the belief that we can control our own destiny. It drives us to set goals and pursue them. It allows us to meet the challenges created by our barriers and problem solve appropriate solutions. Self-determination states that people, based on respect for the principle of equal rights and fair equality of opportunity, have the right to freely choose with limited interference from others.

Traditionally, human services have been designed to provide strong protective oversight. Persons with disabilities often need enhanced clinical services. The higher needs of people served combined with protective services delivered by specialists created a culture of non-choice. Since the professionals are experts, the natural inclination in the past (and to a lesser extent today) was to shift control to professionals or agencies and away from the person receiving the services.

Fortunately, there has been a great awakening in our field to move as much control as possible to those that used to just receive care. Now people can author their own plans.

They can self-hire staff, customize schedules, and create services that put them in the center of their own story. Instead of having an agency as narrator, the stories are theirs to tell.

What is Self-Direction?

Enhancing community integration and social capital is at the core of self-direction. Self-Direction gives you the chance to make decisions about supports and services that help you to:

- Enjoy meaningful relationships with family and friends
- Experience health and growth
- Live in the home and community you choose
- Work, volunteer or do activities you enjoy



Rachel Weiner pictured with her mother, Amy. Read more about their self-direction journey, in "Rachel Writes Her Own Story."

At EPI, we have committed to this process. We are challenging ourselves to think and act differently. We are evolving how we deliver services and in what direction to move. Not all people with disabilities are ready or would even choose to self-direct services and that's okay. But for the people that want to take greater control of the choices and actions, we will continue the effort to make it happen.

2018 is slated to be the largest year of growth in agency history. Almost all of that expansion will be supporting people on their self-directed journey.

A handwritten signature in white ink that reads "Jeff Sinsebox".

Visit www.epiny.org/events for all event details – including registration and ticket purchases!

Follow us on Facebook to stay connected with these and other events.

For more information, contact the Development Department at events@epiny.org.

Saturday, July 7

Salt City Summerfest

Long Branch Park, Syracuse | 10am-12pm

Join EPI at this epilepsy awareness event, which features a variety of fun activities for the young and young at heart including: face painting, arts & crafts, and kid-friendly lawn games.



Sunday, August 5

3rd Annual Golf for Trevor

Carlowden Country Club, Denmark | 8am-4pm

3rd Annual Golf Tournament in Memory of Trevor M. Wren. Registration includes 18 holes, cart, collared golf shirt, hot dogs or hamburgers at noon or stay for the chicken BBQ at 3pm. Registration deadline is July 21st. Proceeds will go to EPI's Epilepsy Scholarship fund.



Saturday, August 12

Out of the Shadows 5K

Otsiningo Park | 9am

Join us for the 2nd Annual Out of the Shadows 5K. There will be raffles baskets, 50/50 and places for kids to play during the event.



August 12-18

Camp EAGR & COAST

Camp Weona, Gainesville

Come to Camp EAGR/COAST and enjoy a week of swimming, horseback riding, rock wall climbing, laughing and having fun with kids who also have epilepsy.



Friday, August 31

Friends & Family Day

Frontier Field, Rochester | 6:00pm

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



Sunday, September 23

Tanya's Trot 5k Run/Walk

Veterans Park, Akron | 2pm

Join us for the 7th Annual Tanya's Trot for Epilepsy 5K Run/Walk. The 5k course is officially certified and timed. Other event activities include an epilepsy information booth, baskets and side raffles, and light refreshments.



Sunday, October 28

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, which features 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.



Self-Direction Success

Rachel Writes Her Own Story



*Rachel Weiner, 26
Self-Direction participant for
seven years*

When Rachel “aged out” of school at 21, her parents were concerned about the transition from the school program to an adult day program. They researched and visited several day program options.

Her mother, Amy, explained their dilemma: “With Rachel’s different struggles and needs, we just couldn’t find a match... Transitions are hard for Rachel and so is being in an environment where there is a lot of coming and going.”

Rachel’s family was among the first to pursue self-direction seven years ago. Her parents purchased

and renovated a home near their property, where Rachel receives community habilitation and respite services every weekday plus a few overnights each week based on staff availability. She enjoys being transported from the main residence to her respite home on her family’s golf cart.

Rachel’s respite home was renovated with her developmental needs in mind, featuring an open design for easier maneuvering and a walk-in shower to assist her in becoming more independent with personal care. Rachel’s family is hoping that one day, she may share her respite home with another person and/or live there full-time.

Success in self-direction requires finding and keeping good staff, which can be challenging. Staff are most often identified by word-of-mouth referral. In Rachel’s case, multiple staff are required and so it is sometimes necessary to advertise job opportunities to increase the applicant pool.

Amy is grateful that EPI facilitates the recruiting and orientation process, so she can concentrate on training the staff to understand and appropriately address Rachel’s needs and wants.

Rachel and her staff start every morning at Rachel’s house. They are free to choose activities based

on how Rachel is feeling and what she is inclined to do. She often takes advantage of her various memberships including the zoo and the YMCA. On days when Rachel prefers not to be so active, she can instead stay at her home to relax and have quiet time.

The self-directed services are “very, very individualized and focused on Rachel,” Amy is pleased to report. Choosing self-directed services has allowed Rachel and her family to tailor the services to Rachel’s specific needs.

New to Self-Direction?

To learn more about Self-Direction services, talk with your Care Manager or Regional Self-Direction Liaison.

If you still have questions, you can call:

OPWDD’s information line:

1-866-946-9733

or visit their website at www.opwdd.ny.gov/selfdirection

(For individuals who have hearing impairment, please use the NY Relay System 7-1-1.)

Need a Fiscal Intermediary (FI)?

Contact Jennifer Levey,
Self-Direction Manager at EPI at
jlevey@epiny.org
or 585-442-6420 ext. 2270

2018 Chocolate Ball

Adventures in Chocolate Land

Additional Winners

(continued from cover)

- Chef Haley Shuman from Special Touch Bakery People's Choice and Best Taste runner up with her cake, "We're All a Little Mad Here"
- Chef Mina Rivazfar-Hoyt of Something Delicious with her cake, "Delicious Adventure", took home the prize of Show-piece runner up
- Chef Tammy Fuchs of Genesee Valley Club took 1st Place for Best Taste with her cake "Chip's & Coco's Chocolate Adventure"



Special Touch Bakery



Something Delicious



Genesee Valley Club

Join us for the 33rd Annual Chocolate Ball!
February 2, 2019 | epiny.org



Board Member Dr. John Langfitt and family really got into the theme of this event!
Love the hats!



Speakers Emma Taylor and Christina Sculley



EPI Employees: Mike Radell, Denise Ester, Sarah Korba, Stephanie Reh, and Shaunta Collier-Santos



Get Caked



Shell's Sweets



Red Horse Bakery

Other Competitors Included:

- Chef Kelly Halligan, from Get Caked, Inc., "Into the Rabbit Hole"
- Chef Michelle Crawford of Shell's Sweets, "Have a Very Merry Unbirthday"
- Chef Aubrey Khederian, from Red Horse Bakery, "The Parade"



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Camps EAGR & Coast August 12-18 2018

Come to Camp EAGR and enjoy a week of swimming, horseback riding, rock wall climbing, laughing and having fun with kids who also have epilepsy.

You'll make new friends and will get to experience things you might not get to do anywhere else. Once you experience Camp EAGR, it will quickly become one of the best weeks of your life!

Register deadline 7-28-2018

Learn more at epiny.org

Like us on Facebook

Salt City Summerfest 2018

Join EPI at this epilepsy awareness event, which features a variety of fun activities for the young and young at heart including: face painting, arts & crafts, and kid-friendly lawn games.

We will facilitate optional breakout sessions on the following topics: Regional Epilepsy Services, Teen Focus, and Salt City Event 2019. Snacks and beverages will be provided, thanks to a number of generous donations from area sponsors. We also will hold the popular T-Shirt Contest, which can include individual or team entries.

To join us for this free event or to donate please visit our website www.epiny.org.



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