

EPI Matters

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

Vol. VII Issue II Fall 2019

Smashing Cars & Building Friendships



Left to Right: Lenny Carman, Charles Rolison, Tyler Lameroux, Guy Raymond, Ryan Goodrich, Bill Spencer, and Chris Hinkley, Broome Community Services Supervisor

When an organization offers truly person-centered services, you never really know where it's going to take you. In our Broome Community Services Programs for adults with developmental disabilities, it has taken us to, among other places, a demolition derby garage.

The connection between Guy Raymond's Demolition Derby shop and our program came about accidentally. One day, Angus Hines, one of our staff, ran into a friend of his, Guy Raymond, while out in the community supporting Frank Johnson. Angus & Guy knew each other from the demolition derby circuit.

What started as a friendly conversation and casual invite has grown into an important feature of our program over the past two years. The connection has retained its casual roots – there is no set schedule and no defined

curriculum – but don't let the casualness fool you. Helping tear cars apart and build a demolition derby car from the shell has significantly impacted the lives of the guys who participate.

One can feel the connection and community that has formed in the garage. Guy greets each person who enters his shop with a friendly warmth and often an inside joke. Guy affectionately introduces Bill Spencer as "The Scavenger." When a new car comes into the shop, Bill gives it so thorough a look over that he finds all the lost change in every nook and cranny possible. Lenny Carman, "The Tornado," comes next and goes through the car like the wind. For safety reasons, all flammable material – carpets, car seats – have to go. Guy jokes that he turns his back on Lenny for a few seconds, and when he turns back

around, Lenny has pulled out everything that's not bolted down. Charles is the "Foreman." He likes to watch and give helpful advice from the sidelines.

Guy's patient and teaching nature is on display when Lenny tells a story about how he used to go home with a number of Guy's tools in his pocket. Lenny taps a table right by the exit, "I put all my tools here when I'm done with them, so they don't go home in my pocket."

Winning demolition derbies is clearly an important passion to Guy. He is proud to show off his shop and the photos of his living room, which has trophies wall-to-wall. "Ask me about any of these, and I can tell you the date, place, and the particulars of the car I drove," states Guy.

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Supporting NextGen Leaders



Associate Board Retreat

The agency has grown a great deal over the past few years and the need for robust community engagement and a positive energy towards EPI's brand and mission are vital to the continued success of EPI.

In response, the agency has created an Associate Board to develop future leaders of EPI.

This group of energized, like-minded people will create and support efforts of agency outreach, brand cultivation, and fundraising.

In July our first Associate Board recruitment event was held at the Cub Room - and it was very successful! We currently have 12 Associate Board members, a few who are past employees and EPI

volunteers. The group has been learning more about the agency by visiting agency programs and meeting with staff. They have held a few different workshops and are in the early stages of planning an event to support EPI.

I had the privilege of spending a few hours with the group in September and I have met with several of the members individually. The energy and enthusiasm sent from the group is infectious.

I love being able to watch a group of future community leaders working together on a common cause. It is especially meaningful that they have chosen EPI as a benefactor of their talents. I can't wait to see what they come up with and where it helps take the agency next.

Epilepsy-Pralid is Hiring!

Start a rewarding career providing assistance to individuals with disabilities! EPI provides competitive pay, a full benefits package for eligible positions, part-time and full-time opportunities and flexible scheduling! For a list of current openings across all the 22 counties we serve, please visit epiny.org/careers.

Direct Support Professionals Recruitment Events

No registration necessary. Please bring your resume. For additional info, please contact recruiter@epiny.org

Onondaga County/Syracuse

November 11

Embassy Suites Syracuse/Destiny USA

10am - 3pm

Broome County/Binghamton

November 20

Courtyard Binghamton, 3801 Vestal Parkway

10am - 2pm

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.

November 2019

Recreation Respite

Various | Check website for details!

Did you know? EPI Recreation Respite offers enriching activities for kids and young adults on weekends and early evenings on weekdays. Recreation Respite's participants fill their day with new exciting adventures with warm, well-trained staff, and a low child-to-caregiver ratio.

November 2019

Dinners with the Doctor

Various | Check website for details!

Expert speakers. Delicious dinners. Increase your knowledge about epilepsy, seizures, and current medical treatments at this powerful series. Free, but space is limited. RSVP today!

November 7 in Rochester | November 14 in Syracuse | November 21 in Binghamton

November 6, 2019

Artist Reception

St. John Fisher College, Joseph S. Skalny Welcome Center | 6-8pm

Engage with EPI and great local artists who are breaking down barriers for people with disabilities at the Artist Reception of *Change How You See, See How You Change: redefining the art gallery, the artist and art*. This exhibit runs from October 30 through December 10 in the Patricia O'Keefe Ross Art Gallery at St. John Fisher College.

November 7, 2019

Holiday Shopping Fundraiser

A Horse With Wings, 775 University Ave | 5pm-7pm

Get your holiday shopping done early at an exclusive after hours shopping event that benefits EPI at Rochester's most unique home & gift gallery. Complementary champagne provided!

November 9 & 10, 2019

Teen Epilepsy Weekend

Hampton Inn & Suites Rochester/Henrietta, NY | 12pm

Come to the Teen Epilepsy Weekend to learn more about epilepsy, find out ways to stay healthy, talk with epilepsy experts, and have fun with other teens who get it! Teens must be self-medicating to attend.

Cost is \$35; scholarships are available. Register online today!

December 3, 2019

ROC the Day

roctheday.org | All day

Save the day for ROC the Day 2019 - Rochester's very own community-wide giving event. Like our Facebook page for more ROC the Day info!

February 1, 2019

The 34th Annual Chocolate Ball

Hyatt Rochester Downtown | 5:30pm-11pm

Join us at Rochester's most delicious gala event! Guests sample award-winning chocolate cakes, bid on silent & live auction items, and dance the night away. Individual tickets, tables of 10 and sponsorships are available.

EPI Profiles

Communities of Choice

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But inside Guy's shop – it's not about the winning. It's about the genuine friendship, it's about teaching mechanic skills. It's about learning by doing and making mistakes. It's about literally tearing something apart in order to build it into something stronger.

Lenny couldn't even operate a hood latch when he first started going to Guy's garage. Now, he proudly shows off his extensive car knowledge. Guy and Angus call out different car parts – battery, horn, radiator – and Lenny finds them all.

It was Frank's interest in working on cars that sparked the initial visit to Guy's garage. Frank has since passed away, but the guys still talk about him fondly – and every year since his passing, they dedicate a car in his memory.

"It's hard to know who gets the most out of this relationship," states Guy, "I teach the guys a lot about cars, but they have helped me immensely. Just knowing that they depend on me to open the shop each day, it keeps me focused."

When you ask each of the guys what their favorite thing about the garage is, they all have the same answer - hanging out with Guy. Ryan states it best "I like the company. Guy and I are friends now."

It's clear that Guy, Lenny, Billy, Charles, Ryan and others have formed genuine friendships. Even on a cold and rainy day, where not much car work can get done - they laugh and joke with each other all morning. Time spend at the garage simultaneously flies by and stands still.

Providing the people we support with authentic opportunities to build connections with people who share similar interests, to participate, in an authentic way, in the communities of their choice is a the heart of what EPI does.



Miranda (Randy) Brundidge enjoys a weekly (or two!) game of Bingo.

Randy Brundidge sustained a traumatic brain injury some years ago. As part of his recovery, Randy attends EPI's Structured Day Program and receives home health aide and companion care services. Randy was a bit of a home body when his aide, Patricia Issac, first started working with him just over a year ago.

Pat, a firm believer that a person needs to be active, suggested several options to get Randy out of the house and more engaged in social situations. Randy decided to give weekly outings to the movie theater and Bingo a try. Randy & Pat applied to the Green Light Fund - a fund through EPI that helps the people we support access social, recreational, and community based opportunities that are financially out of reach - and was awarded a stipend.

Randy and Pat went to their first Bingo

game together nearly a year ago now and Randy had a great time. In addition to enjoying the activity, Randy was completely surprised to find his Aunt Bertha at Bingo! Randy often sees several of his siblings, and enjoys family dinners during the holidays, but had lost touch with the older generation of his family some time ago. A joyful family reunion occurred right in the middle of Bingo.

Randy is no longer the home body he once was. He enjoys attending Bingo one to two times per week, chatting with his aunt and other family members, and with the new friends made at Bingo.

The Green Light Fund, partially funded by the Al Sigl Sports Committee, is one of the many ways that EPI facilitates access to communities of choice. The GLF provides support to nearly 100 people each year.

Epilepsy Services

Trots, Tourneys, and Trails

It was a busy summer here at EPI! We were the beneficiary of several fundraisers for which we are very grateful! We awarded scholarships to two very deserving college-bound students. And lastly, but certainly not least, 70 kids and 17 young adults attended our summer camp programs. Camp EAGR & Camp Coast were huge successes this year! Camp Coast enjoyed a new space at the Rochester Rotary Sunshine Campus and Camp EAGR increased enrollment by almost 25%.

Check out the photos on our Epilepsy-Pralid Facebook page!



Congratulations to Julia Petreikis and Connor Ellison, our 2019 Epilepsy Scholarship award winners!



Team EPI was proud to support the 8th annual Tanya's Trot in Akron, NY! Tanya's Trot raises funds & awareness in memory of Tanya Johannes, who passed away from SUDEP.



Trevor Wren Memorial Golf Tournament raises funds each year for our Epilepsy Scholarship.



In September, Alice Wanzenried, a junior at Gates Chili High School organized the first Wanz's Walk to raise awareness and increase support for epilepsy services. Thank you Alice!



Out of the Shadows organizer Emma Taylor and her mom Renee raise awareness in Binghamton.

Epilepsy Alliance America celebrates Epilepsy Awareness Month

As a founding member of the Epilepsy Alliance America, EPI is celebrating Epilepsy Awareness Month by recognizing the many faces of epilepsy across the nation. Our **#1in26** campaign will highlight the impact epilepsy has on the lives of individual and families that live with seizures. EPI is also excited to participate in the 7th Annual Epilepsy Awareness Day at Disneyland on November 4, 5, 6! The DiStefano Family will be our ambassadors to this amazing event - stay tuned to our social media for updates from their journey.





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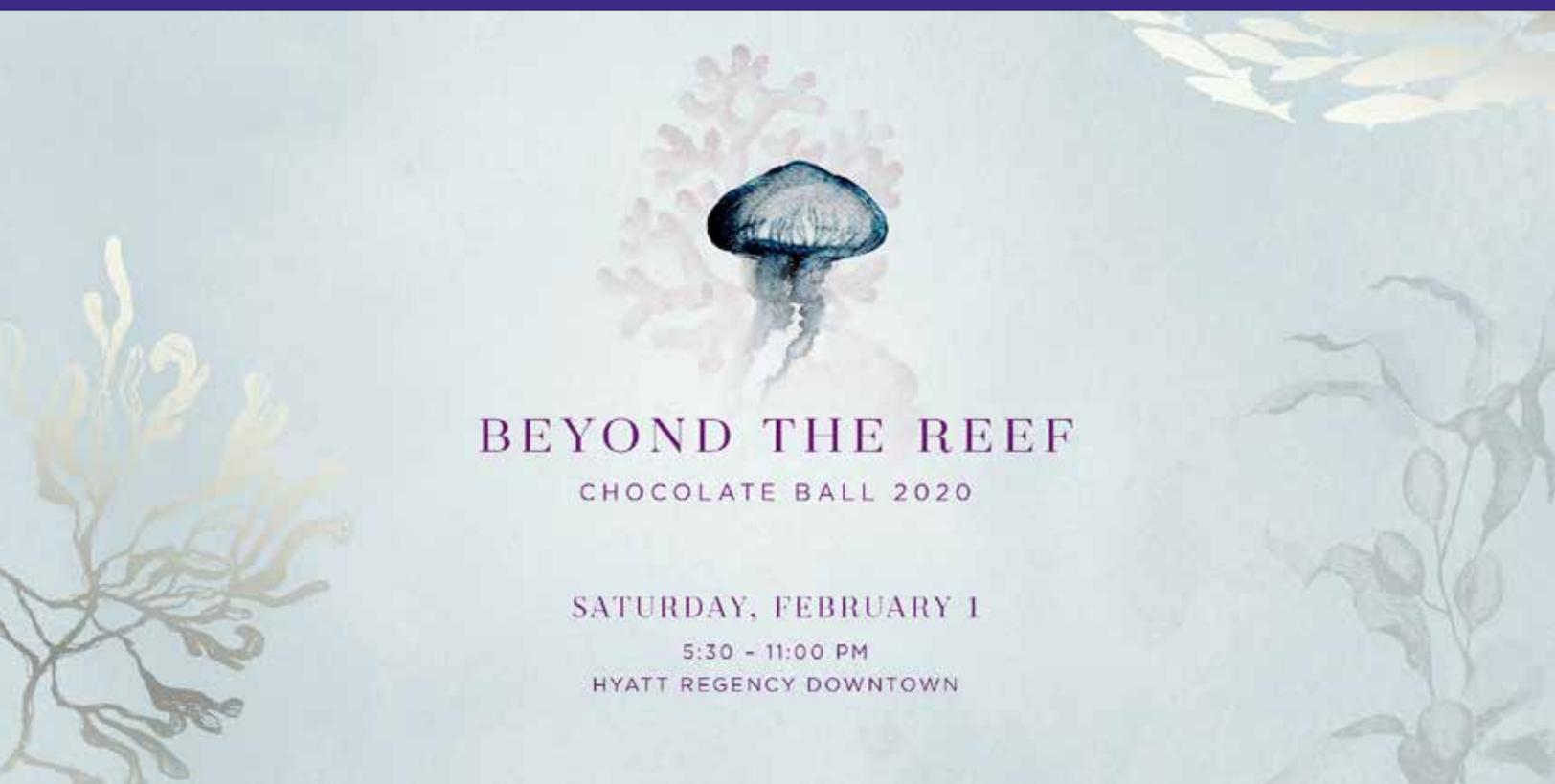
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Teen Epilepsy Weekend
November 9-10

Teen with seizures - come spend the weekend and:

- Meet new friends
- Learn about staying healthy
- Talk with neurologists outside of a doctor's visit

Teens must be self-medicating to attend. **Register today at epiny.org.**

Learn more at epiny.org



BEYOND THE REEF

CHOCOLATE BALL 2020

SATURDAY, FEBRUARY 1

5:30 - 11:00 PM

HYATT REGENCY DOWNTOWN

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