Get ready for the return of the sweetest event in Rochester – the annual Chocolate Ball. The gala supports EPI’s epilepsy programs and services. Mark your calendar for the return of the sweetest event in Rochester – the
37th Annual Chocolate Ball Save the Date
37th Annual Chocolate Ball

SEIZING THE DAY TO HELP OTHERS WITH EPILEPSY

In realizing that not everyone with epilepsy has this option, Amer decided to organize a race – Seize the Day: Amer’s Epilepsy Trail Run. “While having epilepsy has caused some problems for me, other kids with this condition are not as fortunate,” says Amer. “Running has always been a big part of my life. It has been a way to stay in shape, but it has also played an important role in my social life. So, when I decided to help others with epilepsy, a trail race seemed to be a good fit.”

More than 150 runners, including Amer and his family, participated in the inaugural 5k or 10k run, which was held in mid-August at Mendon Ponds Park. It raised $67,000 for EPI’s programs for children and adults with epilepsy in our region.

“Epilepsy is still often misunderstood and still carries a stigma,” explains Jeff Sinsebox, EPI President/CEO. “We are grateful for Amer’s enthusiasm and initiative. It is important to educate our community about epilepsy, its prevalence, and the impact that this condition has on the life of many children and adults in our community.” According to Amer, he would like to make this race an annual Rochester event. “It is my hope to help as many people with epilepsy as possible.”

For more information about EPI’s Epilepsy services, please contact info@epiny.org or (585) 442-4430

When 16-year-old Amer Armbruster was diagnosed with juvenile absence epilepsy in 2019, he didn’t fully realize the impact it would have on his life. Three years later, Amer acknowledges that living with epilepsy hasn’t always been easy. “The drugs I take to help prevent seizures have side effects. Some cause exhaustion and make it hard for me to concentrate,” he says. “It’s been a long process of trial and error. I’m now starting my fifth drug and am trying to stay hopeful that this one will work.”

Having active seizures prevents Amer from learning to drive any time soon – and he needs to be extra careful when participating in sports. “Basically, anything that could result in me getting hurt or hurting others if I have a seizure is off the table,” adds Amer. For Amer, a junior at Honeoye Falls-Lima High School and proud three-season athlete, this meant always having a running or work-out partner when he trains for cross-country and Nordic ski races. Luckily, Amer’s family, friends, and coaches have been extremely supportive and have been there for him every step of the way.

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helping children with Epilepsy become safe swimmers. We are partnering with Disability EmpowHER Network to create in Central and Western New York.

Our Self-Advocate group held its End of Summer Celebration in shore of Lake Ontario!

powerful for people living with epilepsy and those who care for them. Hosted by the New York State Epilepsy Coalition, Connecting with others facing the challenges of epilepsy in your area? RSVP to Michael Radell at mradell@epiny.org for Zoom link or in person meeting information.

EPI Schizophrenia: Faith-Based Recovery Support Group (virtual)

EPI has partnered with UR Medicine and the Brain Injury Association of NYS to host a monthly support group for brain injury survivors and their loved ones. No RSVP necessary; visit our events calendar online for the Zoom link. For more information, contact brainsupport@urmc.rochester.edu. This group meets the 4th Wednesday of each month from 5 pm – 6 pm, 11/23, 12/28

Be sure to check out our 2023 events and mark your calendars! We look forward to seeing you at our upcoming events.


Summer Fun at Camp!

New adventures and great fun at both Camp COAST and Camp EAGR! Camp COAST was held in June at the Rochester Rotary Sunshine Camp. We enjoyed zip-lining, boating, swimming, mini-golf, and a great visit to the Niagara Aquarium. Camp EAGR moved to a new location at Camp Kenan in Barker, NY right on the shore of Lake Ontario!

Calendar of Events

November – December 2022

More information and RSVP links can be found for all events at https://www.epiny.org/events/

November 17th: Binghamton Dinner with the Doctor at The Spot Restaurant 6pm – 7:30pm
Adult EPILEPSY Awareness Month

EPI is celebrating EPILEPSY Awareness Month with education opportunities all month long!

November 11th: Rochester Epilepsy Networking Holiday Party 12/1
Broome/CNY EPILEPSY Networking Holiday Party 12/8
Webinar Wednesday: Rescue Medication Nayzilam 12/14
Brain Injury Support Group (virtual)

EPI has partnered with UR Medicine and the Brain Injury Association of NYS to host a monthly support group for brain injury survivors and their loved ones. No RSVP necessary; visit our events calendar online for the Zoom link. For more information, contact brainsupport@urmc.rochester.edu. This group meets the 4th Wednesday of each month from 5 pm – 6 pm, 11/23, 12/28

Save the Date for these 2023 Events!

February 3, 5pm-7pm EPI Winter Night, Record Archive, Rochester, NY
April 29, 5:30pm – 11pm Chocolate Ball, Hyatt Regency Rochester
June 2023 Camp Coast, Rochester Rotary Sunshine Campus
June 15, 5pm with live music at 7pm EPI Summer Night, Three Heads Brewing Company
July 16 Savour the Day: Ameer’s Epilepsy Trail Run, Mendon Ponds Park
July 23 – July 29 Camp EAGR, Rochester Rotary Sunshine Campus (NEW location!)
October 1 - 26 One in 26 Challenge for Epilepsy, Kick-off Events in Syracuse & Rochester

"The Power of Collaboration

The world has become increasingly complex. EPI is always evolving and changing to meet the needs of the people we serve. And as those individuals and families are confronted with new opportunities and struggles, so is EPI. Operating in new territories requires innovative and collaborative approaches and solutions.

Increasingly, EPI is exploring new relationships, seeking to create services that don’t currently exist, and partnering with other organizations to address problems within the current service environment.

We have been reaping the rewards of these collaborations. Thanks to the generosity of the Golisano Foundation, we have partnered with Catholic Charities Family and Community Services, Urban League of Rochester, and the Ecoo-American Action League to break down access barriers to self-directed services. We have strengthened our relationship with Epilepsy Alliance America (EAA). At the national level, we lead the expansion of EAA with the recruitment of 7 new organizations. And collaboratively, we were able to secure new resources to enhance our offerings to families affected by epilepsy in Central and Western New York.

Collaboration is key to a thriving organization. Building on shared knowledge and experiences, enables us to find new, more efficient, and better ways to serve our community.

From the President

Jeff Sinsebox

We have created a program with the Jewish Community Center and University of Rochester’s Epilepsy Center to help children with Epilepsy become safe swimmers. We are partnering with Disability EmpowHER Network to create opportunities for women with disabilities to grow and lead.

We are exploring other relationships to help shape our future. We have joined Your Health Partners and the Inclusive Alliance as we position for demonstration projects, data collection, group purchasing arrangements that may someday revolutionize the service system. Finally, we are exploring new and creative solutions to assist individuals we serve to find employment opportunities.

EPI Summer Night

EPI hosted its inaugural Summer Night event on June 30, at Three Heads Brewing in Rochester. The well attended event raised awareness and funds in support of children and adults with developmental disabilities. Guests enjoyed refreshing craft beers and music by talented The Blue Sky Brothers, an Allman Brothers tribute band.

Riley Rose Foundation

Beautiful, 16-year-old Riley Rose passed away in September 2020, succumbed to a seizure that lead to a fatal aspiration. Shortly after this tragedy, her parents and some of their closest friends established the Riley Rose Foundation, to honor Riley’s memory and to assist people with epilepsy in the central New York. We were honored to have been selected by the Riley Rose Foundation to receive a $10,000 donation in support of epilepsy services. The check was presented at the foundation’s 2nd Annual Swing and String Golf Tournament and Charity fundraiser held at the Oneida Golf Club on July 7th.

EPI Epilepsy Scholarships

We were delighted to award our annual scholarships to two very talented high-school seniors, Ally and Micah. We were impressed by Ally and Micah’s drive to excel, resilience, determination to increase awareness about epilepsy, and their commitment to help others.

Teaching Kids with Epilepsy to Swim

This summer, EPI, in collaboration with UR Medicine Epilepsy Center and the Louis S. Wolk JCC of Greater Rochester, hosted a successful pilot project – a water safety & swim lesson program for families who have children with epilepsy to teach life-saving skills to kids with seizures. It was a great success and we can’t wait to replicate this program in 2023.

Self-Advocacy End of Summer Celebration

Our Self-Advocate group held its End of Summer Celebration in September at Genesee Valley Park. The annual picnic included games, music, and our favorite tradition: a visit from the ice cream truck!

Scholarships

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