Save the Dates

Walk, run, bike one mile per day for 26 days and The One in 26 Challenge returns in October 2022! Locations! Syracuse: Saturday, 10/1 at Abbott Farms. Help us raise awareness about epilepsy. Two kick-off events at the door in support of EPI’s programs and services. Rochester: Sunday, 10/2 at Wickham Farms. Registration at 8, walk at 9 and enjoy Abbott or Wickham Farms for the whole morning!

The One in 26 Challenge returns in October 2022!

EPI Summer Night. Join us on Thursday, June 30th at Three Heads Brewing at 5:30 pm. Music by Blue Sky Brothers starts at 7:00! $5 suggested donation.

Building Independence

Rosemary “Rosie” Miller is a happy, social, thriving little girl who loves music, movies, ice cream, and attending kindergarten. And although life has been full of challenges for the seven-year-old who has Down syndrome and cerebral palsy, Rosie continues to rise to the occasion and overcome obstacles.

At four months of age, Rosie needed heart surgery to correct a congenital defect, and due to respiratory complications while she was recovering, Rosie was eventually put on extracorporeal membrane oxygenation (ECMO). This technology does the job of the heart and/or lungs, allowing the organs to rest and recover when a patient is ill. “During the procedure, Rosie had a stroke,” says Theresa Miller, Rosie’s mother. “This resulted in her developing cerebral palsy.” Although Rosie was too young to realize the impact this would have on her and the family, Theresa and her husband Jon were thrilled to bring their baby girl home four weeks after her surgery. “At the time, Rosie had an older sister, Violet, who is now nine years of age,” explains Jon. “Since then, our family has welcomed her brother, Will, age four and a new baby sister, Lucy, who was just born in February. They all love each other and the three older siblings enjoy spending countless hours playing together.”

Since Rosie’s family’s goal is to foster her independence, Jon and Theresa made modifications to their raised ranch home in Corning, NY to best meet their daughter’s needs. “We now have a home with features such as widened doorways to make things more accessible for Rosie,” adds Jon. “However, as she continued to grow and gain weight, it became increasingly difficult to lift and move her from one level of our home to another, even though she walks with a gait trainer.”

The Millers researched options and thought about having an elevator installed in their home, but this was a costly investment they simply could not afford. They contacted the Office for People with Developmental Disabilities (OPWDD), however, this office typically will not fund such equipment. It was determined that a vertical platform lift (VPL) would be the next best option – and was determined that a vertical platform lift (VPL) would be the next best option – and it would be placed in front of the garage, allowing her to pull back the garage door and move Rosie from the main garage level to upper levels of the Miller home. “The physical environment can become one of the biggest barriers to independence for a child or an adult with disability,” says Jeff Sinisbax, EPI President/CEO. “But when modified appropriately, the environment can also become one of the greatest facilitators of participation and engagement in daily routines and activities. At EPI, our role is to work with each person to develop a plan that meets his or her needs, find and coordinate the work of reputable contractors, and oversee the project ensuring satisfactory completion.”

According to Theresa, a VPL wasn’t a luxury, it was something Rosie needed for her well-being. She and Jon reached out to EPI, who worked in conjunction with OPWDD, to make a VPL become a reality in the Miller’s home. “We are so thankful for EPI, as well as Rosie’s team of pediatricians, physical therapists, and other healthcare providers, who supported us every step of the way,” states Jon. At first a bit apprehensive about the VPL, Rosie is now excited about it. She’s extremely proud of herself when she can move about independently and enjoys “riding” the VPL.

The big decision was made to install a VPL at the Miller home. “Rosie is so happy being in her own environment. She’s smart and her brain is growing and developing because she is more independent in her home with her siblings,” adds Theresa. “Rosie’s disabilities are lifelong for her as well as our family. We are extremely grateful to everyone involved in helping us obtain the VPL, because it will help maximize Rosie’s quality of life and allow her to be independent for years to come.”

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

EPI Matters

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From the President
Jeff Sinsebox

We all want to live and work in a world where we feel valued and can contribute. A world where words are backed up by actions. A world where we are brave enough to have difficult conversations, where people we rely on. A world open to change, where mistakes are viewed as learning opportunities and not reason to blame or fear repercussions. A world where we listen, are heard, and are treated kindly.

A values-based organization is based on a culture shaped by clear ground rules and guiding principles for decision-making, actions, and a sense of community. The changes and challenges of the past few years have motivated EPI to take a hard look at our culture. We have identified areas for improvement and things we want to strengthen. Working on our values is essential to succeed in our mission and drive towards our vision.

As a result of our strategic planning process, we will focus on building the following values:
- Integrity
- Courage
- Adaptability
- Respect

These are great words. They are powerful and so often used they risk becoming cliché. As we worked through our strategic planning process, we did not want to let these words, these values, get lost. We collectively defined them, aligned with them, and committed to moving forward together around them.

If at EPI we all embrace these values, the job of providing quality service becomes easier. A staff that feels empowered and included in the workplace will not struggle advocating for the people they serve to build a life of choice, of purpose, and a strong sense of community.

New Headquarters

After almost six months of construction, in December 2021, we moved to our new headquarters at 1650 South Avenue in Rochester at the Al Sigl campus. The move brought all our offices in Rochester under the same roof. While our office space’s total square footage did not change, the new office layout is much more efficient.

EPI Administration, Finance, HR, IT, Marketing & Development moved from their previous location in Henrietta to South Avenue. Our Structured Day Program for people with brain injuries also moved from its previous location in Henrietta to a beautiful space at South Avenue which includes a state-of-the-art kitchen, a beautiful classroom, a gym, and office space for staff. Our After School Respite for children with ED/DD is now located in a colorful and beautifully decorated new space at the South Avenue campus. Our OPWDD-certified Day Habilitation move to its new location, in a totally renovated space in Fairport, near the Erie Canal Path, parks, and the village.

While everyone at EPI was involved and helped with the relocation, we’d like to recognize the extraordinary work of Amy Sharpe and Hope Ambroseli in coordinating the very complex move while ensuring that the daily work of the agency continued. We’d also like to recognize Marc Oswaga, Al Sigl Vice President of Operations, for overseeing the construction project, and his dedicated Facilities team. Finally, special thanks to US Ceiling, the project manager for all three phases of construction.

Thank you to all the partners and vendors:
- Al Sigl Community of Agencies
- Clement Electric
- Henrita Restaurant Supply
- McIlister Sign Inc.
- NFP
- Clement Electric
- US Ceiling
- Unlimited Painting
- Rochester Appliance
- Sheridan Brothers

Epiphany Awards 2022

In early January, given the particularly contagious nature of the Omicron COVID variant, we made the heart-breaking decision to cancel our in-person Chocolate Ball. As a health and human services agency, we believed it was our responsibility to prioritize safety.

Chocolate Ball is our largest fundraiser. We knew that canceling it put funding at risk for critical epilepsy program and services. We launched a month-long campaign and the response has been nothing short of phenomenal. We exceeded our goal and raised over $105,000. We are grateful and humbled by the generosity demonstrated by so many people.

And we are determined to hold an in-person event in 2023!

We decided to move our Chocolate Ball to the Spring to avoid a potential COVID spike in the winter months. Save the date for the 37th Annual Chocolate Ball: Saturday, May 13, 2023!

Epilepsy Programs for Kids & Young Adults

Epilepsy Alliance of Western New York, the Epilepsy services division of EPI, is excited to announce that registration for three of our most popular programs is open!

Summer Camp - Planning is well underway for our amazing epilepsy summer camp. Spots are limited, so don’t delay – register today! Camp EAGR is for kids with epilepsy and their siblings, aged 8-17. It takes place June 5 – June 10 at the Rochester Rotary Sunshine Camp.

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Scholarship - We award college scholarships each year to several high school seniors or current college students who have demonstrated perseverance in the face of the challenges that epilepsy and seizures can bring. Application deadline is May 20th.

More information and registration information for all three of these programs can be found on our website at www.epiny.org/epilepsy.

Epilepsy Education Webinars

Our monthly webinar series features epilepsy specialists on a variety of educational topics. RSVP to Michael Radell at mradell@epiny.org for the webinar link. All webinars are on Wednesdays from 5:30pm – 6:30pm.

- Camp Coast – Rochester Rotary Sunshine Camp June 5 – June 10
- Camp EAGR YMCA Camp Kenan (NEW location!) July 24 – 30
- Epilepsy Alliance of West Central NY, the epilepsy services division of EPI, is excited to announce that registration for three of our most popular programs is open!

Calendar of Events

June 2022 – September 2022

- Camp Coast Rochester Rotary Sunshine Camp
- Camp EAGR YMCA Camp Kenan (NEW location!)
- Camp Virtual Hang Outs 8/24, 9/28 (for all current & former students and families)
- Broome/CNY Epilepsy Networking 9/8
- Rochester Epilepsy Networking 6/16 (pims), 9/1

Epilepsy Networking & Recreational Groups for Children, Adults, and Families

Connect 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.

Epilepsy and/or Seizures...