Making Dreams into Reality

Jenny is a young woman with autism and mental health challenges who attends EPI’s Day Habilitation Program. Jenny is also a comic book artist and the author and illustrator of Transformer Moon, an adventure-filled story that’s a creative mashup of Sailor Moon and Transformers. Mary, Jenny’s mom, says that Jenny has always been a big fan of Japanese culture and especially enjoys anime. When Jenny was a teenager, she wrote a letter to Hasbro Anime Studios asking if they were interested in producing her comic. She asked about Hasbro’s response to her letter every day for years and started telling people that Hasbro was going to produce a cartoon based on her comic in 2025.

In the summer of 2020, Jenny’s care team became concerned. Jenny’s dream of Hasbro producing her stories had only grown over the years and 2025 was not so far away. At a team meeting, Michael Helwig, Program Supervisor for EPI’s Day Hab, proposed a solution. “We can teach Jenny how to produce and animate her comic on her own. We will support her in finding an animation program and setting up a YouTube channel to publish the cartoon.”

And so, Jenny, along with Mike and KK, Jenny’s favorite Day Hab staff member, set about learning how to create a digital cartoon using Adobe on an old Day Hab iPad. They were able to complete an animated trailer for the forthcoming series. A grant from the Golisano Foundation enabled EPI to purchase a brand-new iPad that runs Adobe much faster and is dedicated solely to Jenny, making her work much easier.

COVID-19 and necessary quarantines passed much of the animation work, but Jenny, newly energized by the creation of the trailer and the new iPad, put her quarantine time to good use and has written and illustrated all the way up to Season 6, Episode 44.

“If Mike and EPI hadn’t stepped up, I don’t know what we would have done – Jenny would have been devastated. Producing Transformer Tales is the single most important thing in Jenny’s life.” Says Mary, Jenny’s mom. “Mike, KK, and the team at EPI have been incredible at supporting Jenny’s dreams. It means everything to her.”

Mike and KK had no prior experience in creating a digital cartoon, but they recognized the importance of this dream to Jenny and took on the extra work of researching and learning the digital tools needed, so that they could teach Jenny how to become her own animator and digital producer.

Now, Jenny is back at Day Hab Program after an extensive COVID quarantine. You can view her trailer at www.springy.org.

And don’t forget to follow EPI on Facebook for more exciting episodes of Transformer Moon, written, illustrated and animated by Jenny.

ON-SITE COVID-19 VACCINE CLINICS

People with intellectual and developmental disabilities face increased risk of contracting COVID-19 due to frequent contact with support service providers and to often co-existing health conditions. Scheduling COVID-19 vaccinations, difficult for most of us, is often an almost insurmountable challenge for people with disabilities and their families. In addition to lack of access to the Internet and the high-level computer literacy required to schedule an appointment, it is very challenging for people with disabilities to go to a mass vaccination site due to behavioral needs and sensory issues.

In partnership with the UR Medicine Mobile Vaccine Unit and Complex Care Center, we were excited to host on-site COVID-19 vaccine clinics to vaccinate people we support and our staff. Not only were we able to offer the vaccine to people who live in our residences or attend our programs, but EPI also reached out to people with disabilities in the community and coordinat ed all aspects of the vaccination process, from securing the necessary consent to transportation and scheduling. More than 60 people received vaccines at our on-site clinics. We are all in this together, and we are proud to do our part to end the pandemic.
From the President
Jeff Sinsebox

With the new year, setting our sights on the future, we launched our new name, brand, and website.

Our old name was adopted at the time of our merger in 2012. Our legacy agency partners had long complicated names: Epilepsy Association of Greater Rochester (EAGR), Epilepsy Foundation of Rochester – Seneca – Binghamton, and People Rebuilding and Living in Dignity or PRALID. Bringing two agencies together was not a easy feat and there were strong opinions about what our name should be. In the spirit of compromise, a placeholder name was given to the unified entity, Epilepsy-Pardal, Inc. While this unique name solved some problems, it caused others. Some people thought we only served people with epilepsy and that simply is not true. Our name also did not reflect our culture, our identity or convey excitement for our mission and vision. As a convention, we often shortened our name to EPI.

The agency has seen significant growth in the last decade, significantly expanding our services. More importantly, we have implemented innovative service models that offer individually with disabilities and their families, expanding flexibility and more choices to the services they need to improve their health, well-being, independence, and social inclusion. It was time for us to brand.

With wonderful facilitation by Jim Forward, of Forward Branding, we were able to talk about who we are, where we are going, and what important parts of culture and experience we want to share with the world. Through an extensive and inclusive process, we landed on the name Empowering People’s Independence or simply EPI.

Our name embodies the spirit of who we are and what you can expect from our services. It holds true for all the populations we serve and is the common thread in all we do. Our logo emphasizes the “P” for independence and represents the individual who is front and center in all our efforts.

Those who know us as “EPI” can continue to know us that way and our email and web addresses have stayed the same.

We have also launched our sub-brand, Epilepsy Alliance of Upstate New York, highlighting our commitment and participation as a founding member of Epilepsy Alliance America. Through this partnership, we hope to find national solutions to epilepsy challenges executed on the local level.

Our beautiful new brand needed a robust, modern website and indeed we were able to deliver. Our previous site was more than 10 years old – an eternity in this technological age. I am proud to say we have a website worthy of our size, scale, and impact on the community.

The momentum is continuing as we work to update our strategic plan while we navigate this rapidly changing world. All these efforts are EPI focused on our commitment to people we serve, flex and adjust to the challenges of the day, and continue to move us on a path towards a brighter future.

New Services for Children and their Families

Earlier in 2021, EPI launched new services for medically or behaviorally complex children and their families. Offered under the New York State Home and Community-Based Services Children’s Waiver (HCBS), EPI’s new services provide flexible supports for families with a child or youth who needs extra care at home or in the community. The goal of the program is to avoid hospitalization or long-term facility stays for children or youth who are medically fragile, or have physical or medical disabilities, HIV/AIDS, or mental health disorders. HCBS services provide the support needed to enable children or youth to be successful at home, in school, and in their community. Each child or youth is supported with tailored and flexible services that allow them to learn new skills and achieve educational, employment, and life goals.

These flexible support services are provided by highly trained staff at locations and times that best suit each family. Please visit our website at epiny.org to learn more about EPI’s HCBS services and eligibility. Or call (585) 442-6200 x2260.

A Young Epilepsy Awareness Warrior!

A Met成都 Project is a graduation requirement at Our Lady of Mercy High School. For her Met成都, Gracie Viera, a senior at Mercy, organized a fun and unique event to raise funds and awareness for epilepsy. On Sunday, February 21st, Gracie held a fundraiser at the Warrior Factory - an American Ninja Warrior Obstacle Course Gym!

Epilepsy is a condition that affects Gracie’s family and she felt it crucial to bring awareness to this condition. This fun event raised more than $700 for EPI’s epilepsy services. Great job, Gracie!

Want to organize your own fundraiser to benefit EPI? Contact Jill Johnson at jilljohnson@epiny.org.

Gracie’s friends and family (bottom right) were among the more than 70 people who participated in this very challenging fundraiser.

Calendar of Events

May 2021 – August 2021

Chocolate Ball (on the small screen!)
Join us for an evening full of chocolate, cake, and camp! Get tickets and learn more at chocolateball2021.com.
Monday, May 10th at 7:30pm
13WHAM ABC or live streaming on chocolateball2021.com

1 in 26
Our challenge to support epilepsy services is back!
October 1-26

Camp Coast
Robby Sunshine Camp
June 20 – June 25
Register: https://www.epiny.org/epi/youth/camps/camp-coast/

Camp EAGR
YMC Camp Weona
July 25 – July 31
Register: https://www.epiny.org/camps/eagr/

Self Advocates Monthly Meeting
Join our Self-Advocate Group and learn how to stand up for your rights! This group meets virtually and is open to all adults supported by EPI. Contact Megan Hesketh at (585) 442-4300 x2230 or mhesketh@epiny.org to register! Upcoming monthly meeting dates:
May 3rd, June 7th, July TBD, August 2nd. All meetings occur at 3:00-4:00 pm.

Epilepsy Webinars
Our monthly webinar series features epilepsy specialists on a variety of educational topics. RSVP to Michael Radcliff at michael@epiny.org for the webinar link.
All webinars are on Wednesdays from 5:30pm – 6:30pm.
May 19th: Psychogenic Non-Epileptic Attacks (PNEA) with neuropsychologist Dr. Bill Watson and Dr. Dan Millstein from UR Medicine-Epilepsy Center.
June 16th: Epilepsy Medications/Surgery with Dr. Thomas Wychowski from UR Medicine-Epilepsy Center.
July 21st: Ketogenic Diet with Nicole Brescia, a registered dietitian at UR Medicine-Epilepsy Center.
August 18th: Epilepsy in Schools with Dr. Inna Hughes, pediatric epileptologist at UR Medicine-Epilepsy Center.

Epilepsy Networking & Recreational Groups for Children, Adults, and Families
Connect with others facing the challenges of epilepsy in your area! RSVP to Michael Radcliff at michael@epiny.org for Zoom link or in-person meeting information.
Broome/CNY Epilepsy Networking 5/13, 6/10
Camp Hang Outs $26, 6/23 (for all current & former campers & counselors)
Rochester Epilepsy Networking 7/16, 8/3
EPI Rev 6/21, 6/9