Love what you do

Whether it’s at work or play, with friends or family, people should love what they do. Finding ways to enjoy life, add purpose, and develop meaning is often easier said than done. I am inspired by those who give in the capacity they are able. Whether offering knowledge, time, money, or their presence, people who find value through service make our community a better place. The simplest of measures often foster the most significant outcomes.

At EPI, I feel lucky to see so many examples of service. If you visit Camp EAGR, you cannot help but see the efforts of 20+ volunteers in action. Our volunteers give us a week of their lives each year. Spending time away from their families and using their precious vacation time, they work as hard as staff and emanate passion and commitment to what we do. If it weren’t for their efforts, it would be challenging for our Agency to continue Camp.

So many different people support our efforts in a variety of ways. Individuals, families, volunteers, donors, board members, vendors, friends, current and former staff all pitch in quietly and effectively to make us better every day. Many of our programs run on the generosity of donors. Doors have been opened for us because people were thinking of us and made a phone call or arranged a meeting. We are better organized and serve individuals more efficiently because of the expertise, passion, dedication, and effort of the people surrounding us. From neurologists sharing their knowledge, to a ten-year-old participating in the Salt City Walk, volunteers spread awareness and empower others to do the same.

EPI would not be what it is today if it weren’t for the participation of so many unsung advocates. To all of you who make us what we are - thank you!

Updates on expansion

Twist Run

Construction is well under way and slated to be completed by July. We are on track for the home opening in August of 2015.

The backyard at Twist Run in Binghamton, NY.

Pigeon Hill

We have received all State approvals and have officially taken ownership of the Pigeon Hill residence in Binghamton, NY. The architect will collect bids from contractors, with a goal of late summer construction and a December opening.

Broome Developmental Center

We are actively seeking a permanent office, as well as a Day Program site in Broome County, with the intent of having the locations confirmed by August. Our current/temporary office is in the Broome Developmental Center (pictured below) located in Binghamton, NY. Here, we have been working on transition plans, actively recruiting employees, and preparing for the opening of the homes, as well as the Day Program services.
Dog Attack Sparks Frustrating Journey

It happened in the briefest of moments. Toni Breck went inside to get a blanket for her newborn daughter, while her four-year-old, Josh, was playing in the sandbox. She heard her husband screaming, and ran outside to see a “wolf-dog” (part dog, part wolf, according to police) throwing her son around with his head clenched in the animal’s jaws.

This was in 1983, when education regarding traumatic brain injuries (TBI) was minimal at best. Josh went years misdiagnosed. As he grew into his teen years, his “odd” behavior prompted drug testing (which produced negative results), mental health assessments, and arrests. Josh was given pharmaceuticals to help with his “bipolar disorder,” which seemed only to erode his personality. His schooling was spent in Special Education classes, and he graduated with an IEP diploma.

The discovery of Josh’s TBI occurred when he was about 17, despite the fact he had been living with it since he was four. When he was 14, he began a pattern of breaking into unlocked cars, taking credit cards, and would then buy small items, such as Chapstick or gum.

Josh was arrested nearly 25 times. During one incident, he stole the judge’s credit card and later charged $6.51 worth of pop, newspaper, gum, and a donut. The charges were always minimal, but Josh’s repeat offenses landed him in jail. His jailtime resulted in physical abuse by other inmates and a lack of support – support which he needed for his TBI. Most recently, Josh faced seven years in prison if he committed another offense. Meanwhile, the impulse control behaviors causing the arrests were not addressed. The race to get Josh help had more pressure behind it than ever.

Toni and her family had been fighting for years trying to get Josh the support he needed. There were a couple programs the Brecks explored, such as a Day Program at an organization in Auburn. The structure and routine seemed to help. However, unexpected complications and a turnover in staff led to Josh having to leave the program.

Toni was frustrated. She knew her kind-hearted son did not belong in jail or prison, but her family was struggling to find the support Josh needed. Her son’s outwardly “normal” adult appearance and criminal history caused rejections from agencies.

Seemingly out of options and desperate, Toni called Dr. John Langfitt at the University of Rochester Medical Center (URMC) and begged him to do something for her son. After all, the URMC team had been the first to educate the Brecks about Josh’s TBI. Dr. Langfitt connected the family with EPI. Morgan Jackson, EPI Intake Supervisor, worked indefatigably on Josh’s behalf, enduring rejection after rejection, to finally get him the help he needed.

Today, at the age of 35, Josh is at last receiving the support he needs at the Northeast Center for Special Care.

To Toni Breck, Morgan Jackson is a hero. To EPI, it is people like Toni, Josh, and their circles of support who are also heroes – those who refuse to relent, who continue to advocate, who help to prevent the same experience from happening to other families by sharing their story.
WHY CAMP EAGR?

**MARISSA’S STORY**

In 2011, I came to Camp EAGR as a first-year counselor and I went to camp to meet other people who have epilepsy. I am the only one in my family with epilepsy so I was very excited to get to know others who share this in common with me. The friendships I made at Camp EAGR are very special to me. This is a great place to come and have fun for a week, and not feel different from other people. I know at Camp I feel comfortable and confident about myself. I come back to Camp each year so the kids can enjoy themselves for a week and because I also have a great time at Camp EAGR.

**CARRIE’S STORY**

Camp EAGR is home to me. It is the best place on earth to me. It came into my life just after I turned 13. I was scared and felt alone a lot of the time because I was afraid of my seizures. Camp EAGR helped me to realize that it is okay to be different, that it is okay to speak up and share your knowledge about seizures. Camp EAGR enabled me to be comfortable in my own skin. It gave me the chance to be a ‘normal kid’. Now, as a counselor, I get to watch children come to Camp as a ‘new kid’ and leave as family. I love Camp EAGR.

**VANESSA’S STORY**

I have been going to Camp EAGR since 2009. My first year at Camp EAGR, I was 12-years-old and very shy. I had never been away from my family. I was crying into my Dad’s shirt at the check-in line. When my parents left, a counselor named Diana made friends with me, so that I wouldn’t feel alone. We did a lot of activities like arts and crafts, archery, nature, group challenge, low ropes, rock wall and horses. Nature and horses were my favorite activities.

My second year of Camp, I was in the Mohawk cabin. I met my first friends - Emma and Tatiana. Emma pulled me out of my shell. We drew together and sang camp songs after the camp fires were over. My friend Tatiana had the worst laughing attacks before we went to bed. At the camp dance we danced together and had fun.

My third, fourth and fifth year of Camp were fun, because I met new friends every year and became less shy.

This past year I was a Counselor in Training and I was in charge of helping the 8-10 year-olds. It felt good to be there for the girls to help them when they were nervous or homesick. I’d distract them with jokes or games until those feelings went away.

I come back to Camp every year to see my campers and friends and to create new ones. Camp EAGR is important to me, because it has taught me that I am not the only one with epilepsy and I should share that with the world. It also taught me that I can make a difference in a camper’s life and teach each to be proud of who they truly are -- disability or not.

How can you help keep the Camp EAGR experience alive? With support from generous donors like you, we are able to provide kids with epilepsy and their siblings a place where they build confidence, friendships, and meaningful memories.
Sunday, May 31
Epilepsy Awareness & Family Fun Day
Bay View YMCA | 12-4pm
Join us for your favorite camp activities, including rock wall climbing, hiking, bounce houses, digital animation along with arts/crafts/science, canoeing (weather permitting), and more! There will also be a keynote speaker, epilepsy info, and snacks. Register at www.epiny.org.

Friday, June 5
EPI’s Agency Picnic
Frontier Field | Dinner 6:15pm
Join EPI as we celebrate summer on June 5th at a Red Wings baseball game. Gates open at 6 pm, dinner starts at 6:15 pm, game starts at 7:05 pm. Tickets are $5 and will be available to purchase until May 25th. Admission for EPI participants and also for children under four is free. If you are a participant in one of our programs, please contact Camille at (585) 442-6420 or cfuentes@epiny.org.

Saturday, July 11
Long Branch Park, Syracuse
9-11am
Join us at the annual Salt City Walk for epilepsy! A light breakfast and snacks will be provided along with lots of family-friendly activities. New this year will be a team t-shirt contest! Register at www.epiny.org. Contact Mary Nicholas for more details at (585) 442-6420 or mnicholas@epiny.org.

August 9-15
Camp EAGR & Camp Coast
Gainsville, NY
Registration for our summer camping programs is open! For more information, please visit our website at www.epiny.org or contact camp director, Mike Radell at (585) 442-4430 or mradell@epiny.org.

You can have the best week of your life!

Sunday, October 25
Al Sigl Community Walkabout
Eastview Mall, Rochester
This family-friendly event has over 25 entertainers and trick-or-treat tables. To register, go to www.alsigl.org.
Recently, I had the privilege of telling my peer she is my hero. She once had plans to accomplish great goals, but certain aspirations came to a halt when she got into a car accident in high school. As a result, she now has a traumatic brain injury (TBI) with short-term memory loss and emotional volatility, among other effects. However, she manages to stay positive and keep her head up.

I was born with Cerebral Palsy (CP), and have only very early memories of walking, with a little help. Growing up in an era when many treatments were “experimental,” I underwent 17 surgeries, few of them resulting in a positive outcome and none of them resulting in the ability to walk. Therefore, very little of my memory involves life without a wheelchair. I am unable to miss the things I never truly had.

Many of my peers envisioned their lives in a particular way – one had plans to be a carpenter – when an event forced their futures in a drastically different direction. My peers live with unfinished plans that will never be made whole, and pastimes that can never reoccur. Yet, despite all of the challenges individuals with TBIs or developmental disabilities face, there is an abundance of opportunity to create new goals, new aspirations, and new plans. What is truly impressive is when people can focus on opportunities and take action to make them come to fruition.

To me, these are the real heroes --those who experience loss, including physical, emotional, and intellectual, and who must live with the constant feeling of missing something they can never get back. It is these people who remain positive and strive to create new plans for the future that help to guide me. And I will keep coming back, so that I can help guide them.

**Rebecca’s Corner**

*Rebecca Papaleo: Featured Contributor, Receptionist, and Day Program Participant*