

EPI Matters



A successful partner for all individuals with developmental or acquired brain conditions

Vol. II Issue II Fall/Winter 2014



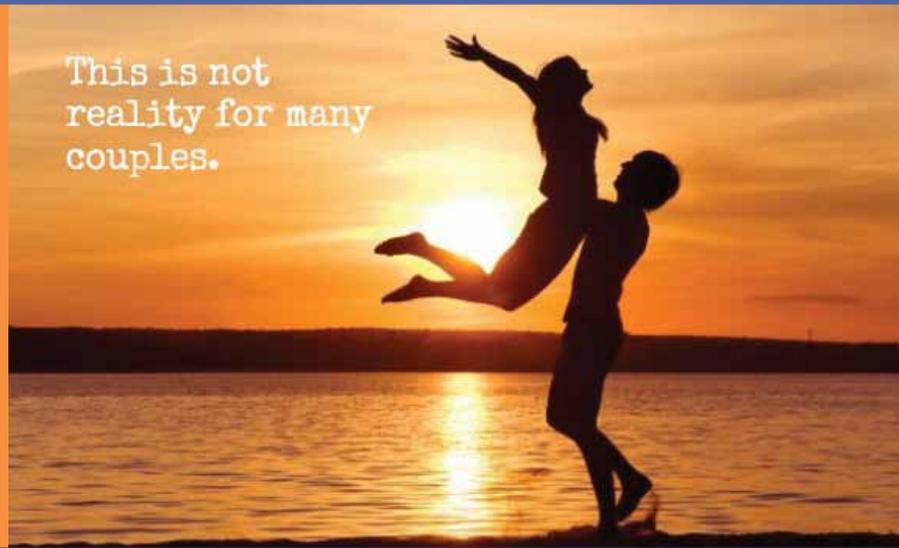
Thank you

for another successful year of Camp EAGR! The campers go horseback riding, swimming, canoeing, rockwall climbing, and more because of you. As only one of only a handful of overnight camps for kids with epilepsy (and their siblings), Camp EAGR draws children from all over New York State. Go to our Facebook page to see the photos from Camp EAGR 2014!

Rebecca Papaleo tells us what it's really like dating

(see inside article), "It's Not Like What You See On T.V." For many couples with disabilities, their romance is far from a T.V. fantasy.

This is not reality for many couples.



Medical marijuana continues to grow as a point of conversation within the epilepsy community.

In New York, medical marijuana is now legal...but it is going to be a while before it can get to patients. We are keeping up-to-date with this topic and offer resources on our website. Go to www.epiny.org for more information.



From the President



Jeff Sinsebox, President, bravely accepted the Ice Bucket Challenge in honor of Sheila Appleby and other agency families affected by ALS.

If someone had told me a year ago I would have the opportunity to expand our mission, meet unmet community needs for our target populations, increase the relevance of our organization, grow the agency by at least 10%, and save taxpayers \$16 million dollars annually, I don't think I would have believed them. Hard work, creativity, and good timing have provided us with a fantastic opportunity that will accomplish all of the above.

In March, we attended a meeting in Binghamton regarding the closure of the Broome

Developmental Center. Our invitation came from the success we've had with people we transitioned out of Monroe Developmental Center in 2013. In a short span of time, we moved this project from planning phases into active development. At minimum, we plan to open 2 group homes and associated day services for 10 people that currently live in the Broome institution.

But there are many other benefits of expanding services into Binghamton. Not only will we be able to serve these 10 individuals, but the door has been opened to serve additional people with individualized day services. The staff at Broome have also asked EPI to expand service coordination. Additionally, our managed care relationships have led us to Binghamton where the lack of existing providers has created service gaps for a variety of populations including those with epilepsy and traumatic brain injuries.

One of the most important reasons to open an office in Binghamton is tied to our commitment to the Epilepsy Foundation of America. Binghamton is within our 22 county catchment area, and has

long been underserved by our agency. We currently provide some service coordination, education, and support to a small number of people there. Years ago a grant had funded a small office in the region but when it ended, we moved control of the services to Syracuse. Operations in Binghamton have been stagnant for years despite requests to expand.

All of these reasons have put us on a rapid track to develop our programs. We are now finalizing the purchase of a home and are planning to renovate it this winter, with a planned opening slated for late summer or fall of 2015. We will purchase a second home over the next few months and hope to have that home opened by next winter. Within 18 months, we anticipate 25-30 staff working in the Binghamton region.

The initiative in Binghamton strengthens our effort to move people into less restrictive settings. It allows us to provide greater support to people in rural regions. It will continue assisting us in our transition to managed care, while enhancing choice for the people we serve. Our donors trust us to be accountable, and we show this through outstanding service resulting in growth.

“The initiative in Binghamton strengthens our effort to move people into less restrictive settings.”



It's Not Like What You See on T.V.



Rebecca Papaleo, front desk staff and Day Program participant

It's not like what you see on TV. We can't just hop in a car and go. The places we travel are limited, holding hands isn't easy, and walking off into the sunset together remains a dream as distant as the sunset itself. We are two people with disabilities, and though I wouldn't trade what we have for the world, I would like the world to get a glimpse into what dating is like for us.

My boyfriend has a traumatic brain injury (TBI) and I have cerebral palsy (CP). Because of his TBI, he says a lot of things that wouldn't be acceptable in a "normal" relationship. I have to choose what to ignore and what not to ignore. I have to have thick skin. When we want to go out, we have to work around potential shortages of staff, barriers to transportation, and coordinating times. Physically, I can't do some of the things I would like to do as a girlfriend, and our relationship is far from the "romance" you see on TV. This is the reality.

"I have learned that there are different ways to express and accept love."

Throughout my life, I've heard words of discouragement (from myself included) – "It's too dangerous," "It's not a good idea," "It's too difficult", and "There are way too many barriers." Any relationship is continual work, but when both of the people in the relationship have a disability, the amount of work multiplies. I have learned that you have to want it, and *really* want it, or it's never going to work. I have learned that there are different ways to express and accept love.

People are afraid for my boyfriend and me. Instead of seeing the beauty in what *does* exist, they fear the hurt that *could* exist – physically, emotionally, and psychologically. But isn't the risk of falling in love what makes it most exhilarating?

I am 57 years old and fully capable of knowing what's good for me and what isn't. The concept of individuals with disabilities dating each other is uncomfortable for a lot of people. But I will not let others' discomfort get in the way of me living. My choice to date continues to provide necessary fulfillment in my life.

Get involved and meet other donors at these upcoming events!

October 26th

Al Sigi Community Walkabout

Eastview Mall



November Epilepsy Awareness Month

Holiday Party
(Rochester and Syracuse)
date TBD



Feb. 7th Chocolate Ball

Epilepsy Support Groups

Broome County 6:30pm – 8:00pm

3rd Thursday of each month

Wilson Hospital, Picciano Building

Cafeteria Conference Room

Johnson City, NY

Tompkins County 6:00pm - 8:00pm

2nd Tuesday of every month

Tompkins County Public Library

Borg Warner Room

101 E. Green St., Ithaca, NY 14850

Onondaga County 6:00pm - 7:30pm

4th Tuesday of every month

Epilepsy-Pralid Inc. (New Address)

1065 James St., Suite 220

Syracuse, NY 13203

Rochester 6:00pm - 7:30pm

1st Thursday of every month

Epilepsy-Pralid Inc.

1650 South Ave., Wolk Building, Suite 300

Rochester, NY 14620

**View our upcoming events
in more detail here:**



You Are Generous; We Are Accountable

How your 2013 contributions helped others

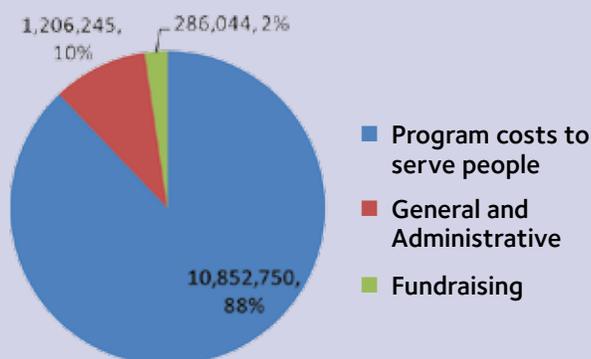
Your support of EPI is not something we take lightly. We work diligently to make every gift go where it's needed most – to the people who turn to us for help.

General and administrative costs: 9.8% (*target 7%-12%). This gives us the highest efficiency rating according to charitynavigator.org! Nearly \$.91 of every \$1.00 you donate goes directly to providing the services for the people who entrust EPI with the task of supporting the life of their choosing.

What are the administrative expenses?

Administrative costs are critical to the organization. They keep a roof over our heads and keep the departments running smoothly. Furthermore, they allow for things like employee development, which boosts both functionality and employee morale.

Expenses



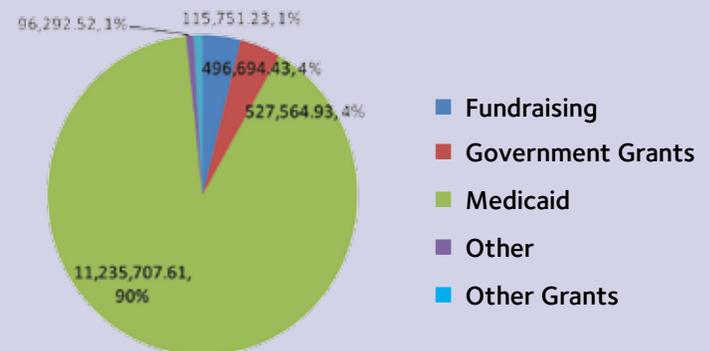
Fundraising: 2.3% (*target 1-3%) of total expenses

Surplus: \$126,457, 1% of revenue. We operated at a surplus during the merger.

Total assets increased \$1.3 million; EPI continues to grow by making programs relevant and cost effective.

*Target range used is from the recommendation of auditors, and is based on local benchmarks with similar sized and non-profit agencies.

2013 Revenue by Source



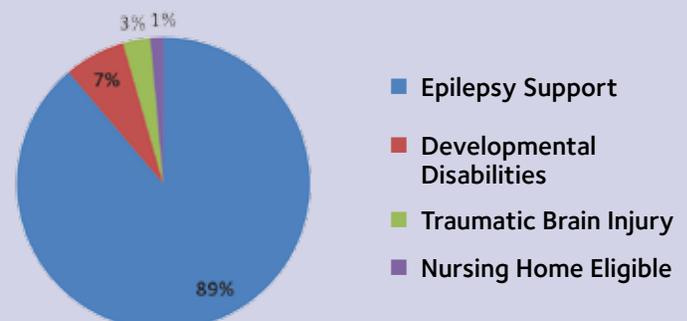
Number of employees: We currently have over 350 employees. With the opening of the Binghamton programs in 2015, we will continue to grow, and anticipate 400 total employees by the end of next year. At the time of the merger (in early 2013) there were about 240 employees.

Development in 2015:

Binghamton

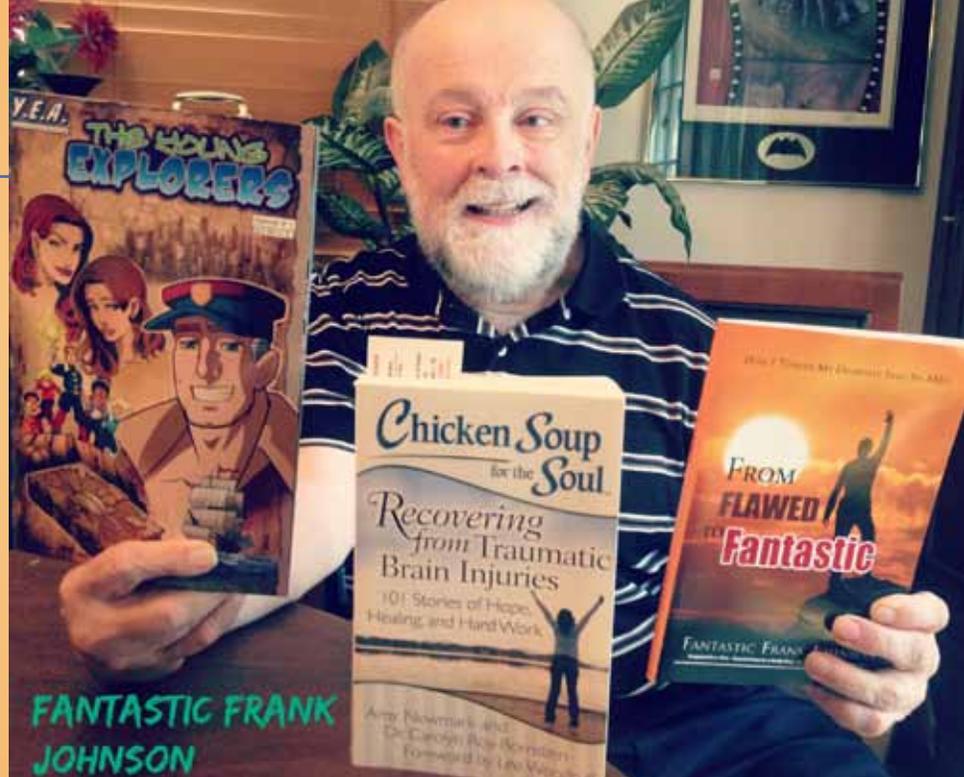
- Opening of two residential homes; Broome County
- Day Program correlated with residential homes; Broome County
- Medicaid Service Coordination
- Expansion of epilepsy services
- Managed Long-Term Care (MLTC) Programs

Population Served



Giving back...

His name is
**Fantastic
Frank Johnson**
and he believes everyone
has a hidden power inside
of themselves.



His name is Fantastic Frank Johnson and he believes everyone has a hidden power inside of themselves.

In this lifetime, Frank has been a chemical engineer, a bar owner, co-owner of one of the first mail-order comic book companies in the country, and creator of the first Clarkson University hockey record book. Frank's creative endeavors include originating *Young Explorers*, composing a copywritten song ("Hero In You"), and authoring a book, *From Flawed to Fantastic*. You can even read about him in Chapter 76 of *Chicken Soup for the Soul Recovering from Traumatic Brain Injuries* (purchase at tbisoup.com). The list goes on, but Frank's real success lies within his ability to inspire others.

Over 30 years ago, Frank was dragged out of his bar, Mugs Up, in a body bag. There had been a fire, and when Frank regained consciousness from his coma, he

was told his survival was a medical miracle. Breathing in carbon monoxide from the fire deprived Frank's brain of oxygen long enough to cause a traumatic brain injury, which greatly impacted his speech and fine motor skills. To this day, Frank has to pay keen attention to his diction so that people can understand him. Physical limitations have forced him to give up hobbies such as playing guitar.

"...He was told his survival was a medical miracle."

A period of emotional and mental distress followed the fire, along with a newfound habit of hoarding. When Frank finally sought help from a local church, twenty people came to his aid to clear out his house. Frank recalled a very special Thanksgiving meal at the Church and explained, "It wasn't until seven or eight

years ago that I found out I had a traumatic brain injury (TBI), and that there were services that could help me." Prior to this, Frank was unaware that his hoarding, speech impairments, and other mental/physical barriers were due to the fact he had a TBI. Although TBI awareness has greatly increased since the 1980s, the need for education and outreach is vast; EPI provides this service to the community so that people like Frank will not have to go years without support.

Sharing his outlook on life, Frank emphasized his need to surround himself with positive people. Frank receives Independent Living Skills Training through EPI, and continues to share his contagious vigor for life with those he encounters.

To learn more about Fantastic Frank Johnson and his work, go to www.fantasticfrankjohnson.com

Save the Date!

Chocolate Ball

February 7, 2015



*Donate
Today!*

How your generosity helps adults with traumatic brain injuries

What your gift can provide:

Group memory games

Supplies for cooking

Wii games for the Wii experience

Yard games for outdoor (or indoor) fun

Reading time supplies

Learning time presentation tools

Basic Program necessities needing replacements

Appliances - to take the cooking experience to the next level

Holiday decorations for Holiday cheer

Interactive video game system

Big Screen TV for the interactive video games



Keep these smiles coming!

Many of the people we serve are on fixed incomes that only cover the most basic needs. We're looking for a few Good Samaritans to provide the little extras that can make someone's day. Please make a gift to keep these smiles coming!