You made it happen!
Thanks to donors to our new “Green Light Fund”, a group of individuals with traumatic brain injuries attended a special screening of The Crash Reel, a documentary about snowboarder and Olympic hopeful Kevin Pearce’s accident and subsequent rebuilding of his life as a TBI survivor.

A photography student generously donated a two-day photo shoot to update our marketing images. Thanks to Lisa, Alex, and everyone else who agreed to participate.

Thank you to everyone who supported the Chocolate Ball! Over $125,000 was raised to support epilepsy programs and services.

Teaching kids to be generous; the Wagner family and others share how See story on page 4!
Jeff Sinsebox, President
Artist and participant Vincent has produced some outstanding portraits this year, including this one of Jeff Sinsebox. See more of Vincent’s work on www.facebook.com/EFofRSB.

In the 1990’s two disabled women from Georgia lived in a state-run institution and couldn’t get out. They sued and their case eventually went to the Supreme Court. What started as an all-too-typical situation for people with disabilities became a landmark court case. In 1999, the US Supreme Court ruled that unjustified segregation of people with disabilities violates the Americans with Disabilities Act. The ruling, called the Olmstead Decision, has had a cascading and profound effect across the country.

New York’s response to the decision has been dramatic – reduce the institutional census to 150 people in only a few years. Our State government is attempting to close several mental institutions and reduce the census in nursing homes, as well as freeze sheltered workshop enrollment and limit congregate housing to four people per new setting. This highly concerted effort is being made to ensure citizens with disabilities live, and are served, in the least restrictive environment possible, increasing integrated employment opportunities, and expanding services that occur within the community. The push for individuals to self-directed services has never been greater.

These changes have created strong responses across the State. Some traditional providers are skeptical of the State’s ability to execute the plan and fear the impact on their participants and their own organization. Many advocacy groups are thankful the State is finally addressing its duty to tear down the barriers of integration. Others claim that Olmstead is a vehicle for service-rationing and cost savings at the expense of those served. The conversations occurring have stressed individuals, families, agencies, and State officials alike. But the situation doesn’t have to be dark.

In every point of change, there is opportunity. Right now, a golden opportunity arises to amend the system. Services that do not currently exist will be created. Existing services will be improved. The choices of the individuals and their families must be heard. At Epilepsy-Pralid, Inc. we see the value of traditional and non-traditional services alike, with the core of all services driven by the people who receive them. The wider array of services available and the more provider options each person has, the better.

Good customer service and the ability to generate creative solutions shouldn’t have to come from a government mandate. Our role is always to be part of the ongoing conversation about continuous improvement. It should be in each person, in each organization, and in the collective will of all to make our world better for everyone.

For more info on Olmstead
http://www.governor.ny.gov/olmstead/home
http://www.ada.gov/olmstead/index.htm

“*The Olmstead Decision, has had a cascading and profound effect across the country.*”

Elaine Wilson and Lois Curtis had to sue the state of Georgia to be allowed to leave a state-run institution and live in the community with supports.
Get involved and meet other donors at these upcoming events!

May 8th UW Day of Caring
We have several projects registered. Call (585) 242-6492 or email dayofcaring@uwrochester.org for details.

June 12th
Agency Picnic
Frontier Field

July 12th
Salt City Walk
Long Branch Park, Syracuse

July 17th
Segar Scholarship Luncheon
Three $1,500 college scholarships are available for people with epilepsy. Apply at epiny.org/epilepsy-scholarship.html

August 10-16
Camp EAGR
Gainsville, NY
Make new friends and experience things you might not get to do anywhere else. It will be one of the best weeks of your life!

July 24th
ADA Celebration
Syracuse

October 26th
Al Sigl Community Walkabout
Eastview Mall, Rochester

Go to www.epiny.org for details
How do you teach children gratitude?

For many of us, gratitude is learned at home. By creating opportunities for your children to experience the simple, non-material joys of life you are allowing them to learn the joy that giving can bring.

The Wagner family has made their support of Epilepsy-Pralid, Inc. a family affair. Fred, his late wife Marilyn, and their five children “adopted” EPI’s Wagner House in East Rochester, where residents loved the huge family atmosphere they brought with them.

“We would come each Christmas and put up the tree together” recalls Fred. “We’d share a meal and open presents. My grandkids really got into the spirit and started asking our family to make gifts to the men and women at Wagner House in lieu of Christmas presents.”

Through births, deaths, and moving to other places, the Wagners have remained close to EPI and a new generation has learned the joy of helping others.

If you have stories of your traditions in giving, we’d love to hear them! Post them on our Facebook page www.facebook.com/EFoRSB and we can feature them in an upcoming EPI Matters!

Other families have helped their kids learn to give back. Read some other examples of how young people are supporting EPI:

• Erica wrote a book about her experiences as a camp counselor at Camp EAGR and donated the proceeds.

• Tatiana is raising money for camp scholarships through the Mudderella event.

• Paige and Grace raise money for the WalkAbout.

Nicky lobbies elected representatives to support epilepsy research.
From the rolling hills of upstate New York to the city streets of Chicago, from the volcanic islands of Hawai’i to the frozen tundra of Alaska, Randy was living an adventurous life as the driver of an 18-wheeler truck in the 70’s and early 80’s. Randy did not take his ability to travel for granted; he was instead an opportunist, taking side trips to explore unknown territory on his own.

Then, in 1984, with nothing out of the ordinary to set this day apart from any other, Randy’s truck tumbled off the Pennsylvania mountains into the Allegheny River. His life would never be the same.

Randy, like many other TBI survivors, has radically altered his life to cope with his near-total short-term memory loss.

Through EPI’s TBI services, Randy is able to live an independent life—and an active one at that.

When talking with Randy, it is easy to see the personality of the young “go-with-the-flow” adventurer. When asked how his TBI affects him, Randy replied “I’m still happy with my life.”

Anti-freeze brought him to Alaska, oranges brought him to Florida, and his TBI brought him to New York. Randy continues his adventure, with his ever-present optimistic outlook on life.

“A story from the field...

“TBI survivors have radically altered their lives to cope with their near-total short-term memory loss.”

After remaining in a coma for nearly four months, Randy looked remarkably unharmed. He was, however, profoundly injured. Randy sustained a substantial traumatic brain injury (TBI), having taken the brunt of the accident on his skull.

One of the most difficult struggles for Randy was the stark realization he would not be able to go back to the work that he loved. “You crave what you used to do, you miss it” Randy says.

Randy is not alone in his situation—among all age groups, motor vehicle and traffic-related accidents are the second leading cause of TBIs.1 Kay Smith, Director of clinical services at EPI, shared some insights regarding the most common consequences of TBIs. “Individuals with TBIs can have aspects of their personalities dulled or amplified...someone who was neat and organized can turn into a hoarder. Short-term memory loss is extremely frequent. Impulse control is often affected and individuals typically experience a speech disorder which can cause slow or rapid speech.”

Small Gifts Matter
Do you ever wonder if a little bit can make a difference? Read below to see that it can!

$10 Sends an individual in our Structured Day program on an outing – a movie ticket, trip to a local museum or farmer’s market for example

$25 Allows an individual with a TBI to go grocery shopping and prepare a meal with a little help from staff

$50 Teaches 20 kids about edible and poisonous plants at Camp EAGR

$75 Turns a bare apartment into home for an individual newly living on their own

Rebecca’s Corner
Front desk staff and Day Program participant

In 1957, the lack of organizations and technologies available for individuals with developmental disabilities resulted in the false belief that sheltering individuals would produce the “best” life for them. The last time I rode in a bus, I was a toddler – I was carried on, not allowed to move from the arms of my guardian.

With the help of EPI, I will learn how the city bus system works and will ride the city bus for the first time, free from the sheltered arms of my past.

Before EPI, it was difficult to even dream of the realities I would eventually experience. From going to my first concert ever at CMAC last summer, to learning the city bus, EPI and modern-day technologies have opened up possibilities that continuously enrich my life.