

EPI Matters



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

Vol. I Issue I Fall/Winter 2013

At Epilepsy-Pralid Inc. (EPI), our mission is to be a successful partner for all individuals with developmental or acquired brain conditions as they strive to remove barriers to their personal fulfillment. EPI has an enduring legacy of partnering with those we serve, their families, and others in the community to provide education, training, advocacy, and tailored support solutions to meet the physical, behavioral, and social needs of each person who chooses our agency as a trusted resource.



A sea of purple t-shirts 300 strong.

And two became one

Epilepsy-Pralid Inc. is the new organization formed by the Epilepsy Foundation Rochester-Syracuse-Binghamton and People Rebuilding And Living In Dignity

Have you heard the news? The Epilepsy Foundation and PRALID have merged into Epilepsy-Pralid Inc. (EPI). The common mission of helping people with epilepsy and brain injuries makes this partnership a good fit.

In joining two small agencies, EPI is better able to weather reimbursement changes under health care reform. We are also able to consolidate expenses, meaning a **greater portion of your taxpayer and donor dollars are spent on services.**

What haven't changed are the same great services and staff, making the merger seamless to the 8,500 individuals and families we serve.

Brian revs the crowd at Frontier Field. He threw a great first pitch too.

Thank you!

- The Merger Task Force made up of Mark Armbruster, Lisa Bianchi, Michael Burns, Christopher Cebula, John Langfitt, and Jonathan Sacks. You preserved the best of what each agency had to offer.
- The United Way of Greater Rochester's Synergy Fund for providing two grants to cover merger related costs.
- YOU, our close friends and donors who have continued to support us with your gifts, your referrals, and your patience as we complete this process of becoming one agency.

See more great photos of our agency picnic at www.facebook.com/EFofRSB



From the President



Jeff Sinsebox, President

Recently I had the pleasure of going on a rafting trip in Letchworth State Park. The water levels were low and the Genesee isn't exactly known as a wild river, but nevertheless the day was full of adventure for me. This day offered me the ability to see a new agency service first hand.

For the past decades, the agency has delivered a quality overnight camp experience for children. The success of Camp EAGR has been so great that many children entering adulthood have not wanted to let go of the experience. We have invited many former campers to stay on as counselors, but not everyone had the cognitive capability to make this transition.

So this year we decided to try something different. We created a pilot young adult camp for six men, ages 18-26. It was to run concurrently with Camp EAGR and allow for an overnight camp experience, but gear activities more in line with their interests. In addition to regular camp activities, this camp was to have vocational elements, a service component, and a higher adventure offering for campers. Since this was the first time for this camp, I helped to choose and run one of the higher adventure offerings – a rafting trip.

I was hoping to have a little fun while evaluating the success of the camp. What I ended up with was one of the most memorable days I have ever had at work. The campers were excited and energized throughout the whole day and the smile on my face never left. My only regret is that I wish I had spent the entire week with the guys. After the trip as we ate our lunch, the campers and the staff all helped discuss ideas for next year.

Not only was this pilot a success for the campers, it resonated with funders too. We have received two small grants to help fund this camp next year and we should be able to at least double our participation. The success of our camps comes from the wonderful people who attend, staff, volunteer, and donate to make it possible. With all of the positive energy involved, there is no telling what we may be able to do in the future.



“It was one of the most memorable days I have ever had at work.”



Your support does GREAT things!

Thanks to the Golisano Foundation, we are building a respite suite in our newest home. Beginning in December, we will be able to provide temporary housing to people with developmental disabilities and intensive behavioral concerns who are in crisis or homeless. Ours will be the only local non-institutional option for this population.

▼ A new home for nine men, among the last developmentally disabled population to leave institutional care.



You raised \$16,000 at the Salt City Walk to support epilepsy services in Syracuse. See photos at www.facebook.com/EFofRSB

▲ Pictured above: Team Jeanne, one of our largest teams this year. Thanks to everyone who participated!



◀ More Camp craziness. Save the date! Camp EAGR will be August 10 – 16, 2014. Children ages 8-17 with epilepsy are eligible.

▶ You helped Ira go to camp by supporting the Camp EAGR appeal earlier this year. In fact, over 40 scholarships were awarded with your support!



Your support of Camp EAGR gave 61 kids with epilepsy and other disabilities the camping experience of a lifetime. The kids wrote thank you notes to every one of you. They really appreciate what you do for them!

Gifts recognizing others

We are pleased to recognize the following gifts made in recognition of others.

IN HONOR OF...

Debbie Baker's Birthday

Jeff Hathorn

Daniel Bayardi

Armand & Elizabeth Bayardi

Callie R. Craik

CJ Irwin Company, Inc.

Ron Dellapenta

Daniel K. Gordon

Christine DiOrio

Julia M. Chiarizia

Gabby DiOrio

Stephen Cavuto &
Madelyn Legg

The Emerson Family

Virginia Meade
Michael J. Underwood

Julia Emerson

John & Carol Mogler

Christine Fantauzzo

Jennifer DiCesare

Mary Gottlieb

Paul Gottlieb

Sophia Hazeltine

Michele Carroll

Laura Ann Hoh

Alice K. Hoh

Iannuzo Family

Lawrence Tuttobene

Eric Johnson

Donald Johnson

Sue Ladd

Bill & Pat Ladd Thurston

Erica March

Michelle Ricigliano

W. John Maxey

Albert & Charlotte Ellis

Douglas Mead

Gary Mead

Jane Muserlian

Nancy J. Muserlian

Vincent Ognibene

EEP Quality Group

Emily Osborne

Donald D. Osborne

Megan Perkins

Margot Perkins

Mike Radell

Daniel Meyers
Thomas Reilly

Christopher J. Ruisi

Christopher and Stacey Ruisi

Stephen A. Segar, Esq.

Daniel Meyers

Jackie Sortino

Joseph Sortino

Lauren Stuck

Maplemere Elementary School
Larry Stuck

Dave & Lynn Wilber

Janet Wilber

Elizabeth Wilhelm

KS&R

Ira Williams

Patricia Landry

IN MEMORY OF...

Sheila Appleby, Ph.D.

Michael Burns
Henry McCartney
Joan & Geoff Powell

James J. Boulger

Natale Anthony Cicciari
Ellen F. Fish

Pearl Cornelius

Ralph Palmer

Stephen C. Duell

Debbie Clark
Norman F. & Doris Paul
Richard & Lorie Schneider

Elmer Fahrner

David & Joanne Stewart

Mary R. Fitzpatrick

Shawn A. Fischer

Gerry Gallo

Francis McKenna

Carl G. Gianforte

Giuseppe Erba

David Iannuzo

Rosemarie Milliman
Paul Tuttobene, Sr.

Clairetta Ann Kehoe

Anthony & Mary Izzo
Joan Kehoe
Luann Kehoe

John Lester

Catherine Blackwell

Sarah Elizabeth McKeown

Binghamton Blizzard Girls
Hockey Association
Lorraine Bodenhorn
Janet R. Cook
Barry & Ann Driggs
Barbara Gannon
Robert & Sandra Hardin
William Infantolino
Robert Johnson
Gary & Terri Kircher
Liberty University
Marching Band
Kerri Lee Loveland
Richard McKeown
Jean Milano
James & Barbara Peak
Stephen & Debra Simmons

Roberta M. Smith

Take Off Pounds Sensibly
(TOPS)
Union Endicott Band Boosters
Martha Weber
Joan White
James Wilcox
William & Laura Woodworth

John O'Grady

Eva Madden

John Sciortino, Esq.

Michael Burns

Janette Tedesco

James Emerson
Stephen & Sharon Gendron
Marie Giardino
Robert & Maria Horrocks
T. Kennedy
LeChase Construction Service
Virginia O'Keefe
Maria Rothstein
Robert Scheg

Elizabeth (Betty) Tuttobene

Lawrence Tuttobene

Marilyn A. Wagner

Linda Bunis
Catherine Feiler
Allison L. Gilday
Edward & Ellen Haak
Gerald and Joyce Hitchcock
Anthony & Jean Luciano
Edwin & Marion Mench
Thomas Roessel
Salmin, Celona, Wehrle &
Flaherty, LLP
Robert Spindler
William Stephan

Dominique Webb

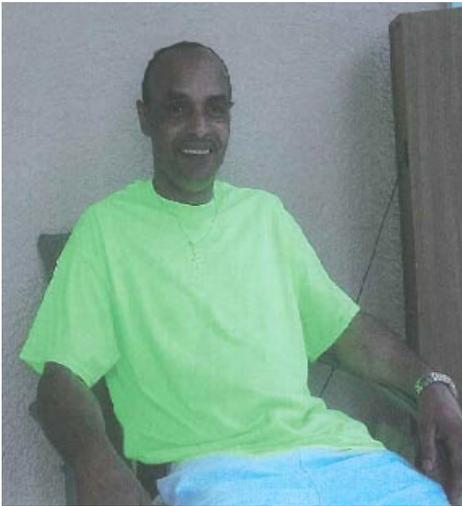
Duane & Linda Bliss
Linda Rowe
Robert and Joanne Rowe
David and Michelle Schoellig

A gift to Epilepsy-Pralid Inc. is a way to recognize an important person in your life. Give online at www.epiny.org or call Carolyn at (585) 442-6420 x227.

Why give?

So we can work together, not alone

A story from the field...



Jose Nuñez

We all have ways to work through problems in our life. For Jose Nuñez, the outlet is poetry.

Nuñez didn't always have a traumatic brain injury (TBI). At age 27, he woke up in the hospital with a ruptured brain aneurism. After a year of relentless headaches, fatigue, depression, short-term memory loss and blindness in his left eye, Nuñez received the news that these side effects of his brain injury were permanent.

Despite this bleak prognosis, Nuñez was determined to keep up his spirits and those of the people around him. He began receiving service coordination from Epilepsy-Pralid Inc. staff member Donna Masters. Masters knew Nuñez

needed more than just poetry to help him adjust to his new life and worked with him to identify other activities that matched his personality and would help him achieve his goal to remain positive.

Now, in addition to writing poetry, Nuñez facilitates a TBI support group. Remembering how alone he felt when he first had to grapple with the realities of his own TBI, Nuñez helps others as they struggle to accept their brain injuries. Nuñez recalled, "It took me about three years to accept it." Reflecting on his support group, Nuñez said, "I can see people grow

and relax; grow and accept their TBIs... We are working together, not alone."

Jose's wife Rose spoke of noticeable improvements in her husband and happily announced, "He now stops and listens." This was a particularly significant statement, as the couple had just finished discussing a time when Jose was blaming others, including Rose, for his forgetfulness.

Nuñez agreed to share his story with you, so you can see the inspiring people who rebuild their lives with the able assistance of our staff and with your generous support.

I'm Like You by Jose Nuñez

*People like us,
We have no need to be last on the bus.
We may seem different to you,
But our heart's like yours, ain't that true.
When you see me in front or back or around,
Just remember, I'm like you and I'm standing
on the same ground.*

Calling all Good Samaritans!

Small gifts can make someone's day

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. If you'd like to purchase one of our wish list items, please call Debbie Baker at (585) 442-6420 x286.

Wish List

Magazine subscriptions – call for the list

Book club books

Movie tickets to Regal Henrietta and Movies 10

Sporting Event Tickets –

Thanks Mike for the Frontier Field tickets!

C-Mac Tickets and concert tickets

Restaurant gift cards for chain restaurants

Not long ago, I heard something that warmed my heart and made my week. Someone had made a generous donation to Epilepsy-Pralid, Inc.!

Our organization couldn't do the things that we do without gifts like this. Our Day Program has group and individual activities to offer its participants daily and your gift helps a lot.

Thank you!

- Rebecca, front desk
staff and
Day Program
participant

