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An affiliated agency of People Inc.

Fall Issue • 2014
Quarterly Newsletter

*Headway is a support
and advocacy agency for
persons with brain injury,
other disabilities and seniors.*

In this issue

501C3 Non-Profit Organization

HEADWAY ANNOUNCES ANNUAL MEETING & ADVOCACY PANEL PRESENTATION

Mark your calendars! On **Tuesday, October 28, 2014** Headway will hold its **Annual Meeting**, from 5:30-7PM at the United Way of Buffalo and Erie County offices at 742 Delaware Ave, Buffalo NY. The meeting is more important and relevant than ever this year, as the NYS Department of Health is considering some imminent changes to the Medicaid Waiver Programs that will have some long reaching effects. Changes to the administration of the Traumatic Brain Injury Waiver and the Nursing Home Transition and Diversion Waiver, both of which Headway has coordinated in the WNY region since their inception, could mean the elimination of a major funding stream used to keep the Headway office running. More importantly, changes to the waiver could affect the services that over 500 people who are a part of these waiver programs in WNY currently receive (see also the lead article in the Summer 2014 edition of the Headway newsletter, which is also available online at www.headwayofwny.org). This is a major issue of concern. While the Department of Health is making decisions about this issue, now is the time for input from the people who may be affected. These waivers have been highly successful in supporting individuals with cognitive, behavioral and physical issues, along with their caregivers and their loved ones, in living in their own homes where they are safer, more comfortable and more productive than in a nursing home. It has specially designed supports, and specially trained staff to further these specific goals. This is part of the reason that this year's annual meeting includes a panel discussion, "How to be an Effective Advocate." Many survivors of brain injury, those with other disabilities and their families, as well as professionals in the health care field, have found that the care and services a person needs are usually not just handed to them. You have to be an effective advocate in order to get the services that you need. How can this best be done? Come listen to our panel, which includes survivors, families and professionals, and add your input from your experiences too! Future Medicaid services need to have special terms and conditions that will provide effective services to the very special and unique populations for which we all serve as advocates.

Headway's full annual report will also be discussed, showing what we have been involved this year with support groups, resource assistance, advocacy, education, and fundraising to support this, as well as with the waiver programs.

The presentation is free for Headway members and \$15 for non members. If you are not sure about the current status of your membership, please call the office at 408-3109 or 3117 to confirm

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**SAVE THE DATE!
HEADWAY'S
ANNUAL MEETING
TUESDAY,
OCT 28TH**

**Headway
is a donor designated
agency of the United Way**

Continued on page 2

HEADWAY WELCOMES NEW AMERICORPSVISTA

Headway welcomes its new Veteran's Outreach Specialist, Shannon Deans, who will be working primarily on expanding outreach efforts to Veterans in Western New York.

She has this to say:

My name is Shannon Deans. I am the new AmeriCorps VISTA here at Headway of WNY. I completed my degree in Religious Studies, Peace and Justice with a minor in Interfaith Studies. Following my degree, I have spent two years out on the west coast traveling with AmeriCorps NCCC which is a program for 18-24 year olds, and we complete between 4 and 6 projects in the 10 month program. After the two years I went in search for a VISTA program, and found the Headway position. I hope to foster my skills and learn more about Headway and the great work that is completed here. I am excited to get to know the Buffalo community as well as the Veteran community.

Shannon may be reached at 408-3110, or sdeans@headwayofwny.org.

Annual Meeting, cont. from pg. 1

your membership status. (Membership is paid on an annual basis). The seating for this event is limited, and we encourage you to RSVP by phone at 408-3100 or by mailing in the form which is at the bottom of the annual meeting flyer in this newsletter. Light refreshments will be served. Off street parking is available in the rear of the building, and the building is accessible. Please let us know if you have any questions. We look forward to seeing you at this very important meeting!

A TEAM EFFORT UB LEADS THE WAY IN TREATING WOUNDED SOLDIERS AND VETS

Michael Sformo, Founder and CEO, Operation Backbone Traumatic brain injury (TBI)—a sudden, forceful trauma to the brain—has become the “signature wound” of the wars in Iraq and Afghanistan. From 2000 through 2012, more than 250,000 military personnel sustained TBIs, resulting in a host of chronic health problems among returning vets, from depression to neuromotor impairments. The U.S. Department of Veterans Affairs is trying to meet demand, but given the sheer number of wounded soldiers—and the complexity of their injuries—it hasn't been easy. Now top medical experts from UB and around the country are teaming up to help fill in the gaps.

Operation Backbone, a Buffalo-based nonprofit formed in 2012, is working to create a nationwide network of care centers that will offer not only advanced brain and spinal surgery but also post-op rehabilitation, partially through a partnership with the NHL, to active-duty soldiers and veterans in need. The idea is to work in conjunction with existing VA hospital care. “If the local VA hospital has 12 wounded soldiers but can treat only 10, we'll take the extra two,” says Operation Backbone's founder, Michael Sformo, a Navy veteran and Western New York native. Here's the best part: Care will be offered at no cost to patients, with all treatments being funded through private donations and corporate sponsorships. One of the primary partners in Operation Backbone is UB, where radiologists and surgeons in the Department of Neurosurgery and at Roswell Park Cancer Institute have been donating their time to develop the program, including formulating a plan to screen patient cases and helping to grow the network (to date, Harvard Medical School, the University of Pittsburgh, Johns Hopkins University and the U.S. Military Academy at West Point have all signed on in various capacities). “Their guidance has been critical,” says Sformo of the UB team, which includes Elad Levy, chair of the neurology department, along with colleagues Adnan Siddiqui and Ken Snyder. The UB team will also be the first to start taking patients, both locally and from around the country, later this summer.

In addition to surgery, patients will have access to cutting-edge imaging services at the Gates Vascular Institute in downtown Buffalo, and to strength and nutritional training from the Buffalo Sabres at their downtown headquarters. The NHL partnership is also something that Sformo hopes to expand, with a goal of bringing Operation Backbone into the remaining 29 NHL cities. “It's an entire community of support,” says Snyder. “That is the key to the healing.”

Source: University at Buffalo

(<http://www.buffalo.edu/atbuffalo/article-page-summer-2014.host.html/content/shared/www/atbuffalo/articles/summer-2014/on-campus/a-team-effort.detail.html#sthash.vJ6fmcSK.dpuf>)



Navy veteran Mike Sformo at the Buffalo Sabres training facility.

Photo: Douglas Levere

MAKING YOUR MARK...MOVING FORWARD



On Saturday, June 21, Headway of WNY was host to a Community Outreach Art Project initiated by artist and TBI survivor, Susan Marie Borden. Susan was awarded a grant for the project through the New York State Council on the Arts; administered by the Arts Services Initiative of WNY. Forty participants came together for a truly remarkable and joyous day!

Susan Marie Borden is passionate about the project and shared:

“The goal of this project was to first bring attention to the issue of Traumatic brain injuries (TBIs) faced by many individuals, including an increasing number of returning veterans. Through this mark making day, abstract art was created and made available for viewing at three public gatherings over the summer of 2014. Secondly, I wanted to demonstrate how getting outside your body by concentrating on an art project (or woodworking or even playing chess) can be a means of redirecting one’s focus from pain and create a sense of satisfaction and accomplishment for TBI survivors.”

An open invitation was extended to all local veterans, survivors of TBI and the Headway community to come together on one day to create a work of art.

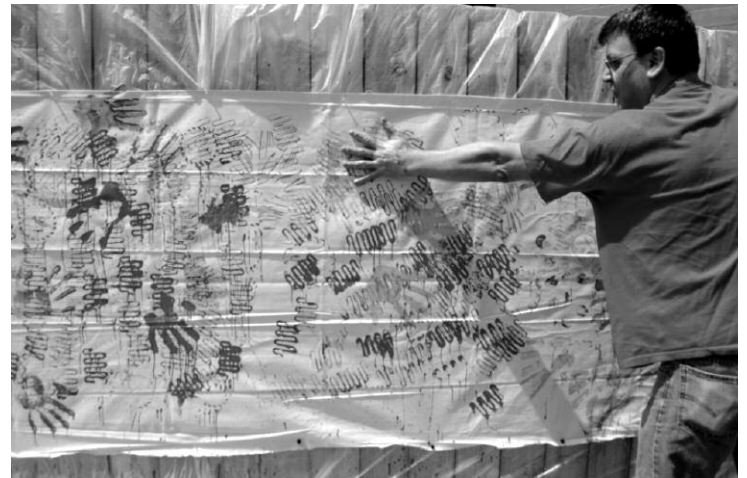
Two large canvases were set out for participants to “make their mark.” Utilizing a variety of colors and stamping tools, each participant contributed to these one-of-a-kind creations in their own way.

Refreshments were served while ideas and stories were shared. Many thoughts were expressed about Headway’s interest in hosting this event on an annual basis.

The canvases were brought in doors to dry overnight and were then delicately divided and mounted on simple wooden framing. These stunningly unique pieces were displayed at three public showings over the course of the summer of 2014 as follows:

- July 5 at Leonard VFW Post, Cheektowaga, NY
- August 3 at Enjoy the Journey Art Gallery, West Seneca, NY
- September 7 at Headway’s 5th Annual Walk, Run & Wheel

Artwork is available for showings by contacting Susan Marie Borden at 716-982-5947.



BIANYS HAS NEW EXECUTIVE DIRECTOR

The Brain Injury Association of New York State is another effective advocacy group for those with brain injury. Check their web site at www.bianys.org for more information on proposed changes to Department of Health Waiver Programs with Medicaid Long Term Care, and issues concerning the new UAS tool used to assess a person’s appropriateness for the waiver programs.

BIANYS has long been led by Judy Avner as Executive Director. Judy has recently announced her retirement, and BIANYS has announced that Eileen Reardon will be joining the Association as Executive Director. Best wishes to both!

MEDICAID HOME CARE CUTS ARE UNJUST, LAWSUIT SAYS

A federal class action lawsuit filed late Tuesday accuses New York State health officials of denying or slashing Medicaid home care services to chronically ill and disabled people without proper notice, the chance to appeal or even an explanation, protections required by law.

The lawsuit, filed in United States District Court for the Southern District of New York, names three plaintiffs: an impaired 84-year-old woman living alone in Manhattan, a frail 18-year-old Brooklyn man with severe congenital disabilities, and a 65-year-old Manhattan man with diabetes and a schizoaffective disorder. But it was brought by the New York Legal Assistance Group on behalf of tens of thousands of disabled Medicaid beneficiaries who need home health care or help with daily tasks like bathing and eating.

It represents a challenge to an ambitious Medicaid overhaul by Gov. Andrew M. Cuomo that shifted \$6 billion in public spending on long-term services, including home care, to private managed care companies that are paid a fixed sum for each enrollee. The goal of the overhaul, which was set in motion in 2011, was saving money and improving the coordination of care. But advocates for aged and disabled people have complained that in the scramble for the most lucrative enrollees, companies are shunning frail people with the greatest needs and signing up those who could be given minimal services.

The lawsuit, filed against the state commissioners of the Department of Health and the Office of Temporary and Disability Assistance, takes these complaints to a new level, charging that the state is now allowing companies to quietly reduce or terminate home care to people whose need for services has not changed, without giving them a meaningful chance to object.

Bill Schwarz, a spokesman for the Health Department, and Anthony Farmer, a spokesman for the disability assistance office, said the state does not comment on pending litigation.

Janie Taylor, the lead plaintiff on the case, was required last year, as part of the Medicaid overhaul, to enroll in one of two dozen plans provided by private managed care companies under contract to the state. Before the changes, Ms. Taylor, an octogenarian with diabetes, high blood pressure and a dangerously unsteady gait, had the help of an aide for 10 hours a day, seven days a week. That care was continued at first by her

managed care plan, VNSNY Choice. But on July 1, the lawsuit says, without notice or explanation, VNSNY cut her services to five hours a day, though her condition had not changed.

“I’ve been trying to figure it out and talk about it with God, why they’re doing this to me,” Ms. Taylor said in a telephone interview Tuesday from public housing in Harlem.

Born in Edgefield, S.C., and orphaned at a young age, she said, she came to New York at 14 to care for other people’s children and clean houses, and finally worked for 15 years as a live-in home care worker, until she collapsed while lifting a patient and found she was sick herself.

A social worker in Ms. Taylor’s physician’s office contacted VNSNY Choice and requested an internal appeal to challenge the cut in hours, the lawsuit said. But VNSNY called Ms. Taylor the next day, telling her the internal appeal had been denied, and that her aide would leave at 2 p.m. instead of 7 p.m. that very day. When a written notice of denial finally appeared, it was mischaracterized as the denial of a request for a service increase rather than the appeal of a reduction.

Ms. Taylor contacted lawyers, who immediately called the disability assistance office, requesting a fair hearing. Despite a state directive to continue the full amount of care while the matter is pending, VNSNY Choice has not restored Ms. Taylor’s hours, the lawsuit said. Her aide used to fix her dinner and help her prepare for bed. Now, “I sleep in my clothes,” she said.

Michael McKeon, a consultant speaking for VNSNY, said in an email: “While we can’t comment on a specific case. VNSNY cares for nearly 165,000 people every year and we work hard to get every case right.”

Ben Taylor, one of the lawyers who brought the suit — and no relation to the plaintiff — countered: “Sadly, with the shift to managed care, Ms. Taylor is only one of many individuals who are suffering because they are denied their basic rights.”

The teenage plaintiff, Eddy LeMieux, has Noonan syndrome, a congenital disorder that affects his heart, lungs, spine and mental functioning. He lives with a severely disabled uncle and an aunt who works two jobs, one at night, to support the family, the lawsuit says, and requires 24-hour care to live safely in the community. Mr. LeMieux was required to enroll in Healthfirst, a managed care company, in 2012.

On Jan. 14, Healthfirst sent a document saying his care would be tapered from 12 hours, seven days a week beginning Jan. 25 to no care on April 22. It treated his 24-hour care as a new request, and denied it, saying that “the medical director has determined that the amount of/level of personal care services requested is not medically necessary.”

Continued on page 6

Janie Taylor, 84, who has diabetes and other ailments, said her aide service was cut to five hours a day from 10 without notice.

Credit: Jennifer S. Altman for *The New York Times*



HEADWAY OF WNY HOLDS ITS 5TH ANNUAL WALK, RUN & WHEEL

On Sunday, September 7, runners, walkers and wheelers of all ages gathered together at The Hatch Restaurant at the Erie Basin Marina for **Headway's 5th Annual Walk, Run & Wheel**. It was a stunning morning in Buffalo to be near the water for this much anticipated fundraising event! Word has gotten out and each year more and more folks are joining in the excitement!

This year, there were more than 170 event participants who raised awareness for those living with traumatic brain injuries and other disabilities. **A record breaking \$10,000 was raised.**

There are many beneficial things about this unique event, and one is that each person has the choice to register as a team or as an individual and may walk, run or wheel all or some of the 5K course. The course is an enjoyable journey along Buffalo's waterfront that heads down to the base of the Erie Basin Marina and back up Marine Drive to Michigan Avenue via Scott Street, continuing back down South Park to Main to Marine Drive. This year in particular will be remembered as "the year of construction" as participants had the unique opportunity to see firsthand how Buffalo's current renaissance is transforming the City around First Niagara Center. We were fortunate that the City of Buffalo and Mortenson Construction Company were willing to collaborate with us to ensure the continuity of our course and the safety of our participants.

Over 35 volunteers helped set the stage for an exciting and fast paced morning. It all began at 8:30am with registration, and wrapped up by noon with an awards presentation, basket raffle, live music, a 50/50 drawing and great food.

A very special thank you to all of the participants, volunteers, sponsors and supporters of the event – we could not have done it without you!

The Buffalo City Police department was in full force blocking off Marine Drive as the participants lined up.

Molly Hayden Saper, TBI survivor and participant, shared inspiring words of encouragement followed by a rousing rendition of The Star Spangled Banner. Mark Reed, event sponsor and Headway advocate, started the race at 9:30am with the shot of the pistol and off they were off.

Enthusiasm filled the air back at the Hatch where family members and friends cheered on their champions while volunteers and staff set up for the post-race festivities.

Inside the Hatch's outdoor pavilion area overlooking Lake Erie, a scrumptious buffet lunch, was set out for all to enjoy – veggie pasta salad, hamburgers and hot dogs with all the fixings, and Daddio's delicious pizza.

Live guitar music was provided by Ron Fernandez, Headway's director of Waiver Services, who also happens to be an outstanding musician who graciously contributes his talents for all to enjoy.

A stunning array of baskets were displayed, raffle tickets and chances at a 50/50 drawing were sold.

Chris VanVeghten provided comments and the awards ceremony capped off the morning. Baskets were raffled off and the 50/50 winner was announced.

Prizes were awarded in the following categories: Team with most funds raised, First and Second prize to Individuals with most funds raised, Male and Female Best time placed, and First and second prize within each age group for best time placed.

A special thanks to the professional timing company, Tempus Fugit, for providing all race timing equipment and crew. The results have been posted on Buffalorunners.com.

Hope to see everyone next September and please help spread the word about this family friendly event to cap off the summer. Watch this publication for 2015 dates and times!

SPONSORS

Dolce Panepinto

Feroletto Law

The Hatch Restaurant

The Ballow Law Firm

Trigilio Ciambone Partnership

The Reed Family

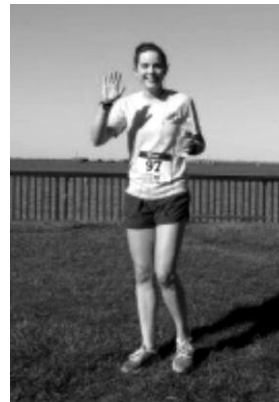
Mark Shaw

The Landwehr Family

Daddio's Pizza

LaNova

Tops Markets of Boston, NY



More than 170 people of all ages participated in this year's event, resulting in a record-breaking fundraising total.

COMMITTEE

After months of preparation, this year's committee members are to be commended for a successful culmination –thank you to the following members:

John Feroletto, Esq.

Diana Landwehr

Beth Mann

Christine Melchiorre

Carrie Mendola

Darlene Robida

Chris VanVeghten

BLUECROSS BLUESHIELD WITHDRAWS FROM MEDICAID MANAGED CARE PROGRAM

WASHINGTON – Some 53,000 Medicaid recipients in the region, including nearly 29,000 in Erie County, will have to look for new insurance coverage this fall because BlueCross BlueShield of Western New York is withdrawing from the Medicaid managed care program.

The insurer, which plans to publicly announce its withdrawal from the program today, informed government officials of the move Thursday in a memo that was obtained by The Buffalo News.

“We have incurred losses in excess of \$40 million over the past three years in these programs,” Don Ingalls, the insurer’s vice president of state and federal relations, said in the memo. “We have a 20+ year history of supporting these programs and members; however, we cannot continue to do so as the losses ultimately have been funded by other lines of business.”

The move means that Medicaid managed care recipients in Erie, Chautauqua, Cattaraugus, Orleans, Wyoming and Allegany counties will have to move to another insurance provider by Oct. 31. BlueCross BlueShield said it would notify Medicaid clients of the withdrawal by the end of August, giving them two months to make the switch.

“In every one of the six counties, there are other providers that will be able to offer these programs,” said Stephen T. Swift, executive vice president and chief financial officer at BlueCross Blue Shield.

BlueCross BlueShield said it would work to make sure the transition goes smoothly, and state officials agreed.

“The state Department of Health will work with Blue Cross & Blue Shield of Western NY to ensure a smooth transition as this process moves forward,” the Department of Health, which manages the Medicaid program, said in a statement. “The department will ensure continuity of high-quality care and no disruption in eligibility for Medicaid members in the region.”

BlueCross BlueShield is the fourth-largest provider of Medicaid managed care in Erie County, with a 19 percent share of the market. Independent Health has the largest share – 29 percent – while Univera Community Health has 27 percent and New York State Catholic Health Plan has 25 percent.

The move means those other insurers will have to pick up those former BlueCross BlueShield subscribers – a move that Rep. Chris Collins, R-Clarence, said could be prohibitively expensive.

“My fear would be that the other carriers follow suit,” Collins said.

Independent Health acknowledged that it has faced the same financial pressures in the program as its rival did.

“As a nonprofit health plan, Independent Health faced similar financial losses to its Medicaid program,” Frank J. Sava, a spokesman for Independent Health, said in a statement. “These losses were driven by

carved-in pharmacy benefits and unique challenges in serving Medicaid beneficiaries in certain counties where there are provider access challenges.”

The Independent Health statement said nothing, though, about the insurer leaving the Medicaid managed care program. Instead, it said the company is working with state officials to identify new sources of funding that could improve care under the program.

The Department of Health statement on the issue included no reference to the funding issues that, according to BlueCross BlueShield, drove the insurer out of the Medicaid managed care business.

“We’ve struggled with this program over a number of years,” said Swift, who noted that BlueCross BlueShield terminated its Medicaid managed care program in Niagara and Genesee counties last year and its programs in northeastern New York seven years ago. Excellus Blue Cross in Central New York also abandoned the Medicaid managed care program several years ago.

And while Obamacare, which took effect last fall, vastly expands the number of New Yorkers on Medicaid, Swift said: “This really is not driven by the Affordable Care Act.” Over many years, “we’ve tried many different avenues to remediate the business.”

But Collins, a consistent critic of Obamacare, said he wasn’t so sure.

“I would argue that BlueCross BlueShield now has a lot more clients on Medicaid because of Obamacare, so they would lose a lot more money,” he said. “I don’t see how they could say that this doesn’t have a connection to Obamacare.”

Source: *thebuffalonews.com*, July 17, 2014

Medicaid Cuts, cont. from pg. 4

Despite his aunt’s fair hearing request, the state did not order his care to continue until officials were contacted by the New York Legal Assistance Group in April. Healthfirst then reauthorized Mr. LeMieux’s home care, but only for “sleep-in” help, not the two-shift continuous care the directive required. Then the plan discontinued all care on May 6, until lawyers intervened.

The third plaintiff, Anibal Santiago, is also a Healthfirst client. Harris Brandt, a spokesman for Healthfirst, said by law it could not talk about its clients.

Source: *NewYorkTimes.com*, July 15, 2014

A version of this article appears in print on July 16, 2014 of the New York edition with the headline: Medicaid Home Care Cuts Are Unjust, Lawsuit Says



HEADWAY IS ON FACEBOOK!

Come on, do you “like” us? Friend us on Facebook and receive Headway postings on upcoming news and events! You can also send messages to our youth counselor, Molly, or you can contact her directly at 408-3100.

WAIVER MYTHS

There is a great deal of misinformation regarding the two waiver programs that Headway oversees in six counties of Western New York so I am going to address in the newsletter myths associated with the Traumatic Brain Injury and/or Nursing Home Transition and Diversion Waivers.

The first myth is that the waiver program waives rules. The programs do not waive anything but actually adds to a person who is on the program services that are paid by Medicaid which are not the traditional medical services which Medicaid funds.

Medicaid is an insurance that is available for people who demonstrate financial need. Without the waiver programs people who have community Medicaid can use it to fund medical visits, medications, mental health services and other medical services including Physical, Occupational and Speech therapies.

Services though that are not traditional medical services such as Service Coordination and Independent Living, if justified, can be paid for by Medicaid for both waiver programs. In short the waiver programs allow Medicaid to meet more needs for individuals to help them stay out of nursing homes.

- Ronald Fernandez

YOUR STORY MAY HELP SOMEONE MOVE TO NEXT STEP IN RECOVERY...

Please Consider Sharing Yours For Inclusion in New Publishing Project!

Everyone has a story to tell - please share yours with us!

Molly Ann Hayden, TBI Survivor and Rehab Counselor seeks story submissions for possible inclusion in an upcoming book entitled "Look Both Ways - Everything I learned before and after my brain injury."

We think this would be a great tool for future brain injury survivors. Here's ideas to get started!

- * *Who were you before?*
- * *What happened?*
- * *What do you remember about recovery?*
- * *What advice do you have for future survivors?*

Please send your stories for consideration to:

Headway of WNY, Inc.

Attention: Molly's Publishing Project

2635 Delaware Avenue, Suite E

Buffalo, NY 14216

Or Email to Molly at mollyaspire@yahoo.com

If you have questions, please contact Headway at 408-3109.

2014 MEMBERSHIP DRIVE

Please consider becoming a Member of Headway of WNY, Inc. or renewing your current membership. During the months of October and November we will be conducting our Annual Membership Drive.

Your membership support helps us increase community awareness by expanding our outreach, support and advocacy efforts.

Annual Headway Membership also helps support our general operating expenses and subsidizes programs for survivors of brain injury and their families.

To ensure that you receive our new membership package, please complete and return the form below. If you have Membership questions, please contact us at 408-3109 or email at support@headwayofwny.org. Thank you!



**Please send updated Headway Membership information
to me at the address below.**

Name _____

Address _____

City _____

State _____ Zip _____

Phone _____

Email _____



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visit our website:

YOU ARE NOT ALONE, MOVE FORWARD WITH HEADWAY.

HEADWAY'S

SUPPORT GROUPS FOR SURVIVORS OF BRAIN INJURY AND THEIR FAMILIES

All meetings, except as noted, will take place at Headway
2635 Delaware Ave., Suite E, Buffalo, NY 14216/716-408-3100
(Please take note of Changes to Dates and Times of Support Groups)

PEER SUPPORT

Enter at Suite B
1st & 3rd Tuesday
6:30 PM to 8 PM

CARE GIVERS SUPPORT

Enter at Suite E
1st Tuesday
6:30 PM to 8 PM

WOMENS SURVIVOR'S SUPPORT

Enter at Suite E
1st Tuesday
1 PM to 2:30 PM

YOUTH SUPPORT BY PHONE

Direct contact with Youth Counselor
Please phone us
408-3100

DeGraff Hospital
Dining Conf. Rm/Gr. Fl.

PEER SUPPORT IN RURAL COMMUNITIES

3rd Tuesday
6:30 PM to 8 PM

VETERANS/ CARE GIVERS SUPPORT

BY PHONE
408-3100

St. Paul's Lutheran Church 4007 Main Street, Eggertsville, NY COMPLEX REGIONAL PAIN SYNDROME SUPP.

4th Monday
7:00 PM

PLEASE NOTE:

If the Buffalo Schools are closed due to inclement weather, support meetings listed here are also cancelled.