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An affiliated agency of People Inc.

Spring 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

PAT'S STORY: NO PLACE LIKE HOME!

Pat McClenathan's list of physical problems is overwhelming. She has severe rheumatoid arthritis, and both her knees and shoulders have been replaced. She also has a rod in her back due to spondylosis, and sees a doctor for pain management. Additionally, she has a thyroid condition and her diabetes has caused neuropathy. Damage to her kidneys has made it necessary for her to attend dialysis three times a week. However, when I met Pat a few weeks ago, she was sitting in her own kitchen with a cup of coffee and a big smile on her face. Despite her serious health issues, hospitalizations, nursing home stays, and an arduous struggle, she is now where she most wants to be – back at home with her husband, Melvin.

The latest chapter in Pat's medical saga began when she suffered a serious seizure and ended up hospitalized with a coma, leaving her with cognitive issues and increased physical weakness. Due to an involved recovery process, she was not able to return home safely for some time. In fact, medical staff were not sure she would ever recover to the point of being able to live at home again with Melvin.

She needed to go to a nursing home for further rehabilitation, but most of the nursing homes in the area were not willing to accept her. Her care was expensive, with multiple medications, and it was costly to arrange transportation to dialysis three times a week. She did finally get admitted to a nursing home, but it was about 45 minutes from her home, and also 45 minutes from her dialysis facility.

Pat continued to recover, and is grateful to the nursing home for her care. She was exhausted after dialysis, and the treatments and long trips back and forth, took up most of the day. Mel drove out to visit her regularly, but as Pat admitted, "We would wind up having an argument almost every time. I was tired, he was tired, and I kept begging him to take me home." Mel was also concerned with her care. Although he believes the nursing home had good standards, he says there are unavoidable difficulties which occur with institutionalization – such as staff to patient ratios and medication management.

Melvin wanted very much to take Pat home during this time, however he understood the reality of the situation – it would be difficult for him to address her multiple health concerns on his own. It was just the two of them in the house. He wondered how he was going to manage on his own.

While at the nursing home, Pat continued her determined recovery, surprising many on the staff. She went from transferring in and out of the bed or wheelchair with two people and a mechanical lift, to doing this with just one person. She was much more alert, and now is able to carry on a good conversation.

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SAVE THE DATE!
HEADWAY'S
SPRING FUNDRAISER
THURSDAY MAY 15TH
AT WINDOWS ON
THE GREEN
SEE PAGE 4
FOR DETAILS

Headway
is a donor designated
agency of the United Way

Knowing how much she wanted to be home, one of the social work staff at the nursing home discussed a program with Pat and Mel called the Nursing Home Transition and Diversion Waiver. This program, they were told, could provide more help in the home, and potentially make Pat's discharge a safer situation.

This Nursing Home Transition and Diversion Waiver program is administered in WNY by Headway of WNY. Initially, a member of the Headway waiver staff interviewed Pat and Mel, and agreed that they could help start a safe plan for her to get home. Because Pat had exhausted her Medicare coverage in the nursing home, she had already applied and been accepted for Medicaid. Pat and Mel chose one of the waiver agencies to help formulate and staff her home plan. Mel decided that since he knew help was on the way, he would take Pat home after 7 months in the nursing home while waiting for the waiver aide services to be put in place. (He had already sent up some ingenious ramp systems to make the house more accessible for her.) She was then home for about 2 months, with 2 hours of aide service twice a week. Mel said that that was even harder than he anticipated it would be. "I couldn't leave her alone," he said, "and that meant I could almost never leave the house. Just getting her up, bathed and having breakfast took up a big share of the day."

"Still it was good to be home," Pat said.

When her services began, both Pat McClenathan and her husband were extremely relieved. Pat now has 38 hours a week of aide service, from 8am-4pm most days, and a shortened schedule on days she goes to dialysis (and that is a much shorter trip now!). Mel is able to get the grocery shopping and errands done, as well as take an occasional class, and though he still does much of her care, he feels much less stress. Pat is now under the care of her own community doctors who are more familiar with her complex medical history, and she and Mel both feel much more comfortable with that. She has aides who see her on a one-to-one basis and are willing to make accommodations to meet her needs and preferred routines. She feels that her physical, as well as her mental recovery has progressed further at home because she is in a less stressful and more familiar environment. She also enjoys having her grandchildren visit and being able to talk to them on the phone more easily. "I am living a more normal life," she says.

"If I could sum up in one word how I feel about what this program has done for me," Pat said, "it is a godsend."

Do you know someone in WNY who might benefit from the NYS Department of Health Nursing Home Transition and Diversion (NHTD) Waiver?

There are a number of requirements, among them that the person:

- Be eligible to receive Medicaid coverage for Community Based Long Term Care Services in NYS.
- Be 18 years of age or older

- Be able to live safely in the community with the help of the waiver and available community resources
- Need at least one waiver service to stay at home or return home from the nursing home.

The NHTD waiver can potentially provide a number of other services that Pat did not need, such as:

- Independent living skills training
- Assistive Technology
- Community Integration Counseling
- Behavioral intervention and supports and more.

The philosophy of the program is that individuals with disabilities and/or seniors have the same rights as others to be in control of their lives, and encounter and manage risks and learn from their experiences. Call Headway at 408-3120 and find out more!

ARE YOU AN ADVOCATE FOR PERSONS WITH BRAIN INJURY?

How are you going to promote brain injury awareness this year? Consider the following:

- **Brain Injury Awareness Day** was held this year on Capitol Hill on March 12. Check the Brain Injury Association of America home page, www.biausa.org for information about this annual event to become more involved. You can also sign up for the BLAA weekly e-newsletter *Policy Corner*, which covers government relations activities.
- **The Brain Injury Association of America's** message this year is that "a brain injury can happen anytime, anywhere to anyone-brain injury does not discriminate." Go to their website www.biausa.org/brain-injury-awareness-month.htm and download the web graphic of the Brain Injury Awareness Month logo and use it as your Facebook picture.
- **Check the Headway Facebook page** for updates on what is happening in our area. Encourage your friends to check this page also!
- **Be a part of Headway's Speaker Bureau!** Diana Landwehr, Headway's Director of Support and Advocacy, is always looking for survivors of brain injury and their families who have a story to tell and who are willing to help her speak to groups and organizations on the subject of brain injury, and who are willing to help us promote awareness of brain injury through Health Fairs & other local events. Call Diana at 408-3103 for further information.

Here are some upcoming events Headway will be attending:

April 6: WNY Health Expo at the Fairgrounds in Hamburg. Free! Check wnyhealthshow.com.

May 22: DDDay (Developmental Disabilities Awareness Day) at the Conference Center in Niagara Falls. Check dday.org.

WOMEN'S BRAIN INJURY SURVIVOR SUPPORT AVAILABLE

The “quietist” group of TBI survivors, the ones you probably hear the least about, are women. In every age group, TBI rates are higher in males than a female, which has led to the perception that TBI is a man’s problem. When you hear “brain injury,” you might think of young men engage in risky behaviors, veteran’s with blast injuries (who are overwhelmingly male), and athletes (usually male) playing sports such as football and hockey. But what about women victims of domestic abuse, car accidents, and many other injuries?

Brain injury affects women...millions of them...and in ways professionals are just beginning to understand. Overwhelmingly, past research in brain injury has concentrated on men; women are only beginning to be studied. A 2010 study, for instance, found that women with brain injuries have fewer children and experience more problems after childbirth. Another study found that the female hormone progesterone may be a protective factor in better recovery from brain injury.

Women’s problems and issues with brain injury recovery can be very unique. Headway has a support group specifically geared to the needs of women who have survived a brain injury, held on the 1st Tuesday of each month from 1 PM to 2:30 PM at the Headway office. Call Diana at 408-3103 for more information!

VETERANS OUTREACH UPDATE

Headway has been continuing our outreach to veteran survivors of brain injury. Over the past six months, Americorps VISTA member and Veterans Outreach Specialist Sarah DePerrior has attended health fairs and veterans services fairs, presented information about Headway’s services to community organizations, assisted in providing referral information to individuals seeking services, and worked on event planning and coordination. She regularly attends veterans service organization meetings as well as events at the Buffalo VA Medical Center and the Veterans One-Stop Center of WNY. Sarah is continuing to work to gather information on organizations in Western New York that provide relevant services for veterans with brain injury, which will be brought together in a “Resource Guide for Veterans with Brain Injury.” She is also working in conjunction with the Headway fundraising team and Susan Borden to plan a large-scale community art-creation event entitled “Making Your Mark” (see information at right). For more information on our veterans outreach initiatives or to get involved, feel free to contact Sarah at 408-3110 or sdeperrior@headwayofwny.org.

COME JOIN HEADWAY IN “MAKING YOUR MARK”

All Veterans, any survivors of Traumatic Brain Injury, and the Headway community at large are invited to join together for a large-scale, community art event on **June 21st from 11am to 3pm at Headway of WNY, 2635 Delaware Ave, Buffalo, NY 14216**. Participants in this event will have the opportunity to make their “marks” on a communal canvas in any fashion of their own choosing and ability using paint. We will have a variety of tools available for people to choose from, including paint rollers, brushes, balls, and old army boots. The imprinted canvas created on “mark-making day” will then be divided and mounted onto individual frames to be displayed at public gatherings over the summer of 2014. This project has been initiated by TBI survivor and artist Susan Marie Borden. It is funded by the New York State Council on the Arts administered by the Arts Services Initiative of Western New York. Community partners are Headway of Western New York and Enjoy the Journey Art Gallery.

The public is invited to participate in viewing these abstract art creations at the following showings:

- **1st Public Showing**—Leonard VFW Post, 2450 Walden Ave, Cheektowaga, NY 14225 - Saturday, July 5th 11am-3pm
- **2nd Public Showing**—Enjoy the Journey Art Gallery, 1168 Orchard Park Rd, West Seneca, NY 14224 - Saturday, August 3rd 11am-3pm
- **3rd Public Showing**—Headway’s “Walk, Run, and Wheel,” Erie Basin Marina, 329 Erie Street, Buffalo, NY 14202 - Saturday, September 7th 9am-1pm

For more information about this project or to get involved, please contact Sarah DePerrior (408-3110, sdeperrior@headwayofwny.org) or Susan Borden (982-5947, smb.artist@yahoo.com)

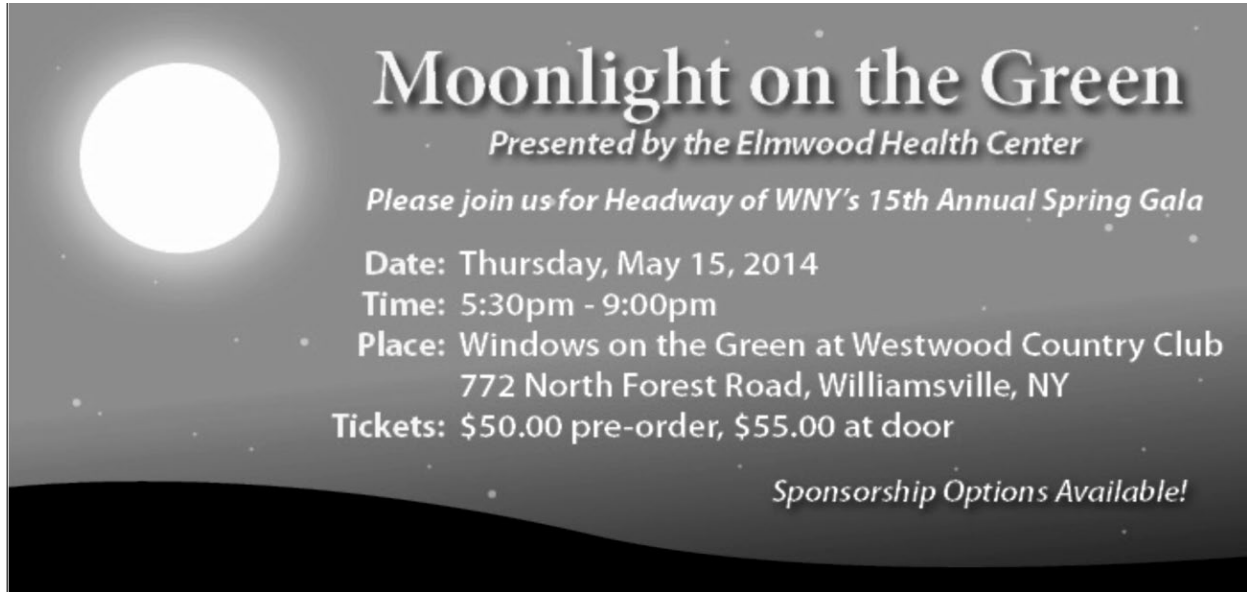
Tell your family and friends!



HEADWAY OF WNY, INC. IS A DONOR DESIGNATED AGENCY OF UNITED WAY

MOONLIGHT ON THE GREEN

We are pleased to announce that
THE ELMWOOD HEALTH CENTER
Located at 2128 Elmwood Avenue in Buffalo, New York
**HAS COME ON BOARD AS THE LEAD SPONSOR FOR
THIS YEAR'S 15TH ANNUAL SPRING GALA**
Thank You Elmwood Health Center!



MAKE PLANS NOW TO JOIN US FOR THIS EXCITING AND MEMORABLE EVENT!

Festivities include: Basket Raffle, Silent Auction, eligibility to win prizes, two hours open bar (beer, wine & soda) and a scrumptious buffet dinner.

Proceeds go directly to Headway of WNY's mission of providing access to support services, advocacy, and resources for individuals in WNY with brain injuries, other disabilities and seniors.

SPONSORSHIPS ARE STILL AVAILABLE

See Sponsorship Overview Form enclosed, or you may also visit us at headwayofwny.org and click on the "How to Help" tab.

A LIMITED NUMBER OF \$50 PRESALE TICKETS ARE AVAILABLE NOW!

See Ticket Order/Donation Form enclosed or purchase your tickets online at headwayofwny.org.

WE ARE CURRENTLY ACCEPTING BASKET RAFFLE/SILENT AUCTION DONATIONS

See Basket Raffle/Silent Auction Form enclosed.

OTHER WAYS YOU CAN HELP

We are also in need of empty baskets for the Basket Raffle and/or any basket filler items such as gift cards, bottles of wine and other small items.

FOR FURTHER INFORMATION

Call Christine at 716-408-3117 or cmelchiorre@headwayofwny.org

WE TRULY APPRECIATE YOUR SUPPORT AND LOOK FORWARD TO SEEING YOU ON MAY 15!

JUNE BRAIN INJURY CONFERENCE SCHEDULED IN ALBANY

The Brain Injury Association of NYS has scheduled a one day professional symposium June 5, 2014, 9 AM to 5PM entitled “Latest Developments in Brain Injury: Identification, Rehabilitation and Treatment.”

A variety of topics will be discussed, including Epidemiology, Sports Concussion, Return to Learn and To Play after Concussion, Neuroradiology developments, Neuropsychology, Behavioral Problems, Assistive Technology, New Advances in Visual Rehabilitation, and Latest Concussion Research.

Visit www.bianys.org for more information..

BRAIN INJURY ASSOCIATION OF NYS ANNUAL CONFERENCE

The BIANYS annual conference “Uniting as the Voice of Brain Injury” will be held June 6th in conjunction with the professional conference in Albany. The Keynote Address will be by Ray Ciancaglini, “The Invisible Opponent.” Ray is a former boxer and founder of the website *The Second Impact*.

He has been battling Dementia Pugilistica and Parkinson’s syndrome for many years. His personal experiences with undiagnosed and unaddressed concussion led him to become an advocate for brain injury awareness, prevention and treatment.

The BIANYS Annual Conference features workshops on a number of different topics, as well as the opportunity to network with individuals with brain injury, their family members and friends, professionals in the field, advocates, health care providers, and agency representatives, among others. Visit www.bianys.org for more information or call 518- 459-7911 for information on both events.

VOLUNTEERS IN THE NEWS!

Ron Pokorski was named ECMC Volunteer of the Month for February, in appreciation of his work on the rehabilitation inpatient unit as a volunteer with patients surviving brain injury and their families.

Kenneth M. Sroka, Ph.D. was also named ECMC Volunteer of the Month for his work with the Reading/Support Clubs run through the ECMC Rehabilitation Department, specifically designed for those with brain injury and those suffering with chronic pain. Dr. Sroka was also the speaker at Headway’s annual meeting in 2013, discussing the Reading Clubs and how they have helped.

Chris Van Veghten, CRC, retired in January after 30+ years at ECMC. She was the Rehabilitation Counselor and discharge planner for many years on the Rehabilitation inpatient unit at ECMC and specialized in working with survivors of brain injury and their families.

Congratulations to all, and your dedication is appreciated!

In Loving memory...

Our condolences to the family of **Janet Kurtz**, who recently passed away. Janet and her husband Ted were among the original founding board members of Headway. Janet in particular was a force behind making Headway a membership organization; to be more responsive to the people we serve.

We would again like to thank the family of **Dakota Jimerson**, for further donations that have been made to Headway in his memory.

Our sincere sympathy to Mark Shaw and his family on the recent passing of his grandfather, **Theodore H. Shaw**. Thank you to Mark and his family for having donations sent to Headway in his memory.

How these donations help survivors of brain injury in the community

All memorial donations that Headway receives are placed in our special Grant Fund, which was started this past year with a donation from the Olmstead Foundation. This donation and this fund were created to fund items, goods and services which are not available through Medicaid or other established funding sources, and are needed by individuals with a traumatic brain injury who are either living in the community or transitioning to community living. Those items could include such things as assistive technology, durable medical equipment and other items. Several people have benefitted from this fund already!

How can you access this fund?

Individuals with a traumatic brain injury, or someone writing on their behalf who would like to apply to this emergency fund should write a letter to Headway detailing what their need is, what the cost is, and what other resources have been approached to fund this need. Please address the letter to Diana Landwehr, Director of Support and Advocacy, or email it to her at support@headwayofwny.org.

COMPENSATORY STRATEGIES FOR COGNITIVE DEFICITS, OR ANOTHER WAY TO SKIN THE CAT!

Compensatory strategies are tips & tricks, or new methods for accomplishing tasks. If you have problems with memory, for instance, or getting lost, or have trouble focusing and finishing a task because you get distracted...all these problems can be addressed by changing how you get the job done. Putting your glasses on to read, for instance, is a compensatory strategy for poor eye-sight: glasses allow you to complete a task or reach a goal. When you wear your glasses you function more efficiently. Each strategy needs to be tailored to the individual—their difficulty, as well as their strengths and what they need to accomplish. Some compensatory strategies will come naturally to you, and others will need a trial-and-error period and/or a coach or counselor to help you create them. Once you develop a strategy, it is necessary to use it, consistently, if you want to avoid difficulties. Cleverness and creativity count!

Some common compensatory strategies you may want to try out and modify to fit your situation:

Getting Lost: GPS is the single most helpful device to use for travel in a vehicle. However, if you have auditory processing problems, you will also want visual cues because just listening to the directions may not be good enough. If you are not in a vehicle but in a building or walking on the street, make a drawing, write down turn by turn directions, make notes in a pocket recorder, even take pictures with your cell phone so you know visually where you are and have been. Cell phone “Apps” can also track you in real time on a map.

Finding the Car: Park in the same (relative) spot in every parking lot—no matter what. Your car will always be in that corner of the lot so you will never lose it. Always go in and out of the same store entrance so you don’t get turned around. There are cell phone “Apps” for tracking your car too. Tie something big and bright on the antenna.

Cooking: Use a crock pot with a timer so it shuts itself off—no more burned food or things left on and forgotten. Carry the kitchen timer with a cord around your neck, so no matter where you go in the house, when the bell goes off you will go back to

the kitchen—if needed, label the timer with what happens next. Put a chair in the kitchen door way to block your ability to leave the kitchen when cooking. Rewrite recipes, broken down into each small step, and then cross off each as you complete it.

Losing Your Keys: Put keys in only one place—one hook or location and no other place. Have a very large key ring—one that would be hard to overlook. Ladies: do NOT change purses! Have your keys on a cord around your neck—can be worn under your shirt if you edit it down to car and house key only.

Forgetting to turn devices/appliances off: Use timers on most if not all appliances so they turn themselves off. Have a routine check list to determine if you have done something so you are not constantly going back to re-check.

Taking your medication on time: Use a medication box that is labeled with the day and time of the medication. Use an alarm clock (or series of them) on your kitchen counter that is set for when the medication is due. Label each clock with what meds are due. When the alarm goes off, you have to turn it off, read the label, and then take the medication. Get a calendar and each evening after you take the last medication, cross out that day, so you are always oriented to what day it is.

Do you have compensatory strategies that you use to help remember things? Write us a note, or send an email to support@headwayofwny.org. Further information on compensatory strategies will be featured in future newsletters!



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.

MARCH IS BRAIN INJURY AWARENESS MONTH

ADVOCACY...WHAT DOES IT MEAN?

Headway is a support, resource and advocacy agency for persons with brain injuries and other disabilities. What does it mean to be an *advocacy* agency?

- *Advocacy* means to promote a cause, a position, an issue, such as brain injury. Headway works to promote the issue of brain injury through our newsletter, through our web site, through our resource directory, and through other media outlets, reaching thousands each year.
- *Advocacy* involves actions taken by concerned citizens to demonstrate their support for an issue. Headway regularly works with local government and other officials to advocate for better services for survivors of brain injury.
- *Advocacy* means effecting change through education and awareness. Headway acts as an advocacy agency when we conduct a large variety of in-services each year, educating the community about prevention of brain injury and the issues around living with brain injury.
- *Advocacy* means to serve as a voice for persons with disabilities, to provide them with information and resources. We are an easily accessible no fee resource for community members to call to inquire about referrals to health care professions who deal with brain injury, to talk to people about how to obtain Medicaid and other insurance coverage, to link people with other community resources and more.
- *Advocates* are passionate about their cause, and about the change they want to help happen. Most are volunteers. Headway has been an advocacy agency since our beginnings as a volunteer agency in 1985, and we are proud to continue to champion the cause of services for individuals with brain injury.

BECOME PART OF HEADWAY'S ADVOCACY TEAM...VOLUNTEER WITH US!

You can be a part of helping with the newsletter, with fundraising to help promote our case, as part of a group speaks to community agencies about brain injury and more. Call Diana at 408-3103 to talk more about advocacy opportunities!

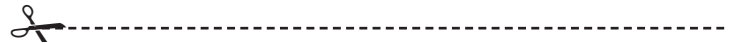


BECOME A MEMBER!

Support our mission by becoming a Member of Headway of WNY, Inc.!

Annual Headway Membership helps support our general operating expenses and makes it possible for us to provide valuable benefits to our subscribers. Benefits include invitation to our Fall Annual Meeting; discounts for select special events; free publications, such as a quarterly newsletter filled with informative and inspirational information; and a valuable Resource Guide for services throughout WNY. Membership support also helps subsidize programs for survivors of brain injury and their families. Membership is on an annual basis.

If you are not currently a Headway member and would like to join us, or if you would like to renew your membership, please complete and return the form below:



- Individual \$20 new
- Family \$30 renewal
- Professional \$55
- Supporting \$100
- Lifetime \$250

Name _____

Address _____

City _____

State _____ Zip _____

Phone _____

Please also consider supporting our efforts with a Tax Deductible Donation

Amount Enclosed \$ _____

Make your check payable to:

Headway of WNY, Inc.
2635 Delaware Avenue
Buffalo, NY 14216



HEADWAY OF WESTERN NEW YORK, INC.

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visit our website: www.headwayofwny.org

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 for 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	WOMEN'S 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
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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 408-3103	St. Paul's Lutheran Church 4007 Main Street, Eggertsville, NY COMPLEX REGIONAL PAIN SYNDROME SUPP. 4th Monday 7:00 PM
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PLEASE NOTE:
If the Buffalo Schools are closed due to inclement weather, support meetings listed here are also cancelled.