

### FALL 2015 QUARTERLY NEWSLETTER

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

# HEADWAY'S ANNUAL WALK, RUN & WHEEL, 5K TAKES OFF DESPITE THE RAIN

Headway's 6th Annual Walk, Run & Wheel took place on Sunday, September 13, at Templeton Landing and Erie Basin Marina, and despite the rainy weather, many turned out for this much anticipated fundraising event!

This year, there were over 120 participants who raised awareness and funds for those living with traumatic brain injuries and other disabilities.

More than 35 volunteers helped set the stage for an exciting and fast-paced morning. It all began at 8:00 a.m. with registration in the front entrance dining area of Templeton Landing. Much excitement filled the air as packets were distributed and numbers were assigned for the 5K.

Participants who pre-registered were able to quickly receive their packets and bib numbers and volunteers helped distribute this year's specially designed sponsor T-shirt.

The walk-in registration process proceeded and guests warmed up with light breakfast fare provided by Wegmans.

Representatives from Tempus Fugit, the organization that provided timing services for this event, started lining up participants at the new start line at 9:00 a.m.



WALK, RUN & WHEEL
6th Annual 5K Run to Benefit Headway of WNY
Presented by Feroleto Law

Volunteers who were present to help with traffic flow and water distribution received special transportation to and from various locations throughout the course, thanks to We Care Transportation services.

Although the start line was moved closer to Templeton Landing this year, the course remained the same – an enjoyable journey along Buffalo's waterfront heading down to the Erie Basin Marina and back up Marine Drive to Michigan Avenue via Scott Street, continuing back down South Park and Main Street to Marine Drive.

We owe a special thanks to the City of Buffalo who provided us with safe and effective parade/motorcade services in a timely fashion. This ensures the continuity of our course and the safety of our participants.

Molly Saper, traumatic brain injury survivor, advocate and 5K participant, provided an inspiring rendition of The Star-Spangled

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Headway is a donor designated agency of the United Way

501C3 Non-Profit Organization

2635 Delaware Ave., Suite E • Buffalo, NY 14216 Phone: 716.408.3100 • Fax: 716.882.1289 support@headwayofwny.org Banner. Mark Reed, event sponsor and Headway advocate, provided the shot gun start at 9:30 am. And they were off.

Enthusiasm filled the air back at Templeton Landing where restaurant staff, volunteers, friends and family members prepared for the post-race festivities.

A special awards presentation/post party was held in the Skyline Room at Templeton Landing. Guests enjoyed hamburgers, hot dogs, salad and pizza, coffee, water and soda, and most of all — lively comradery. The party also featured a basket raffle, a 50/50 drawing and live music provided by Ron Fernandez, Headway's Director of Services and Support. Prizes were awarded in the categories below.

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!

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

Thank you to all who supported Headway this year by your participation in the Walk, Run & Wheel 5K! We look forward to seeing you next year!

#### Prizes were awarded as follows:

Best Time Placed, 5K Team Team Lattimore

Best Time Placed 5K, Male Jay List

Best Time Placed 5K, Female Jennifer Simpson

#### First Place Best Time Placed Age Groups

| 14 & Under | David Lattimore  |
|------------|------------------|
| 15-19      |                  |
| 20-24      | Alex Kuhrt       |
| 25-29      | Amanda Poropat   |
| 30-34      | Andrea Ridings   |
| 35-39      | Jose Quiros      |
| 40-44      | Chris Fox        |
| 45-49      | Fran Warthling   |
| 50-54      | Daryl Hart       |
| 55-59      | Lloyd Kitzmiller |
| 60-64      | John Feroleto    |
| 65-69      | Jim LoVallo      |
| 70-74      | Sr. Gerry Murray |
| 75-79      | Rick Schoellkopf |
| 80-84      | _                |
| 85-89      |                  |

**Top Fundraising Team** First Place Top Individual Fundraiser Second Place Top Individual Fundraiser

Lisa's Angels Lisa Robida Molly Saper





### Thank you to the 2015 Walk, Run & Wheel Sponsors

#### **Presenting**

Feroleto Law

#### Gold

Dolce Panepinto National Seating and Mobility

Venture Forthe Mark, Nancy and Connor Reed Sam and Annette Dalfonso

#### **In-Kind Sponsors**

Buffalo Athletic Club Buffalo Bills Mayer Brothers The Public House on the Lake Templeton Landing Wegmans We Care Transportation

It is through the work of the committee and volunteers that this event is made possible. After months of preparation, this year's committee members and event volunteers are to be commended for a successful culmination

— thank you to the following:

#### Committee

John Feroleto, Esq. Beth Mann Beth McMahon Christine Melchiorre Darlene Robida Chris VanVeghten

#### **Volunteers**

Mary Jo Alessi Bill Bergmann Susan Borden Ron Fernandez Bridget Flynn Mary Herby Kristin Hewlett Carolyn Isbrandt Aidan Isbrandt Mary Beth Iwanski Antoinette McMyne Tim, Megan and Matthew McMyne Mark Reed **Jeff Sanderson** Judy Sanderson Molly Saper Carleen Warington Shannon Winney Linda Wolmer Margy Zezhauser

A special thanks to Tempus Fugit for providing all race timing equipment and crew. The results have been posted on Buffalorunners.com and Headway website.

## HEADWAY WELCOMES NEW ASSISTANT REGIONAL RESOURCE DEVELOPMENT SPECIALIST

Bridget Flynn joined Headway of WNY in July 2015 as an Assistant Regional Resource Development Specialist. She holds a degree in health and wellness and has previously worked in pediatric and adolescent healthcare, as well as women's health services. Bridget is providing much needed assistance to both the Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) waiver programs. She is currently involved with the referral process for potential participants of both programs. She would like to help people remain in their homes, living as comfortably as possible and giving them the opportunity to live with independence and success.

Welcome, Bridget!



My name is Shannon Winney and I'm excited to be the new AmeriCorps VISTA here at Headway of WNY. I just graduated from Nazareth College this past May with my bachelor's degree in social work. I have had internships doing direct service at Charles Settlement House Senior Center, and most recently I worked with homeless students in the Rochester City School District. After graduation, I started looking for jobs when I came across the VISTA program. I have always wanted to work with the veteran population, so I felt that this was the right fit for me. I hope to grow as a professional, as well as learn more about the great services Headway has to offer. I am excited to learn more about the Buffalo community as well as the veteran community.

Please join us in welcoming Shannon!



### **VETERANS OUTREACH UPDATE**

Traumatic brain injury (TBI) is a blow or jolt to the head, or a penetrating head injury that disrupts the function of the brain. Each year, there are a reported 1.7 million civilian brain injuries in the United States. In the military from 2000 through 2012, more than 266,000 service members sustained a TBI. Brain injury has become known as the signature wound of the wars in Iraq and Afghanistan. Most brain injuries are mild, and most people recover in a matter of weeks. BrainLineMilitary. org provides military-specific information and resources on TBI to veterans or service members in the Army, Navy, Air Force, Marines, National Guard and Reserve and their families.

At Headway, we provide resources to survivors, caregivers and professionals alike. We act as an advocacy and referral agency for brain injury survivors in need. To reach veterans, Headway has partnered with the Service Collaborative of WNY as part of the Serve New York AmeriCorps VISTA Program. The VISTA program is focused primarily on expanding services to veterans through Headway as we continue to help veterans find the supports they need in order to manage their condition. We are able to help each individual find the services they need.

For more information, contact Headway's veterans outreach specialist at 716.408.3110.

# Making Memories, One Day at a Time



People Inc.'s Seniors Unlimited is a unique social day program which meets the needs of those who have developed dementia or memory loss caused by Alzheimer's or Parkinson's disease, stroke, heart disease or any other illness.

#### We offer:

- Opportunities for socializing
- Hot, nutritious meals
- A safe, friendly atmosphere
- Stimutating programs in art, music and exercise
- Respite and support for caregivers

Now accepting program participants
2635 Delaware Avenue, Buffalo • Call 716.768.2370 for more information

# TRACY MORGAN'S BRAIN INJURY: RECOVERY CAN TAKE YEARS, EXPERTS SAY

JUN 2 2015, 3:42 AM ET Article by NBCNews

Almost a year after the horrific traffic accident that wounded his body and injured his brain, Tracy Morgan says he is on the mend, although he still walks with a cane and has headaches and memory problems.

"I have my good days and my bad days when I forget things," he told Today's Matt Lauer. "There are times when I have the headaches and the nose bleeds."

In the end, Morgan's ability to come back from his brain injury will most likely determine whether he can return to his old life and take up comedy again.

Morgan is one of 275,000 Americans who suffer a brain injury each year that is severe enough to require hospitalization, according to the Centers for Disease Control and Prevention.

How well any of those people recover is something experts currently cannot predict, said Dr. Douglas Smith, a professor of neurosurgery and director of the Center for Brain Injury and Repair at the University of Pennsylvania.

"We're really missing information on how to provide a prognosis for these patients," Smith said. "Some become vibrant members of society again and if you met them you would never know they had had a brain injury. Others face a lifetime of disability."

For Morgan, things looked pretty grim right after the accident on June 7, 2014. His lawyer, Benedict Morelli told the Associated Press, "when you have a traumatic brain injury, it takes a very long time to find out how you're going to do and how much you're going to recover. You just don't know. He's still fighting and trying to live his life at the same time and trying to get better, and he's just not better. We're hoping and praying to get him back to where he was. But the jury's out."

After a brain injury patients are tested so that rehab specialists can zero in on the abilities that have been most damaged, Smith said.

"Two very common issues are memory and what we call processing speed," Smith added. "Beyond that people with brain injury can be disinhibited which can lead them to say things that are inappropriate."

The good news for patients with brain injuries is recovery can continue throughout a lifetime and isn't limited to the first one or

two years after the initial damage has been done, Smith said.

Still, getting quality rehab right away is essential. "You want to mobilize neuroplasticity," said Wayne Gordon, the Jack Nash Professor and vice chair of the department of rehabilitation medicine at the Icahn School of Medicine at Mount Sinai and director of the Mount Sinai Brain Injury Research Center.

That means, the sooner you can get the brain to start to rewire around damage, the better the prognosis, Gordon explained.

Rehab starts with getting patients back on their feet and walking.

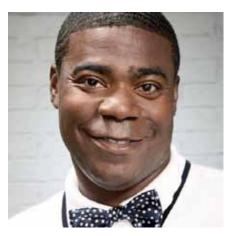


Photo credit: Twitter, @RealTracyMorgan

"In physical rehab, patients get heavy doses of physical, occupational, and speech therapy," Gordon said. "Then there is individualized and in-group learning to compensate for and manage what your cognitive challenges are. You're learning how to minimize those cognitive challenges on a day to day basis."

Though people remember clearly who they were and what they did before the brain injury they need to realize there will need to be "a new you," Gordon says.

That doesn't mean the patient's essential personality changes, he explained, adding, "you might be viewing the world a little differently now. You might understand things need to take more time,

so you don't rush through things. You realize that everything takes a lot more thought and planning, a lot more organization. You think ahead more. You make sure you get enough sleep."

Some will learn to lean on memory aids, such as phones programmed to keep track of their schedules.

Gordon is an optimist, though he allows rehab can last a lifetime.

"I think rehab is basically about hope," he said. "It's like a marathon, but you really don't know how long the road is."

Tracy Morgan believes he'll make it to the finish line, that he'll one day get back to doing the thing he loves best, comedy.

"I can't wait to get back," he told Lauer. "But right now my goal is just to heal and get better 'cause I'm not 100 percent yet. And when I'm there you'll know it. I'll get back to making you laugh."

### HEADWAY SEEKS PART TIME SUPPORT AND ADVOCACY SPECIALIST

This position coordinates Headway's support groups, provides support and advocacy and performs educational outreach.

#### **ESSENTIAL FUNCTIONS/RESPONSIBILITIES**

- Coordinate and lead support groups and lead select monthly support groups.
- Provide support and advocacy by phone and home visits if necessary for survivors and families in crisis.
- Assist with basic information, referrals both for Headway (waiver) and outside agencies, doctors, etc.
- Provide information and answer questions about brain injury and resources, etc.
- Deliver in-service presentations to various schools, hospitals, nursing homes, group homes, therapy and nursing students and professionals and other organizations.
- Attend health fairs and community events to provide Headway information.
- Maintain library of resource materials.
- Complies with all agency policies and procedures.

#### Requirements

- Associate degree in human services or equivalent experience working with brain injury.
- Experience with organizing and leading staff/volunteers preferred

To apply for this position, please go to www.people-inc.org/careers

# All we need is YOU!



### Senior Companion Program Volunteers Needed

Seniors in your neighborhood need your help! Volunteers, known as Companions, assist with:

- Grocery shopping and errands
- Light cooking and housekeeping
- Alerting doctors and family members to potential problems

Companions are currently being accepted to enroll in our September training.

Want to volunteer or know someone in need of services? Call 716.768.2381 today to learn more!



# A SURVIVOR SHARES HIS STORY OF INSPIRATION

Mark Shaw provided his story previously in the Spring 2013 and Summer 2014 issues available on our website.

By Mark M. Shaw

June 15, 2004, is a day that will forever live in my mind. That is the day my life changed forever! I had an arterial venous malformation (AVM) rupture, and surgery caused a stroke/hemorrhagic aneurysm, leaving me with a traumatic brain injury. I was not expected to live and was in a coma for a month in intensive care at Millard Fillmore Gates Circle Hospital.

When I survived, it amazed the professionals. My family was told that I would be wheelchair bound forever and I argued. I began walking again. They were also told that I shouldn't and likely wouldn't have either long-term or short-term memory, and by the grace of God, I do!

I had a bad attitude towards life in general at first, but I turned a negative situation into a positive. I went back to school in September 2008 to Niagara County Community College and graduated with an associate degree in human services. I then went on to University at Buffalo to obtain a bachelor's degree in health and human services. Currently, I am in my third and final year at Niagara University where I am working to obtain my master's degree in clinical mental health counseling.

Now they are taking down the former Millard Fillmore Gates Circle Hospital building, and I am kind of feeling like my place of "rebirth" is being taken away.

My advice to anyone who suffers a traumatic brain injury is NEVER SETTLE or GIVE UP!

# A BRAIN INJURY SUPPORT GROUP COULD BE ONE OF THE BEST THINGS THAT EVER HAPPENS TO YOU

By Barbara J. Webster, BrainLine



# Barbara Webster shares her experience.

I never thought I was a "support group person." I thought support groups were more for people who wanted to talk about their problems instead of doing something about them. In 1991, when a car skidded into mine on a slippery road and my life was turned upside down, little did I

know that a support group would be one of the best things that ever happened to me. I looked okay after the accident, no obvious head wound, but on the inside I was far from okay. Prior to the accident, I was a problem-solving, multitasking, achieving mother, wife, and career woman. Now I struggled with simple every day tasks and I didn't know why. I felt like I was going crazy. After more than

two years of confusion, frustration, and despair, I attended a program at my son's school featuring a speaker from the Brain Injury Association of Massachusetts. I remember trying to hide the tears than ran down my cheeks as I listened and realized that finally I was not alone!

Since 1995, I have had the privilege of facilitating the Brain Injury Survivor Support Group in Framingham, MA. I also work part-time for the Brain Injury Association of Massachusetts assisting other support groups. What I hear regularly from support group members is that the most valuable benefit of a support

group is finding a place where you feel comfortable and can talk with people who "get it," who truly understand your issues. What surprised me was all of the additional ways that I found a brain injury support group to be helpful.

At my support group, I discovered "strategies," those amazing little tools that help you do things you couldn't do otherwise. At one meeting, I was describing how much trouble I was having performing simple everyday tasks like getting dressed in the morning and making supper. A fellow survivor mentioned a "strategy" that he used to help himself — and it felt like a light bulb lit up inside my head! He said he left the cap of the shampoo bottle flipped open as a signal to himself that he had already washed his hair. Another useful suggestion was putting everything you need to leave the house in one specific spot so you always know where to find your keys, phone, sunglasses, or purse. Instead of dwelling on all of the things that I couldn't do, I began thinking about how to do them. I love strategies! Each one feels like a little miracle to me.

And it was through the support group I discovered that there were professionals who could actually help me. I learned that speech and

language therapy wasn't just for people who had difficulty talking and that there was such a thing as cognitive rehabilitation. What a revelation! What a relief! I didn't have to figure this out by myself with an injured brain, which clearly wasn't working very well. Those therapists, "my earth angels," helped me start the long process of putting my life back together. Finally, I had HOPE.

Healing from a brain injury takes a long time. My insurance coverage and therapies stopped long before I was ready. My support group helped fill the gap. Most brain injury support groups offer much more than a forum for listening and sharing. They can also provide educational, recreational, and social opportunities. They can be a place to make new friends. They can be a place to volunteer, providing a safe environment to practice skills and challenge your abilities. They are also a link to the state brain injury association, keeping you informed of activities and opportunities statewide.

I think the biggest additional benefit of participating in support

group was the inspiration I received from seeing other survivors reach their goals. Time and time again, I found myself thinking 'if they can do it, I should at least try, maybe I can be successful too'. I was afraid to try the computer; how could I remember all of the steps just to turn it on? I'll never be able to do email! Would I be able to figure out my new digital camera before my sister's wedding? How would I ever be able to figure out how to use a cell phone? How does that survivor work part time; I'll never be able to do that! I achieved all these goals because I was inspired by my fellow survivors. Other support group members frequently echo

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my experience. I think we inspire confidence and courage in each other just by witnessing each other's journeys.

Gradually this group of people that I never thought I would be part of, became like my extended family. I still remember the person who greeted me at those first meetings. This simple, friendly gesture was the highlight of my week, a week that was otherwise filled with failure and frustration. Through the support group, I've made lifelong friends. What a gift!

After I had been part of the group about a year, we were about to lose our facilitator — and our support group. I still don't know how I had the courage, but I took a leap of faith and volunteered to be the facilitator. In the beginning, I just tried to give everyone an opportunity to share. Gradually, as I felt more capable, I composed monthly newsletters and invited an occasional guest speaker. Before long, I was developing resource lists, arranging social and recreational activities, and organizing projects. Running the group became my vehicle for rehabilitation. I could work on it at home, at my own pace, when the house was quiet and I was having a "good brain day." The more I challenged myself, the more

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### WAIVER TRANSITION GROUPS FORM

The first meeting of the Nursing Home Transition and Diversion (NHTD) and Traumatic Brain Injury (TBI) Waiver Transition workgroup met in Albany August 24. This workgroup is part of New York State's efforts to continue to provide needed services to participants of the waiver program during and after the transition to managed long term care.

The meeting was led by Mark Kissinger, Director of the Division of Long Term Care for the Department of Health (DOH). The workgroup representatives included other DOH staff Maribeth Gnozzio, Project Director of Home and Community Based Waivers, Bureau of Community Integration and Alzheimer's disease; representatives from the Alliance which represents providers of waiver services; directors of some of the waiver agencies; a father with his son who is in the program; one managed long term care insurance company; and Dominique Mathurin from Centers for Medicare and Medicaid Services (CMS). In addition, there were questions posed by others in attendance and on the internet answered by the workgroup.

The meeting clarified that there was not a completed transition plan at this point. The projected date of transition taking place on the TBI and NHTD waivers is January 2017. It was clarified that a transition plan will be open for public comment before it is submitted to CMS, and that the DOH needs to show that the comments were addressed and what changes to the plan were done as a result of these comments.

There were plans to form subcommittees to address the issue of services, the kind of providers that would be giving services, financial issues and how a plan will be presented to participants of the waiver programs. These subcommittees will be open to the public and if a person is interested in joining, they can email waivertransition@health.ny.gov.

Then next public meeting of the group is scheduled for October 8 with at least two more meetings to take place. Anyone can monitor and get more information regarding the workgroup process and transition in general at the website: health.ny.gov/health\_care/medicaid/redesign.

# WELCOME TO OUR NEW NURSE EVALUATOR!

Lisa Ciavarella began working as a Nurse Evaluator with Headway's Nursing Home and Transition Waiver Program in July.

Prior to this she was a middle school nurse. She has worked at Strong Memorial Hospital as a Medical Surgical Nurse and Brothers of Mercy Nursing Home on their rehabilitation floor. She also worked for Port-a-Medics drawing blood and doing physicals for insurance companies, and at the Olmstead Center as a Senior Vison Nurse.

Lisa received her master's degree in school counseling and worked as a long term substitute at Attica Central High School.

Lisa is a veteran and currently is in her 27th year of service for the United States Air Force Reserve. Her passion is working with animals and she hopes to one day start a chapter in Buffalo of Pets for Vets. This program is dedicated to supporting veterans and providing a second chance for shelter pets by rescuing, training and pairing them with America's veterans who could benefit from a companion animal. It is a volunteer-run program. She says anyone who might be interested in trying to start this chapter in Buffalo can send her an email at lciavarella@HeadwayofWNY.org.

Lisa says she prayed that God would put her in a position where she could help people and make a difference in someone's life. She believes that God brought her to Headway for this reason.

Since she has begun working for Headway, she has found it to be very rewarding. She enjoys traveling to meet people and seeing how Headway's waiver program could help them in being more independent. She is very happy where she is and looks forward to learning more about her role as a nurse evaluator.

Glad to have you on board, Lisa!

"Brain Injury Support Group" continued from page 6

I redeveloped my skills and promoted my own rehabilitation process. Talk about unexpected benefits.

At the support group, we were hungry for any information related to brain injury and were eager to share anything that might be useful. I began writing up notes from our meetings as well as from the workshops I attended, organizing it for myself and for future meetings, adding to it as I learned more and more. Eventually, my collection of tips, tools, and strategies became a book to

help other people with brain injury. Brain injury survivors and their caregivers have a special wisdom, a wisdom gained from unique experiences, priceless to others in similar situations. My book is intended to help share this special wisdom with others who are living with brain injury and make their journey just a little bit easier.

Support groups aren't for everyone, but everyone needs support after something as traumatic and life changing as a brain injury. To find a support group in your area, please contact your state Brain Injury Association. It could be one of the best things that ever happens to you!

Barbara Webster is the long-time facilitator of the "Amazing" Brain Injury Survivor Support Group in Framingham, MA and the support group leader liaison for the Brain Injury Association of Massachusetts. She is also the author of Lost and Found, A Survivor's Guide for Reconstructing Life After a Brain Injury, available through Lash Publishing.



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### 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 of WNY 2635 Delaware Avenue, 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 First and third Tuesday of each month 6:30 p.m. to 8 p.m.

# PEER SUPPORT IN RURAL COMMUNITIES

DeGraff Hospital/ Administrative Board Meeting Room Second Tuesday of each month 4:30 p.m. to 6 p.m.

#### **CAREGIVERS SUPPORT**

Enter at Suite E First Tuesday of each month 6:30 p.m. to 8 p.m.

#### **VETERAN'S READING GROUP**

Enter at Suite B First Thursday of each month 6:30 p.m. – 8 p.m. 716-408-3110

#### **PLEASE NOTE:**

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

Do you wish to continue to receive this newsletter? If not, please contact our office at 716.408.3100 to be removed from the subscription list.

## **HEADWAYOFWNY.ORG**