

# FALL 2016 QUARTERLY NEWSLETTER

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

## **NEW DATE FOR WALK, RUN & WHEEL, 5K**

Headway's Annual Walk, Run & Wheel, 5K has been rescheduled from September 10 to Saturday, October 22, 2016.

Some of you have asked why and we wanted to provide you with a little background.

The Walk, Run & Wheel is Headway's second largest fundraising event of the year and has historically been held at the Erie Basin Marina in Buffalo. For the first five years of its existence, the check-in location and awards festivities were held at The Hatch. Last year, although we were able to keep most of the course intact with minor revisions, we had to select a new location. Templeton Landing was chosen at that time, due to its proximity to the course.

This year, Headway's Advisory Board asked if the course and event could be moved to an entirely new location, in the hopes of making the event more cost effective. Additionally, it was decided to investigate the possibility of using a USA Track and Field official Certified Course to attract more dedicated runners.

Many courses were considered throughout Western New York, and LaSalle Park in Buffalo was chosen. The loop around the park appeared to be a solid solution and permit applications were filed with the City of Buffalo, and a pre-certified course was selected.

Plans moved along swiftly throughout the summer to move the event, complete with rentals (including a tent, tables, chairs, etc.). Food donations were secured and all volunteers were lined up. Unfortunately, three days before the event, Headway was notified by the City of Buffalo that part of the course would not be accessible due to unforeseen prolonged construction and a shortage of motorcade vehicles and traffic control officers.

It was determined to reschedule the event to ensure the safety of our



# **NEW DATE**

participants and to allow ample time for construction to be completed.

We are pleased to report that the course is intact and plans are fully back underway for what was to be an end of summer event, to a fantastic fall adventure – please join us!

If you have already registered and wish to participate on October 22, no action is needed on your part – Headway will simply transfer your registration to the new date. If you are not able to participate on the new date, the registration expense will be refunded to you. Preregistration brochures are available online at headwayofwny.org and details are outlined on the following page.

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Headway is a donor designated agency of the United Way

501C3 Non-Profit Organization

### FROM THE DIRECTOR



Autumn is my favorite season. The slight chill in the air is invigorating after a hot summer; and this year's was the hottest ever.

Our new support and advocacy staff member will be addressing those who are trying to navigate this ever changing health care system, and help us in our efforts to increase our volunteer and community education efforts. Both of our waiver programs have had an increase in referrals, underscoring the importance of what Headway provides to Western New York. I am hopeful that all who are able to participate will do so as much as possible

to help further our mission. The roots of this agency are in volunteerism and there are many opportunities here, particularly if you have an interest in sharing your experiences during our presentations and outreach events. Watch for up-to-date information regarding these volunteer opportunities and other Headway activities on our website at headwayofwny.org. We will continue to update this site to ensure communication with all of you.

We hope everyone has a safe and enjoyable fall!

Ronald Fernández, RRDS, CRC, LMHC Director



# **NEW DATE!** Saturday, October 22, 2016 • LaSalle Park, Buffalo

A family-friendly fundraiser to help make a difference in the lives of persons with brain injuries and other disabilities

Registration/Check-In: 8 – 9am Start Time: 9:30am Awards and Festivities to Follow

**Pre-Registration Rates** Run/Wheel, 5K: \$25 Walk/Wheel, 1-3 Miles: \$20 Day of Registration Rates Run/Wheel, 5K: \$28 Walk/Wheel, 1-3 Miles: \$23

DISCOUNT FOR MEMBERS!

# PRE-REGISTER ONLINE AT ACTIVE.COM

Headway of WNY, Inc., an affiliate of People Inc. 2635 Delaware Avenue, Suite E • Buffalo, NY 14216 headwayofwny.org • 716.408.3100





# MOLLY'S STORY OF HOPE, PART II

Some of our readers may remember the moving article that appeared on these pages in the Winter 2013/2014 issue, "Molly's Story: The Day that Changed My Life."

The story featured a young girl who sustained a brain injury in high school and described her road to recovery. It was full of hope and was the impetus for including other such stories of hope and encouragement on these pages. We invite you to share yours as well.

Here, we are pleased to offer an update to that story from Molly herself!

66 Life is a song. 99

The only thing that is a constant in life is change. A change can be a metamorphosis, for example, a caterpillar into a butterfly. Seasons change, nature erodes, a seed blooms, and with every storm comes a rainbow. A change can bring about beauty, because

life is all in how one views their experiences. A change is merely a gateway to a new, better reality. There are no accidents, only hurdles to becoming our greater selves.

Changes can be challenging. A new home, a new school, a new job (characteristics of anyone's life) or even the return to the life you THOUGHT you knew before your

brain injury. Often when a person with a TBI is thrust into life again, relationships change and friends leave. A person with a brain injury can't function as they did before, and MUST capitalize on strengths and talents possessed to find new friends and interests to help us get through this crazy journey we call life.

My life has been full of changes since that fateful day in February of 1997, as I am sure everyone with a TBI can

list multiple changes in their lives. My TBI, my return to school, and my high school graduation can start my list of major life changes. College, choosing a different path for grad school and graduating college were my next hurdles. When I graduated from grad school and

had to find a job, I had no idea what life had in store. Marriage and two kids later, I now firmly believe that the only constant in life is change!

A traumatic brain injury is a change for the individual as well as for the family and friends around them. Like many, my rehab process included a tracheotomy, because my parents knew I loved to sing. Little did they know that saving

my vocal chords would one day lead to me being the lead singer in a band! My band, "Hello Molly," will be performing following the Walk Run and Wheel, and we would love to see you there!

Carpe Diem!



### HEADWAY ANNOUNCES ANNUAL MEMBERSHIP DRIVE

If you are a current member, we hope to see you at our Annual Meeting on November 3, please see the enclosed flyer for details.

If you're not yet a member, please join us today and make plans to attend the presentation. You may also join as a new member today even if you are not able to attend the meeting (see option on response form).

Note to current members: You will receive your annual membership renewal letter in the mail when it's close to your membership renewal date.

**Thank you** to all members who participated in the membership phone survey, which was conducted in August by our summer intern.

We received valuable feedback on ways to enhance your membership. Most importantly, we learned that you like what we're doing and you would like to see more informational updates and activities, including afternoon support groups. Please note that you do not need to be a member of Headway to attend support groups, however your membership dues help sustain these groups.

We listened to you and have responded by incorporating many of your suggestions/comments into the updated benefits associated with each level of membership listed below.

Level/Dues	Benefits Include
Individual, \$20	Quarterly newsletters, monthly informational updates, Resource Guides, 10% discount on events, and no charge for educational presentations.
Family, \$45	Same as above for up to 4 individuals and also includes notices about reduced rate arts enrichment opportunities in WNY.
Professional, \$70	Same as above, and also includes opportunities to provide presentations/ information at educational presentations/member events.
Supporting, \$125	Same as above, and also includes recognition on website.
Corporate, \$350	Same as above, and also includes ¼ page ad in quarterly newsletter for one year.

Memberships are valid for one year (12 months from start month) and may be renewed annually. Lifetime membership dues are \$250 (and include all benefits of an Individual membership) and are valid throughout the individual's life.

### **HEADWAY ADVISORY COUNCIL UPDATE**

Headway's Advisory Council meets on a quarterly basis and is currently seeking new members for 2017/2018.

If you are interested in serving on the Advisory Council, please send a letter of interest, along with your current resume to:

Advisory Council Positions Headway of WNY, Inc. 2635 Delaware Avenue, Suite E Buffalo, NY 14216

### The Advisory Council's Mission statement is:

To provide consumer and professional guidance to Headway of WNY and other local and state agencies who plan and provide services and support to individuals with special needs. To advocate and ensure that people of WNY with brain injuries and other disabilities have access to resources and support systems which enable them to participate and succeed in an accepting society.

### **HEADWAY WILL PARTICIPATE IN #NYGIVESDAY 2016**

### What is #NYGivesDay?

#NYGivesDay is a 24-hour online giving challenge to celebrate the life-changing work of nonprofits across the vast state of New York. Thousands of nonprofits across the Empire State will work together to raise awareness, collect donations and build a stronger sense of philanthropy throughout their local communities.

On November 29, 2016, nonprofits across the Empire State will work together to raise awareness, collect donations and build a stronger sense of philanthropy throughout their local communities.

This online giving event will be held from 12 AM Eastern Time – midnight only on November 29. The giving takes place online at NYGivesDay.org. Your direct link to Headway's giving page that day will be: nygivesday.org/organizations/headway-of-western-new-york-inc.

This day will also coincide with #GivingTuesday, a movement to add a national day of giving on the first Tuesday following Thanksgiving, Black Friday and Cyber

Monday. This year, nonprofits throughout New York state will join together to encourage a statewide spirit of philanthropy and collect the funds necessary to continue changing the world for the better!

### Who is leading #NYGivesDay?

The New York Council of Nonprofits (NYCON) and United Way of New York State (UWNYS) along with their technology partner, GiveGab, formed a partnership to launch #NYGivesDay, New York's first ever statewide day of giving in 2016. NYCON and UWNYS work throughout the year to strengthen and support nonprofits around the state. GiveGab is a year-round platform

that nonprofits can leverage for online fundraising and supporter engagement. #NYGivesDay will bring resources and attention to the nonprofit sector and the crucial role it plays in New York's communities. Other nonprofit networks and organizations that support nonprofits are welcome to join in and promote New York Gives Day.

Headway supporters can donate online via credit or debit card on November 29 at nygivesday.org/organizations/headway-of-western-new-york-inc

More information will be provided by email in the upcoming weeks and on our website at headwayofwnyorg.

## **ARTS ACCESS**

Did you know there's a program in Western New York that offers free and/or discounted access to the arts in our community? Check out the website arts-access.com.

Here is what Arts Services Initiative of WNY has to say about their Arts Access program: Arts Access aims to increase the accessibility of Western New York arts and culture by connecting residents to free and low cost cultural opportunities in their communities. We do this by providing individuals with low-incomes and their families the chance to see live theatre, music, art and more through the Arts Access pass, and by promoting already existing discounts offered by area organizations.

We envision a community where the arts are for everyone, regardless of means or abilities.

To learn more about the program, go to asiwny.org or go directly to the Arts Access website listed above.

### **NEWSLETTER SURVEY**

To help improve our communications with you, our readers.

Please take a moment to complete the form below by November 30, 2016, and return to us via postal mail to:

Headway of WNY 2635 Delaware Avenue, Suite E Buffalo, NY 14216

Or, if you prefer, you may choose to complete the form, scan and email back to us at support@headwayofwny.org. Thank you!

# Please check all boxes below that apply to you and/or your organization:

Parent/Caregiver	
Provider Agency	
Student	
School:	
Major/Area of Study:	
Current Headway member	
Past Headway member	
Other	
Please explain:	
First Name:	
Last Name:	
Address:	
City:	
State:Zip:	
Email:	
Preferred Phone Number:	

# NEWS FROM THE BRAIN INJURY ASSOCIATION OF AMERICA DATED SEPTEMBER 23, 2016

This BIAA Policy Corner is an update on federal policy activity related to traumatic brain injury (TBI) and is published weekly when Congress is in session.

### Special Needs Trust Fairness Act

On Tuesday, the U.S. House of Representatives passed H.R. 670, the Special Needs Trust Fairness and Medicaid Improvement Act, sponsored by Rep. Glenn Thompson (R-Pa.). The legislation allows individuals with disabilities who are non-elderly to create a special needs trust for themselves. "D-4-A" Special Needs Trusts were first recognized by Congress in 1993 to help ensure that individuals with disabilities can use what savings they have to provide for their supplemental needs while still qualifying for long-term services and supports from means-tested programs, such as Medicaid. An oversight in drafting the law concerning these types of trusts meant that individuals who do not have a parent, grandparent, or legal guardian had to petition the court for guardianship. H.R. 670 corrects that error that presumed that all persons with disabilities lack the mental capacity to handle their own affairs.

### CDC Final Report on Guideline for Managing Mild TBI

The Centers for Disease Control and Prevention's Injury Center issued a press release providing further information on the National Center for Injury Prevention and Control Board of Scientific Counselors (NCIPC BSC) September 7 meeting, during which the Pediatric Mild Traumatic Brain Injury Guideline Workgroup presented a detailed overview of their Final Report. Entitled "Systematic Review and Clinical Recommendations for Healthcare Providers on the Diagnosis and Management of Mild Traumatic Brain Injury Among Children," the Workgroup Report is the most comprehensive review of pediatric mild TBI (mTBI) scientific evidence to date. It is the first set of U.S. evidence-based clinical recommendations for healthcare providers that covers all causes of pediatric mTBI and includes guidance for primary care, outpatient specialty care, inpatient care, and emergency care settings.

The NCIPC BSC voted unanimously to accept the Workgroup Report. Over the coming months, CDC will use this report to inform the development of a CDC guideline on diagnosis and management of mTBI among children and adolescents. Link to article: www.cdc.gov/injury/pdfs/bsc/systemicreviewcompilation\_august\_2016.pdf

# **GUEST CONTRIBUTION**

### THE SEAT BELT

By Joan Harms

On Friday, August 5, our 21st wedding anniversary, Bill, my husband and I were travelling north on Transit Road (RT 78) in Clarence, NY on a shopping trip. We were driving our leased 2015 Chrysler 200. At approximately 12:50 p.m., we were involved in a three car crash. We hit the rear end of a 2012 Honda that stopped abruptly in front of us, and almost immediately after the initial crash, we were slammed in the rear by a 2006 Accura.

I am writing to tell you that although the crash was a terrifying experience, Bill and I sustained only minor injuries of bruises and shock from the crash. Our Chrysler 200 performed exactly as it was supposed to. We were protected in the cockpit which did not collapse

around us. Since we were driving under 30 miles per hour, the airbags did not deploy. The seat belts worked exactly as they are designed to. They held us back and distributed the force of the crash across our bodies. The head rest on the top of our seats prevented whip lash. Although we were bruised and dazed, we are grateful to be alive.

In the early 1980s, I became a seat belt champion and with the assistance of the State University of New York at Buffalo, Bio-Medical Department, I formed a task force in the Western New York area to promote the use of seat belts for adults and car seats for child passengers. The program was affiliated with People Inc., a human service agency that serves people with developmental disabilities and other specials The original intent of the program was to prevent injury to individuals who were already disabled. The program was affiliated with the New York State ARC, the National Highway Traffic Safety Administration, the New York

State Police, local legislators, parents and teachers and others interested in the issue.

The chairman of the task force was the late Dr. George Alker, Director of

Trauma Surgery at Erie County Medical Center in Buffalo, New York. His passion for continual use of seat belts came across loud and clear as he described patients he had operated on who were injured in car crashes.

Under his direction, the group held public meetings with police agencies, held demonstrations including vehicles that has been involved in crashes, and spoke at high schools and other locations to prove the benefits of seat belt use. The task force became active in the early 1980s, before any state in the United States passed laws requiring mandatory use of seat belts. Since that time, all states require mandatory use of seat belts

for drivers and passengers, as well as mandatory use of car seats for child automobile passengers.

How could I have known that 20 years later, long after I retired from advocating for automobile passenger safety, I would personally be involved in a car crash? By using my seat belt, I did not sustain serious injury, or even death. Please consider me a lifelong user of this simple device that saved my life, the SEAT BELT.



The head rest on the top of our seats prevented whip lash. Although we were bruised and dazed, we are grateful to be alive.





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FACEBOOK.COM/HEADWAYOFWNY



2635 Delaware Ave., Suite E Buffalo, NY 14216 NONPROFIT ORG US POSTAGE PAID Buffalo, NY PERMIT #281

## 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 to 8 p.m.

### **CAREGIVERS SUPPORT**

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

### VETERAN'S READING GROUP

Enter at Suite B First and third Thursday of each month 6:30 to 8 p.m. 716.408.3110

### PEER SUPPORT IN RURAL COMMUNITIES

DeGraff Hospital/Admin Board Meeting Room 445 Tremont Street, North Tonawanda, NY 14120 Second Tuesday of each month 4:30 to 6 p.m.

If you have questions, call 716.694.4500 or 716.523.9623

### 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**