



HEADLINES

FALL 2004

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Blackduck

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October 19

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November 3

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December 1

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Brain Injury Association of Minnesota helpline:
1-800-669-6442

www.braininjurymn.org

TBI on the rise in the military

by Sharon Rolenc

Chances are you have seen the signs in your own neighborhood – “Support Our Troops.” This message takes on new meaning as waves of our soldiers make their journey home. While communities welcome home their troops, thankful for their safe return, many families will face the life long challenge of living with their loved one's traumatic brain injury (TBI).

TBI is one of the leading casualties of warfare, due largely to the inherent high risk involved in military duty. The current Global War on Terror is the first wartime situation where the cases of TBI are being looked at carefully.

The Defense and Veterans Brain Injury Center (DVBIC) has been addressing the issue of brain injury in the military for the past twelve years. Established originally as the Defense and Veterans Head Injury Program in 1992, DVBIC serves active duty military, their dependents and veterans with traumatic brain injury (TBI).

DVBIC is a collaborative effort between the Department of Defense (DOD) and the Department of Veterans' Affairs (VA) with three military sites at Walter Reed Army Medical Center in Washington D.C., Wilford Hall Medical Center in San Antonio Texas, the Navel Medical Center in San Diego; one civilian partner center, Virginia NeuroCare; and four lead VA sites in Richmond, Tampa, Palo Alto and Minneapolis.

“The program originated at the time of Desert Storm to ensure that military and VA patients with TBI received TBI-specific evaluation, care and follow-up. If people came back from combat and had problems that may have been related to a TBI, such as difficulties with behavior, sleeping, anxiety, or irritability, we wanted to make sure that if this was related to a TBI, that we identify that and that they get



The Brain Injury Association of Minnesota celebrates 20 years of providing education, advocacy and support for persons with brain injury. Pictured above: the 1992 rally in Washington in support of the TBI Act; Minnesota had a bigger turnout than any other state. Turn to page 8 for more pictures and the 20th Anniversary story of the Association.

proper treatment,” said Dr. Rose Collins, neuropsychologist for the Minneapolis VA site.

The core focus of DVBIC is to deliver state-of-the-art clinical care, clinical research, and education and outreach.

Clinical care has currently taken a front seat at DVBIC. “With the war, the clinical care component has taken priority,” said Collins.

Transport and care for patient happens through a coordinated effort between the military, military case managers, national TBI case managers, and local VA case managers. Patients are taken through a complex system that moves them from the battlefield to a local DVBIC site.

When soldiers are injured in Iraq or Afghanistan, they are treated in the combat support hospital. They are then flown to either Germany or the USS Comfort which is set in the Persian Gulf. After that they typically come through Walter Reed and

when they are medically stable, they go to one of the four lead VA sites in Richmond, Tampa, Minneapolis, or Palo Alto.

One huge benefit to the program is the ability to keep patients longer, offering more extensive rehabilitation opportunities.

“Our patients on average have a longer length of stay, which allows us to actually work on the cognitive issues, whereas in the private sector, once the person is ambulatory, they are often discharged,” said Collins.

The longer stay allows persons with TBI to learn compensation techniques in an inpatient setting. As a result, patients in the four VA lead sites are seeing better rehabilitation results. “We look at the Functional Independence Measure (FIM) at discharge, which is the standard rehab benchmark, and the discharge FIMS for the VA program are

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3rd Annual Walk for Thought Two Minnesota locations this year



MINNEAPOLIS – The Brain Injury Association of Minnesota is hosting its third annual Walk for Thought at 9 a.m. on Saturday October 2 at Phalen Park in St. Paul, and Saturday October 9 in Blackduck, Minn. The walk is open and accessible to all - including those in strollers or wheelchairs. Walk teams from throughout the state are encouraged to participate. This walk is a fundraising and public awareness event. More importantly, this walk is a celebration of life, hope and healing.

Each year in the United States, 1.5 million people sustain a brain injury. That's more than *six times* the annual incidence rate of Multiple Sclerosis, breast cancer and HIV/AIDS *combined*. Brain injury is the leading cause of death and disabilities among children and young adults. However, despite the high rate of prevalence, brain injury is largely an invisible epidemic.

The Brain Injury Association of Minnesota is the only nonprofit

organization in the state devoted solely to serving the needs of the 94,000 Minnesotans who live with a disability due to brain injury. The mission of the Association is to create a better future through brain injury prevention, research, education and advocacy.

Last year we had over 60 walk teams and more than 600 walkers - a fifty percent growth over the Walk's inaugural year. This year's goal is to bring together 1,000 walkers in celebration of life, to increase awareness of brain injury and to raise funds to support the Association's efforts to provide help, hope and a voice to the 94,000 Minnesotans living with brain injury.

Last Spring, the Brain Injury Association of America adopted Minnesota's Walk for Thought to replicate nationwide. "This is an opportunity to increase awareness of brain injury nationwide, as well as in Minnesota. By building upon our successful model in other states, the Brain Injury Association of Minnesota continues to position itself as a leader in the brain injury community," said Tom Gode, Executive Director, Brain Injury Association of Minnesota.

For more information about the Walk for Thought call 612-378-2742, or 1-800-669-6442 in greater Minnesota. Registration brochures, team captain packets, posters and directions to the walk can be found on the Association's website, www.braininjurymn.org.

CALENDAR of EVENTS

October 19 : Brain Injury Basics

Confusion. Frustration. Sorrow. Anger. Fear. Isolation. These are some emotions a person with brain injury may feel after injury. Families, friends & loved ones may feel this way, too.

Learn about the impact of brain injuries caused by concussion, traumas such as crashes or falls, stroke, aneurysm & coma.

Learn about what brain injury is; the common side effects of brain injury; compensation techniques; and tips about how to relate to people who have sustained brain injury.

These classes are offered bi-monthly. Class begins at 6:00 p.m. and runs until 8:30 p.m. Further dates for 2004 are October 19 and December 21. To register, call 1.800.669.6442 or 612.378.2742.

November 3: Discharge Planning in Today's World

Turn to page 6 for full story about the annual Discharge Planner's Conference.

December 1: Long-Term Care and Participants with Brain Injury

The Brain Injury Association of Minnesota, in an effort to improve the quality of life of adults in group homes, independent learning services, home health care, chemical health units and long-term care facilities, offers training to enhance communication and relationships between caregivers and residents.

Program highlights include:

- "Train the Trainer" course;
- Learn to enhance relationships with care givers and residents;
- Create quality homelife for persons with brain injury;
- Demonstrate specific methods to manage interruptive behaviors;

Cost is \$250 per person for 8 hour training. Participants will receive a train-the-trainer manual, handouts and CD for overheads. A certificate of attendance will be provided upon request, and may be applied towards CEUs for eight contact hours.

For more info, call Anne Schuller at the Association at 612-378-2742, or 1-800-669-6442.



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Mission

The mission of the Brain Injury Association of Minnesota is to create a better future through brain injury prevention, research, education and advocacy.

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Headlines is published quarterly by the Brain Injury Association of Minnesota. The Editor reserves the right to edit submitted materials for style and space. The Association does not endorse, support, or recommend any specific method, facility, treatment, program, or support group for persons with brain injury and their families. Please call for advertising rates.

Volunteer Receptionists Needed!



Looking for a way to get involved with the Brain Injury Association of Minnesota? We have several openings for volunteer receptionists at our new office in Northeast Minneapolis.

The Receptionist has an integral role in creating a welcoming, helpful atmosphere for callers

and visitors. Duties include answering incoming calls and directing them to the appropriate staff member, creating information packets, photocopying, filing and faxing.

This is an opportunity to work with caring, motivated professionals in a congenial environment while helping persons with brain injury.

We'll provide training and offer a flexible weekday schedule and free parking.

We're looking for a few friendly people with good oral communication skills who can commit to a minimum of four hours per month.

Willingness to have fun is also important. If interested, contact Kimberly Ferencik, Volunteer Coordinator at 612-238-3221 or via email at kimberlyf@braininjurymn.org.



PERSPECTIVE

Message from the Board of Directors

With Fall sports come concussions

Last summer my daughter sustained a concussion(s) while playing goalie on her soccer team. I sent her to an out of town game with her

coaches while I took her sister in a different direction. While in goal she got hit on the side of her head by another player. On a subsequent play she hit her head on the goal post. Finally, she got "clobbered" by a player.

That is the last thing she remembered until she heard her coach calling her name. She proceeded to throw up on the sidelines and in the coach's car as they brought her home. Needless to say, I immediately brought her to the hospital. Fortunately, the scans were normal and she was sidelined for one week. However, she also saw her pediatrician the next day and he took her out of sports for one month. She whined and pouted. Yep, those were the expected reactions from her. However, this was my time to dig deeper into concussive disorders. I'm glad that I did and I'm grateful that her doctor knew how to respond.

As fall approaches, the schools will once more be immersed in football and soccer. However, this does not negate the risk in other sports and recreational activities including ice hockey, gymnastics, wrestling, equestrian, martial arts, horseback riding, cycling, skiing, diving, and snowboarding.

HealthLink, through the medical College of Wisconsin, reports that "40,000 high school football players nationwide suffer concussions." And "about 300,000 traumatic brain injuries occur each year in sports and recreation in the United States." For this reason alone, it is important that all persons that have contact with the player have some knowledge of concussive disorders.

Concussions are typically called mild traumatic brain injuries. They can interrupt the normal functioning of the brain for a short period of time or for extended periods of time. Multiple concussions suffered over a period of time can cause permanent damage. The Brain Injury Association of America lists the following frequently observed symptoms of a concussion.

From the Chair Nancy Carlson

1. Vacant stare (befuddled facial expression)

2. Delayed verbal and motor responses (slow to answer questions or follow instructions).

3. Confusion and inability to focus attention (easily distracted and unable to follow through with normal activities).

4. Disorientation (walking in the wrong direction; unaware of time, date and place)

5. Slurred or incoherent speech (making disjointed or incomprehensible statements).

6. Gross observable incoordination (stumbling, inability to walk tandem/straight line).

7. Emotions out of proportion of circumstances (distracted, crying for no apparent reason).

8. Memory deficits (exhibited by the athlete repeatedly asking the same question that has already been answered, or inability to memorize and recall 3 out of 3 words or 3 out of 3 objects in 5 minutes).

9. Any period of loss of consciousness (paralytic coma, unresponsiveness to arousal).

While proper equipment and following safety standards can reduce the number of concussions in Grade 1, Grade 2, or Grade 3, depending upon the presence of transient confusion, loss or no loss of consciousness, and length of time to resolve concussive symptoms. They also provide guidelines for sideline evaluation, management of the player, and when to return to play. These are printed on a laminated card that each coach or medical professional working with players should have. The cards are titled *Management of Concussion in Sports* and are available online at Brain Injury Association of America, www.biausa.org.

Every parent/guardian should also be aware of the symptoms of a concussion. We are ultimately responsible for protecting these young athletes by assuring that they receive the proper medical attention. The doctor told my daughter something like, "You will have many games ahead of you if you take care of your brain now." He didn't give into her whining either. Thank you Dr. Snellman!

Wrapping your mind around it

"What is it like to have a brain injury?" If you haven't actually been asked this, you know that people are wondering it. The only thing harder than trying to understand brain injury if you've never had one,

is trying to explain it if you have.

Nothing makes you feel more isolated than when someone tells you that they know just how you feel. That they too have a terrible memory, or that they too get confused. The fact that they think they know how you feel only underscores how far they are from that fact.

The next time someone tells you that they have the same problems you do, earnestly suggest to them that they get a neuropsych evaluation so that they can identify their disability and get correct medical help. They will laugh it off of course, and joke that perhaps they ought to. Then you can tell them THAT is the difference between you and them.

I'm not seriously suggesting that you do that. They are just trying to be polite and offer solace.

Every once in a while a situation or example occurs to me, that brings to light some aspect of brain injury that most people can identify with from their own experience. One of these is the concept of "wrapping your mind around a concept."

Everyone has these moments; times when you're so tired and worn out that you just can't grasp the situation. The time and place when you know that if you just walk away, maybe get some rest

and come back fresh, that you will be able to handle it. That in the morning the answer will seem so obvious that it is hard to believe that you couldn't see it last night.

That is what brain injury is like. All you know is that constant nagging feeling that

the answer is right there, but you just can't see it. Except there is no walking away from it; no coming back fresh.

Day after day, month after month, year after year, all you know is this constant off-center feeling. This unbearable maddening certainty that the obvious is staring you right in the face only you just aren't seeing it, and more than likely, you never will.

Even after fifteen years I still feel this way. I definitely have a much better grasp of the obvious than I used to, but it happens often enough that I miss something, or totally misread a situation, that I realize I'm not out of the woods yet.

It is not easy for me to accept that I need the help of others. It does not sit comfortably in my self-image that I can not always trust what my senses are telling me, or more accurately, what my brain is telling me my senses are telling me.

I will look to my sense of compassion for my sense of worth.



Here & Now

Mike
Strand

Member of



Formerly The HealthFund of Minnesota

Letters to the Editor Policy

Readers are encouraged to submit electronic letters to the editor for consideration of publication in the next edition of Headlines.

Letters to the Editor should be limited to 300 words. Letters may be edited for spelling, grammar and length. In order for letters to be considered, please include your name, address and the daytime phone number of the author. The Association reserves the right to refuse letters for publication, and submission of material does not guarantee publication. Opinions expressed in Letters to the Editor are solely those of the author and do not represent the opinions or positions of the Association.

Please send letters to: *Headlines*, c/o Brain Injury Association of Minnesota, 34 13th Ave NE, Suite B001, Minneapolis, Minn. 55413, or via email (preferred method) to info@braininjurymn.org.

Medicare Prescription Card Program

Staff Report - Due to the Medicare Modernization Act of 2003, Medicare Beneficiaries have started getting bombarded with mail. The purpose of the mail is to inform people of a new, temporary prescription card program to provide some relieve on drug costs. Also included will be marketing recruitment materials to attract members to the various discount drug card programs. There will be an annual enrollment fee, which varies per program. People who have outpatient prescription drug coverage through MA are ineligible for this benefit. The program will provide access to discounts and up to a \$700.00 credit annually for certain enrollees who qualify based on income and other drug coverage. Some important things to know:

- This is a temporary program beginning June 2004 and ending through December 31, 2005
- It is illegal to solicit beneficiaries to enroll in a program by phone or door to door sales. Beware of potential scams. Approved providers will always have an authentic Medicare Seal
- For more information see www.cms.gov, www.medicare.gov

Association's Discharge Conference Scheduled for November 3

Staff Report -The Brain Injury Association of Minnesota, in conjunction with the Minnesota Department of Health is offering the 2004 Discharge Planner's Conference: *Discharge Planning in Today's World* on Wednesday, November 3, 2004.

Keynote speaker Ben Wolfe, M. Ed., from St. Mary's Medical Center Grief Support Center, will kick-off the day's event with his presentation "Grief and the Iceberg Theory:" Helping Patients, Families, and Friends deal with Brain Injury."

A licensed social worker, Wolfe is founder and Program Manager of St. Mary's Medical Center's Grief Support Center in Duluth, Minn. He is certified in



Thanatology (CT) by the Association for Death Education and Counseling, and provides counseling for individuals dealing with life-threatening illness, terminal illness, or who are bereaved.

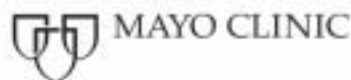
He provides training programs, lectures, consults internationally, is on a regional Critical Incident Stress Debriefing Team, and has taught graduate courses for 23 years on death and dying and for 16 years at the University of Minnesota, Duluth School of Medicine.

The conference breakout sessions include topics on returning to work, life after TBI, family supports, multicultural considerations for discharge, healthy learning environments, and sports related concussions.

Keynote speaker Holly Kostrzewski closes out the event by speaking about her success in college and life following brain injury. She is a 2004 graduate of the College of St. Scholastica, with a major in Business Communication and a triple minor in American Indian Studies, Management, and English. Kostrzewski is a speaker for the Think First Program, TBI Residential (Duluth), and has been a speaker at Brain Injury Association conferences in Minnesota and Ohio.

The Brain Injury Association of Minnesota is accredited through the Department of Health for Continuing Education Units (CEU) for nursing, physical therapy, occupational therapy and speech therapy. The Association has also submitted for CRC and Social Work Credits.

Registration brochures are available on the Association website - www.braininjurymn.org. For more information or registration brochure, contact Anne Schuller at 612-378-2742.



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Program Relieves Minnesota Workers with Disabilities

Staff Report - For some who live with a disability, rejoining the workforce may not only seem challenging, but financially impossible. Logic tells us that when monthly medical bills exceed what would be a monthly income, people with disabilities cannot afford to find a job, for fear of losing essential benefits upon reemployment. The result is a perpetual barrier for those seeking independence and financial mobility.

However, a number of Minnesotans participate in a state program aimed at relieving this problem. It's neither a secret, nor new; in fact, a growing number of people have signed up since its implementation in 1999.

Currently, over 6,000 Minnesota workers with a disability participate in a program called Medical Assistance for Employed Persons with Disabilities (MA-EPD). The program allows employed people with disabilities to receive comparable medical assistance while employed under higher income levels.

The Minnesota Department of Human Services initiated MA-EPD to assist people with disabilities in receiving the benefits of being employed and reducing their dependence on government programs. According to a study, in December 2001 the average MA-EPD enrollee increased their income by \$305.

Unlike other government programs, there is no income limit for MA-EPD enrollees, with the exception of specific asset limitations. The program also protects employees in the event of job loss and medical leave for up to four months.

Recipients must pay a sliding-scale premium according to income and household. Enrollees may supplement MA-EPD as a secondary source along with their own primary health insurance plan.

For more information, contact the Minnesota Department of Human Services at (651) 297-7139, or visit www.dhs.state.mn.us

Information in this report was compiled by Cory Prestrud.

Support Groups

Brain injury support groups can help you find others with similar experiences, useful information about brain injury and solutions to problems. The following results are just some of the key benefits of support groups:

- Emotional healing comes when people interact with other people.
- Sharing of similar experiences helps members feel less alone and more ready to deal with day to day issues.
- Education results from the exposure to information and personal experiences in a group.
- Socialization occurs when connections with people are made and confidence in social skills develops when appropriate interaction occurs in support groups.
- Safety, in the environment of a confidential, supportive, non-judgmental group, allows for honest disclosure and sharing of common difficulties.
- Self-expression, as emotions are experienced and released, creates a greater understanding of oneself.
- A sense of growth occurs as long-term members see new participants and reminisce about where they began and how far they have come in their personal journey.

The Brain Injury Association of Minnesota makes referrals to support groups throughout the state, including for persons with brain injury, their families and friends and for young persons.

These groups are autonomous, self-determined peer groups and are independent of the Association.

For meeting times, location, and a contact person for a specific support group, or for information about how to start your own group, call the Brain Injury Association of Minnesota at 612-378-2742 or 1-800.669.6442.

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MILITARY TBI from page 1

higher than the national benchmark,” said Collins.

Tackling the Numbers

During peacetime, there are approximately 7,000 annual TBI admissions to military and veterans hospitals. During war, the military estimates that approximately 20 percent of the surviving soldiers sustain a TBI.

But the numbers are problematic for several reasons. Due to combat conditions, the military can not always accurately track the percent of deaths that are related to TBI.

“It’s also challenging to compare the incidence to other wars, because this is the first war where there has been a proactive screening while the war is currently underway,” said Collins. This is the first war where there has been a comprehensive effort between the DOD and the VA to track TBI cases, including tracking the mild to moderate cases that were historically missed in previous wars.

Recent studies offer conflicting results.

A larger scale two-year study of TBI cases in the military, conducted during peacetime, addressed the prevalence of TBI in U.S. Army Paratroopers. Concluded in 2000, the study estimated that 23 percent of all soldiers surveyed reported sustaining a TBI, and that paratroopers were at twice the risk of sustaining a TBI due to the nature of their specific duties.

The most recent study of TBI prevalence at Walter Reed Army Medical Center places the number of TBI cases as high as 67 percent. However these estimates are problematic as well.

“The number has the potential of being misleading. Of the injured soldiers who are being seen at Walter Reed, 60 to 67 percent of those have also sustained a TBI. It’s really too early to tell if that number is characteristic of the active duty military overall,” said Collins.

The way the military categorizes injury presents another set of challenges for tracking TBI cases because the military makes very specific distinctions about the geographical location of where people are injured.

“What we’re tracking is Operation Iraq Freedom, Operation Enduring Freedom which is Afghanistan, and the Global War on Terror. We also treat people who may have served,

come back and then gotten into a car accident as they came home. But they won’t be counted as combat injured, though they served in Iraq. Injuries may have also happened when they were training to go, and all these different distinctions make it difficult to track,” said Collins.

Regardless of the overall numbers, it is clear that TBI cases in the military are on the rise.

Better Protection, Higher Rate of TBI

Since past wars, improvements have been made to the body armor and the Kevlar helmets that soldiers wear during combat, as well as improvements to emergency medical care, resulting in more lives saved.

The Kevlar helmets in particular have reduced the number and the severity of penetrating head injuries, the sort of injury that often lead to fatalities in past wars. Ironically, while these helmets have saved lives, they have likely increased the number of mild to moderate brain injuries due to the concussive force of blasts.

In fact, the military has seen a considerable increase in blast injuries, which has led to focused clinical care and research at DVBIC. Because of the mechanism of the blast, brain injuries can be sustained in a number of ways: the overpressurization wave; shrapnel hitting the head and face; dislocation, or being thrown from the blast and then hitting something; or being hit by crumbling walls or other surrounding material.

“The type of warfare is having an impact. As you move further into war, the other side is going to figure out where your vulnerabilities are. The warfare of choice in terms of Iraq and Afghanistan is the rocket propelled grenade and the Improvised Explosive Devices (IED),” said Collins.

IEDs are packed with dirt, glass, rock, nails, anything available, and when they explode, the shrapnel can have devastating effects.

“Now we’re seeing patients with single or multiple amputations, and they may also be blind. So a challenge for a rehabilitation therapist is developing and adapting our standard TBI rehabilitation approaches for these individuals with multiple injuries,” said Collins.

The Tampa VA has developed a Blast Injury program, which includes the development of a

specialized Blast Injury Treatment Center. Multiple providers are involved to better identify and treat blast-related head injuries.

At the local level, the DVBIC program at the Minneapolis VA collaborates with the amputee and blind rehab programs. Collins said that whenever possible, patients are sent to TBI rehab first, so that therapists can develop a plan of action that will enable the other rehab programs better understand potential cognitive deficits that may affect traditional approaches to blind or amputee therapy. “We can help determine that a high tech prosthesis may not be the best bet for someone with a brain injury and that something more simple may be just as effective,” said Collins.

“We are certainly positioned to respond to the demand and the challenges that are posed by the global war on terror,” she added.

PTSD and mild TBI

The similarities of mild TBI and Post-Traumatic Stress Disorder [PTSD] present another challenge in identifying cases of TBI that may have been missed during a tour of duty. There are essential overlaps in symptoms including sleep disturbances, irritability, physical restlessness, difficulty concentrating and some memory disturbances.

While there are similarities, there are also significant differences in what Collins calls the profile or “constellation” of cognitive impairments.

“In PTSD memory disturbances are typically involved with aspects of the trauma. In TBI, the patient has preserved older memories, but has difficulty retaining new memories and new learning. We’ll see more problems with executive functioning, planning, organization, problem solving, insight and awareness, difficulties with attention and information processing in TBI,” said Collins.

Coming from a combat situation, some patients can experience both PTSD and TBI, making diagnosis and treatment even more challenging. “It’s critical to have thorough evaluations so that we can treat each appropriately,” Collins said.

When TBI is Missed

Despite ongoing efforts to monitor TBI in the military, some cases are still missed due to the sheer volume of injuries, the limitations of combat medicine, and limited awareness among military personnel about brain injury or the DVBIC program.

“Typically what happens in an acute medical situation is that you focus on the obvious. So there’s focus on the blindness and/or the loss of limb, but these people may have sustained a mild TBI too. If they are walking and talking, the mild TBI can get missed. That’s a definite challenge for us, to identify those mild TBIs and get those individuals to one of our sites,” said Collins.

DVBIC has made strides to improve TBI screening. Walter Reed is proactively screening injured people who come through their doors.

There are potentially devastating consequences for soldiers with TBI who return home without a diagnosis including difficulties retaining employment, failing relationships, alcohol and substance abuse and potential homelessness.

“They will not understand why they are having a hard time doing things or retaining employment, why their relationships are failing, or why people treat them differently,” said Tom Gode, Executive Director for the Brain Injury Association of Minnesota. “Soldiers who are not diagnosed may ultimately be misdiagnosed at a later date when their behaviors resemble mental illness, and yet without a brain injury diagnosis any mental health treatment and recovery strategies will have limited affect.”

The Wilder Research Center is currently undergoing a study examining the issue of veterans and homelessness in Minnesota. Preliminary results show that 65 percent of homeless veterans had experienced a serious blow to the head that resulted in seeing stars or loss of consciousness. Of the veterans who had sustained a blow to the head, 46 percent reported problems with headaches, concentration or memory, understanding, excessive worry, sleeping or getting along with others - indicating a suspected brain injury.

While the military offers a structured setting that could be potentially beneficial for persons with TBI, undiagnosed cases of TBI can provide problems for enlisted personnel as well. A 1996 study by Alexander K. Ommaya, M.A., at Johns Hopkins University found a connection between brain injury and less than honorable discharges from the military. Brain injury in military personnel increased the risk of discharge for behavior reasons by four times and increased the risk of criminal

Falling through the cracks: One soldier's story of TBI

By Sharon Rolenc

Ted Bittle didn't expect it to happen so quickly. He didn't see the suicide bomber sneak up on him. On April 10, 2003, on his first day in Baghdad, Navy Corpsman Ted Bittle and the Marine unit he was working with were clearing a bunker across the street from the stadium where authorities suspected Saddam Hussein was hiding.

Ted bore the brunt of the suicide bomb. The shrapnel broke the corpsman's right eye socket, collapsed his sinus cavity and he sustained a traumatic brain injury (TBI) as a result. His TBI wasn't discovered until several months later.

After rebuilding his face and caring for his physical injuries, the military sent Ted home on convalescent leave. Thankful to be alive, Ted was happy to be home with his wife Denise and his son Ari, who was seven months old at the time.

But his symptoms never went away. Ted experienced ongoing pain, chronic fatigue, depression, syncope and seizure like activity, imbalance, problems with his right leg and violent mood swings.

As a combat medic, Ted was well versed in medicine, but didn't put together that he had a brain injury. He struggled to find answers to his ongoing challenges. His anger often got in the way of getting medical personnel to attend to his needs. "I wasn't communicating right or effectively. Every crack that was available to slip through, I slipped through," said Ted.

"We traveled several times from New York to [Bethesda

Navel Hospital] to see the doctors. They were trying to figure out what could possibly be bothersome to the point where Ted was having seizures, he was forgetful and he was having facial pain. After seeing a number of doctors, it wasn't until November or December that we received the diagnosis of traumatic brain injury," said Denise.

Because of the delay in diagnosis, and Ted's struggles with military paperwork, he was not given permanent disability. The couple is currently fighting to rework his disability status. Ted is unable to work, and gets easily frustrated with day to day tasks.

"I would have rather lost my hand than the stuff from my brain. Things I used to do with ease, now I go at and go at, but I can't make it happen. It's like solving a puzzle I've solved a hundred times before, but now I can't figure out where the pieces go. That's my life," said Ted.

One of the toughest transitions for Ted has been going from the person who provides help, to the one who needs help. He has a long military history, serving with the Army, Navy and Marine Corps. He was active duty at the Pentagon during Desert Storm, and his service to the community didn't end between wars.

In the mid nineties, he obtained a degree in Psychology, and worked as an Emergency Medical Technician (EMT). His last job before returning to the military was as a substance abuse counselor at the Covenant House in New York City where he worked with homeless teens.

As the second World Trade Center tower fell on the morning

of 9/11, Ted grabbed his medical bag, hopped on his bicycle and rode to Ellis Island where he took the first rescue boat to the twin towers. He did not know at that point that two of the planes involved in the terrorist attack were from United Airlines, where his wife worked as an airline attendant.

"We both were in shock for a long time," said Denise.

Two months later he entered the Navy as a corpsman with the goal of becoming a combat medic. At the time of his injury he was stationed and training with the Marines. "Things didn't turn out exactly as I wanted them to, but I'd do it again without any regrets," said Ted.

He was medically retired from the US Navy on August 17, and the couple recently moved to Allentown, Pennsylvania to be close to Denise's family while they figure out how to map their new life. They considered moving back to Minnesota, where Ted spent part of his childhood, but were worried that the extreme cold during the winter might aggravate Ted's headaches.

Denise was forced to take an extended leave from United



Ted, Denise and Ari Bittle

Submitted photo

Airlines. She looks forward to flying again, but the time demands of a flight attendant's job have proven too much after Ted's injury.

"Ted use to be very independent. Now I have to take time off of work in order to help support him and our son," she said.

The couple takes their son out frequently, to get out of the house and escape feelings of depression. "It can be a hard life if you make it that way. But our son makes it easy. He brings a lot of joy into our lives, and we like to do things for him," said Denise.

For now, the couple is getting adjusted to the changes in their life after TBI. "The Ted that I knew and married died in Iraq. The Ted that I still love and care for is a very different person right now."

DVBIC research of benefit to TBI community

The Defense and Veterans Brain Injury Center (DVBIC) is currently involved in nearly a dozen research studies involving brain injury and the military. These studies have the potential of impacting the brain injury community as a whole due to the size and depth of the research involved.

"In the past, research has been hampered in the [brain injury field] by very small numbers. The idea with DVBIC is that we provide excellent clinical care, and we then have a cohort of patients who are able to participate in research programs, and we are able to develop enough of a patient base to provide good randomized clinical trials for clinical care issues facing people

with brain injury," said Dr. Barbara Sigford, lead principal investigator for the Minneapolis DVBIC site, director of the TBI Program at the Minneapolis VA, and VA's National Program Director for Physical Medicine and Rehabilitation.

Some of DVBIC's research includes: cognitive versus functional rehabilitation approaches; the prevalence of chronic problems after TBI in the military and veteran populations; long term outcomes of concussions, moderate and severe TBI; enhanced helmet protection for paratroopers; and the development of evidenced-based guidelines for return to duty/return to the battlefield. For more information, visit www.dvbic.org.

Myrna Yenter, MS, LICSW

Mental Health Services

1719 Kathleen Drive

North Mankato, MN 56003

Phone and fax: 507-345-5281

Myrna has had extensive experience with survivors of traumatic brain injury and their families. She has experienced TBI in her immediate family.

Myrna does complete mental health services such as counseling for couples, families, for anxiety and depression.

The Association celebrates 20 years of bringing help,



archive picture

The Association's first office in the basement of the Neighborhood Involvement Program at 2431 Hennepin Ave.

By Sharon Rolenc

Twenty years ago, a small group of families and providers came together to form what is now the Brain Injury Association of Minnesota. The organization was founded to advocate for services at a time when resources were limited at best for persons with brain injury and their families.

"It was a really critical stage to get this off the ground and get services, to get people to understand what brain injury was all about," said Baba Finch, an early family member who joined the board in 1986. Her daughter was struck by a motorcycle while she was jogging in 1983.

"It was really grassroots. Families used to say that they'd pick these kids off the roads and



archive picture

Three time winner of the Tour de France, Greg Lamond was the spokesperson for the Association's HeadSmart Campaign in 1994

get them breathing again, then send them home. There weren't services, there wasn't anybody to help. It was a desperate feeling. When you have had a child severely injured, you just can't take care of them by yourself at home all of the time," said Finch.

The intention from the start was to make the organization a state affiliate of the national organization, known at the time as the National Head Injury Foundation (NHIF), and that the organization leadership would have a balance of families and professionals.

attempts to form an organization that ended up alienating a lot of the providers in town, and we knew going into it that we wanted the support of the providers," said Dr. Robert Karol, one of the founding members. Dr. Karol is currently the Program Director of Brain Injury Services at Bethesda Rehabilitation Hospital.

"The providers brought professional strength, and the families brought the very emotional content, very real situation passion and that's certainly very good if you are trying to be an advocacy organization. There's urgency with the family members to get things done. So it was important to keep the two together," said Ellie Hands, who was the first executive director for the Association. Her son sustained a brain injury from a motorcycle accident.

Christopher Duff, a manager of the TBI program at Courage Center at the time, was instrumental in providing guidance in the beginning. Duff was on the board of directors for NHIF when the Minnesota chapter started organizing.

"In retrospect, I think our [NHIF] greatest accomplishment was simply establishing that there is a life after the occurrence of a TBI. We strongly advocated for specialized rehabilitation programs designed to serve this population. What we really did was try to find 'champions' in every part of the country, be them survivors, family members, professionals or others, who would drive awareness and services in their local area. This eventually led towards the establishment of State Chapters. Our biggest challenges were tearing down the generally held misconception that learning and/or improvement was not possible after the first few months following a TBI," said Duff.

In January 1985, the founders held the first open membership meeting. "Despite record cold

"We needed to make sure that we would balance the interests of professionals and families and persons with brain injury. There had been previous

temperatures and wind chills, 75 people showed up. We explained what we were working on, what we wanted to accomplish, and that we wanted to form an organization. We held a vote, selected a board, and started having periodic board meetings," said Karol.

From 1985 to 1988, the organization was run entirely by

"The organization secured federal funding to establish Community Support Network I that proved instrumental in building the Brain Injury Community Committee (BICC) activity that still remains," said Hands.

From 1991 through 1993, the Association was involved in the HeadSmart program, delivering



archive picture

Board member Bill O'Dowd, Executive Director Ellie Hands, Senator Rudy Boschwitz and board president Chris Duff at the National Convention in Washington D.C., 1988

volunteers. The first office opened in 1986 in the basement of the Neighborhood Involvement Program on Hennepin Avenue. The volunteer staff had one small room of about 120 square feet, behind the clothes closet.

In the first ten years, the Association grew from an all volunteer organization to one with a paid staff that provided service statewide. They advocated for key pieces of legislation that set up the brain injury legislative commission, the TBI Trauma Registry, and the establishment of the Neurobehavioral Hospital.

safety education to over 10,000 elementary children, and distributing 6,000 low cost helmets.

The early nineties brought a change in the name of the organization, shifting it from the Minnesota Head Injury Association to the Brain Injury Association of Minnesota. The National organization officially changed the name first, and the affiliated followed.

"A bunch of [persons with brain injury] got together at a national conference in Chicago



archive picture

Several persons with brain injury participated in a public awareness project that produced the 1996 video "Survivor to Survivor" Pictured from left to right: Craig Martinson, Tom Patnaude, Ken Steffke, Derrick Saville, Kim Davis and Jim Cotton.

hope and a voice to Minnesotans with brain injury.



archive picture

Donor recognition ceremony in the Spring of 2000 honoring (left to right): Dr. Gaylan Rockswold (HCMC), Kathy Carlson (Department of Economic Security), Jeanne Gode (Pentair), Penny Hunt (Medtronic), Baba Finch, Steve Larson (Department of Human Services) and Mark Kinde (Minnesota Department of Health)

and said we don't like the term head injury anymore. It's not the head that suffers the long term injury, it's the brain. We had a role in making the change nationally," said board member Craig Martinson. Martinson sustained a brain injury in 1988 from an automobile crash. He joined the board in 1992 and has served off and on since.

One significant event that bridged the Association's efforts from the first and second decades was the final passage of the TBI Act of 1996, signed into law by President Clinton. Efforts to push the legislation date back to the late 1980s, and representatives from Minnesota traveled several times to Washington D.C. to advocate for the TBI Act.

The mid-nineties brought federal funding for Community Support Network II, which allowed the organization to build the information and referral (I & R) infrastructure.

"We found the need for documentation and research. We started to invest heavily in the

database, website and organizational infrastructure," said Tom Gode, executive director. Gode was hired when Hands retired in 1994.

Next came a Health Resources and Services Administration (HRSA) grant that set up the Hospital Discharge pilot project, which has now grown into Resource Facilitation.

At the same time, the Association began to dedicate resources for public policy. "At some point the realization hit that we could continue serving the people on an individual basis, but we couldn't resolve their issues if we couldn't change the policies at the state level," said Gode. "We got tired of telling people that there were no services for persons with brain injury."

The last decade has positioned the Association as a leader among state organizations. The Center for Disease Control and Prevention is looking at the Association database as a possible model for tracking national TBI data.



archive picture

Viking Hall of Famer Paul Krause poses with walkers Brad Farrell and Lauren Beck during the Walk for Thought's inaugural year in 2002. Paul and Pam Krause were spokespersons for the walk.



archive picture

Family member Jeff Zinn, board member Russ Philstrom and executive director Tom Gode meet with Senator Paul Wellstone during a 2001 public policy convention in Washington D.C.

"Just five years old, the Multicultural Outreach Program, funded by Medtronic, is being touted as the national model for outreach into underserved communities," said Gode.

This year, the Walk for Thought was adopted by the Brain Injury Association of America to replicate nationwide.

In the past ten years, the Association has doubled the number of people it serves through I & R. Annual website hits to the Association website went from 1,000 hits in 1998 to over 500,000 hits in 2003.

"Every bit of growth and success that this organization has had since day one had been based off of personal relationships, and from internal advocates within state and federal agencies, and the relationships that we've had with those people," said Gode.

"One of the things I am most proud of in my career is the Brain

Injury Association of Minnesota. I think it is more impressive than we could have predicted when we first started," said Karol.

"It's a thrill to those of us who got things started that the organization is being carried on so successfully," said Finch.

Despite the challenges of securing long-term funding that face most nonprofits, changes in leadership and staffing, changing trends in rehabilitation and shorter hospital stays, the Association has stayed true to its mission, and unwavering in its dedication to bring help, hope and a voice to the 94,000 Minnesotans with brain injury.

Thank you to the countless individuals, families, professionals and advocates who have partnered with the Brain Injury Association of Minnesota over the years, and to those who continue to support the organization. We couldn't do it without you!

Association to host 20th Anniversary Party



Singer-Songwriter Farrell Quinn

The Association is hosting a 20th Anniversary Party on Thursday October 14, from 5:30 – 7:30 p.m. The celebration includes an open house at the Association office, and a reception at the Walter Rasmussen Community Room at Northeast Bank. Entertainment will be provided by singer-songwriter Farrell Quinn. For more information, contact Ottar Schmitz at 612-378-2742

Civil lawsuit filed over Medical Assistance Co-Pays

By Cory Prestrud

On July 26, four Minnesotans filed a class-action lawsuit alleging the state's Medicaid policy illegally requires low-income recipients to copay for prescription drugs and medical appointments.

According to the federal Medicaid Act, individual states may legally require a copay policy; however, providers may not illegally deny medical service to a patient due to inability to pay.

The 2003 Minnesota state legislature implemented the copay policy on Oct. 1, 2003 as part of a budgetary fix. Currently, nearly 25 percent of Minnesota's total budget supports health and human services.

The complaint states that the Department of Human Services (DHS) failed to provide Medicaid-eligible persons correct notices about their right to prescriptions and other medical services when they cannot afford a copayment.

Defendant Kevin Goodno, Commissioner of the DHS, recently responded "pleading" to

the filed complaint. According to his written statement, Goodno said "The federal government has approved the copay provisions of our state plan - the formal plan for administering the Medicaid program in Minnesota." Goodno oversees the state Medicaid policy regarding Medical Assistance (MA). The DHS did not respond to a request for comment from HEADLINES.

Copayments for MA comprise a \$1 charge for each generic prescription and a \$3 charge for brand-name drugs and doctors' visits.

While the monthly cap on copayments is \$20, Abigail Turner, lead attorney for the plaintiffs, reported more people are affected than one may think. "I'm getting several calls everyday of people reporting the same problems," Turner said. Also involved in the lawsuit is the National Alliance for the Mentally Ill. Sue Abderholden of the Minnesota chapter of NAMI says reports of illegal denial of medical services have been occurring for the last three to six months.

"For people who do not have discretionary income it's hard to decide what to give up - food, clean clothes, bus pass or medicine," Abderholden said. "People on Supplemental Security Income in particular have difficulty, as do people who have more than one health condition, which necessitates more frequent trips to the doctor and more medications."

Janis Erickson, an unemployed recipient of social security disability, depends on medical services to live. Erickson sustained a traumatic brain injury in 1992 in a car accident, and says she has faced similar challenges in making copayments because of her limited income.

"Personally, I think the cuts to [the DHS] are devastating for a lot of people who are disabled and unable to work," Erickson said.

Mid-Minnesota Legal Assistance provided free information cards for MA recipients to bring to medical appointments and the pharmacy. The card states law and statute regarding co-pays, in addition to

contact information for reporting denial.

Erickson recently used the card when trying to pick up her prescriptions. "The pharmacy owner was very upset that I was using it. He told me that I would have to pay and he would send me out a billing statement till I had paid it. He went on to tell me that it was unfair for pharmacies to have to go through this," said Erickson.

"I was very embarrassed by this, as there was also some one waiting in line behind me who heard everything," she added.

Interesting in
Becoming a
VOLUNTEER?
Call
Kimberly
Ferencik at
612-378-2742



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Legislative Corner

Keeping up to date with public policy

Learning how to hire my public official

by **Shannon Robins**
Public Policy Director

This autumn is an especially important time in our nation and our state, its election time! Primary elections in Minnesota will be held on September 14, and the general election will be held on November 2, 2004.

Normally, I write the Policy Corner from a professional stance, but in this issue, I would like to share my own story with you.

Five years ago, when I began working at the Brain Injury Association of Minnesota, I had never voted. I filled my supervisor's ear with lengthy diatribes on how my vote didn't matter, what difference did it make? Politics is boring, it has nothing to do with me, why bother? Plus, I didn't even know who the candidates were or what they stood for, and frankly, I didn't care.

Then my supervisor told me that if I wanted to continue working at the Association, that I needed to learn why politics is important. In the name of job security and passion for the incredible difference I had

witnessed this organization make in people's lives throughout Minnesota, I went on my first visit to the Minnesota State Capitol to find out what I could about policy.

Of the many lessons that I have learned from that day forward, there are several that I want to share with you prior to this election.

Politics DOES matter. Politics affects each and every one of us, every second of every day.

Your vote DOES matter. Your vote is your voice and your power.

Politicians are PEOPLE. I now truly believe that the people involved in politics get involved because they want to make their communities better places to live and use policy initiatives as the vehicle to accomplish those changes.

Politics matters to you and me because politicians create and vote on the laws that we all live by. Public programs like Medical Assistance (MA) and the Medical Assistance Waiver Programs (e.g.; Traumatic Brain Injury Waiver and the Community Alternatives for Disabled Individuals (CADI) Waiver), County Case Management, the Individuals with

Disabilities Education Act (IDEA), and Resource Facilitation are just a few programs that we use every day that developed in response to the high demand for disability services.

People like you and me came forward and told their elected officials that they needed to respond to the needs of their constituents.

Your vote matters because your vote is how you hire the people that you want to represent your voice in creating policy. If you don't like the way that an elected official represents you, you have the chance every election cycle to fire or rehire that official. If you do not make the effort to hire the person you want, then you do not have the right to complain about their job performance.

When the official is in office, you also have the responsibility to educate them on how to represent your views. If you do not educate your elected official, you do not have the right to assume that they will address your concerns.

Believe it or not, politicians are just people like you and me. They are human beings who strive to improve the lives of those who elected them. You have the power

to convince them to see life from your point of view. You have the power to educate them about issues that are important to you. Best of all, you have the power to get your voice heard. If you do not exercise these powers, you cannot expect your elected officials to represent you to the best of their ability.

I do not want to mislead you, laws can be difficult to change, and it can take a lot of energy and a lot of time. But if you don't ask and you don't try, then you can't expect to succeed.

My entire viewpoint about getting involved in politics has changed in a very short time. Political change can be tremendously exciting.

One thing I have come to realize is that we are extremely lucky to be in the United States of America. In very few countries do people actually have a voice in how their country should be run. We have fought hard and long to have a voice and to have that power.

This fall, please do not throw away everything that we have fought so hard and long for. Please vote. Vote like your life depends on it, because it does.

Interviewing your candidates

As elections swiftly approach (September 14 Primary, November 2 General election) you will have a variety of opportunities to interview the candidates that you will be considering. There will be Town Hall meetings, Legislative Home Visits, door knocking, and a variety of other times and places where you can ask the candidates what their views are on issues that are important to you.

Each election cycle, the Association publishes some questions to help you consider what you want to know about the candidates and how you want to ask them. Below, you will find some example questions to help you prepare to find out which candidates will best represent your views if elected.

1. If you are elected, what initiatives will you pursue to improve the lives of people with disabilities in this community?

2. Do you know what a brain injury is? Brain injury is one of the only preventable disabilities. What would you do as a legislator to help prevent brain injuries?

3. How would you help people with brain injuries better access needed health services?

4. In the face of a budget deficit, how would you propose to balance it?

5. What will your top priorities be if you are elected?

Are you registered to vote yet? Do you need an absentee ballot? Would you like to find out more information about how to register or find your polling place? For more information on exercising your vote, contact Shannon Robins at the Association, 612-378-2742.

Voter information can also be obtained through the Minnesota Secretary of State's Office at 651-296-2803 or via the web at www.sos.state.mn.us.

Citizen Advocate Sign-up Form

Yes! I'd like to become a Citizen Advocate and make a difference in the lives of the 94,000 Minnesotans who live with brain injury.

Name: _____

Address: _____

City, State, Zip _____

Day Phone: _____

Night Phone: _____

Fax: _____

Email: _____

I am a:

Person with brain injury Family member Professional

Issues that are important to me:

Timely access to information and resources
 Public Awareness Education
 Supported Employment Prevention
 Other: _____

Please return the form to Shannon Robins, Brain Injury Association of Minnesota, 34 13th Ave NE, Suite B001, Minneapolis, MN 55413

For more info: 612-378-2742, shannonr@braininjurymn.org



PEOPLE *in* PROGRESS

Stories of persons with brain injury, their family members and professionals

Small business weathers owner's TBI

by Sharon Rolenc

Joe Kopp was a small business owner looking forward to an expansion. He started working at the Roseville FASTSIGNS five years ago, and ended up buying the shop within a year. His wife Marcia was considering coming into the business to help it grow. They called their business partnership the "dynamic duo...together at last." But their best laid plans had to be put on hold.

On February 2, 2003, Joe went snowmobiling with some old friends from high school. He was on the back of a snowmobile that struck a tree. One of his friends was riding behind them. "He didn't see the accident, but he found us and went for help. He saved our lives," said Joe.

"Well, you can only imagine what it's like when you get a call at 3:15 in the morning from a sheriff who says that your husband had been in a snow mobile accident. That's where it all started. They made it very clear from that phone call that it was very serious, and that Joe was non-responsive. It was very scary," said Marcia.

The people in the neuro-trauma ICU warned Marcia from the beginning that a brain injury is not like a broken arm, that will within an expected timeframe.

"There's no roadmap like that for a brain injury. It was like you had no foundation, no framework to prepare yourself for what to expect. You just have to deal with one moment at a time, take what comes and really surrender. That was so difficult for me, because I am kind of a control freak. I like to know what to expect," she said.

Throughout Joe's hospital stay, Marcia took care of their son Spencer, and worried over how much to tell him.

"He was nine when the accident happened. I thought, what do I go home and tell him? Do I tell him that his dad was in a coma, and I we don't know whether he'll ever wake up – do I tell him the truth? Where is that fine line between protecting children, not frightening them, but yet being honest and upfront with them?" Marcia said.

Her church counseled her to be upfront with Spencer. "They were absolutely right. Kids know if you're not fessing up and then they'll get more frightened about what is she not telling me? Spencer knew if I wasn't telling him. I tried to pooh-pooh the accident as a minor bump on the head, but he knew that you don't go to the hospital for a little bump. He forced me to be real with him," said Marcia.

The ICU recommended that Marcia not bring in small children because it can very frightening for them. "Because it wasn't life threatening, Joe's vitals were okay at that point. I think it would have changed had he gone downhill," she said.

Joe was in a coma for two weeks, in the hospital for two months, and spent another six weeks in outpatient physical and occupational rehabilitation, working on learning how to walk again. He continued after that with speech therapy.

"I also couldn't speak that well, and still can't. I used to talk a mile a minute," he said. Today he walks with the aid of a cane, and struggles with his speech, and is working at halftime at the shop.

In May 2003, Joe returned to work for about an hour a day. In June, he was driving himself into work. By August, he had worked his way up to half days. "I had set goals for myself. By this time I wanted to be working 10 hours a week, by this time fifteen hours, and so on. When I got to twenty I said, okay that's enough," said Joe.

His business continued to flourish during his absence due in large part to two of his dedicated, long-term employees, Dan Bell and Ben Bigelow.

"Dan called me at home on that Sunday [after the crash]. He said that Joe was in an accident and was pretty banged up. I couldn't believe it. I took a minute to digest the news and I said, 'what are we going to do?' Dan told me to come into work and we'll figure it out," said Bigelow.

"They really came together and kept the doors open, and the work flowing through. After the accident when I didn't show up,



photo by Sharon Rolenc

Marcia Kopp, Joe Kopp and Ben Bigelow at the Roseville FASTSIGNS shop

they didn't say 'well, I guess we're off then.' They kept the shop open. Dan did what he does best which is to manage the work flow, get the projects done, making sure the signs got made," said Joe.

Joe's brother Jim came in a couple of times a week to make sure the vendors and taxes got paid. His brother worked with the accountant to figure out how to do the books, and other Twin Cities FASTSIGNS business owners pitched in when they could to help keep the business going.

"Joe was a pretty big force in terms of our sales. He was the one that went out and talked to our outside sales. A large percentage of the repeat customers that walked through the door wanted to deal with him, so it was a big blow when he was gone. It wasn't easy. I'd be lying if I said that I didn't think about leaving my job. But I just couldn't do that to Joe," said Bigelow.

"People look at me and think 'gosh Joe, you have come so far, this must be so difficult.' But this is nothing to be admired, I don't have a choice. People that came to help me, from my brother, to the guys in the shop, to the people that visited and prayed for me, they did

have a choice, and they chose to help. That is what should be admired," said Joe.

Bigelow said that having patience with Joe's speech, and maintaining a sense of humor helped the work environment when Joe started coming back to the shop.

"When he first started coming back, he looked terrible. He was pretty banged up, his speech was slurred. But I guess the most surprising thing was the improvements he made over the course of a few months. I would come in one Monday, and the next Monday there'd be a huge difference. And it happened every week for a couple of months," said Bigelow.

The shop won the 2003 Adversity Award at the FASTSIGNS national convention in Dallas. "It's meant for a store that has overcome obstacles, and I guess I qualified. This shop was given the award for overcoming my accident and staying open," said Joe.

The entire Twin Cities FASTSIGNS cooperative was

**JOE KOPP
on page 16**

Association Teams With Medtronic For Safety



photos by Sharon Rolenc

Above: Jennifer Houston Quintanilla and Maria Benavides at La Clinica's Health and Safety Information Fair. Lower Right: Two neighborhood boys demonstrate the proper fit of their new helmets.

By Cory Prestrud

The Brain Injury Association of Minnesota partnered with the Latin Cultures Network on July 1 to strap bicycle helmets on youngsters during the Health and Safety Information Fair at La Clinica en Lake in Minneapolis.

The Latin Cultures Network is an interdepartmental organization of Medtronic Inc. that collaborates with several organizations to spread health awareness and education to the local Latino community. The Network sponsored The Association by donating \$250 towards new bike helmets for the fair.

Maria Benavides, Chairperson of The Network, represented Medtronic during the event and

fitted children for free helmets. "It's really important for Medtronic to be involved because we're on the other side of prevention," Benavides said. "It just makes sense for us to participate in this kind of event with the Brain Injury Association of Minnesota."

In addition to distributing the helmets, The Association offered bilingual information on bicycle safety to parents and children. "We have a great opportunity here to provide the community with valuable information regarding health and safety, the first step to prevention of a brain injury," said Jennifer Houston Quintanilla, the Multi-Cultural Outreach Coordinator of The Association.

Fifteen organizations presented information to attendees at the 3rd Annual Health and Safety Information Fair. Some of the organizations entertained the visitors with free massages, African drumbeat, and rigorous aerobics. La Clinica en Lake, a healthcare facility for diverse communities, organized the fair in effort to educate their clients in health care resourcefulness.

"A lot of people who come here have limited access to health care and resources," said Cheryl Perez, Clinic Director of La Clinica en Lake. "Our goal is to

expose them to the resources that are available to them."

For two years The Association has maintained a relationship with the clinic by providing consultations to patients who sustained a brain injury. Houston Quintanilla continues to meet with patients bi-weekly to discuss the resources available for patients living with a brain injury.

"The collaboration with La Clinica en Lake has been a great one, I have met with many persons who have heard of me through word of mouth," said Houston Quintanilla.



La Asociación acompañó a Medtronic para La Seguridad

Escrito por Cory Prestrud

La Asociación de Lesión Cerebral de Minnesota se hizo pareja con la Red de Culturas Latinas el 1 de Julio para ajustar cascos de bicicleta sobre niños durante la feria de salud y información de seguridad a La Clinica en Lake en Minneapolis.

La Red de Culturas Latinas es una organización interdepartamental de Medtronic Inc. que colabora con algunas organizaciones de difundir la conciencia de salud y la educación a la comunidad local latinoamericana. La red patrocinó la Asociación con una donación de \$250 hacia nuevos cascos de bicicleta para la feria.

María Benavides, Presidente de la red, representó Medtronic durante el evento y ajustó cascos gratis para los niños. "Es muy importante que Medtronic está involucrado porque estamos al otro lado de la prevención", dijo Benavides. "Sólo tiene sentido para nosotros participar en este tipo de evento con la Asociación de Lesión Cerebral de Minnesota."

Además de distribuir los cascos, la Asociación ofreció la información bilingüe sobre la seguridad de bicicleta a los padres y niños. "Tenemos una oportunidad buena aquí de proveer la comunidad con la información valiosa al respecto de la salud y la seguridad, el primer paso a la prevención de una lesión cerebral", dijo Jennifer Houston

Quintanilla, la coordinadora multicultural de la Asociación.

Quince organizaciones presentaron la información a los asistentes en la 3rd feria anual de información de salud y seguridad. Algunas de las organizaciones divirtieron a las visitas con los masajes gratis, el tambor africano, y los aeróbicos difíciles. La Clinica en Lake, una agencia de salud para comunidades diversas, organizó la feria en el esfuerzo de educar sus clientes en como utilizar los recursos de salud.

"Muchas personas que vienen aquí tienen un acceso limitado al cuidado de salud y los recursos", dijo Cheryl Perez, Directora de La Clinica en Lake. "Nuestro objetivo es exponerlos a los recursos que están disponibles a ellos."

Durante dos años la Asociación ha mantenido una relación con la clínica proveyendo la consultación con los pacientes que tuvieron una lesión cerebral. Houston Quintanilla continúa reunirse con pacientes bi-semanal para hablar de los recursos disponibles para los pacientes que viven con una lesión cerebral.

"La colaboración con La Clinica en Lake ha sido una buena relación, he reunido con muchas personas de la comunidad que han oído de mí a través de la palabra de boca", dijo Houston Quintanilla.

Traducido por Jennifer Houston Quintanilla

UPS Foundation awards \$5,000 grant to Association

MINNEAPOLIS – The Brain Injury of Minnesota’s Kids REACH program was awarded a \$5,000 grant from The UPS Foundation, the charitable arm of the United Parcel Service.

Kids REACH (Kids Resources, Education and Advocacy for Children with Head Injury) a pediatric services program, is committed to strengthen, empower and support children with brain injury, their families and service providers. The program focuses on early intervention beginning at onset of brain injury to provide education and direct service to assist with transition back to community and school, and improving the quality of life for the child and family.

U. S. Congressman Martin Sabo (DFL-Minneapolis) helped present the check to the Association on August 20. “UPS is making a positive difference in our community by its support of nonprofit organizations like the Brain Injury Association of Minnesota,” said Sabo.

“It is only with the financial support from key corporate

partners like UPS that the Brain Injury Association is able to provide the critical information and resources to assist children who have sustained a traumatic brain injury and their families deal with the catastrophic changes in their lives and move forward with their lives,” said Tom Gode, executive director. “The Association has had the good fortune to have had the UPS Foundation and volunteers involved over the past four years.”

The Association’s grant was awarded, in part, in recognition of volunteer efforts by Ardis Sandstrom, associate director, and her spouse, Terry – a UPS employee. The couple annually donates significant time to the Association and other charitable causes.

The UPS Foundation, which was established during 1951 and is based in Atlanta, provides funding for initiatives that support family and workplace literacy, volunteerism and prepared and perishable food distribution.

“UPS and its employees have always been committed to serving



submitted photo

Rommel Carlson, UPS community relations director, Tom Gode, executive director for the Brain Injury Association of Minnesota, and Congressman Martin Sabo at the UPS check presentation ceremony.

the communities where we live and work. In fact, community service is a key part of our company charter,” said Evert Cooper, president of The UPS Foundation.

During 2003, The UPS Foundation distributed \$39.8 million worldwide. More than \$18 million of that was awarded through the Corporate Grant Program.

Fall Volunteer Opportunities at the Association

School’s back in session. The cabin will be closing for the winter soon. The days are shorter and we’re all spending more time indoors. What a great time to start volunteering! Volunteer opportunities abound at the Brain Injury Association of Minnesota. People are needed to help with a variety of projects so if you’ve been thinking about volunteering, give us a call. Here are just a few of the opportunities we have for you to support our mission by volunteering.

Database Volunteers

Help us maintain accurate records so we can reach people in a timely manner. Some computer experience required but we will train you to use our database. Flexible weekday hours or join us on the first Thursday of the month from 5 – 7 pm. A six month commitment is required.

English to Spanish Translator

Provide essential information and resources about brain injury for Spanish-speaking communities. Translate into Spanish documents about the effects of brain injury and resources for people with brain injury. Must be fluent in Spanish and English and able to set and meet deadlines. There’s a minimum time commitment of five hours per month but you can set your own schedule and work from home.

Volunteer Mail Corp

Looking for a way to help, but don’t have a lot of time? Join the volunteer mailing corps at the Brain Injury Association of Minnesota. Small groups of volunteers gather at our office in Minneapolis to send out all kinds of information. Time commitment is flexible (including some evening and weekend mailings). Once you sign up for the mailing corps, we’ll contact you prior to a project to see if you’re available.

Tell us about your skills, interest and availability and we’ll tell you how you can help! For more information, visit our web site www.braininjurymn.org or call Kimberly at 612-378-2742.

‘Aphasia’

Aphasia is a condition that results from brain injury, usually in the aftermath of a stroke. The portions of the brain where language and linguistic ability are stored are injured, creating difficulty with language, including speech, comprehension, and the ability to read and write.

Check out the upcoming Winter issue of HEADLINES for a feature story on Aphasia.

WISH LIST

We welcome a variety of in-kind donations at the Brain Injury Association of Minnesota. The following are a few of our immediate needs:

- Digital Camera - 3 megapixels or better
- IBM compatible computers – 500mhz or better, 256RAM or better, 6 gig hard drive or better
- Computer accessories including anti-glare screens, keyboard trays, wrist rests and power strips
- Scanners
- Laser printers
- Copier
- New first aid kit
- 2 plastic cutting boards
- Tickets to local events (sports, theater, music, etc.) to use as volunteer thank you gifts

If you would like to donate these or other items, please contact Mark or Kimberly at 612-387-2742. Thanks!



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94,000
 Minnesotans live
 with **brain injury.**
 These are some of our faces.

We're the boy next door, your grandparents,
 your neighbor's best friend, your spouse.

**Become a member today of the
 Brain Injury Association of Minnesota
 and make a difference in the lives
 of people you already know!**

Name: _____
 Address: _____
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 Telephone: _____
 Email: _____

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| <input type="checkbox"/> Individual: \$35 | <input type="checkbox"/> Non-profit organization: \$250 |
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I am (please check one):

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- Family member/friend
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Turn your used car into cash
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For more information,
 visit www.donateacar.com
 or call Mark at 612-378-2742.

Please note that the process takes up to
 two weeks and the Association cannot
 store your car.

Bethesda Rehabilitation Hospital's Fifth Annual Conference

JOE KOPP
from page 12

Managing Challenging Situations in Brain Injury Care

October 8, 2004
7:30 am to 4:30 pm
Northland Inn - Brooklyn Park, MN

Speakers include:

- ▶ John Corrigan, PhD, professor at Ohio State University
Dr. Corrigan will address chemical dependency issues in brain injury.
- ▶ Jennifer Manly, PhD, assistant professor at Columbia University
Dr. Manly will speak on culture and cognition.

Other topics include neuroplasticity and cortical reorganization after brain injury, issues in funding, brain injury and sexuality, sensory integration, funding and biomechanics of brain injury.

Download the conference program and registration materials at www.bethesdahospital.org

**Early Bird Rate of \$125 for registrations
received before September 24, 2004.**

Bethesda Rehabilitation Hospital

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MILITARY TBI from page 6

conviction five times compared with the control group.

"With a diagnosis they can begin to understand the changes in their lives, with connections to services and resources they can begin to develop the compensatory strategies to assist them to return to a civilian life better able to cope with their challenges," said Gode.

Education and Outreach

Education and outreach are key factors in addressing TBI in the military, and play an important role in catching cases of mild TBI.

"Part of our job at DVBIC is to inform people about the program, informing the military case managers, VA case managers and veterans' affairs staff that this coordinated system of care exists, and getting soldiers with TBI to our centers," said Collins.

The Veteran's Health Initiative just produced a web based TBI Education program for primary care providers, to educate them

about TBI, and about services for patients with TBI in the VA system. The program is free for service providers and CEU credits are available.

The Brain Injury Association of Minnesota is also poised to offer assistance for Minnesota soldiers with TBI when they return to their communities.

"The Association is prepared to provide soldiers who have sustained brain injury and/or their families the resources and support to better cope with the residual effects of the brain injury. The Association can provide information and resources on a one time basis or support an individual over two years with Resource Facilitation," said Gode. Resource Facilitation offers regular telephone contact to assist with problem solving, coping strategies and support.

Further Resources

To request services for active duty military or veterans who were injured while on active duty, call DVBIC Headquarters at 1-800-870-9244.

For more information about VA care, contact Gretchen C. Stephens, DVA National TBI Coordinator at (804) 675-5597. For more information on the Minneapolis VA TBI Program contact Stacy Tepper, LCSW, at (612) 467-3235.

Further information about DVBIC can be found at www.dvbic.org.

The Veterans Health Initiative course on Traumatic Brain Injury is available online at www.ees-learning.net/dod to all VA, DOD and other interested persons. CME and CE credit is available for physicians, nurses, social workers, psychologists, speech-language pathologists, and audiologists through June 2005 at no cost. The program is available in pdf format on the web at www1.va.gov/vhi/docs/TBIfinal_www.pdf

Minnesota veterans are eligible to participate in the Resource Facilitation program. For more information, a Resource Facilitator may be contacted by calling 612-378-2742, or 1-800-669-6442.

Cory Prestrud contributed research to this story.

given the Humanitarian Award, for their collective effort in helping Joe stay in business. Normally the award goes to a single store for service to the community.

Joe learned some valuable lessons about being a small business owner when unexpected strikes. "During my rehabilitation, I have had much time to contemplate what I had planned for well and what I could have done better," he said.

His advice? Plan for the best, prepare for the worst. Make sure that someone has a list of all of your passwords for your accounting systems, e-mail, or any other protected information. Make a list available of key contacts like the accountant, lawyer, banker, insurance agent, and support personnel. Designate a second person that can sign your business checks, and train a backup person to run your bookkeeping system, make payroll and pay taxes.

"Through all of this, asking for and accepting help from others has been one of the toughest things for me to do. The business

relationships I have established have provided invaluable support during my personal and my business recovery," said Joe.

"Our lives have changed forever. The first year for me was coming to grips with that loss. It's like you have to grieve – you have to go through that grieving process. We lost the life that we had before. Now, this isn't gloom and doom. We still have a lot, but it's all about building a new sense of normal in your life, and starting from there. We have so much that we are blessed with, so much to be grateful for," said Marcia.

"Marcia has been my main support, I can't even put into words how much she means. I didn't just do this to myself, I did this to her and my son, and she still loves me," Joe said.

Prominently displayed on his office door is a sign that says "Life is 10 percent of what happens to me, and 90 percent of how I react to what happens."

"I think that is very profound. You can't always control what happens to you, but you can control how you deal with it," said Joe.