



HEADLINES

SPRING 2006

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May 19-20

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**Brain Injury
Association of
Minnesota helpline:**
612-378-2742
1-800-669-6442

www.braininjurymn.org

Ardis Sandstrom named Executive Director



Ardis Sandstrom

MINNEAPOLIS – The Brain Injury Association of Minnesota Board of Directors voted unanimously to name Ardis Sandstrom, MS, LICSW, CRC, as its new Executive Director, ending an extensive national search. She succeeds Thomas C. Gode who previously held the position for eleven years.

“It’s an exceptional privilege to have someone with the hands-on experience and personal knowledge of our organization. She’s prepared

to step in with an immediate understanding of how we operate,” said Russ Philstrom, board chair. The Association has seen an explosion of growth in the past three years and the board expressed a desire for continuity in leadership.

For the past seven years, Sandstrom served as Associate Director, or deputy to the Executive Director. In that role, she developed several programs that have served as national models for success in the traumatic brain injury (TBI) field including Resource Facilitation and Multicultural Outreach. She also introduced two fee-for-service programs, the Education Department and waiver Case Management.

“I am very honored to accept the position. Working in the brain injury field has been incredibly rewarding. Every time someone returns to work after a brain injury, every time a child can succeed in school, every time we can reach someone that was falling through the cracks, there is cause for celebration. Once you are involved in this field, you can’t ever walk away,” said Sandstrom.

A passionate advocate for disability services, Sandstrom knows first hand what life is like for persons with disabilities. An injury as a small child severed part of all her fingers on both hands. “In the grand scheme of things, the challenges I face with my disability are fairly small. But some of the stories I could share about how I was treated growing up are pretty horrific. What I experienced opened my eyes, not only to the need for systemic change, but the critical need for community awareness and understanding. From the time I was very young, I knew I would have to do something to impact change,” she said.

Previous to her tenure at the Association, Sandstrom served as Director of Residential Programs at Mary T. Inc, Program Supervisor at Courage Center, and Program Coordinator for Direct Connections TBI program in St. Cloud. Sandstrom was recently appointed by Gov. Tim Pawlenty to the Minnesota State Rehabilitation Council. She has spoken nationally on topics related to brain injury.

Awareness Month drive collects helmets for kids in need

Bicycling is the leading cause of sports-related brain injury among children ages 5 -14. Most of these injuries are entirely preventable by wearing a helmet.

In recognition of Brain Injury Awareness month, the Brain Injury Association of Minnesota is sponsoring a helmet drive throughout March. Helmets collected from the drive will be distributed to programs and community organizations that serve at-risk children and youth through the Association’s Kids Need Lids program.

Previous Kids Need Lids recipients include: Southside Community Health Services, Stairstep Foundation, Indian Health Board of Minneapolis, Family Means, La Clinica En Lake, Hubert H. Humphrey Job Corps, Minneapolis Park and Recreation Safety Camp, and the Fond du Lac Tribe of Lake Superior Chippewa.

Bicycle and skateboard/multisport helmets may be dropped off at any of the following locations:

- Any Minneapolis Fire Station
- Blaisdell YMCA, Minneapolis
- Southdale YMCA, Edina
- Southwest Area YMCA, Eagan
- Minnesota Safety Council,
- Brain Injury Association of MN

All helmets must be brand new, and must meet the Consumer Product Safety Commission (CPSC) and/or SNELL certification. Helmets that meet these levels of safety certification will have stickers on the inside of the helmet and/or on the packaging that says “CPSC” and/or “SNELL.” Want to help out, but the drop-off sites are not convenient? Monetary donations can also be mailed to the Brain Injury Association

of Minnesota. Please note that the funds are for the “Helmet Drive.”

More drop-off sites may be added throughout the month. Please visit the Association website periodically for updates at www.braininjurymn.org. There will be a formal announcement and recap of the helmet drive during the 4th Annual Xtreme Safety Fest at the Mall of America, April 2. Read more about the event inside on page 7.



**Brain Injury
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34 13th Ave NE, Suite B001
Minneapolis, MN 55413

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Guest Commentary: Emotional support animals covered by law

By Kim Larsen, Staff Attorney
Minnesota Disability Law Center

The Winter 2005-2006 edition of Headlines had an excellent summary about service and therapy dogs by Lexi Bush. In the article Ms. Bush discusses the social implications and the legal rights of persons with disabilities when it comes to having a service dog.

This article will further detail the legal aspects of using service animals, particularly emotional support animals. The Americans with Disabilities Act (ADA) provides legal protection for people who use assistance animals. Assistance animals include service animals, therapy animals and emotional support animals. Other laws that provide protection include the Fair Housing Act (FHA) (42 U.S.C. § 3604), Section 504 of the Rehabilitation Act of 1973, and the Minnesota Human Rights Act (MHRA) (Minn. Stat. § 363A.10).

Ms. Bush highlighted the particular problems that occur with housing providers when a person is prescribed an emotional support

animal. Many apartments, group homes and other adult living settings have "no pet" policies. People with emotional support animals may be faced with either the possibility of eviction or with having to get rid of their support animal because the landlord is unaware of their legal obligations.

Emotional support animals may be prescribed for a person with a mental health disability by his or her treating professional, such as a medical doctor, psychologist, or licensed therapist. Emotional support animals provide stability and support for the individual. As such, emotional support animals are considered to be "auxiliary aids" and not pets.

The law requires landlords to make exceptions to "no pet" policies so an individual with a disability can fully use and enjoy his or her dwelling. If a person with an emotional support animal lives where there is a "no pet" policy that person will need to ask for a reasonable accommodation from the landlord. The FHA and the MHRA require a landlord to modify rules and policies in order to accommodate a person

with a disability. Many courts have determined that granting an exception to a "no pet" policy qualifies as a reasonable accommodation. A landlord's refusal to consider modifications to a "no pet" policy may result in a finding of discrimination against the landlord if the individual requesting the exception files a complaint with the Department of Housing and Urban Development or the Minnesota Department of Human Rights.

There may be some circumstances where a landlord can refuse to make a reasonable accommodation, such as if the accommodation would cause an undue financial burden on the landlord. Tenants are obligated to properly care for the support animal,

including providing obedience training, current vaccinations, and proper house training. If an animal becomes disruptive or unsafe the landlord may also be able to deny the accommodation.

The Minnesota Disability Law Center provides advice, and in some cases representation, for individuals who need a reasonable accommodation for an emotional support animal. MDLC is designated as the protection and advocacy system for persons with disabilities in Minnesota. MDLC addresses the unique legal needs of persons with disabilities and receives federal funds for that purpose. Please call MDLC intake at 612-334-5970 if you have questions about assistance animals.

CALENDAR of EVENTS

To register for any of the following classes, please call the Association at 612-378-2742 or 1-800-669-6442 in greater Minnesota. Unless otherwise noted, classes are held at the Association office, 34 13th Ave NE, Suite B001 in Minneapolis.

March 21, April 18: Brain Injury Basics 1

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.

Class starts at 6:00 p.m. and runs until 8:30 p.m.

Please note: March 21 class will be held at Bethesda Rehabilitation Hospital, 559 Capital Blvd, St. Paul.

April 2: 4th Annual Xtreme Safety Fest at the Mall of America

Save the date! The 4th Annual Xtreme Safety Fest is an exciting family event with live BMX demonstrations, safety information and helmet fittings. Send the message to your children that they can play it safe while playing hard! The event takes place from 1:00 - 4:30 pm. Read full story on page 7.

May 23: Brain Injury Basics 2

This class addresses the life change that occurs with brain injury, including: major stages of adjustment, emotional aspects of the change, and adjustment difficulties.

Adjustment to disability may be described as a series of stages or major tasks, which may not always be neat and orderly. Individuals progress through the stages at different rates, and adjustment is a life-long process. Emotional aspects of disability can be a major factor in outcomes. Class starts at 6:00 p.m. and runs until 8:30 p.m.

May 19-20: 21st Annual Statewide Conference on Brain Injury.

Mark your calendars for the 2006 Annual Conference, "Reaching Out, Growing Together." The event will take place at Earle Brown Heritage Center in Brooklyn Center on May 19 and 20. Keynote speakers for the event include Roberta DePompei and Holly Kostrzewski. Read the full story on page 5.



**Brain Injury
Association
of Minnesota**

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Email: info@braininjurymn.org

Mission

The mission of the Brain Injury Association of Minnesota is to enhance the quality of life and bring the promise of a better tomorrow for all people affected by brain injury.

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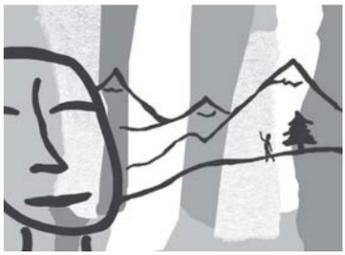
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Janice Webster, Volunteer Program Associate

Editorial Policy

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.

Letters to the Editor Policy

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.



PERSPECTIVE

Passion at the heart of grassroots success

**From the
Executive Director
Ardis
Sandstrom**

I am humbled and excited to move into the role of Executive Director. I follow two great leaders for the Association and have had the immense opportunity of receiving mentorship through Tom Gode's tenure of vision and growth.

As Associate Director for the past seven years, I have met and worked with many persons with brain injury, their families and loved

ones, as well as professionals from across Minnesota. I am amazed at the passion and care that so many people carry with them every day to address service needs and look for ways to make the system more supportive and accessible for persons with brain injury.

It is time for us to all tap into that passion and take "brain injury" into the next realm. The Board of Directors and Association staff has begun this move by identifying a strategic plan and creating a new mission. The Association's mission statement now reads: "To enhance the quality of life and bring the promise of a better tomorrow for all people affected by brain injury." Our challenge is there, looking forward to a better tomorrow for all people.

Brain Injury has always been termed the "Silent Epidemic" and often called a low incidence disability. As a group we know this is not a true representation of the issues we face. It is time to emphasize the importance of brain injury as a public health problem. Today, as a group and as individuals, it is our responsibility to educate the community and work daily to get the word out that brain injury is impacting the individual, the family, and the community.

We have much work ahead of us and it is imperative that we join together to use our voices to talk with our lawmakers at the local, state and federal levels, as well as work with local service providers to address service supports for persons

with brain injury. Through the passion of the grassroots movement we strive to bring forth issues and attention to brain injury. We "live the mission" through every interaction and every conversation.

I encourage all of you to get to know the Brain Injury Association of Minnesota. Take time to understand what Association programs offer and how they can be of assistance to you.

You can work with the Association to assure that Public Policy is addressing issues that impact your life. Join the Association in raising awareness around brain injury.

Together *we can make a difference* when your passion, your voice, joins the voices of others.

Dating and TBI

So you're alone and you want to start dating again. Maybe you're lonely and you want to find someone to love or maybe it's been awhile and you just want to find someone (wink, wink). If you want to optimize your chances there are a few things you will want to do before you embark on this journey.

The first thing you need to do is ask yourself, "Am I the kind of person who the person I'm interested in is going to be attracted to?" Be honest. As anxious as you may be to find a partner, it is still a two way street. A frustrated, angry, and needy person is not going to be very successful at attracting a quality person. A quality person is the kind of person who is going to see past your TBI, but if the real you is hidden behind an impenetrable wall of anger and self-pity, you will remain isolated.

You have to love yourself first if you want someone to love you. Likewise, you have to like yourself first if you want someone to like you. I say this because trying to get a date when you don't have any friends is putting the cart before the horse. How to find a friend is beyond the scope of this article. Further reading about the topic can be found in my book "Meditations on Brain Injury."

What else can one do to improve one's chances of getting a date on Saturday night? Physical appearance is important. I didn't say "good looks." There is no guarantee that you are going to be able to attract



someone based solely on looks, good or otherwise, because everyone's tastes are different. What you can do is try to look your best. I'm talking hygiene first, then style. Hygiene

is so important because you are not going to attract very many people with a slovenly appearance; it advertises that you don't respect yourself or anyone else. For style, your best bet is to ask someone for help (I still have to ask my wife what to wear and whether or not something goes with something else).

Next we move to communication. I'm not going to give you a laundry list of dos and don'ts. That just causes confusion and nobody can ever keep it all straight anyway. There are no secret words or sentences that will unlock someone's heart. What works best is compassion; be concerned about them and what they have going on. Many times I have responded to questions about my brain injury with too much information. Nobody cares about the exact scientific names of your condition or about the specific meds you're taking; they are just being polite and asking. Answer their question being as brief as you can. You are not your brain injury; your brain injury is only a part of you. Impress them with your strength and calm in spite of your brain injury.

Strand, a regular newsletter contributor, has a book "Meditations on Brain Injury" now available on Amazon.com. The book is a collection of essays, many of which were printed in previous editions of HEADLINES.

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:

- 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.

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.



Injury and Violence PREVENTION

We're looking forward to working with our partner, the Brain Injury Association of Minnesota, to make RESOURCE FACILITATION a reality for all Minnesotans with brain injury.

www.health.state.mn.us/injury

Visit our website to ...

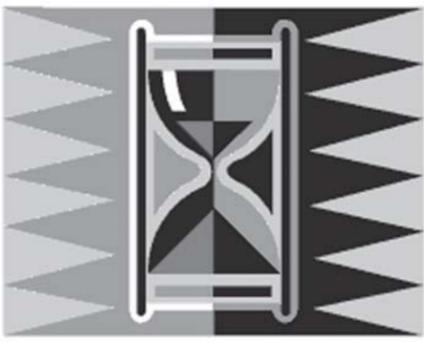
- Sign up for our free newsletter
- Create your own data tables about injury and violence in your part of Minnesota (See MIDAS: the Minnesota Injury Data Access System)
- Read reports, fact sheets, and data briefs on injury and violence

Or call or write ...

Injury and Violence Prevention Unit	P.O. Box 64882
Minnesota Department of Health	St. Paul, MN 55164-0882
(651) 281-8954 – telephone	(651) 215-8959 – fax
injury.prevention@health.state.mn.us	

Our mission is to strengthen Minnesota's communities in injury and violence prevention. We do this by ...

- Collecting and interpreting data on injury and violence,
- Developing and evaluating prevention programs and policies, and
- Providing tools, technical assistance and information to others.



NEWS BRIEFS

What's new at the Association and in the brain injury community

Save the Date: Walk for Thought 2006 scheduled



The Brain Injury Association of Minnesota is hosting its 5th Annual Walk for Thought. The St. Paul and Blackduck walks will be held Saturday, October 7.

This year the St. Paul walk has moved to Como Park. New this year: a third Walk was added at Lake Winona, in Winona on Saturday, September 30.

The walk is open and accessible to all - including those in strollers or wheelchairs. Walk teams from throughout the state are encouraged to participate.

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.

This Walk for Thought is a fundraising and public awareness event - an opportunity to increase recognition about the consequences of life with brain injury. More importantly, this walk is a celebration of life, hope and healing.

This year's goal is to raise \$100,000.

Several levels of corporate sponsorships are available. For more information on Walk sponsorships, or how to start a walk in your area of the state, contact Melissa at 612-378-2742, or 800-669-6442 in greater Minnesota.

Visit the Brain Injury Association of Minnesota website for periodic updates at: www.braininjurymn.org. Registration brochures, promotional posters and team captain packets will be available online this summer.

New "Wednesday Workshops" Series

New for 2006: The Brain Injury Association will offer monthly professional development workshops on the last Wednesday of the month.

The Association's first Wednesday Workshop session will kick off on Wednesday, March 29. "Beyond Brain Injury: Supported Employment" will be held from 1:30 until 4:00 pm. Continuing education credit is approved for CRCC. Social work credits are pending. A certificate of attendance will be provided, that persons with CBIS status can use for required CEUs.

On Wednesday, April 26, Jim Stolz, LICSW, will lead the session from 1:30 until 4:00pm. The focus of his presentation is case management interventions for persons who live with brain injury, chemical dependency and mental health concerns. Stolz was originally scheduled as keynote speaker for the Discharge Conference. A certificate of attendance will be provided.

Unless otherwise noted, Wednesday Workshops will be held in the conference room at the Brain Injury Association of Minnesota. Sessions will be 2.5 hours in length, at a cost of \$40 per person, and attendance is limited to 20. For more info, or to register, call 612-378-2742 or 1-800-669-6442.

TBI State Advisory Committee openings

This 30 member committee advises the Commissioner of Health and Human Services regarding policies, program and service needs of, and potential models for service delivery for persons with TBI.

Committee members are appointed by the Commissioner of Human Services for a one or two year term and must include people with brain injury, family members, advocates and professionals. Meetings are held six times per year, usually at the Department of Human Services building in Roseville.

This is a volunteer position, but expenses will be paid. (Minnesota Statutes 256B.093) The application deadline is April 1. For applications contact:

Jolayne Lange
MN Department of Human Services
444 Lafayette Road
St. Paul, MN 55155-4981
Or email: markh@braininjurymn.org

2006 Family Retreat

Mark your calendars! A Family Retreat will be held the first weekend in May 2006 at Camp Courage. The retreat is offered in collaboration with the Minnesota Department of Education's MN Low Incidence Projects, and is geared towards families who have a school-age child with brain injury. For more information, contact Anne Schuller at 612-378-2742 or 1-800-669-6442.

New Info and Resources

Toll-Free Number 1-800-444-6443

Brain injury information and help has been expanded for all persons in Minnesota with the addition of the National Brain Injury Information Center's national toll free number. The National Brain Injury Information Center (NBIIC), in collaboration with the Brain Injury Association of America, is a pilot project to evaluate an 800 number that will be directly linked to the Brain Injury Association of Minnesota.

The project will provide information and resources to individuals with traumatic brain injury, family members, professionals, and the general public. The project is currently being funded through the Centers for Disease Control and Prevention. A person calling the additional 800 number in Minnesota will link to her/his state affiliate Resource Facilitation department to access local services, resources, and information. The NBIIC pilot project will support the standardized protocol for responding to calls, a customized packet of information on brain injury topics, consistent data element collection, and resources to brain injury services for the caller's local community.

The importance of information and resources in supporting people with traumatic brain injury cannot be overestimated. Studies funded by the CDC and the Health Resources and Services Administration (HRSA) have shown repeatedly that access to information and resources is one of the greatest needs of people affected by traumatic brain injury. According to one study, people who were interviewed reported moving long distances to obtain access to services, not realizing that appropriate services were available nearby. The problem is particularly

acute for people in rural areas, where financial hardships and limited access to transportation make it difficult to travel to places where information and resources might be available. These are among the biggest obstacles to rehabilitation and are all problems that could be improved with appropriate access to information and resources.

Perhaps the most compelling evidence of the need for information and resources comes from a study that used traumatic brain injury surveillance data to link persons with brain injury to information and resources. The study confirmed "a strong need on the part of persons with traumatic brain injury to be linked in some formal way to a source of information about services."

Similarly, in 1998 the National Institutes of Health (NIH) Consensus Panel on the Rehabilitation of Persons with traumatic brain injury noted the need to educate family members to help them support rehabilitation more effectively. Despite the absence of research documenting the effectiveness of information and resources for families, the panel cited "substantial clinical experience" supporting the need. The panel also recommended services to help persons with traumatic brain injury "navigate through the public assistance and medical-rehabilitative care systems" and education to make community care providers aware of the problems people with traumatic brain injury experience.

The NBIIC project will be able to evaluate the effectiveness of an 800 number and begin to address some of the above questions posed by individuals with traumatic brain injury, their families and professionals. One of the goals is to collect standardized data in several states to know what people need; what types of information are being requested and at what point in their recovery; and what further resources are recommended to meet the unmet needs of our callers and to best provide the most accurate, reliable and individualized information possible. Also, the system will be evaluated in order to answer whether an 800 number is the best way to connect our callers to local services and supports.

If you would like more information on the NBIIC, please contact Janis Wack at 612-238-3246.

21st Annual Statewide Conference on Brain Injury

Staff report

Mark your calendars for the 2006 Annual Conference, "Reaching Out, Growing Together." The event will take place at Earle Brown Heritage Center in Brooklyn Center on May 19 and 20. Keynote speakers for the event include Roberta DePompei and Holly Kostrzewski.



Roberta DePompei

Roberta DePompei will provide keynote presentations each morning, as well as breakout sessions each day. Dr. DePompei's professional positions have included speech/

language pathologist/ audiologist in hospitals, rehabilitation facilities, home health agencies, public school and private practice. She is currently employed as school director, professor and clinical supervisor at The University of Akron.

Dr. DePompei's major area of research is traumatic brain injury (TBI) in children and adults and resultant cognitive-communicative disorders. She collaborates nationally, and has conducted research on the impact of TBI on the family system and communication. Her research also includes home, community and school reintegration for people with TBI, including school



Holly Kostrzewski



age through college levels. She has conducted numerous workshops and presented papers on these topics at international, national, state, and local conferences.

Holly Kostrzewski, of Duluth, will be closing the conference on Saturday by sharing her experiences of living with brain injury. In 1999, she sustained a life-changing brain injury during a motor vehicle crash, and has faced significant challenges during her on-going recovery.

Through determination, faith and a positive attitude, Kostrzewski graduated college with honors and now serves as the Injury Prevention Program Coordinator for the Fond

du Lac Band of Lake Superior Chippewa. Kostrzewski also founded the HUGS (Helmet Use and Grab your Seatbelt) program. She has appeared at events and conferences nationwide and in Canada, inspiring thousands with her message of hope and inspiration.

For more information about conference sponsorship and exhibit opportunities, call 612-378-2742 or 1-800-669-6442. Conference registration forms will be mailed to homes and businesses in late March. Registration forms are also available online at www.braininjurymn.org/EvntAnnualCon.cfm.



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Mayo Clinic Physical Medicine and Rehabilitation

provides comprehensive rehabilitation and medical services for people with traumatic brain injury and other types of acquired brain disorders

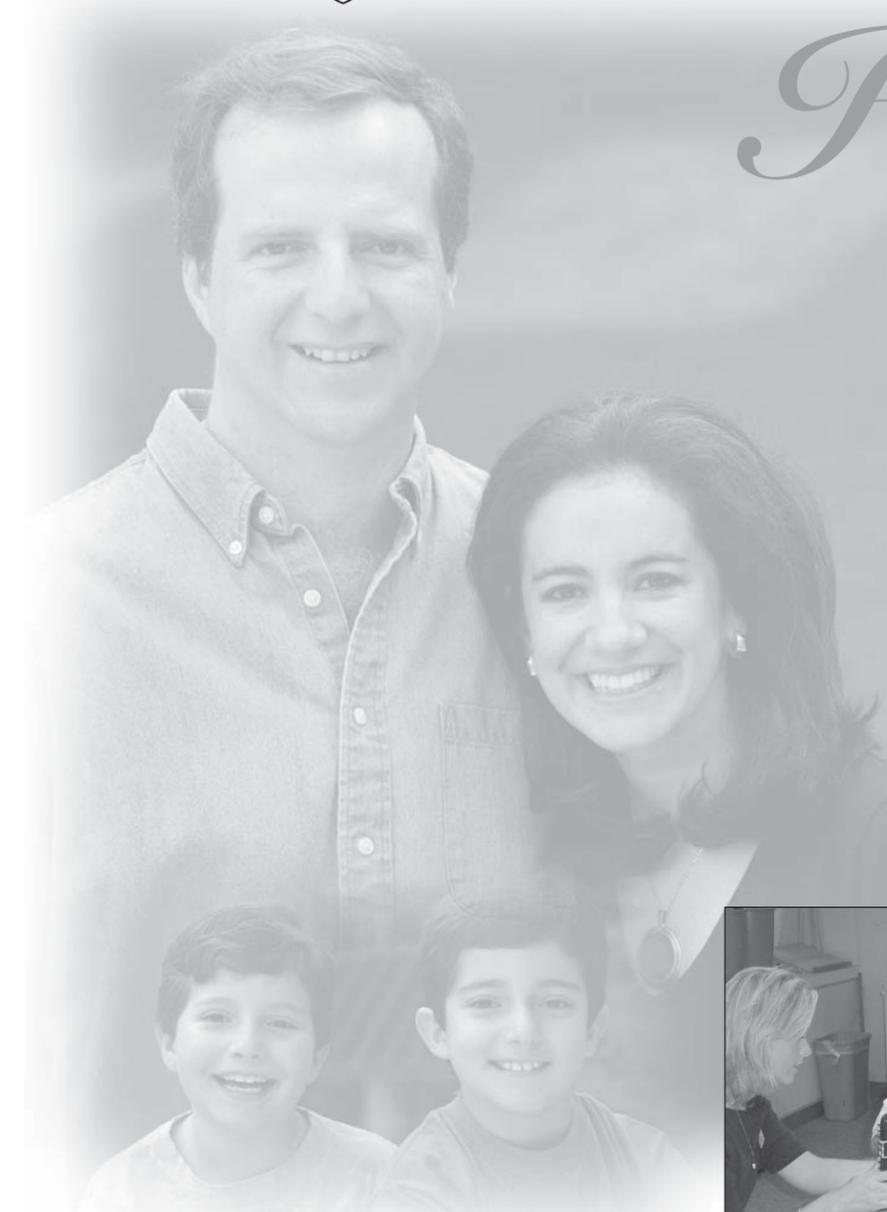
Why Mayo Clinic?

- Only Midwest NIDRR* designated Traumatic Brain Injury Model System
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Mayo Clinic
200 First Street SW
Rochester, MN 55905

For more information contact:
Program Secretary 507-255-3116

*National Institute on Disability and Rehabilitation Research



Resource Facilitation: Our Hospital Partners Make It Work

By Janis Carey Wack
Director of Consumer Services

Partners generally work together to achieve mutually beneficial outcomes. In the business world partners work to improve their profit margins, to expand their marketing reach and to innovate and improve the quality of their products.

In the people helping business, partners work together to ensure that the people they serve receive the most and the best care possible so that those people's lives are enriched. The numerous hospitals, large and small, throughout Minnesota and the Resource Facilitation program work together to help people who have sustained brain injury achieve the highest quality of life.

For example, hundreds of individuals referred by staff at Hennepin County Medical Center have participated in the Resource Facilitation program and benefited by receiving education around brain injury and access to information and resources that connects them to services. They also learned how different support systems work and the best way to approach various situations.

Consumers in Duluth having received services at Miller Dwan were referred to the Resource Facilitation program and assisted with learning about local resources which abound in that port city. Folks living in the Rochester area were connected with resources and supported via telephone contacts over a two year period. Parents of children served at Gillette Children's Specialty Care

who sustained traumatic brain injuries were educated about school related supports and assisted in understanding the Special Education process.

Adult children of elderly parents with brain injury being discharged from Bethesda Rehabilitation Hospital were assisted with problem solving issues and eligibility for financial programs that their parents could access.

1,001 people who have sustained brain injuries throughout the state of Minnesota found support, information and referral to appropriate resources when they were referred to the Brain Injury Association of Minnesota's Resource Facilitation program by the hospital staff who had cared for them and their families. This demonstrates the continuum of care that hospitals provide during the discharge planning process, but it is also an effective tool to ensure customer satisfaction.

Patients and families remark that it is because of the care shown by hospital staff that they were referred to the Resource Facilitation program. This extension of the care received at the hospital into the home and community is extremely valued and ultimately very important for a successful outcome. Resource Facilitation is the partner that hospitals who value customer satisfaction turn to when their patients with brain injury are being discharged.

During the past year, Association staff made nearly 300 contacts with hospital staff to share information

The extension of the care received at the hospital into the home and community is extremely valued and ultimately very important for a successful outcome.

about the Resource Facilitation program. These contacts consisted of individual meetings with doctors, nurses and social workers, presentations at staff meetings, training provided during "Lunch and Learns" and representing the Association and the program at various vendor exhibits.

Educating hospital staff is essential to the success of the program which in part is measured by the number of referrals. But there is still work to be done with establishing these partner relationships. To date, 30 hospitals in Minnesota routinely refer to the Resource Facilitation program. We applaud these hospitals for being proactive and truly focused on patient care and customer satisfaction.

At the same time we continue to reach out to the remaining hospitals to educate staff about the program and invite them to partner with us to improve the quality of life for their patients living with brain injury. It is important for the remaining hospitals to understand that their staff can receive support and assistance through Resource Facilitation making their jobs easier by utilizing a service that specializes just in brain injury.

Whether or not the hospital is identified as a trauma center is not

the issue. If people with brain injury receive care (any kind of service) in your hospital then your staff can refer them to the Resource Facilitation program. We want to ensure that people with brain injury do not fall between the cracks and miss the opportunity to receive this two year free service.

Consumers can assist with the process of educating hospitals and establishing this partnership by asking if their local hospital or the hospital where they received care are knowledgeable about the Resource Facilitation program and how to refer to it. By contacting the Social Service Department or the department in charge of customer satisfaction at the hospital or simply talking with the staff when you receive services, you can encourage staff and the hospital to join in this partnership.

We highly encourage consumer participation in the grassroots aspect of building community supports. Consumers as well as hospital staff have the power to make sure that knowledge about this program is widespread and that referrals are the outcome.

If you would like more information about the Resource Facilitation program and how to make referrals, please contact Janis at the Brain Injury Association of Minnesota at 612-238-3246 or janiscw@braininjurymn.org.

Brain Injury is one of the most unrecognized consequences of domestic violence.

A brain injury can often increase a victim's feelings of hopelessness, confusion and fear - making independence from her abuser more challenging.

Other common causes of brain injury include automobile crashes, falls, sports concussions and strokes. If your head has even been hit hard enough to see stars, lose consciousness, or experience a concussion, we can help!

Call the Brain Injury Association of Minnesota at 612-378-2742 or 1-800-669-6442.



Brain Injury
Association
of Minnesota

www.braininjurymn.org
Bringing help, hope and a voice.

4th Annual Xtreme Safety Fest at Mall of America

Event includes grand finale to March's Helmet Drive

Staff Report

Spring is almost here, and soon area streets and paths will be occupied by bicyclists, skateboarders and inline skaters. Unfortunately, the majority of these individuals will not wear helmets. To increase public awareness about the importance of wearing a helmet, the Brain Injury Association of Minnesota is hosting the Fourth Annual Xtreme Safety Fest at the Mall of America Rotunda.

This free event is scheduled for Sunday, April 2, from 1 – 4:30 p.m. Last year, over 1,500 people attended this exciting and educational event. Low cost helmets will be available for purchase throughout the event while supplies last.

Rich Wieber's Bicycle Stunt Show headlines the event, with performances scheduled for 1 pm and 3:30 p.m. Rich uses his talents to deliver fun and educational messages to people of all ages. He has appeared in national television commercials and at over 3,000 events including Minnesota Timberwolves games and the ESPN X-Games-Road Show. Rich was a big hit last year when he awed the

crowd by jumping over Brain Injury Association of Minnesota staff without the assistance of a ramp. Come see what Rich has in store for the crowd this year.

New this year: PJ the DJ and Radio Disney AM 1440 will be on-site at the event to provide music, games, and prizes for all in attendance, from 2 – 3:30 p.m. All kids get to spin the prize wheel, and a few lucky winners will get to step into the Prize Tornado.

This year's event will include the grand finale of March's Helmet Drive. People who donate helmets at the Brain Injury Association of Minnesota collection site or send in monetary donations for the helmet drive will have their names entered into a drawing for a free bike. Donations brought to the Mall during the event up through 3 p.m. are also eligible for the bike drawing. The drawing will be held at 3:30 p.m. The winner need not be present at the drawing, but is responsible for arranging bike pick-up. The bike was donated by the Daily Grind Coffee Shop in Stillwater, Minn.

Visit the Association website for periodic updates at www.braininjury.org.



submitted photo

Rich Wieber awes crowd with "flatland" BMX tricks.

The Association is looking for several volunteers to help out at the event – particularly teens and their

families. For more information, contact Kimberly Ferencik at 612-378-2742.

For Learning. . .



For Living . . .



Quality of Life Areas:

- * Relationship Building
- * Memory Enhancement
- * Socialization Skills
- * Recreation Planning
- * Coping Techniques
- * Health and Wellness

Day to Day Activities:

- * Grocery shopping
- * Cooking
- * Money management
- * Grooming
- * Housekeeping

For Life

Mains'l Services, Inc. can help with all aspects of a person's life, both self enrichment and daily living routines.

Call Kelly at 763-416-9174 or visit our web site at www.mainsl.com



"The Choice is Yours"

What life is like after brain injury

My Life After Brain Injury

1. Ride my bike on the road.
2. Cut grass with lawn mower.
3. School work is harder.
4. Leave school earlier.
5. Play on different sports teams (adaptive now).
6. Wear helmet while doing chores.
7. Cannot climb trees.
8. Before my accident, I had a job at the Dairy farm next door and I can't work there anymore.
9. I also have memory problems.
10. I also get angrier faster.

Keaton Bowden, age 13

Before my brother's accident, my family was busy with baseball every night of the week. We play baseball with my dad and my two brothers. We always did fun things as a family like camping, hunting and sledding in the winter.

Me and Keaton were riding our bikes and waiting for dad to get home from work so we could go to my baseball game. That's when my

brother got hit by a pickup truck in front of my house. He spent two and a half months in the hospital.

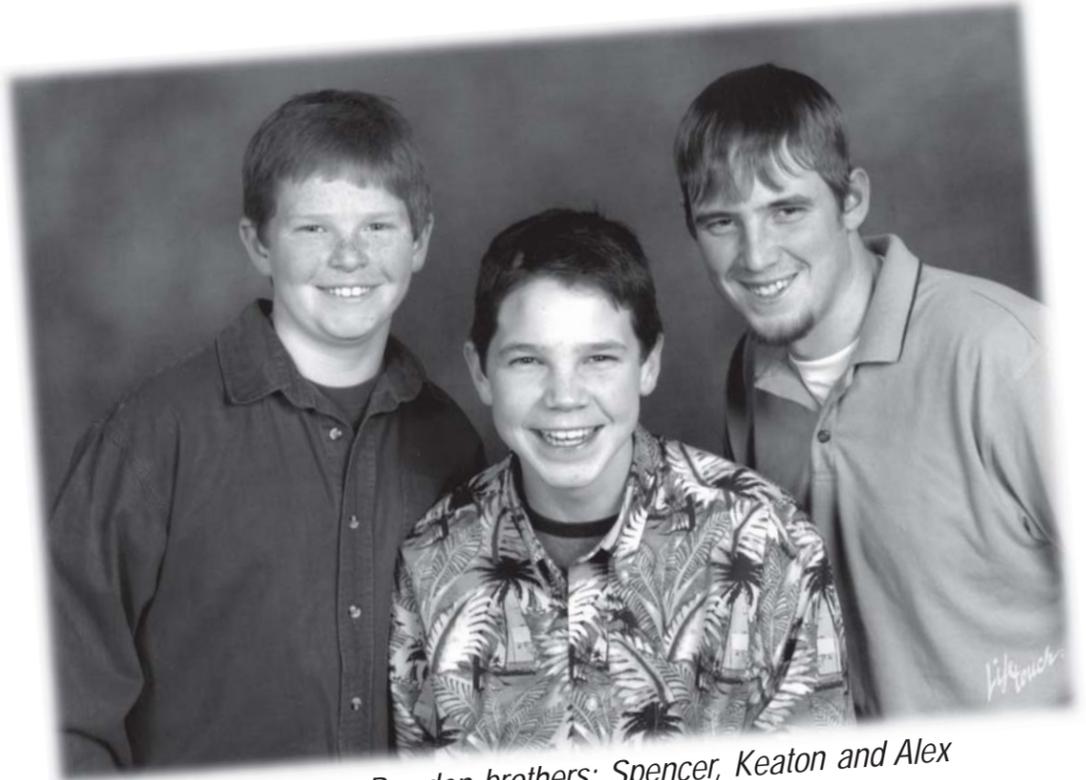
Now it's hard because we have to watch him all the time. Someone has to be with him when mom and dad are not around. Keaton gets mad at me when we play a video game and he's not winning. Mom had to leave her job to stay home and take care of him because he gets

really tired after school. Sometimes I have to watch him so mom can cook us dinner. Sometimes I get to go over to a friend's house to stay over the weekend.

It's hard for me to understand what he is going through because I'm 11 years old. We don't have much of the fun things anymore. I wish we could have my old family and my brother back.

It's hard to understand what TBI feels like. All I know is now I have to wear my bike helmet when I ride a bike. I wish one day he could be his old self. But for now, I'll just help mom and dad with my brother. Because baseball is starting soon.

Spencer Bowden, age 11



The Bowden brothers: Spencer, Keaton and Alex



Colleen McCann

My name is Colleen McCann. When I was 15 I suffered cardiac arrest during gym class and I stopped breathing. I was in a coma for a month and I had an anoxic brain injury. I spent three more months in Gillette Hospital learning how to walk and talk and eat. Before my injury, I was a normal kid with few problems, but now I am in Special Ed and everything has changed. Some days do not seem fair but I have learned to deal with them. If anything goes wrong for you, just remember this: Take life one day at a time and it will all get better.

I wrote this poem for Brain Injury Awareness Month

A Day in the Life of Colleen

Every morning I wake up at 6:30.
Some days I am sad because I don't know who I am.
It has been two and a half years and I still need help getting ready in the morning.

I am bummed and I don't know why.

I ride the bus to school, I sit with people and try to remember their names.
I get to school.

My locker is not out in the halls anymore,
My locker is in the Special Ed room.
I have normal classes and Special Ed classes.
This is different than before.
Different.

My days are hard but.Fun and exciting.

I am happy and I don't know why.

Sometimes it's really sad that I am in the Special Ed room.
My three Special Ed friends help me; they know everything I am going through.
Sad.

I am 17.
My goal now is to be a role model,
Maybe even a Special Ed teacher.
Maybe.

Colleen McCann, Age 17

- Through the eyes of our youth

Life before my brother's accident was great. Me and my two brothers played baseball just about everyday of the week, and did a lot of things together. So we really stayed busy throughout the week.

Then, June 24, 2004 at 6:30 pm everything changed. We had just got done eating dinner and were getting ready to go to Spencer's baseball game that he had that night. Keaton and Spencer decided to go out and ride their bikes while they were waiting for dad to get home from work. During that period of time, Keaton was struck by a pickup truck in front of our house. Spencer managed to make it up to the house to let us know what happened.

When he mentioned it, I thought nothing of it cause he said Keaton crashed, so I assumed that it was a normal crash that every kid goes through. But Spencer said no. Again, I figured maybe he might have ran into him, but when he said Keaton was hit by a truck, it shocked me and it was hard to believe, so when I ran out there, and sure enough it was true. And still it was hard to believe it.

I managed to stay calm, take care of Keaton the best as I could before paramedics got there, and kept mom calm. But the next day I went to visit him in the hospital and when I saw him lying there in a coma, I just broke down in his room, and

couldn't bare to see him like that. As the months went on it seemed to get harder because he could barely walk and do the task he needed to do during physical therapy. But I'm really thankful he is still with us and I thank the Lord for that.

Now that he is home, it hasn't been the easiest because he has the weirdest mood swings I have ever seen, cause one moment he is really, really happy and the next he's really, really angry and trying to fight you. So you really need to watch what you say cause you don't know what he will do or how he will react, so basically you're walking on egg shells around him. It can be hard to get

through the day or the week, so sometimes it can be a little stressful. But it is also hard to see that he can't do most sport activities anymore and the things he loved to doing like baseball, going outside to have fun.

Since the accident now we can't throw the baseball around and all the fun things me and him use to do, which stinks. It's been hard that we can't have as much fun like we used to have together. But other than that, he is still an awesome brother and still fun to be around, and be aware he will get you laughing really hard. We all love you Keaton.

Alex Bowden, age 17



Sergio, Simon, Adriana and Juan Pablo

What was wrong or what happened to my dad?????

My dad had a Brain Injury. Nothing happened to him - no accident no nothing. It happened when we were in our farm. He sit on a swing and he was going to puke so he threw himself down, landed on the floor and started to sweat. It was really scary and he had to drink a special kind of tea. When we came back from the farm, we went to a clinic in the city where he had nine surgeries in his head. Then he went to Jacksonville where he had his tenth surgery on his head. He was six months in a clinic, and he couldn't stand, move, talk, he couldn't do nothing. It was really sad seeing my dad almost dead for 6 months - it was terrible. When I talk to my mum and dad I always say mum and dad but when my dad was in the clinic I only said mum, mum, mum. It was starting to get annoying! When my dad came out of the clinic I didn't say mum and dad I only said mum and I felt really bad for my dad because when I talked to both of them, I only said mum. I didn't remember to say dad because I was getting use to saying mum and not dad. I was really scared that my dad was going to die. I was really nervous but when we came to Jacksonville he got really good. He was doing so good he needed more therapies and they couldn't do so much. We had to travel to Rochester Minnesota. Now he is so much better! We can play tennis together again and much more he couldn't do when he was in the hospital. I'm really happy I have my dad back and I'm glad to have a mum like mine because she helped my dad, me, my brother, my grandma, and my whole family. It was incredible she was like a super mum. I love my whole family.

By Juan Pablo Espinosa, age 9

Qué salió mal o que le pasó a mi Papá?????

Mi Papa tuvo una lesión cerebral. No tuvo un accidente ni le pasó nada. Pasó cuando estábamos en mi finca. El se sentó en un columpio y con mi hermano le dimos muchas vueltas jugando como lo habíamos hecho con mi Mamá y abuelos. Mi Papá se sintió mareado, se tiró al piso y empezó a sudar. Fue muy miedoso. Después de un rato, ya se paró sintiendo mejor. Cuando nos devolvimos de la finca fuimos a una clínica en Bogotá, la ciudad donde vivimos. Le hicieron un scanner y le dijeron que tenía hidrocefalia. Cuando mi Papá nos contó que lo iban a operar de la cabeza, yo me puse a llorar porque le tenía susto que quedara bobo. Lo operaron y le pusieron una válvula. Después estuvo bien pero unos meses mas tarde tuvieron que volverlo a operar y todo salió mal. Tuvo diez cirugías en su cabeza. Cuando lo visité las últimas

veces en cuidados intensivos ya no me hablaba, ni se reía, ni nada. Siempre salía llorando de la clínica y también lloraba en el colegio y por la noche con mi Mamá. Pensaba que se iba a morir y me iba quedar sin Papá. Después mi Papá se fue a Jacksonville a la Clínica Mayo donde tuvo la décima operación en su cabeza. El estuvo seis meses en una clínica, y no se podía parar, o moverse, o hablar no podía hacer nada. Era muy triste ver a mi papa casi muerto por seis meses, era terrible. Cuando le hablo a mis papas yo siempre digo mamá y papá pero cuando mi Papá estaba en la clínica, yo solo decía mamá, mamá, mamá y solo mamá. Eso empezaba a aburrir. Cuando mi Papá salió de la clínica yo no decía mamá y papá solo decía mama y eso me hacia sentir muy mal porque le estaba hablando a los dos pero solo decía mama. Yo no

me acordaba de decir papa porque ya estaba acostumbrado a decir mama y no a tener en cuenta a papa. Yo estaba muy asustado de que mi papa se fuera a morir. Yo estaba muy nervioso pero cuando nosotros vinimos con mi hermano a Jacksonville se mejoro un poquito porque aunque no podía hablarnos ni hacer nada, por lo menos podía estar sentado en la cama y no siempre acostado como en Bogotá. Mi hermano y yo le podíamos dar pedacitos de hielo y helado y él podía abrir la boca como un bebé. El seguía estando tan mal que necesitaba mas terapias pero en Jacksonville no le podían hacer mas. Teníamos que viajar para Rochester, Minnesota. Mi Papá se fué con mi Mamá en avión ambulancia para Rochester y nosotros nos fuimos con mis abuelos en avión. En Rochester le enseñamos con mi hermano a

hablar, a coger una bolita, a patear. Mejoró poco a poco aunque estuvo mucho tiempo en silla de ruedas. Algunas veces alquilábamos una silla de ruedas eléctrica y con mi hermano nos subíamos y jugábamos. Estaba mucho mejor!!!! Cuando volvimos a Bogotá después de mas de un año de vivir en Rochester, mi Papá ya podía hacer todo pero no era mi verdadero Papá. Ahora si es. Ya podemos jugar tennis juntos y el juega super bien. Trabaja y es un Papá de verdad. Estoy realmente feliz de que tenga a mi Papá otra vez y estoy super orgulloso de tener una Mamá como la mía porque ella ayudó mucho a mi Papá, a mi hermano, a toda la familia y a mí. Fue increíble, ella era como una super mamá. Amo a toda mi familia!

Por: Juan Pablo Espinosa, tiene 9 años, Bogota, Colombia



PEOPLE *in* PROGRESS

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

Just Jayne: One woman's journey after brain injury

By Barb Danson

"Do you see that pressure ridge over there?" Jayne Sundeen asked her husband, Tom, as he drove their snowmobile onto Lake Vermillion February 1, 2003.

"Yes," Tom answered, and that is the last thing Jayne remembers from that day. It was another nearby section of buckled ice—camouflaged by falling snow—that changed life forever for the high school sweethearts who had been married more than twenty-two years.

As the snowmobile launched off the ice ridge, Tom hung onto the handlebars and Jayne was catapulted ten feet into the air. When she landed, the back left side of her helmet slammed against the unyielding ice. She was knocked out cold, but gurgling sounds indicated she was still breathing.

Tom needed help, and made the difficult decision to leave Jayne on the ice while he rode the snowmobile to a nearby home. By the time the Tower ambulance crew arrived twenty minutes later, Jayne had been out for forty-five minutes. As the EMTs loaded her on a backboard, she started to vomit, a classic sign of traumatic brain injury (TBI).

Doctors at the hospital in Virginia performed a CAT scan and detected blood pooling inside Jayne's skull. She was immediately transferred to St. Mary's Hospital in Duluth, where a neurologist diagnosed left subarachnoid hemorrhage. Jayne was given medication to relieve the pressure against her brain and prevent further injury.

Most of Jayne's family surrounded her while she was in the intensive care unit. Even though she was alert and communicating, she only remembers seeing two of her many visitors. Three days later she was transferred to the Rehabilitation Unit at Miller-Dwan Center in Duluth. She experienced dizziness, lack of coordination, difficulties with balance, mild facial paralysis, lethargy and headaches.

"I hope they didn't listen to some of the things I was saying," Jayne says, "because I didn't know what I was saying." Even though she does not remember much from her three weeks at Miller-Dwan, the occupational, speech and physical therapy she received helped her to become independent in all basic

activities of daily living. While she was not yet ready to return to work, her prognosis was good and she was expected to do well.

Jayne returned to her home in Soudan, Minnesota, and she received outpatient therapy three times a week in Virginia. Her sisters, Kristy and Lynne, played a big role in providing help so that Tom could keep working. She appreciated having others there for her. "My brother Jimmy and my niece Shelby would have contests to see who could make me laugh," says Jayne. "If I laughed, it felt good."

Unfortunately, the laughs became fewer and further between as Jayne soon began to experience serious spells during her speech therapy in Virginia. "I would be talking," she says, "and my head would go down, chin to chest, and I would go out for up to three minutes. I knew it was happening, but I couldn't get myself out of it. If I tried, it would start all over again. I had to let it go its course."

Jayne refers to these spells as "dropping," and they lasted long enough that she was not allowed to participate in physical therapy for fear that she would hurt herself. In addition, she experienced episodes where her entire body would freeze up and she babbled her speech. "I was like a baby," she says. "I knew something was coming out, but I couldn't say the words."

Doctors initially suspected that Jayne's dropping episodes were caused by narcolepsy. A sleep study ruled out that diagnosis. By June 2003, she was having more than fifty spells per day. She had become nearly bedridden and was no longer able to prepare meals, keep house, or socialize with friends and family. In addition, she experienced crying spells, worry, anxiety, and painful headaches that would not go away.

Doctors referred Jayne to the Mayo Clinic. After a full day of testing, the psychiatrist requested that she return after the 4th of July weekend to be admitted for a week of psychiatric evaluation. "I wanted



submitted photo

Jayne Sundeen pauses for a rest break during the 2005 Walk for Thought

tears to come down," says Jayne at the thought of entering the psych ward, "but I said, 'I'll do anything.' If that's what it took to get better, that's what I would do."

Even though Jayne struggled with the confusion of being surrounded by people who had different problems from her—people she had difficulty relating to—the inpatient program allowed doctors to thoroughly observe her behavior. She was diagnosed with depression and conversion disorder, an illness in which emotional stress is expressed through physical symptoms.

"If my depression had been diagnosed earlier," Jayne says, "maybe I wouldn't have landed as bad as I did." She recommends that other people with TBI watch for and act on early signs of depression.

While at Mayo, Jayne learned that emotional topics were particular triggers for her spells; she was taught coping and relaxation skills. Her spells had decreased and were nearly absent by the time she was released. She also learned that it is important to talk openly about her recovery and her goals with Tom, her adult children Andrew and Elizabeth, and other close relatives. Jayne continues to work on these skills. In fact, her Christmas list this year did not include any material goods; her biggest wish was to communicate

better as a family and to have more of a "can do" attitude.

"I could do a lot more," Jayne says about her life before TBI. "I never tried to take on a project that I could not do a good job on or put my 100% into." What has changed? "I can't give back as much as I want. I just can't get up and go when I want. Sometimes I feel like a child. I have to ask for help and I wish I could do it myself." Jayne holds the same high expectations for herself that she always has, and sometimes it is difficult to remember that one of her main tools, her brain, has been changed by a traumatic injury.

Jayne finds it even more discouraging when her recovery and progress is compared to others. People have said, "Jayne, I know someone who has been in a worse accident than you and she is working." Others may see what she looks like on the outside, but they have no idea what is happening on the inside. "Don't you think I want to do those things?" Jayne asks. "Every brain injury is different. Don't expect the same results from one person as another. Don't treat them the same. They are all different." Jayne's experience illustrates why open dialogue is so important to help improve understanding and recovery.

In the three years since her accident, Jayne has had good times and bad times. "Everybody does that in life," she says. "We go forward some steps and back some." She has painful headaches most of the time and feels numbness all the

Jayne holds the same high expectations for herself that she always has, and sometimes it is difficult to remember that one of her main tools, her brain, has been changed by a traumatic injury.

Just Jayne
on page 16

Frequently Asked Questions (FAQ) About the Medicare Prescription Drug Benefit (Part D)

The following FAQ list was reprinted in part from information provided by the Minnesota Department of Human Services, Aging and Adult Services Division. For further information, please use the contact information at the end of this article.

Question #1. What is the new Medicare prescription drug benefit?

Answer: It is new prescription drug coverage available to people who have Medicare. Beginning January 1, 2006, if you enroll in a Medicare Prescription Drug Benefit Plan (also known as Medicare Part D), a portion of your prescription drug costs will be paid for by the Plan.

Question #2. Do I have to enroll in this program?

Answer: No. But if you don't, you may pay a higher premium later. Most Medicare beneficiaries must make a decision to enroll in a Medicare Prescription Drug Benefit Plan beginning November 15, 2005 through May 15, 2006, or risk having to pay a higher premium (see question #4). However, if you are currently receiving Medicare AND Medicaid (the Minnesota Medical Assistance program) or Medicare AND Supplemental Security Income, you will automatically be assigned to a Medicare Prescription Drug Benefit Plan. You may then opt out of this Plan or choose another.

Question #3. When do I need to sign up for the benefit?

Answer: All individuals entitled to Medicare Part A or enrolled in Part B can enroll in the Medicare Prescription Drug Benefit Plan from November 15, 2005 through May 15, 2006. After May 15, 2006, enrollment will only be allowed under special circumstances, and you may have to pay more for the same drug benefit because you enrolled late. If you become eligible for Medicare after November 15, 2005, Medicare will inform you of the dates of your six-month enrollment period.

Question #4. Can I wait a year to see how this new program goes before I enroll?

Answer: You could, but then you may have to pay more for the Medicare Prescription Drug Benefit. The longer you wait to enroll after May 15, 2006, the more you may have to pay for the premium.

Question #5. How do I get the new drug benefit?

Answer: You can enroll with the plan of your choice beginning November 15, 2005. You will have at least two

plans to choose from, perhaps more. You may compare plans and choose the one that is best for you by going to www.Medicare.gov or by calling the Minnesota Senior LinkAge Line® at 1-800-333-2433. The Senior LinkAge Line® is the State Health Insurance Assistance Program (SHIP) for all Minnesota Medicare beneficiaries and is designated by the Centers for Medicare & Medicaid Services to provide Medicare assistance.

Question #6. How much will it cost?

Answer: If you do not qualify for extra help with Medicare Prescription Drug Benefit Plan costs, you will pay a monthly premium, an annual deductible, and co-payments, which will vary according to the plan you choose and where you live. Under the standard plan, individuals will pay an estimated premium in 2006 of \$37 every month and a \$250 deductible before Medicare starts helping with costs. After you have paid \$3600 for your prescriptions in a year, your Medicare Prescription Drug Benefit plan may pay 95% or more of the costs for your prescriptions for the rest of the year.

Question #7. Will all plans cost the same?

Answer: Probably not. Each plan can decide to provide more than one option which may have a higher premium and more coverage. Each plan must have a total package of benefits that is of equal value to the standard plan. However, no matter which plan you choose your total payments for prescription drugs during the year will be no more than \$3,600, after which the Medicare Prescription Drug Benefit plan pays 95% or more of the cost of your prescriptions for the rest of the year.



Question #8. Will all plans offer the same drugs?

Answer: No. The drugs covered may vary from plan to plan, so you will need to make sure that the plan you choose covers the drugs that you need.



Question #9. How much will I save?

Answer: The amount you save will depend on your drug costs, your income, and the discounts that your drug benefit plan negotiates for the drugs that you take. If you spend more than \$694 per year on drugs (which equals the 2006 estimated \$444 yearly premium + \$250 standard deductible), then you will likely save on your drug costs. It is important to keep in mind that your drug costs may increase as you grow older, or if you become sick, so while you may not need coverage now, you may want it later. Enroll now (no later than May 15, 2006) to avoid paying increased premiums later.

Question #10. Is there any additional assistance for persons with disabilities or low-income elderly Medicare enrollees?

Answer: Extra help paying for Medicare Prescription Drug Benefit Plan costs is available. If your income is less than about \$14,000 (or less than about \$18,800 for couples) and your assets are less than \$10,000 (\$20,000 for couples), you may qualify for this extra help. Assets that are counted include: savings accounts, stocks, bonds, real estate, and life insurance, excluding your home and car. Some people may automatically qualify for extra help. If you receive supplemental security income benefits (SSI), prescription drug coverage from the Minnesota Medical Assistance program, or are enrolled in a Medicare Savings program (QMB, SLMB, QI), or Minnesota Prescription Drug Program, you will automatically qualify for extra help and do not need to complete an application.

Question #11. How can I find out if I qualify for the extra help with my Medicare Prescription Drug Benefit Plan costs?

Answer: You can apply for extra help by completing the Social Security

Administration's "Application for Help with Medicare Prescription Drug Plan Costs." Beginning July 1, 2005 you can apply over the Internet at www.socialsecurity.gov or by calling SSA at 1-800-772-1213. Applications will be available at many community sites. You can also obtain an application form by calling the Senior LinkAge Line® at 1-800-333-2433. Senior LinkAge Line® has staff and volunteers available to assist you with completing the application form. If you want to find out if you automatically qualify for extra help because you are enrolled in the Minnesota Medical Assistance program, contact your local county social service office.

Question #12. I am enrolled in Tricare—will my military retiree or veterans' drug benefits change?

Answer: No. Military retirees and their dependents can choose to stay in Tricare-for-Life, and veterans may get drugs through the Veterans Affairs health system if they are enrolled in it. You can later decide to enroll in the Medicare Prescription Drug Benefit without paying a higher premium.

Question #13. I am a retiree covered by my former employer or union plan—can I still get the Medicare Prescription Drug Benefit?

Answer: Yes. You can choose to keep your retiree coverage or switch to Medicare Prescription Drug Benefit. In order for you to make the right choice, your former employer or union must tell you if they intend to continue offering drug coverage in your retiree plan, if the coverage is as complete as the Medicare Prescription Drug Benefit coverage, and whether the plan will receive a subsidy for continuing the drug coverage. To ensure you make the right choice, call your employer or union benefits department.

**Medicare Part D
from page 11**

Question #14. I have Medical Assistance, can I stay with it?

Answer: You will no longer be able to get your prescription drugs through Medicaid – the Minnesota Medical Assistance program (a few exceptions may apply). Medicare will provide your prescription drug benefit beginning in 2006. Medicare may pay for your prescription drug costs, except for co-payments that could range between \$1 and \$5, depending on your income and if the drug is generic or a brand name. You may not need to pay co-payments after your total drug expenses reach about \$5100. If you do not enroll in a plan by January 1, 2006, you will be assigned to a plan.

Question #15. Can I get discounted drugs from a manufacturer-sponsored program if I sign up for the new benefit?

Answer: This will depend on the manufacturer's policy. Many pharmaceutical companies limit their patient assistance programs to low-income individuals who do not have access to drug coverage. Such programs may exclude Medicare beneficiaries starting in 2006. You

should contact the company to find out how they are planning to respond to the new Medicare Prescription Drug Benefit (also known as Medicare Part D).

Question #16. Do I have to change pharmacies?

Answer: You may have to change pharmacies, depending on your Medicare Prescription Drug Benefit plan. Some plans may have a limited pharmacy network. You need to check the network of pharmacies in different plans to see if your pharmacy is included.

Question #17. Can I switch Medicare Prescription Drug Benefit plans if I don't like the one I'm in?

Answer: You may switch plans once a year, between November 15 and December 31, beginning in 2006. If you switch plans, your new coverage will begin the following calendar year. For example, if you complete the paperwork to switch plans on November 29, 2006, you will be enrolled in a new plan as of January 1, 2007. There are some special circumstances where you may get a special enrollment period.

Question #18. Does the Medicare Prescription Drug Benefit pay for all drugs?

Answer: No. While Medicare Part D covers most drugs, it does not cover all drugs. Each plan will have a list of drugs that are covered (called "formulary"). Your plan will have a process to request an "exception" to receive coverage for medically necessary drugs not on the formulary. Some drugs will continue to be covered under Medicare Part B.

Question #19. What if the drug my doctor prescribed is not on the list of drugs covered in my plan?

Answer: You or your doctor can request that your plan pay for a medically necessary drug not on the plan's formulary, or drug list. If your plan refuses to pay, there is an appeal process. Drugs listed as "excluded" from your plan cannot be appealed. If your appeal is denied, you will be responsible for paying the full cost of any drug that is not on the formulary. This cost will not be counted toward the annual \$3,600 out-of-pocket amount.

Question #20. What is Medicare Advantage and how does the new benefit work with those plans?

Answer: Medicare Advantage is the new managed care program that is replacing Medicare+Choice. Medicare Advantage plans may offer a combination of health coverage and

the Medicare Prescription Drug Benefit, and perhaps additional benefits not offered by traditional Medicare, such as dental or vision care. Most Medicare Advantage plans will require you to choose a doctor in the plan's network or pay more to go to an out-of-network doctor. During open enrollment in the fall of each year, you can choose whether you want to stay in a Medicare Advantage plan, switch to a different Medicare Advantage plan, or return to traditional Medicare.

For more information on Medicare Part D, contact the following:

Disability Linkage Line, 1-800-333-2433

Social Security Administration
1-800-772-1213, or
www.socialsecurity.gov

www.Medicare.gov or 1-800-Medicare

This information is available in other forms to people with disabilities by calling 651-296-2770 or 1-800-882-6262 or through the Minnesota Relay Service at 711 or 1-800-627-3529 (TDD), 1-877-627-3848 (speech-to-speech relay service).



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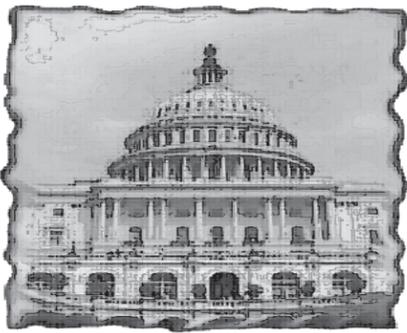
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LEGISLATIVE CORNER

Keeping up to date with public policy

2006 Legislative Priorities Set



By Jeff Nachbar
Public Policy Director

Primary and Universal Seatbelt Law

Public policy plays a critical role in accomplishing our mission of enhancing the quality of life for all people affected by brain injury in Minnesota. We work hard every day to see that people get the services they need and deserve. But we must do more than ensure quality services. Preventing brain injuries from occurring in the first place is also a big part of bringing about the promise of a better tomorrow. Getting more people to “buckle up” is an important step in that direction. That is why we will be pushing hard this legislative session on enhancing Minnesota’s seatbelt law.

We know this proposed law change will reduce the personal devastation caused by lost lives and serious injury. But it will also reduce the state’s medical costs. Here are some facts to consider:

- ❑ Each year more than 3,500 Minnesotans are hospitalized due to a Traumatic Brain Injury (TBI)

- ❑ Taxpayers pay more than \$256 million through Medicaid each year in for long term care for Minnesotans who have sustained a TBI.
- ❑ Almost half of TBIs are related to motor vehicle crashes.
- ❑ If everyone wore seatbelts, there would be 11% fewer TBIs every year.
- ❑ This would slow the growth in Medicaid spending by a cumulative \$2 million per year or \$30 million over the next 5 years for TBI spending alone.
- ❑ Minnesota would receive \$15 million in federal incentive funds for highway safety improvements by passing this law change.

Medical Assistance Income Standards

Qualifying for Medical Assistance (MA) is the primary key people with a TBI need to open the door to services. Currently, a person must have very low income and very few resources in order to qualify for MA. For example, a family of four must have monthly income below \$742 and have under \$3,100 in resources in order to qualify. We feel that this is an incredibly unrealistic and unfair standard to use in order to determine if somebody should get help. We will be pushing the legislature to act to raise the income and resource standards to get more help to more people. Too many people, who are poor, but apparently not poor enough, are falling through the cracks.

Please join us in helping support this important legislation.



2005 Minnesota Advocacy Project graduating class

A Leadership Training Program for Persons Affected by Brain Injury

The Minnesota Advocacy Project is a joint venture of the Brain Injury Association of Minnesota and the Mayo TBI Model Systems to provide advocacy training to persons with brain injury and/or their family members. This one-year, comprehensive program involves four Saturday workshops as well as field assignments designed to teach advocates how to navigate public policy and advocacy specific to brain injury.

Advocates will gain the skills to:

- ✓ Maximize personal access to quality services
- ✓ Increase public awareness of brain injury issues and solutions.
- ✓ Affect change within their community and state to improve their life or the life of a loved one.

The Minnesota Advocacy Project will teach participants how to improve their skills and the skills of others so they can obtain full access to their community. We invite you to dedicate your time and energy to become a change-agent and community leader. For more information please contact Kim Kang at 612-378-2742 or 800-669-6442 or kimk@braininjurymn.org.

Citizen Advocate Program Unveils the Advocacy Action Center

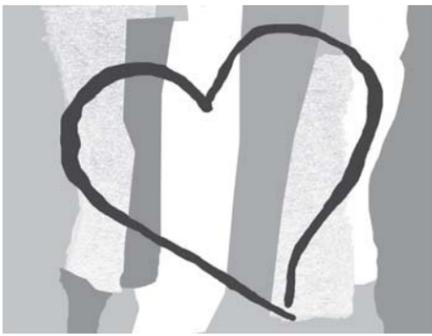
Ever wondered how you can help? Want to stay involved and informed, but not sure how? We too have been looking for ways to make it easier for people to participate in the political process. We are very excited to report that our Advocacy Action Center is up and running! The Advocacy Action Center (AAC) is our new online portal for keeping you informed and showing you how to make a difference.

You can access the site in one of two ways. Go to our website www.braininjurymn.org, highlight advocacy near the top of the page and then click on Advocacy Action Center or go directly to www.capwiz.com/braininjurymn.

The first step is to sign up online. Then watch for our alerts or come back anytime to see what is going on. You’ll find issue descriptions, updates, action alerts and tons of information. I encourage you to explore the site and take advantage of the many tools that are provided to help you become a more effective advocate. As always, please contact me if you have any questions, comments or need help.

Get Involved!

For more ideas on how to get involved with the Brain Injury Association of Minnesota and/or the brain injury community, visit the Association’s Get Involved! Webpage at www.braininjurymn.org/AUInvolved.cfm



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Peer/Mentor Support Connection

Staff report

The Brain Injury Association of Minnesota is excited to announce the addition of the Peer/Mentor Support Connection. Through Resource Facilitation, we have received significant feedback about the need for a mentorship program. Through our interactions, persons with brain injury and/or their loved ones have often expressed "If only I had someone to talk with that has experienced brain injury."

In an effort to expand the capacity of our Resource Facilitation program and fulfill an expressed need from the brain injury community, we developed the Peer/Mentor Support Connection. This program is modeled from a similar mentorship program through the Brain Injury Association of New Jersey.

The Peer/Mentor Support Connection matches trained volunteers (Mentors) with individuals living with a brain injury or their family members (Peers). For up to one year, mentors and peers connect weekly by phone or computer at mutually convenient times. Mentors volunteer to support their peers through the process of adjustment to brain injury, deal with the challenges

associated with brain injury and appreciate their accomplishments. Peers benefit from a confidential, consistent source of support, and gain encouragement and coping strategies.

Mentors are chosen from volunteer candidates who apply for the program either through the Association website or by simply calling the Brain Injury Association of Minnesota. Peers can access the program through similar means. Mentors are asked to commit to one year as a volunteer for the Brain Injury Association of Minnesota, and upon applying, they submit a background check, and are thoroughly interviewed and screened, including reference checks.

The process for the peer includes being referred to the program and completing a phone interview. A telephone interview is required for the Mentor and the Peer which assists the Association staff in identifying an appropriate match. A schedule is set by the Association in which the Peer and Mentor are contacted periodically after the match is made to establish how the Peer/Mentor relationship is progressing. These contacts allow for Peer/Mentor feedback to Association staff

of any concerns or issues that needs to be addressed. Staff assists Peers and Mentors in problem solving or identifying strategies that may be helpful during feedback. Mentors agree during the training process that building personal relationships are not an outcome of the Mentor program. Thus, the Association and the Mentor enter into a contract that there will be no face to face contact between peer and mentor. All interactions are through the telephone or email.

Currently, we have mentors from throughout Minnesota who are eagerly awaiting their first match with a peer. We are excited about the Peer/Mentor Support Connection and the support it can offer to residents of Minnesota who are impacted by brain injury. To participate in the Peer/Mentor Support Connection, or for more information contact the Brain Injury Association of Minnesota at 612-378-2742, or 1-800-669-6442.

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Just Jayne from page 10

way up her legs, on two patches of her arms, and on one thumb. Due to the numbness, Jayne has learned to interpret the different pressures in her head to determine when it is time to go to the bathroom or when it is time to eat.

While Jayne still stutters and her body occasionally freezes up, she no longer experiences dropping episodes. She has set up railings in her bathroom and on her front step, and sometimes she uses a walking stick; these tools help her get around without falling, and that helps her feel more independent.

Setting goals is a successful method Jayne uses to continually challenge and improve her abilities. "I like to set goals," she says. "When I set my mind to 'you have to do it' then I just do it. There are no ifs, ands or buts." Two significant goals that Jayne accomplished in 2005 were getting her driving certificate from the Courage Center and participating as a Stampeding Turtle in the Walk for Thought. Jayne created a walking program at home months in advance to prepare for the three mile walk around Lake Phalen.

"I joined yoga," says Jayne. "That was another goal. I never in

my life have stretched so much as that first time!" She enjoys both the exercise and the opportunity to get out of the house and visit with friends. She loves the outdoors, so mowing the lawn on her riding lawnmower and learning how to use the snowblower were other goals. She has discovered opportunities to get outside and help other people at the same time, like walking her sister-in-law's dog, Riley, and shoveling a path to the garage for her 90 year-old neighbor. She also has a reputation for making delicious tarts, and she has filled requests from friends and family for dozens of the treats.

Some day Jayne hopes to work her way back up to taking long walks and spending more time at her lake cabin. She would like to return to genealogy, one of her favorite past-times. She loved tracing family history so much she "could do it 24 hours a day." In fact, one of her proudest accomplishments was working with another relative to complete her father's genealogy book.

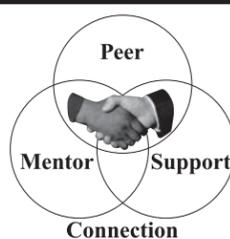
In addition to setting goals, Jayne's faith helps keep her positive. "There are people way worse off than I am," she says. "I have to look at each day making sure I am doing God's will and not just thinking of myself. There are a lot of people out

there who need help. I have a lot of time. If I can help you, I will try to help you."

Jayne has learned to take each day at a time and do her best for that day. She always felt that it was her calling to work with the public, and her own challenges have taught her to have more empathy and compassion for others.

This unassuming woman, who refers to herself as "Just Jayne,"

acknowledges that other people observe her life. The results of doing her best may be different today than they were before her accident, but different does not mean less. In fact, every time she overcomes the challenges of TBI to achieve a goal or help a neighbor, Jayne Sundeen is producing results that cannot be measured; she is letting her light shine as a source of encouragement and inspiration to others.



Want to be a mentor to someone affected by brain injury? Looking for support adjusting to life with a brain injury?

The Peer/Mentor Support Connection matches trained volunteers (mentors) with individuals with brain injury or their family members (peers).

Mentors can be an individual with a brain injury, a family member, partner or friend of an individual with a brain injury, or a caring community member.

Peers share challenges and accomplishments with their mentors to gain a better understanding of the process of adjustment to life with a brain injury.

To find out more...
Contact the Volunteer Program Associate
612-378-2742 in the metro area
1-800-669-6442 in greater Minnesota
www.braininjurymn.org