Condeluci and Kling featured at the Annual Conference

Dr. Al Condeluci

Dr. Al Condeluci is one of America's leading consultants on human services and community issues. He has worked as an attendant, caseworker, advocate, planner, program director and now, CEO of United Cerebral Palsy/Community Living Assistance and Support Services (UCP/CLASS) of Pittsburgh, since 1973. He's campaigned for a number of policy changes regarding people with disabilities, including the Americans with Disabilities Act of 1990. Each year, Dr. Condeluci speaks to national and international audiences, reaching some 15,000 people annually. He is called upon often to be a keynote speaker, trainer, and leader of board retreats.

Condeluci is also a professor at the University of Pittsburgh's School of Social Work and a Masters professor in Nonprofit Management at Robert Morris University. Three of his books, Interdependence (1991), Beyond Differences (1995), and Cultural Shifting (2001) are being used in more than 100 colleges and universities. Dr. Condeluci's latest book, Advocacy for Change: A Manual for Action, serves as a hands-on guide for community activists.

Kevin Kling

Kevin Kling is a local playwright, humorist, storyteller and stage performer. When he writes, the details are usually specific to the upper Midwest, but his work is more of a universal experience: full of childhood stories and topical observations. Kling has the ability to capture the many details of a moment in just a few words. As he explains it, “I have a small command of the English language so I try to make each word a hero.”

Xtreme Safety Fest returns to the Mall of America

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 third annual X-Treme Safety Fest at the Rotunda in the Mall of America.

This free event is scheduled for Saturday, April 23, 2005 and will feature Rich Wieber's Bicycle Stunt Show.

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.

Miss Great Plains, Holly Kostrzewski will make a special appearance at the event. Kostrzewski has dedicated her platform to brain injury awareness and prevention.

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 Bike Event on page 12
April 19 and May 17 - Brain Injury Basics 1
Confusion. Frustration. Sor-row. 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 the third Tuesday of February, May, August and November at the Association office at 34 13th Ave NE, Minneapolis, and in April and October in the St. Paul/East Metro area at the Luthern Church of Peace, 47 South Century Ave.
Class begins at 6:00 p.m. and runs until 8:30 p.m. Remaining dates for 2005 are August 16 and November 15.
To register, call 612-378-2742 or 1-800-669-6442 in greater Minnesota.

April 23: 3rd Annual Xtreme Safety Fest at the Mall of America
Save the date! The 3rd Annual Xtreme Safety Fest is an exciting family activity with live BMX demonstrations, safety information and free helmets. 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.
A special appearance will be made by Miss Great Plains, Holly Kostrezewski. For more information, read the story on page 1.
New this year - the Association will be taking its safety and injury prevention program on the road. You organization has the opportunity to have the Association bring free helmets and safety information to your community event. Watch the Association website for RFP information.

May 6-7: Family Retreat
Open to families with school aged children with brain injury, the family retreat offers recreational and educational activities in a rustic camp environment. For more information, view the news brief on page 4, or contact Anne Schuller at 612-378-2742.

May 20 & 21: 20th Annual State-wide Conference on Brain injury
Save the date! The 20th Annual Conference on Brain Injury will be held at the St. Cloud Civic Center in St. Cloud, Minn. Turn to page 1 for complete details!
June 21: Sports Concussion Conference
The Association will host “The Evaluation and Treatment of Concussion in Student-Athletes” at St. Cloud State University on June 21, 2005. This conference will provide a training opportunity for coaches, trainers, parents of athletes, and other interested persons to learn more about the topic of concussions. For complete details, turn to the new brief on page 4. Contact Anne Schuller, Education Coordinator, if you have questions at 612-378-2742 or annees@braininjurymn.org

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.

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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Editorial Policy
Headlines is published quarterly by the Brain Injury Association of Minne- sota. 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.
Happy Spring! It’s hard to believe that we are three months into 2005 already. Growth and activity at the Association is at an all-time high. This Spring brings our 3rd Annual Safety Fest at the Mall of America, a new Family Retreat, our Annual Statewide Conference on Brain Injury, and a new conference on Concussion in Student Athletes. Whew!

Couple all that with our growing Resource Facilitation Program, Multicultural Outreach Program and Case Management Services and we definitely have a lot to be proud of about the Brain Injury Association of Minnesota.

It’s times like these that we must step back as an organization of members, volunteers, board and staff and look at how we got here. Our services have grown to meet the diverse needs of persons with brain injury, to reach out to underserved communities, and to promote the only known cure for brain injury – prevention.

Our capacity to serve these needs is made possible through funding from membership, private donors, sponsorships, foundation grants and government grants. While no source is more important than others, we do rely heavily upon revenue from government grants. As members, consumers, professionals and supporters of the Association, you will be called upon in the coming weeks to show your support by contacting your legislators.

At the Federal level, the Health Resources and Services Administration (HRSA) TBI Program is at risk of being eliminated. HRSA provides the means for organizations like the Brain Injury Association of Minnesota to fund research and demonstration projects for persons with brain injury. For our organization, HRSA funded the pilot project that led to Resource Facilitation, the initial development our first Consumer Guide and the creation of Spanish materials just to name a few. Some of the many initiatives the Association is working on at the state level include supporting legislation to make seat belt use a primary law, Shaken Baby Syndrome prevention training for new parents before they leave the hospital, instituting a universal bike helmet law, and lifting the cap on waivered services for persons with TBI. Watch our website (and sign-up to be a citizen advocate while you’re at it) to track the progress on these issues.

While supporting our initiatives at the capital, it is equally important to support the Association at the most fundamental, grassroots basis, through your membership. When listening to Minnesota Public Radio recently during their membership drive, one of the announcers said “Many of you tune in everyday, but how many of you support us through your membership. You obviously believe in our programming and trust our abilities to deliver news if you tune in everyday. It’s time to demonstrate that belief and trust by becoming a member.”

I learned that only 12 percent of their regular listeners were also members. Only 12 percent!

I thought – we have so much to be proud of at the Brain Injury Association of Minnesota, we can certainly do better than that! Yes, the Association is here to serve all persons with brain injury, their families and professionals. Yes, you can still receive the newsletter without being a member. However, what better way can you demonstrate that you believe in our organization and its mission than becoming a member. Signing up is easy! Just turn to page 14, fill out the form and send it in to the Association with your payment. You can also sign up in person at one of our many activities this spring.

As you comb through the beautiful 2005 edition of the Consumer Guide when it comes out in April, while you are relaxing with your spouse and school age child at the family retreat, or as you laugh at the charming hometown humor of storyteller Kevin Kling at the Annual Conference in May, think about how your membership can only enhance what the Association offers to the Minnesota brain injury community.

**Membership demonstrates belief in Association and its mission**

**From the Chair**

**Nancy Carlson**

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**Perspective**

Message from the Board of Directors

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**Asking for help is not begging**

When to ask for help, when to accept help, and when to say ‘no’ to help. These are cross-roads we all faced with in the path of life.

The child within us would always like to get help. When I was very young I was watching a movie that was taking place in the 1930’s. A man’s family was hungry and cold, it was Christmas and there were no toys for the children. Help was offered and he turned it down. The narrator explained that he was too proud to accept charity.

I did not understand this. I reasoned that if you wanted something and it was offered to you, then you should take it. Issues can be so simple to a child. They can seem simple because a child does not have the experience of life that teaches how to balance living in society with being an individual, which teaches there are costs other than monetary that have to be considered.

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Association Offers Family Retreat

The Brain Injury Association of Minnesota will offer a family retreat at Camp Courage on May 6 - 7, 2005. The camping experience begins Friday evening and concludes mid-afternoon on Saturday. Three meals are included in the retreat. Families needn’t worry about “roughing it” – the retreat doesn’t require sleeping in tents. Camp Courage has lovely cabins, situated in a rustic environment. If you have a school aged child with a brain injury, this retreat is designed just for you. Families are welcome.

Camp Courage is a completely accessible facility. The retreat provides a structured, enriching personal and recreational experience. Watch Enews and the Association website for more details. For more information, contact Anne Schuller, Education Coordinator at annes@braininjurymn.org, or by phone at 612-378-2742; or Deb Williamson, State TBI Specialist via email at dchwilson@int287.k12.mn.us or by phone at 612-638-1532.

Summer Camp Options

Looking for some recreational opportunities this summer? The following is a partial list of local camps that cater to persons with disabilities. This list is not exhaustive, so for more information about camp options, check out Camp Resources at www.campsresource.com.

Camp Courage
Diane Casey 763-520-0504
www.campcourage.org

Friendship Ventures
952-852-0101 or 1-800-450-8376
www.friendshipventures.org

Wilderness Inquiry
612-676-9400 or 1-800-728-0719
www.wildernessinquiry.org

Camp Buckskin
952-930-3544 or summer 218-365-2180
www.campbuckskin.com

Camp New Hope
218-426-3560
www.campnewhopemn.org

Walk for Thought Chair Announced

Sarah Moelser
The Brain Injury Association of Minnesota is pleased to announce that Sarah Moelser has accepted the position of 2005 Walk for Thought Chairperson.

After three years of tremendous growth, the Walk faces new challenges and opportunities. Moelser’s corporate experience, including positions managing international clinical studies at Medtronic, Pfizer, and Ortho-McNeil, makes her an excellent individual to help manage the transition to an even larger and more complex event.

With more media attention, higher attendance, and increased corporate support, the Walk will benefit from the management abilities that Moelser will bring as a new chair. Moelser is a familiar presence around the Brain Injury Association of Minnesota, as she chaired the National Symposium Volunteer Committee and served on the Board of Directors for 3 years before stepping down in 2004. Moelser’s involvement with the Association, combined with her corporate experience and contacts, will help her as the event continues to evolve and grow.

We look forward to working with her and her committee on this very important and meaningful event.

The Brain Injury Association of Minnesota would also like to extend Sandra Smith and her committee members a profound appreciation for their role as the Walk for Thought Chairperson for the last 3 years. Under her direction, the Walk has grown exponentially since its inception and her tireless dedication and hard work was clearly evident in its success. Thank you Sandra!

This year’s walk is scheduled for October 1, 2005. If you have any questions on how you can participate as a Walk for Thought volunteer, please contact Ottar Schmitz or Kimberly Ferencik at (612) 378-2742.

Sports Concussion Conference

A visible threat or blow to the head can cause a concussion. There is no such thing as a minor concussion that you just shake off as if nothing has happened. Although not usually life threatening, a concussion can have serious effects, and healing takes time. A concussion does cause at least temporary loss of brain function. Bleeds in the brain, bruising, and swelling can occur. It is important to prevent a condition known as second impact syndrome. This occurs when a person experiences a second head trauma while still recovering from the first injury. What may seem like a minor bump to the head can cause devastating swelling in the brain, which may even be fatal. It is critical to get a doctor’s clearance before returning to contact sports.

More than 300,000 athletes sustain concussions each year, according to the Mayo Clinic. Saint Cloud State University has been tracking athletes who have sustained a concussion for the past three years. Neuropsychological testing has shown cognitive changes, especially for those athletes who have sustained more than one concussion.

The Association will co-sponsor a sports/concussion conference at St. Cloud State University on June 21, 2005. The conference will provide a training opportunity for coaches, trainers, parents of athletes, and other interested persons to learn more about the topic of concussions. Featured keynote speaker for the conference is Dr. Michael Collins. He is Assistant Director at the University of Pittsburgh Medical Center’s Sports Concussion Program, and a nationally renowned sports concussion clinician and researcher. For more information, contact Anne Schuller at annes@braininjurymn.org or via phone at 612-378-2742, or 1-800-669-6442 in greater Minnesota.

Resource Facilitation

The Resource Facilitation Program is a free support service through the Brain Injury Association of Minnesota. It provides support for Minnesotans to cope with the issues of living with a traumatic brain injury and help them transition back to work, school and their communities. This service does not replace any medical or rehabilitation follow-up that may be needed. The program is funded through a contract with the Minnesota Department of Health, making it possible for every hospital in the state to offer the program as a free service to their patients.

For more information, contact the Association at 612-378-2742 or 1-800-669-6442.

La Facilitación de Recursos

La Asociación de Lesión Cerebral de Minnesota Provee Ayuda por personas con lesión cerebral traumática. El programa de facilitación de recursos es un servicio de La Asociación de Lesión Cerebral de MN. Se provee ayuda y apoyo por la gente de minnesota quien esta viviendo con lesión cerebral, y con los temas de trabajo, escuela/ educación, y otras. Este servido no reemplaza atención médica o servicios de rehabilitación. El programa es para apoyar pacientes y sus familias, y también profesionales en lesión cerebral.

Este programa esta fondado por un contrato con el departamento de Salud de Minnesota. Por eso, cada hospital del estado puede ofrecer el programa gratis a sus pacientes.

Por personas con lesión cerebral, y sus familias, Facilitación de Recursos puede ayudar: responder a preguntas, resolver problemas, identificar servicios y recursos en su comunidad, educar miembros de familia, maestros, y empresarios sobre que significa vivir con lesión cerebral. Por personas con lesión cerebral, o sus familias quien quiere más información o servicios, contactanos.

Contacta La Asociación de Lesión Cerebral de Minnesota a 612-378-2742 o 1-800-669-6442. Para hablar con alguien en espanol, pide por Luisa.
New Multicultural Outreach Coordinator to Increase Scope of Program

Staff Report

The Brain Injury Association of Minnesota is thrilled to welcome Raye Black as the new Multicultural Outreach Coordinator. Black brings significant experience to the position. For the past eight years, Black has worked for Tubman Family Alliance, and recently with the Bloomington Public Schools.

She specializes in domestic violence, health program coordination, case management and nursing.

According to a report on TBI in Minnesota by the Minnesota Department of Health, “the burden of injury and violence in Minnesota is not equally shared.” The rate of TBI in African Americans and American Indians in Minnesota is four times the rest of the population. To address this epidemic, the Association has increased the scope of its successful Latino Outreach Program to provide assistance to all underserved communities. The focus of the Multicultural Outreach Program is to broaden awareness of brain injury in racially/ethnically diverse communities. This is achieved by working closely with existing cultural service organizations to provide education and support to professionals and community members about brain injury. The Multicultural Outreach Program is funded primarily by the Medtronic Foundation, and in part by the Minnesota Department of Health through Resource Facilitation.

“I really feel a passion about educating and promoting injury prevention in the community. I’m also very committed to raising awareness about brain injury and the fact that an organization like ours exists to help people affected by brain injury get the services they need – the services they deserve to live their lives fully and with dignity,” said Black.

Committed to reducing the incidence and severity of brain injuries, as well as supporting persons with brain injury, the Brain Injury Association of Minnesota works collaboratively to support the education needs of community organizations and clinics.

Consumer training includes Brain Injury Basics, Shaken Baby Syndrome prevention, and bike safety. A wide range of professional development opportunities exist. Specialized training tailored to the needs of professionals, spiritual leaders or consumers is also available. Contact Raye Black at 612-378-2742 for more information.

Leaders Needed for Advisory Committees

The Brain Injury Association of Minnesota is looking for leaders from communities of color to serve on the African American and American Indian Advisory Committees. Committee members will help guide the direction of the Multicultural Outreach program. For more information, and a detailed position description, contact Raye Black at 612-378-2742.

• Family Involvement
• Prevention Services
  • Emergency Services
    • Inpatient Trauma Services Coordination
      • Acute Inpatient Stabilization
      • Brain Injury Rehabilitation
      • Knapp Rehabilitation Center
    • Mild to Moderate TBI Clinic
    • Pediatric and Adult
    • Community Reintegration Referrals/Follow-up
  • Interdisciplinary Teams
  • Survivors Group
• Statewide Physicians Referral Network
• Community Education

(612) 873-3950   www.hcmc.org
The need to communicate and be understood is an essential desire of human nature. When people possess the cognitive ability, but lack the physical ability to effectively communicate, their overall quality of life is compromised. With technical advancement in assistive technology, there are numerous options to aid people that experience communication difficulties. The biggest challenge then becomes matching the best device to the individual person.

United Cerebral Palsy of Minnesota offers the Minnesota Assistive Technology Loan Network (MATLN) as an opportunity to test out communication devices. MATLN has over 75 different devices to choose from ranging from simple switches to more complicated devices that can interface with computers.

“We want people to make the most informed purchases possible. [After borrowing through MATLN,] they might find out that it is not the appropriate device for that individual. It really is in an effort to save the system money, save the individual from reaching a point of frustration, and to make sure that the individual gets the most appropriate device for their circumstances,” said Jo Ann Erbes, Executive Director for United Cerebral Palsy of Minnesota (UCPM).

It’s about finding the right fit. According to Erbes, 51% of the people that borrow a piece of assistive technology equipment don’t end up buy that device. In an age where every medical assistance and insurance dollar counts, MATLN becomes a cost-effective method of evaluating and finding the best communication tool for the individual.

There are other benefits for utilizing MATLN. “Through the evaluation process, an individual’s cognitive and physical abilities to use and understand a device are determined,” said Erbes.

Access to all this equipment is great, but how do you use it? “We provide training for professionals, family members, whomever on how to use the device, the inner workings of and how to program the device,” said Erbes. Training is provided on equipment from three different vendors: DynaVox, Prentke Romich and Assistive Technology.

To encourage the use of communication devices, UCPM also hosts the annual “Zippity Zoo Day” at Como Park. This year’s event is June 17. Anybody who uses a communication device is encouraged to come out and socialize, have fun and learn how to use assistive technology equipment.

Equipment through MATLN is available to anyone with a communication disability regardless or age or type of disability. Devices are available statewide. The loan period is 30 days at no cost to the individual, other than the return postage. Typical postage costs run under $20. Borrowers can extend the loan period if a formal request for extension is sent to UCPM, and if there is not a waiting list for the equipment. Equipment loans kept for more than 30 days without a formal extension granted are subject to late fees. All equipment must be returned in the same working order as it was received.

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The speech language pathologist, occupational therapist or other communication specialist who is working with the person needing the device must make requests for loans through MATLN. To borrow equipment, mail or fax requests on company letterhead to 651-646-3045. The following information must be included: age, gender, race, primary diagnosis, county of residence and specific device requested. Requests will either be filled or added to the waiting list if the particular device is already on loan. Several devices do have waiting lists – particularly for new equipment that has recently come on the market.

MATLN does accept equipment donations. For more information on the MATLN program, call 651-646-7588, or 1-800-328-4827, ext. 1437.
Listen to Me!  How to Talk to a Person with a Speech Impairment

By Carrie Smoot

The bus driver had just dropped off a passenger at his house. The young man, about 15, was on his first summer job doing office work. He walked with difficulty, and spoke with a great deal of effort. It often took a great deal of time to understand him. Being shy, I didn’t know what to say, except hello. We didn’t know each other well.

A woman on the bus turned to me. “What good is he?” she asked after he had gotten off the bus. I had already told her a little of what my secretarial job was like. She was very surprised that anyone with a disability could work. Like that young man, I have cerebral palsy. I use a wheelchair, though, and have no speech problems.

“What good is he?” she repeated, as I remained silent. “He can’t answer the phone, and no one can understand him. Why did they pick him to work in an office?”

I recall saying “At least he’s trying.” What a lame statement! There were so many things I could have said.

This incident happened several years ago. The other day at work, my phone rang, bringing back that memory. This caller also had severe speech difficulties. He struggled to get his message across.

The call also revived memories of the frustration and impatience I witnessed from a few people whenever they had to deal with someone who has speech difficulties. I promised myself that I would never respond to anyone in that way.

For the record, my caller and I communicated very well. He received the information he needed, and I felt like I had helped someone. Here’s how I handled the situation:

My voice had a smile in it. Let’s face it; no one enjoys talking to a harried person or to a grump. If a smile begins in your voice, it usually spreads over your whole outlook and to the person on the other end of the line. Don’t forget to introduce yourself and offer assistance.

I developed good focus. When the call came in, I was in the middle of a project, but I dropped everything to listen. Every once in a while, I try to be Superwoman, working on two things at a time. Guess what? It doesn’t work. A caller seeking assistance is the first priority. When you are dealing with someone who has a speech difficulty, it is imperative that you give your full attention to the conversation. This lets the caller know you are interested, and helps you follow the person’s words. If you are actually thinking about other work, meetings, and a myriad of other things, you won’t hear.

I repeated what I thought he said as we went along. Doing this helps to assume that the two of you are understanding each other. This practice slows the conversation down a bit and lessens nervousness for the person answering the phone, who may not have met this situation before. Don’t be afraid to ask questions to find out what the person needs. If you can supply any information, do so. With my caller, I read his address listing to him to make sure it was current.

If you don’t understand, be honest. People who have speech difficulties know how to put others at ease. Don’t be nervous about making mistakes. During our conversation, I couldn’t catch this man’s name no matter how hard I tried. “This guy must think I’m an idiot for not getting his name right!” I berated myself inwardly. Finally, I just had to say, “I’m sorry, but I’m not hearing your name properly. May we try again please?”

He replied, “Sure, let me spell it for you.” This time I understood. I verified what he needed and offered my assistance in the future. He thanked me, we exchanged pleasantries, and then hung up.

Follow up with a letter or note. After I prepared his package of materials, I enclosed a letter summarizing our conversation and any special instructions or information. Good communication is achievable. All it takes is patience and understanding.

Smoot is a graduate of St. Andrews Presbyterian College in Laurinburg, North Carolina, who has cerebral palsy.
Helmet saves Minnesota teen in bike crash

By Sharon Rolenc

Eric Whaylen loves jazz music, and plays his trombone any chance he gets. This self-described band geek is what his step-mother Michelle calls a “rule-follower.” Michelle is an emergency flight nurse and her husband Tim a medical emergency helicopter pilot, so both understand the fundamental importance of safety including the use of seat belts, car seats, and bike helmets.

“We require our children to use proper safety gear. Some rules are easier to enforce than others, and just like any other household, you have the rule followers and the rule breakers. Fortunately, for Eric and us, Eric is one of the rule followers,” said Michelle.

“Well, not exactly,” says Eric. As far as wearing a bike helmet, he admits in the past to sporadic use, donning the helmet only when in his father’s presence. But Eric is extremely thankful that he was on his way to visit his father that summer day last June or things could have turned out very differently.

“My dad had bought me the helmet, and because I was going to see him, I wore it, because I wanted to be safe for him,” he said.

Wanting to visit his father at work in Superior, Eric decided to bike across the bay from their home in Duluth. Although it had stopped raining, a heavy mist had collected on the ground. Like much of the terrain in Duluth, Eric’s neighborhood has steep hills and the occasional hairpin curve. Before he realized it, his bike gained speed on the rain slick street.

“I think I went getting pretty fast at that point, then the ground levels off pretty fast, and then there are some railroad tracks. I think I remember knowing that something bad was going to happen,” said Eric.

He hit the railroad tracks at the wrong angle, and flew over the handlebars. Eric’s head hit the ground hard enough to crack his helmet and the occasional hairpin curve. Before he realized it, his bike gained speed on the rain slick street.

“Eric is the oldest boy in the family,” Michelle said. “He kept repeating the same thing as people with fresh head injuries often do, and freaking his dad out. Even though his dad, who for the last 12 years has worked medical emergency helicopters and has seen people be confused, it is a whole different thing when it happens to your own child,” said Michelle.

Eric’s crash reinforced the importance of safety and injury prevention with his five siblings. “It was certainly a wake up call to the non-compliant members of the family. I think the impression it made to the rest of the family is that you can be doing what you consider a every day type activity and something could happen to completely change your life. Our other teen boy, the oldest boy in the family who’s driving now, kept saying ‘I can’t believe Eric’s so sick.’ I said to him, yeah, now imagine what you can do with that car,” said Michelle.

For about six weeks after the crash, Eric experienced some subtle changes in memory and mental slowing. Michelle is thankful for her years of experience in the medical profession, and is concerned for parents who do not have the same awareness about the serious consequences of even a mild injury. Because of their knowledge of brain injury, Eric’s parents were prepared to have him reassessed due to his on-going struggles.

“I think it’s easy to think oh he’s just being a teen, he’ll snap out of it. But for neurological things, those subtle changes, that little slowdown could have been a sign of increased brain pressure, it could have been anything. It’s important not to hide your gut feelings as a parent. You know your kids better than anyone. If they just aren’t right, especially after an injury you can’t blow it off as situational. You have to first rule out the physical stuff,” said Michelle.

Luckily, as they were about to make another follow-up appointment, Eric’s symptoms cleared up.

So how often does Eric wear his helmet now? “Absolutely all of the time! I learned that you can get hurt a lot worse than I thought you could. It’s really easy to think that you won’t crash because most of the time you usually don’t. But when it does happen, you can hurt yourself pretty bad,” he said.

Eric Whaylen

After getting neighbors to watch her younger children, Michelle rushed to the scene. “He didn’t recognize me and I knew that he was critically injured.” The EMS personnel at the scene asked her if she wanted to take him in to the hospital. “I said, no he needs an ambulance. I could see right away that he needed care on the way to the hospital,” she said.

Eric sustained a level three (out of a scale of one to four) concussion, and damaged his spleen from the impact of the handlebars during the crash. The neurosurgeon at the hospital said that had Eric not worn his helmet, he would have either died or been injured severely and would have most likely spent the remainder of his life in a nursing home. As it was, he spent two days in intensive care and another two days in the hospital before going home.

Throughout his hospital visit, Eric’s family was pretty worried about his outcome. “Apparently I got pretty goofy, but I don’t remember that part at all,” said Eric.

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Protect, Inspect, and Respect: Three Easy Rules to Biking Safety

By Lexa Hoffner

It won’t be long before tulips begin to spike out of the ground, drain sewers ring with the music of spring-time run-off, and bicycles emerge from their seasonal banishment in garages all over Minnesota.

Whether you bike for transportation, personal enjoyment, exercise, or competition, the first thing you should think about this season is your safety. There is an easy rule of three when it comes to bike safety. Protect your head by wearing a helmet. Inspect your bike and perform routine maintenance, and Respect others by knowing and obeying traffic laws.

Protect Your Head

Did you know that 75% of injuries and deaths from bike-riding involve a blow to the head? A crash can happen anytime, anywhere, so even on short rides protect your head with an approved bike helmet.

The highest level of testing standards comes from the Snell Memorial Foundation. If a helmet meets Snell standards, it will sport a Snell certification sticker.

Since 1999, all helmets have been inspected by the Consumer Product Safety Commission (CPSC), and any helmet you purchase from a local retailer or on-line store at least meets their standards. The same cannot be said about hand-me-down helmets, or helmets you purchase from garage sales. This is not an area to try to save a few bucks.

In fact, manufacturers recommend replacing your helmet after three to five years because even normal use can compromise its ability to protect. Immediately replace any helmet that has been involved in a crash. The foam inside the helmet is designed for one-time use. Even if the helmet looks fine on the outside, it may be useless on the inside.

After purchasing the helmet, realize that it will do you no good if used incorrectly. First ensure that your helmet fits properly. It should sit levelly on top of your head and cover the top of your forehead. The helmet should not move when you shake your head.

Use your bike helmet for biking and in-line skating only. It is not recommended to use a bike helmet for snowboarding. Also do not keep your helmet on while doing other things. There have been reported injuries and deaths by strangulation when children have not removed their helmets before playing on playground equipment.

Inspect Your Bike

Keeping your bike well tuned might prevent collisions in the first place. Brake failure and tire blowouts can lead to some pretty nasty crashes, but they don’t need to be part of your riding experience.

Before you ride, look at all of the exposed parts on your bike. Ensure the chain is secure, taut and properly lubricated. If your brake cables look frayed, loose, or extremely tight, bring your bike into a shop for an expert inspection.

Put air in your tires before every trip. This may seem like a pain, but unlike cars, bikes have a very narrow range of proper inflation. Too little or too much air can cause damage to your rims, or worse, cause a blowout that could send you out of control. The proper pressure is printed on the side wall of your tire.

Just as your helmet must fit, so must your bike. Part of maintaining your bike is adjusting it to fit your body. If your seat is too high or too low you won’t be able to control your bike as well as when the seat is properly aligned.

Respect Traffic Laws

As a biker, you may not contribute to smog, but you are a part of traffic and most of the laws for motorized vehicles apply to bikes too. You do have to stop for a red light and for stop signs. You must travel on the right hand side of the road.

Contrary to some information, it is not safer to ride against traffic. You cannot make a left hand turn from the right lane. If you operate a bike at night it must have a white head lamp and a rear red reflector.

Although you must follow the traffic rules, remember that most car drivers still do not view bikes as another vehicle and are not used to sharing the road with cyclists. Before riding out in front of a car, it is a good idea to get eye contact with the driver. Do not assume that the driver sees you. Be especially mindful of intersections and cars in turn lanes. Your light may be green and you may have the right of way, but it is likely that the driver does not see you and will turn in front of you.

Please use common sense when riding your bike. Bikes are made for one person unless it is a tandem bike, or has an attached baby seat. Putting a friend on your handle bars can obstruct your view, cause your friend’s foot or clothing to catch in the front spokes, and make your bike incredibly hard to balance and control. Also, do not cling to a motor vehicle while riding a bike. You cannot react fast enough to unexpected movement from the car. You also increase the likelihood that other drivers will not see you.

So, as the days get warmer and longer and you can no longer ignore that itchy feeling calling you to your bike, take a minute to secure your helmet, pump up your tires and remember some basic traffic laws. Protect, Inspect, and Respect. These rules are simple and quick to follow and they can ensure that you can get on your bike tomorrow.
At Bethesda, we reconnect patients to their lives through science and sensitivity. With devoted, one-on-one care; the latest advancements in technology; and a holistic approach to healing, we help body and soul work together to achieve greater independence.

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Keeping up to date with public policy

Proposed Federal Budget Threatens the Traumatic Brain Injury Act

By Shannon Robins
Public Policy Director

There are many programs, services, and supports that people with a disability due to brain injury use to lead successful, quality lives. Decisions made at the state level, or even the county level, are rooted in federal policy. Many of the programs and the funding that exist in our state originate at the Federal. The state then has to work within the guidelines laid out by the federal government to implement the law. The federal government uses a process very similar to the state to make these decisions.

The President, like the Governor, looks at budget projections for the upcoming biennium and develops his proposal based off of those projections that address the various different Departments responsible for administering existing federal programs. The budget proposal is then presented to Congress, much like it is to our state legislature. Legislators use the proposal as a sort of guide to making their decisions. Although the Brain Injury Association of Minnesota concentrates at the state and county policy levels; we work with our national organization, Brain Injury Association of America, to make sure that the Federal programs exist to support the state’s efforts.

The Traumatic Brain Injury (TBI) Act (P.L. 104-166) is the only Federal law that specifically addresses the issues faced by people with TBI and their families. The program includes planning, implementation and post demonstration activities. The program is intended to provide information and referrals, individual and family advocacy, legal representation and assistance in self-advocacy.

Unfortunately, the budget proposes the complete elimination of the HRSA TBI Program as described above.

“The Brain Injury Association of America is cautiously optimistic that Congress will restore funding for HRSA’s TBI Program. To that end, we are working closely with our partners at the National Association of State Head Injury Administrators, the National Association of Protection and Advocacy Systems, the National Brain Injury Research, Treatment and Training Foundation, with the Congressional Brain Injury Task Force and others,” said Susan H. Connors, President and CEO of the Brain Injury Association of America.

Connors added that in the coming weeks and months, the national Association will call on advocates to urge Members of Congress to reauthorize the TBI Act and appropriate funds to federal agencies to carryout the law’s purpose.

The Brain Injury Association of Minnesota is committed to keeping its Citizen Advocates informed as we move forward in what promises to be a tough but winnable fight!

Background research for this story was provided by the Brain Injury Association of America’s factsheet “Support Adequate Funding of the Traumatic Brain Injury Act in FY 2005.”

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

*B National Institute on Disability and Rehabilitation Research

Helping patients rebuild their lives

Also appearing at the event is Eric Whaylen, a high school student from Duluth. Whaylen will share the story of how he experienced a level three concussion when biking last year. According to his neurosurgeon, had he not worn his helmet, he would likely have died or been under 24 hour nursing care for life. Read more about his story on page 8.

Bike Event from page 1

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.

Last year, over 1,000 people attended this exciting and educational event. By testing their knowledge of safety and injury prevention, event participants are eligible to receive a free helmet while supplies last. In addition, there will also be prize give-aways and helmet fittings.

The Brain Injury Association of Minnesota is looking for volunteers to help out at the event – particularly teens and their families. For more information, contact Kimberly Ferencik at 612-378-2742.

Rich Wieber demonstrates “flat-landing.” His stunt team will make an appearance at this year’s Extreme Safety Fest.

Miss Great Plains, Holly Kostrzewski
Amy’s Cardinals Nest Offers Club Atmosphere for Youth

By Sharon Rolenc

Edward Graham blames his daughter Amy’s selective memory. A transplant from Philadelphia, Graham was simply trying to watch the Penn State basketball game a couple of years ago when the discussion started something like this:

Amy: Hey, I want to have my friends over.

Graham: You know you can’t have your friends over right now.

Amy: Well…I want to go dancing.

Graham: Amy! Let me watch the game please.

Amy: I need a club to go to, where I can go and have a good time. I want to dance.

Graham: Amy, if you will just leave me alone and let me watch the game, I will get you a club.

Amy never forgot the conversation, nor did she let her father forget.

Two years later, Amy’s Cardinals Nest recently celebrated their first anniversary. A dance “club” for persons with disabilities, Amy’s Cardinals Nest is rapidly becoming a hot spot, attracting an average of 200 people every Monday night at its current home at the American Legion Post 334 in Coon Rapids.

Spend just a few minutes listening to Graham talk, and it is clear that Amy’s Cardinals Nest is a product of love. Having survived a bout of cancer, a round of surgery and intense rehabilitation on his leg, and living now with multiple sclerosis, Graham is driven to give something special to the community, and to his daughter Amy.

“It’s a wonderful club and I’m very glad that the man upstairs would have me to do this. I’m thankful to be here to give back the blessings that the lord has given me, because you can’t keep it unless you give it away,” said Graham.

In conducting the research needed to develop Amy’s Cardinals Nest, Graham met with special education personnel from the Coon Rapids School District, as well as countless youth with disabilities and their families. He found out that 97 percent of students with disabilities did not attend their high school proms.

“They don’t go to their proms or out to clubs to dance because of the scrutiny they get if they are in a wheelchair or if they have another disability and the fear that they will be looked at like the outsiders,” said Graham.

The Cardinal is the mascot of Coon Rapids High School, and

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Volunteer Program Provides Valuable Experience for Persons with Brain Injury

By Emmie Drews and Sharon Rolenc

The Brain Injury Association of Minnesota’s Volunteer Program is growing by leaps and bounds. Since its inception in January 2004, volunteers have clocked over 3,000 hours of service in its first year. The volunteer program has also produced internship opportunities that have provided for-credit experiential learning for half a dozen college students.

After two months in a coma and several months of rehabilitation following her brain injury, Sue Larsen decided to volunteer at the Association to “keep her brain busy” and to help her get back in the swing of things as she returned home. “My daughter said that you really helped her when she needed it during my recovery, so I wanted to give something back,” she said.

Volunteer opportunities have become a wonderful tool in providing valuable work experience in a safe environment for persons with brain injury.

Often people are left with unanswered questions about how to return to work after sustaining a brain injury. Sometimes the nature of their injury makes it impossible for them to return to the same profession. Feelings of a loss of identity, confusion, isolation and grief can make reassessing career goals after a brain injury a significant challenge.

Physical limitations after a brain injury can also confound the process of returning to the work force. “The Association offers a nurturing, supportive environment where a person with brain injury can ‘test the waters’ of work, and gain the valuable skills and insight needed to forge a new path in life,” said Kimberly Ferencik, Volunteer Coordinator.

“The Brain Injury Association has a wonderful volunteer opportunity for our consumers who need some work experience. I have a client working as a volunteer receptionist there who is just thrilled with her experience. She does not have the work history she needed to be part time employed, but with the support of a wonderful and caring staff she is gaining those skills and could not be happier. It has truly been a great experience. Volunteer opportunities like this are hard to find,” said Diane Acord, Vocational Rehabilitation Placement Coordinator for the State of Minnesota Rehabilitation Services Minnesota WorkForce Center.

Volunteers are referred to the Association by a number of agencies. Agencies that provide employment supports are Vocational Rehabilitation, Rise, Inc., Hired, Access to Employment, Vision Loss Resources, and Kaposis. Many of these volunteers will be able to use the skills acquired at the Association to find employment further down the line.

Volunteers are also referred to the Association by MN Corps, who provides a day program for persons with disabilities. Volunteers have also come to the Association through the Twin Cities Volunteer Resource Center, Volunteer Match, and other online venues, as well as from the Association’s newsletters.

Interns gain valuable experience at the Association while receiving credit from their respective colleges. “I really enjoyed the friendly working environment. The work itself was challenging, and I was able to utilize and hone my skills,” said Elizabeth Sowden, Junior at Sarah Lawrence College, Bronxville, NY. Internships are available in a variety of areas including communications, education, and public policy.

Volunteer work in all programs, with every staff member, serving people across the state, increasing awareness of brain injury and the Association. Volunteers build skills while giving back to the community and feel good about what they’re doing. Volunteers are valued, supported and understand their role in achieving the mission of the Association.

Currently, the Association is in need of working professionals to join various committees to support the mission and strategic planning of the organization. Professionals are needed for communications, finance, resource development, quality assurance and technology. Committee descriptions can be found at www.braininjurymn.org/vo.cfm

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‘I have a client working as a volunteer receptionist there who is just thrilled with her experience. Volunteer opportunities like this are hard to find.’

- Diane Acord, Vocational Rehabilitation Placement Coordinator
RESOURCE FACILITATION
Helping You Navigate Life After Brain Injury

When facing the unknown after brain injury, you have somewhere to turn. The Brain Injury Association of Minnesota can help you through Resource Facilitation - a free service for persons with brain injury and their loved ones.

Benefits to consumers:
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- Our Resource Facilitators are well-versed in community resources unique to your region of the state. They can help you navigate the system.
- This consumer driven program allows you to determine the level of support needed. Call your Resource Facilitator when questions arise or discontinue service at any time.
- Consumers are able to refer themselves to the program.

Benefits to professionals:
- Save time and provide support to your discharge planners, nurses, social workers and others involved with the discharge process.
- Provide quality customer service to your consumers and serve as a positive indicator of consumer experience.
- Support consumers after they leave the hospital to cope with the issues of living with a brain injury.

This service does not replace any medical or rehabilitation follow-up that may be needed, but is intended to provide on-going support for consumers and their families.

Want more information?
Contact the Brain Injury Association of Minnesota at 612-378-2742, toll free at 1-800-669-6442 or visit our website at www.braininjurymn.org.

A Minnesota native and graduate of Gustavus Adolphus College’s Theatre Program, Kling has been awarded numerous prestigious arts grants and fellowships including The National Endowment for the Arts, The McKnight Foundation, The Minnesota State Arts Board, The Bush Foundation and The Jerome Foundation. A central figure in the Minneapolis Theatre community, Kling has written over a dozen plays and adaptations. Kling is a frequent storyteller on National Public Radio’s “All Things Considered,” and has addressed disability issues in many of his creative endeavors.

Conference from page 1

A limited number of sponsorship and exhibiting opportunities are still available. For more information, call Ottar at 612-378-2742 or email ottars@braininjurymn.org.