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The Messenger

News and Information from Mayo Clinic Traumatic Brain Injury Model System Center | August 2015

http://www.mayo.edu/tbims

The Bona Fide Story of Heather Sharpe

Nov 23, 2008. *T-boned at highway speed on Highway 52 in Cannon Falls, MN and knocked out. Airlifted to Mayo Clinic in Rochester. Diagnosed with a concussion, shattered collar bone, and fractured pelvis. Spent 8 days in the hospital. Remained off work as a pilot for a year.*

Oct 31, 2010. *While clearing trees at her home, struck by a 40 foot falling tree. The same EMT arrived on the scene, another helicopter ride to Mayo Clinic. Sustained a dozen spinal fractures, a severe TBI requiring brain surgery followed by an induced coma and placement of a trach and feeding tube. Spent 32 days in the hospital including a stay on the rehabilitation unit. Not yet flying as a pilot 4½ years later.*

Two accidents in two years. Two freak accidents in two years. Two traumatic brain injuries in two years. Welcome to the bona fide story of Heather Sharp.

For many reasons, recovering from a second brain injury can be slower and more frustrating, arduous, and complex. "I recovered very well after the first accident," says Heather. "I was not aware until just now that the second one is harder. Mayo probably told me but I didn't process that at the time. At the hospital, Dr. Bergquist (her Neuropsychologist) came in to talk to me because I wasn't "getting it". He said, "The first was a 2. This is a 10. This is much worse."

How did she do it, find something within her to endure all that goes along with trying to recover twice in order to regain her beloved roles in life as a parent to two young sons, wife to Jack, friend to many, horse lover and rider, and pilot? She did it because she persevered, in both traditional and creative ways. She also discovered the very critical roles attitude, patience, humor, perspective, hope and faith played in her recovery. And, she started writing…and hasn't stopped. In fact, Heather Sharp the author is in the midst of writing her third book and first screenplay.

Sit back, relax, and enjoy these enlightening, touching, and witty musings from Heather.

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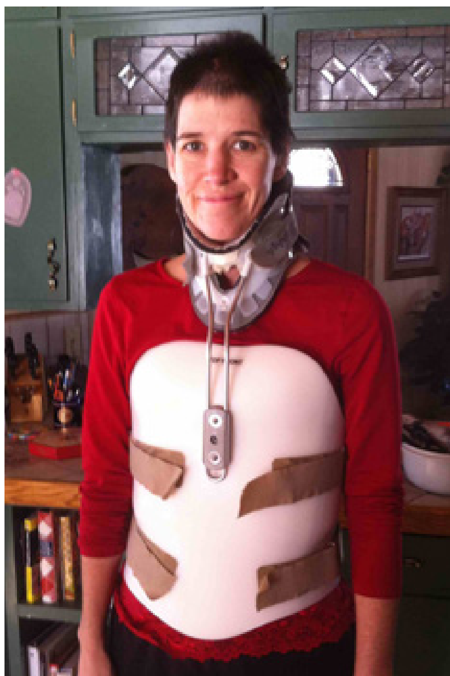

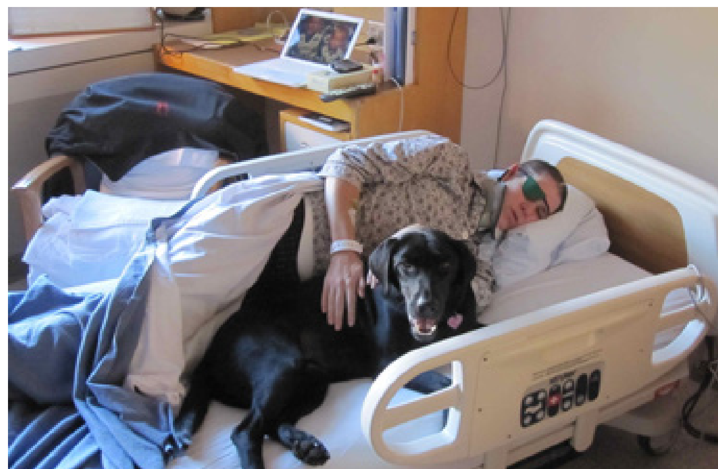

On attitude and heart

When people experience a tragedy, they often say, "The timing of this could not be worse." As if there is a good time for a disaster? As if you would say, "Yes, I have room for cancer in between my kid graduating and moving my parents into assisted living. I could fit it in." Or, "Sure, I have loads of time for a traumatic event. I will just put my job on hold. They don't really need me anyway. My life isn't built around that income. No problem." Let's face it, there is no good time. You would not say yes to this. It was not invited in. Although we would like to, we can't go back. We can't erase and re-record. I got T-boned and then a tree fell on my head. That's not going to change. We can admit, "Yes, this is the pits." But am I going to give this thing (whatever it is) power over my spirit? My emotions? My attitude? Oh, I don't think so. I feel sorry for the disaster or the illness. It has no idea what it signed up for. You seemed like such a nice, mild-mannered person and now it is in your life. You have to deal with it and, more importantly, IT has to deal with YOU.

If you have heart, use it. I needed a lot of it to become a female pilot. I did not stop until I got what I wanted. I was a nice person, just determined. After the tree fell on me, I used that same skill. This time I wasn't going to fly jets, I was going to get better. I recently talked to a guy with terminal cancer and the cancer was winning.

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"You seemed like such a nice, mild-mannered person and now it is in your life. You have to deal with it and, more importantly, IT has to deal with YOU."

I said, "Well, what did you do before all of this?" After a while he said, "I was an Eagle Scout." "Really? I bet that was hard." He said, "It was VERY hard." "So, that's good news! You know what to do, you still have the skills, just dust them off and apply them to this target. Cancer is your new bull's-eye." This guy was not a wimp. He still had terminal cancer but after that he was in control.

On patience and persistence

Society tells me I deserve everything quickly. We are used to instant results. We want it our way and we want it fast. I use the drive-thru because I don't want to wait. I text because the phone takes too long. My progress was dramatic the first few months but it tapered off. It's not until I look back and see how bad it was that I realize I am still making a recovery. I jot down assessments of where I am and date them so I don't forget. They say a frog won't jump out of boiling water if you turn the heat up slowly as he doesn't notice small changes. Yet, if you put him in hot water abruptly, he will jump right out. Sixteen months post-accident I went walking with a friend. I could listen and walk—no problem—but when I wanted to talk I had to stop. No multi-tasking for me! Twenty-one months post-accident, I went walking with my friend and I could walk and talk. That's a big improvement but it didn't happen overnight. I am like a frog, day to day I don't notice, when I look back I see big changes.

On recovery

I imagined I would always be on an upward trend. I anticipated my rate of change would be steady. In reality it has been a roller coaster. I do really well and then have downturns. But, each peak is higher than the last and each valley not

as low. When I am in the trough, I wait and have faith that I will climb the hill again. At first I was upset and thought, “Dang it! I was doing so well and now I am worse! What the heck!?!?” What I think happens, is when I am doing well I tend to do too much and overtax myself. My advice is don’t hold back but know that after an upswing you might have a downturn indicating you need time to regroup. At 4 1/2 years post-accident the roller coaster is starting to dampen out.

On humor and personality

Before the accident I had a quick sense of humor. I was lightning fast. My husband said this was one of the most dramatic shifts in my personality. Right after the accident I couldn’t comprehend sarcasm. Funny things were happening around me but I was not part of it. My brain was so busy dealing with the basics it didn’t have room for comedy or laughter. It was a milestone the first time I laughed. We were praying at the table, it was a somber and thoughtful moment, and my young son couldn’t hold it in anymore…he lifted his rump and let it rip and the chair vibrated. I cracked up. “I can’t believe such a big noise came from such a little person!” Along with humor, the Type A I had always been started to reappear. But, I realized my perception might be tainted. My brain was telling me, “You are right. There is nothing wrong with your sense of reality.” But also, “Hold on, you bumped your head, you are taking lots of drugs”. At follow up appointments the doctors would ask me questions then Jack would offer his two-cents’ worth. I would say, “Really? That’s not how I remember it.” The doctor laughed and said, “I have it written down, last time Jack said, ‘You were a pit bull on steroids.’” I wrinkled my nose, “Really?” I guess I knew it was not my fault. I was goofy because of the meds or the TBI. I shrugged my shoulders a lot and said, “Humph, probably.” One doctor told me later my willingness to accept someone else’s perspective was a BIG step in my recovery. I asked Jack the most valuable thing he heard. He said an ICU nurse told him, “She may say crazy stuff. She might blame you. She might be angry this happened. Who knows what she is going to say. You need to be like the Teflon Man. Let it slide right off. Don’t take things personally.” A steady sense of humor and an eye on the horizon helped both Jack and I cope.

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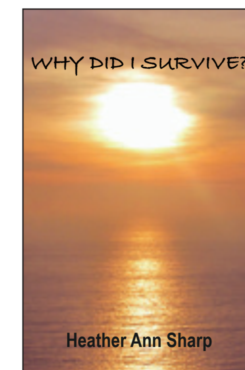
On faith and the power of prayer

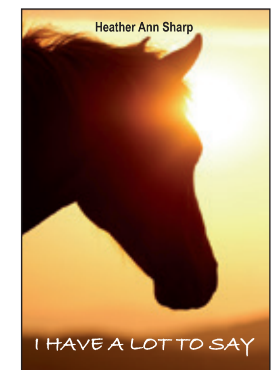
In the first accident I was T-boned by a Catholic Priest; let me tell you it is good to be hit by the Catholic Church because you have people you don’t even know praying for you. Afterwards, I had an epiphany—it’s not about the horizontal; it’s about the vertical. It really doesn’t matter if you know the person. Our church bulletin has a prayer list. It doesn’t matter that those saying the prayers haven’t met the person; it is the fact that they are praying that matters. Let’s say Marian is having surgery in California and through email the name and location gets mixed up. Bob, let’s say, is praying for Marian from Tennessee. Well, God knows whom Bob is praying for. God knows what’s in Bob’s heart. It doesn’t matter if Bob got the specifics correct or if he even knows the person. The fact that he has a relationship with God—THAT is what is important.

On the healthcare team and hope

There is a really fine line between being hopeful and being a realist. The staff did a great job balancing the two. Jack wanted answers about the future from my doctors. Jack wanted to know if I would fly again. The doctor never said if I would or if I wouldn’t. Jack would ask, “Is she going to get back to her old self?” The doctor would not predict or guarantee anything. He would say, “The goal is full recovery; that’s what we are aiming for. To get there, THIS is what she needs to do TODAY.” I just kept going along, one foot in front of the other. No one put any limits on me. No one told me about any bell curve. I figured I was supposed to get better. Hope is very important. Hope can alter the brain and the brain can alter the body. That makes sense to me. I got the impression that I was supposed to recover 100 percent because no one told me differently.

There’s more where this came from. You can access Heather’s books (*Why Did I Survive* and *I Have A Lot To Say*) at amazon.com.





> “I imagined I would always be on an upward trend. I anticipated my rate of change would be steady. In reality it has been a roller coaster. I do really well and then have downturns. But, each peak is higher than the last and each valley not as low. When I am in the trough, I wait and have faith that I will climb the hill again.”

Department of Defense (DoD) Alzheimer's Research Program Convergence Science Research Award

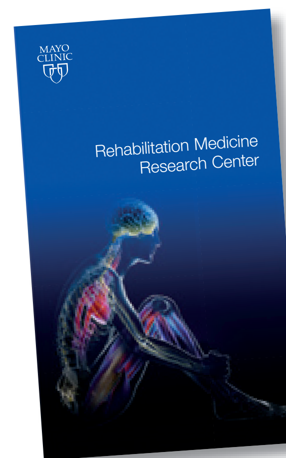
Allen Brown, MD and Michelle Mielke, PhD received a DoD award for a project entitled "Understanding the connection between traumatic brain injury and Alzheimer's disease: a population-based medical record review analysis".

It seems true that some people, like boxers, are more likely to develop Parkinson's disease after being repeatedly knocked out or taking punches to the head. But not all boxers appear to have that risk. And it is well known that TBI can cause thinking problems right after the injury. Some research has shown that a history of TBI can increase the risk for developing thinking problems (like dementia) later in life that they otherwise would not have developed, while other studies have shown no such risk. The reason for this disagreement most likely relates to the many different ways researchers have defined TBI and other conditions, the varied populations chosen for study, and the many different groups used for comparison. People in military and civilian life are at greatest risk for milder TBI and this group is not commonly represented in this research. The best and most accurate way to find out whether having a TBI increases risk for developing conditions like Alzheimer's disease, Parkinson's disease, or other age-related thinking problems, is to identify a large group of individuals within a defined population (for instance, in an entire county) who we know had a TBI by looking in their medical record with their consent. That allows Mayo to collect a sample of individuals that represents the population of that county (all ages and both sexes), determine how severe the TBI was (mild, moderate, or severe), and count how many injuries an individual had. When a group of individuals with TBI that represents the population is identified, each of those individuals can be matched to like member of the population (same age and sex), but who did not have a TBI. By following both groups over time and reviewing their medical records to determine which people in either group develops Alzheimer's disease or one of the other related conditions, it can be determined with confidence whether TBI increases the risk for developing one of those conditions.

Research that requires reviewing thousands of medical records is extremely difficult and time-consuming. Mayo Clinic established the Rochester Epidemiology Project (REP) in the mid 1960's, linking all the medical records of everyone in the population of Olmsted County in Minnesota who consents, and has been doing exactly this sort of research since then. The scientists involved in this application have over a decade of experience specifically studying TBI and Alzheimer's disease and related conditions in the entire population of Olmsted County. In this way, Mayo Clinic provides the unique resources and expertise required to determine whether a history of TBI adds risk for developing Alzheimer's disease or a related condition.

From extensive clinical and research experience with individuals with TBI and Alzheimer's disease, we expect to find no consistent connection between them overall. But because we anticipate having a large sample of almost 2,500 individuals with TBI of all severities, we are likely to find that individuals with certain characteristics – such as those who have many injuries or injuries at a certain age or of a certain severity – might show an increased risk for developing Alzheimer's disease or a related condition. If so, we could contact those individuals for additional clinical evaluation and potentially be able to identify those at the highest risk earlier in life.

Rehabilitation Medicine Research Center



The Rehabilitation Medicine Research Center at Mayo Clinic opened in 2014. The Center draws on the strong clinical practice, research and education efforts in rehabilitation medicine and surgery at Mayo Clinic and focuses on the discovery, translation and application of new knowledge to provide hope to people with disabilities.

In the Rehabilitation Medicine Research Center, physicians and scientists from more than a dozen departments and sections work together to improve health care and restore function and quality of life for people with a wide range of disabilities. Basic science researchers work with clinical partners in neurological, musculoskeletal and medical rehabilitation areas to achieve these goals.

Research activity in the Rehabilitation Medicine Research Center is organized around three clinical research themes:

- Medical rehabilitation
  - Amputation and prosthetics
  - Cancer rehabilitation
  - Cardiac rehabilitation
  - Disabilities of aging
  - Pediatric and developmental disabilities
- Musculoskeletal rehabilitation
  - Arthritis
  - Spine and osteoporosis rehabilitation
  - Sports medicine
- Neurological rehabilitation
  - Neurodegenerative disorders
  - Spinal cord injury
  - Traumatic brain injury and stroke

Focus areas of research are applied across the three clinical research themes and include:

- Assistive and restorative technology
- Functional outcomes of rehabilitation
- Regenerative rehabilitation

TBI Rehabilitation Recognition

A Mayo Clinic physician received special recognition for his work during the American Academy of Physical Medicine and Rehabilitation annual convention in San Diego.

Allen Brown, M.D., is with the Brain Rehabilitation Research program, which is a part of Mayo's Rehabilitation Medicine Research Center.

He has been selected as the recipient of the 2014 AAPM&R Outstanding Council Service Award-Central Nervous System Rehabilitation Council.

AAPM&R established the award to recognize service/volunteerism of Council Members who contribute to the success of the Academy and who serve its membership in ways not limited to research, education and product development.

Dr. Brown said the award has to do with work he did with others for the AAPM&R, developing an educational tool to help physicians prepare for the upcoming Brain Injury Subspecialty Board Examination.

"It is an honor to receive this award and work together with my fellow brain rehabilitation specialist colleagues," said Brown.

He will be officially recognized on Saturday, November 15 at the 46th Walter J. Zeiter Lecture and Awards Ceremony, 9:30-11 am.

Here is Dr. Brown talking about the honor: http://youtu.be/gyAtfrxPxlA?list=UU8fQzKHIhSoZeSq3bwQx4mw

TBIMS Center Collaborative Research

Mayo's TBIMS Center is currently participating in three module research projects in collaboration with other TBIMS Centers:

- Internet use and online social media use among individuals with traumatic brain injury
- Testing the reliability of acquiring patient reported TBIMS data by phone
- Resilience after traumatic brain injury

The **Internet-Use module** will provide current data about how often patients with TBI access and use the Internet and other electronic media. This information will help health providers determine whether online resources are a potentially effective way to provide care and resources for patients. The **Reliability module** aims to validate the consistency of the data collected by TBIMS Centers. In this study, the Centers participating in the module are essentially validating the bank of questions that TBIMS research subjects are asked during follow-up calls, so researchers can be confident that the data they collect is consistently accurate. The **Resilience module** examines the data collected about patients' outlook on life after TBI and how they handle challenges after returning to their families and communities. Look for the preliminary findings from these studies to be published in the future.

The Mayo TBIMS Center also engages in **collaborative research** with others within Mayo Clinic. New projects include:

- *Effect of Antipsychotic Use within 7 days of Traumatic Brain Injury on Length of Stay and Duration of Post-Traumatic Amnesia*
  Mayo Clinic Divisions of Brain Rehabilitation and Pharmacotherapy
- *Incidence of TBI in the Olmsted County 1976-1982 Birth Cohort*
  Mayo Clinic Division of Brain Rehabilitation and the Rochester Epidemiology Project (REP) Pediatric Traumatic Brain Injury Birth Cohort Study

Recent Mayo Clinic TBIMS Center Publications

Brown AW, Watanabe TK, Hoffman JM, Bell KR, Lucas S, Dikmen S. *Headache after traumatic brain injury: a national survey of clinical practices and treatment approaches.* PM&R. 2015 Jan; 7(1):3-8.

Eum RS, Seel RT, Goldstein R, Brown AW, Watanabe TK, Zasler ND, Roth EJ, Zafonte RD, Glenn MB. *Predicting institutionalization after traumatic brain injury inpatient rehabilitation. Journal of Neurotrauma.* 2015; 32(4):280-6.

Brown AW, Leibson CL, Mandrekar J, Ransom JE, Malec JF. Long-term survival after traumatic brain injury: a population-based analysis controlled for non-head trauma. Journal of Head Trauma Rehabilitation. 2014 Jan-Feb; 29(1):E1-8.

Bergquist, T.F., Yutsis, M., Micklewright, J. (2014). Comprehensive assessment. In Sherer, M., Sander, A; (Eds.). Handbook on the Neuropsychology of Traumatic Brain Injury. New York, NY: Springer

Bergquist, T.F., Yutsis, M., Sullan, M.J. (2014). *Satisfaction with Cognitive Rehabilitation Delivered via the Internet in Persons with Acquired Brain Injury.* International Journal of Telerehabilitation, 6 (2): 39-50.

Education Conferences and Other Happenings

September 19, 2015

The 2015 Minnesota Brain Injury Alliance Walk for Thought will take place at four locations around Minnesota:

- Duluth - Canal Park
- Rochester - Silver Lake
- Saint Cloud - CentraCare Health Plaza
- Twin Cities - Battle Creek Pavilion/Battle Creek Regional Park (Maplewood)

For more information:
https://www.braininjurymn.org/ or info@braininjurymn.org or 1-800-669-6442

October 20, 2015

Rochester Area Brain Injury Community Committee conference
Audience: individuals with brain injury, families, care provides
For more information: RochesterBICC@gmail.com or 507-413-7983

November 7, 2015

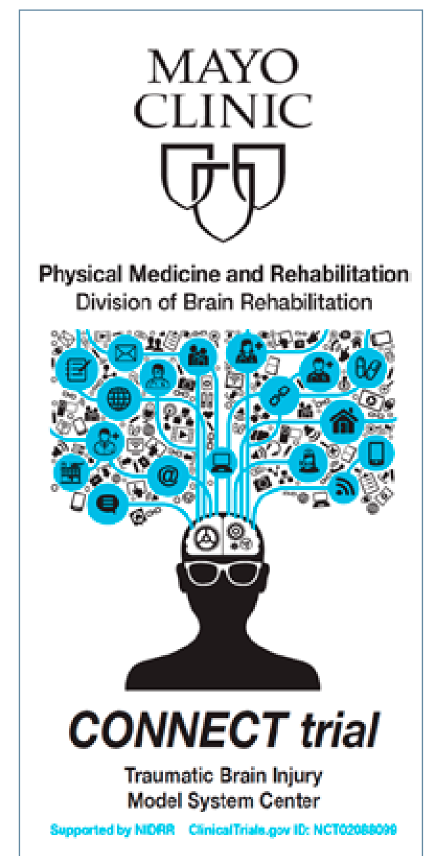
Minnesota Brain Injury Alliance 2015 Consumer and Family Conference will take place at New Life Presbyterian Church, Roseville, MN
1 – 4 pm. There is no cost to attend this conference.
For more information:
https://www.braininjurymn.org/ or info@braininjurymn.org or 1-800-669-6442

Brain Rehabilitation Clinic Monthly Support Group

Patients who have been seen in the Mayo Clinic Brain Rehabilitation Clinic are invited to attend a monthly support group, held the second Wednesday evening of each month, at 7 p.m. at Mayo Clinic Hospital, Saint Marys Campus, 1-Domitilla. Meetings are also open to current and past family members.

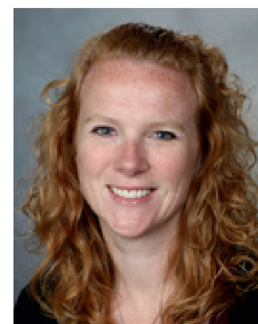
Partnership Approach to Brain Injury

Family members, friends, and interested persons are invited to attend The Partnership Approach to Brain Injury offered twice a year. This educational program teaches ways to cope with common problems following brain injury. For more information, or to be added to the mailing list for the Partnership program, call 507-255-3116.



Staff Updates

Anne Moessner, APRN-MS, resigned from her clinical position as the midlevel provider in the Brain Rehabilitation Clinic and relocated to Oregon to be closer to family and to spend more time outdoors enjoying a milder climate. Anne has spent her entire career in Physical Medicine and Rehabilitation at Mayo Clinic, St. Marys Campus, starting as a staff nurse in 1985 on the inpatient Rehabilitation Unit where she worked for six years before assuming the Nurse Coordinator position in the Brain Injury Outpatient Program in 1992. Somewhere along the way after completing graduate school, she and Dr. Jim Malec wrote a grant proposing the concept of medical and vocational care coordination for patients with TBI, thus were born the TBI Clinical Nurse Specialist and Vocational Coordinator positions. Anne served as the TBI CNS for 19 years until transitioning to a midlevel position in the Brain Rehabilitation Clinic in 2010 where she remained until her departure. Since 1998 Anne has also worked as the Research Coordinator of the Mayo TBI Model System Center federal research grant, she is grateful to be able to continue in this role in Oregon as a Mayo teleworker and key staff for the CONNECT Trial.



Kari Bottemiller, APRN-MS, accepted the position as the midlevel provider in the Brain Rehabilitation Clinic, replacing Anne Moessner.

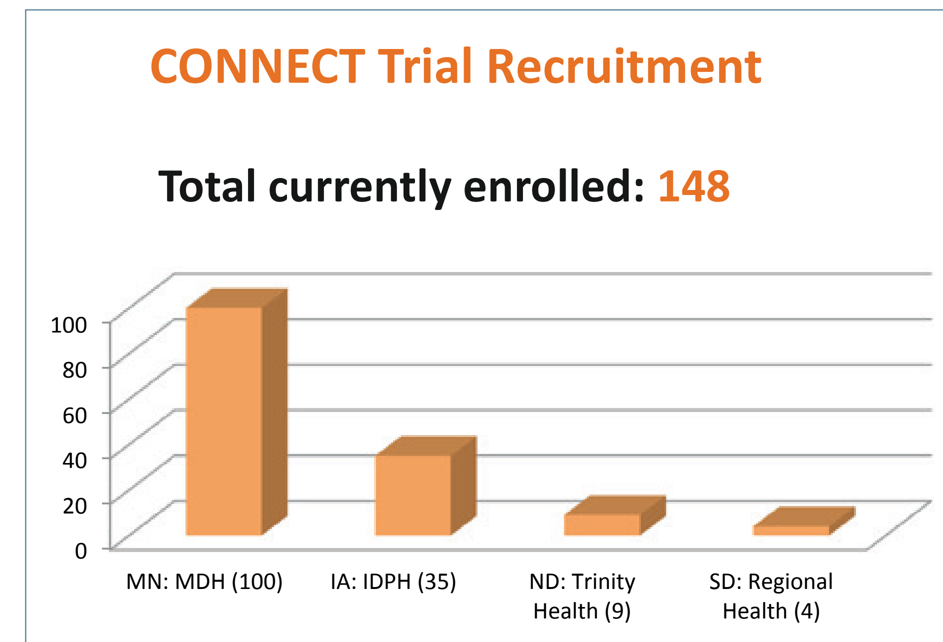
Kari began her career at Mayo in 1998 as a staff nurse on the Rehabilitation unit at Mayo Clinic, St. Marys Campus. From there she spent time as an RN educator and ICU nurse.

From 2003 until January, 2015, she served as a Clinical Nurse Specialist in Mayo Neurology for the Stroke Center. Kari brings a wealth of experience in nursing practice, systems change, program development, data driven practice, education, quality, accreditation, and leadership. Her husband is an engineer, and they have two beautiful and spirited daughters. Kari has begun seeing outpatients on 1 Domitilla and is enjoying increased contact with patients and families affected by brain injury. We welcome her back to the Physical Medicine and Rehabilitation department!

Kathy Kendall, BSN, RN, has worked at the Mayo Clinic, St. Marys Campus, for 36 years, nineteen of these on the inpatient Rehabilitation Unit first working as a staff nurse, and then as a Lead Nurse on the brain team. For the past 17 years she has served as the Brain Rehabilitation Clinic Nurse Coordinator and been actively involved with the Mayo TBI Model System Center serving in a variety of roles including consenting research subjects, conducting follow up calls, working on several collaborative research projects, and participating in data entry and quality. Currently Kathy does all of the recruiting of St Marys Hospital in-patients who qualify for the TBI Model System Center National TBI Data Base, as well as the follow up calls for subjects who have enrolled in this Data Base since Mayo was first funded in 1998. If you are a TBI Model System research subject and due for your 1, 2, 5, 10, or 15 year follow up calls it is Kathy's voice you will be hearing on the phone.

CONNECT Trial Update

Enrollment in the CONNECT Trial continues. As a reminder, this project will help us understand how tele-medicine (providing services from a distance using technology like phones and computers, versus in-person) might be an effective way to connect TBI expertise with those who may need it. We are doing this study because many people with TBI often identify lack of access to specialized TBI services and providers after they leave the hospital as a barrier to their ongoing recovery. Family members and local health care providers may also be invited to participate in the study. Collaborative partners for this project include the Minnesota Department of Health (MDH), Iowa Department of Public Health (IDPH), Trinity Hospital in Minot, North Dakota, and Regional Health in Rapid City, South Dakota. Individuals eligible to participate were dismissed in the last several months from a hospital in Minnesota or Iowa or from Trinity or Regional Health and are at least 18 years of age. Recruitment will continue for about another year, with the goal of enrolling 400 subjects into the study.



OUR MISSION:

The primary mission of the Mayo Clinic TBI Model System is (1) to study the course of long-term recovery after traumatic brain injury (TBI), and (2) to develop, provide and evaluate innovative services to address identified needs for service coordination and community reintegration for persons with TBI.

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Mayo TBI Model System Advisory Council *(external members):*

Craig Martinson, Survivor with brain injury
Audrey Nelson, MS, CVE, Survivor with brain injury
Thomas Tatlock, MD, Survivor with brain injury
Kasey Johanson, BA, CBIS, Brain Injury Alliance of Wisconsin, Family member of a person with brain injury
Gregory Lamberty, PhD, LP, ABPP, Minneapolis VA Health Care System
Rose Collins, PhD, Minneapolis VA Health Care System
David King, Minnesota Brain Injury Alliance, Executive Director
Mark Kinde, MPH, Minnesota Department of Health
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Brandi Jensen, BS, CBIS, Brain Injury Alliance of Iowa
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