

The Messenger

News and Information from the Mayo Clinic Traumatic Brain Injury Model System Center | Winter 2017

<http://www.mayo.edu/research/centers-programs/traumatic-brain-injury-program/overview>



Tyler and his fiancée Lea at Valley Fair Amusement Park, Shakopee, MN.

You are Tyler Distad

Editor's note: This essay was written in 2013 by Tyler Distad for a college class. It is being reprinted with his permission.

I rolled over, looked up, and realized I was in a hospital bed. I started to read this 8 x 11 piece of paper taped to the wall, at the end of the bed. In large bold font the sign said:

**You are Tyler Distad
You live in Albert Lea, Minnesota
You are currently in Rochester, Minnesota,
at the Mayo Clinic
Your Mother and Father visit regularly
You have 2 younger brothers**

As I get ready for the day, someone bursts in and asks "You ready Tyler?" I look at her and respond "Sure, where we goin'?" I hear "We're going to therapy". I remember thinking what is wrong with me because I'm walking, talking, and I just dressed myself. Then we enter a Speech Pathologist's office. I knew what this meant as my littlest brother has seen one all his life, they're more commonly known as Speech Therapists. But why am I here? About 30 minutes into therapy, I chuckled uncomfortably, and had the courage to ask, "What am I doing in the hospital?" Gina my therapist responded calmly and collectively, "Tyler you had a severe traumatic brain injury". I looked at

You are Tyler Distad *continued*

her puzzled as she explained what that meant, in a medical and methodical way, slower than I thought I needed as a college student. I found myself speaking in circles. Gina asked me to write down my questions.

I was in a car accident on July 11, 2010. I was stopped in the southbound lane of Interstate 35 driving through Owatonna, Minnesota, where the traffic was merging into one lane due to construction, creating gridlock. My car was rear ended by a pickup going 70 miles per hour and I was knocked out instantly. The force caused a TBI. The first responders stabilized my neck though the rear window. The Jaws of Life were not needed as my driver's door was fully functional. I was airlifted to St. Marys Hospital-Mayo Clinic in Rochester where I lay unconscious for 96 hours. My mother, the rock of the household, came with my middle brother and saw me hooked up to a feeding tube. I was also attached to multiple IVs with a diaper wrapped around my hips making me the most vulnerable I have been since birth. With the sight of her oldest son in diapers just like her youngest son, my mother was in emotional turmoil. My middle brother

didn't have as big of a meltdown when he first visited me but a few days later he knew I wasn't the same Tyler. I talked and had mannerisms like a pre-teen, not the 20 year old I was. I blushed when female nurses came in my room and snickered at Sponge Bob Square Pants. He went home with a glazed look on his face, my parents asked what's wrong, and he melted down. This wasn't the older brother he once had.

Gina gave me loose leaf, wide ruled paper, so I could write my questions down, and told me to write my name and the date in the corner of the page, treating it like school. I attempted to do what she asked and ended up writing "2009/", not how you write a date. I struggled to hold the pencil with my supersized hands. I needed something with a bigger grip because my fine motor skills were a big problem. She offered me a large grip pen but I responded with "Pens not like." My writing was the true definition of chicken scratch. This fractured my already shattered ego. Trying to formulate my questions and write them down made me realize how much the TBI was going to affect my life.

*Photo at right:
Tyler's car in the
aftermath of his
July 11, 2010,
accident involving
a high speed rear
end collision.*



Gina was kind enough to attempt to decipher my hieroglyphic text. She answered all the questions I could muster in that session. With my session over we walked over to the physical therapy department. Kyle the PT was another new face I didn't remember, yet he knew so much about me. Kyle wanted to work on my balance and equilibrium so he grabbed and inflated a balloon and put a belt around me for safety so if I fell, he could grab the belt. There was a foot height difference between me and Kyle, with me towering over him. While standing, he tossed the balloon in the air and as it descended he asked me to keep it in the air. I played sports all my life, this was a balloon falling at an astronomically slow pace, I was confident I would have the balance and coordination to keep it in the air. However, when I tried to lean forward to catch it I stumbled, the balloon hit me in the face, and I needed the belt! This further crushed my feeble ego.

This was a crisis. I was a varsity hockey player. I lived in the state of hockey. This TBI became an undeniable problem very quickly, going from varsity athletics to this. What is a TBI? When will I see my Mom and Dad so I can truly have my questions answered? Just as this thought mutters into my head both my parents enter my room. I hug them like I haven't seen them in years. They are confused since they saw me last night. Gina and Kyle told them about my realization and enlightenment today. Both my parents smile, "Tyler is back". I finished therapy that day not needing the support of the therapy belt; my parents were all the belt I needed.

Being released from the hospital was a joyous day for me but what was the point of leaving the hospital when I was coming back so frequently for more therapy? The therapists said I needed to relearn body language and the social dynamics of the real world, that the hospital setting was too controlled for me to recover there anymore. The first few days at home were chaos. My



The Distads (from left to right): Hunter, Michelle, Jeff, Dalton, Tyler.

father drove me home and tested my memory by seeing if I could direct us back home, which I did. When we arrived I went to my room to unpack. The next day, I came down in just underwear, and sat on the couch. My mother asked if I was going to shower. I told her I didn't know where a clean towel and clothes were. Because I "found" our home on the drive the day before, my parents were thinking I could take care of myself. I could hardly run the TV remote. I needed supervision for most things. My parents did give me one freedom--I could walk our chocolate lab puppy to the park to play. I took the dog for walks and to the park three to five times a day with no recollection of any trip I had already made. With my lack of memory and coordination, the doctors wouldn't let me drive. I struggled with these drastic changes and wanted to hit the "resume" button of my life. I remember having the conversation with my parents about more freedom and them respecting "Tyler's time." I told them I felt like my life had been "put on stop" and was revolving around things I couldn't do. My parents said "Your life has not stopped, just paused" and reinforced how much progress I had made since the accident. They needed to remind me of all the small steps. Many people don't even survive a severe TBI, but I, I am a Distad!

You are Tyler Distad *continued*

Fast forward to Spring semester of 2011.

I left home for St. Cloud State University. The therapists recommended starting with something small, a light schedule, as they wanted me to succeed. I wanted to be the survivor that makes them love their jobs. I felt as if I was not only carrying the pride of the Distads, I was carrying the pride of Mayo Clinic. All my life I have thrived under pressure. I played goalie in hockey. I now had control over how my life was going to redevelop in front of me. The TBI statistics doubted my ability to succeed in school, but I proved them wrong with my 3.00 GPA at the end of that semester.

TBIs are often an invisible disability; many people don't know I still struggle with side effects. Many people will not know about the daily memory test, the conversations, the emotions shared and felt. I have good and bad days. Many lessons can be learned from my experience. Take time to appreciate the people in your life. Friends fade; family is forever. Do not drive distracted. Ever. Distracted driving was the cause of my accident; cell phones are a major contributor to car accidents and deaths happen because of the attention-sucking power of the device. Do me a favor and realize your distracted driving may not change your life, but can drastically change another person's.

*Photo at right:
Graduation day,
May, 2014, at
St. Cloud State
University,
St. Cloud, MN.*



“Life isn't a matter of playing the cards you were dealt. But deciding what game you're going to play. Hint: Go Fish is harder to lose.”

Fast forward to Fall of 2016. We recently caught up with Tyler to see what he's up to now, 6 ½ years after his accident.

Mayo: Tyler, thank you for sharing your essay with our readers! It sounds like you've graduated from college?

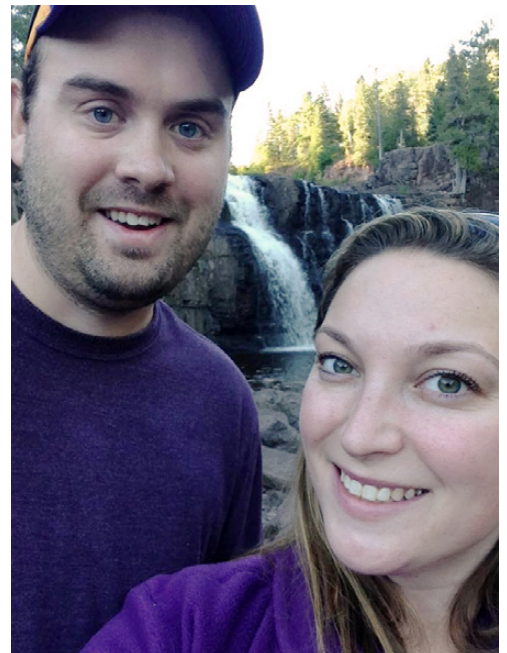
Tyler: I did. I graduated in May of 2014 from St. Cloud State University, with an Interdepartmental Communication Studies BA.

Mayo: Impressive. Where you are living?

Tyler: I am currently residing in Saint Cloud, Minnesota.

Mayo: How are you spending your days?

Tyler: I am a Banker at a customer contact facility. Helping customers and changing banking for good.



Tyler and his fiancée Lea at Gooseberry Falls State Park, Two Harbors, MN.

Mayo: Again, impressive. I heard mention of a girlfriend?

Tyler: I was dating a wonderful woman named Lea for 2 years and we recently got engaged on July 4th, 2016! She is constantly pushing me outside my comfort zone. However, she will always be the safe haven to catch me when support is needed.

Mayo: Congratulations!

Mayo: Do you still have effects from your injury, and good and bad days?

Tyler: I have days when I struggle to express the turmoil of emotions I am feeling. These days are few and far between as time goes by. I do best when I have some time to think and nap on my thoughts. Napping helps me be present and in the moment.

Mayo: We are big proponents of rest breaks to help manage mental and physical fatigue. So then, what's next for you? Other than a wedding of course.

Tyler: The wedding is still in the planning stage, no dates have been set. Thanks for the support!

Mayo: Do you still play hockey? Or other sports? It seems like sports have been something you've enjoyed and gotten a lot out of?

Tyler: I no longer play hockey. But, I do referee as an involvement in the sport and dedicate many weekends and early mornings to this. I now have the advantage of choosing when and what weekends I ref. I also spend time fishing and enjoying the unplugged nature of it.

Mayo: We hope your family is doing well. It sounds like they played a big role in your recovery?

Tyler: My family is currently residing in Northfield, Minnesota, and without their support my recovery would be very different. My middle brother is finishing up his studies at the University of Wisconsin-Stevens Point in Fisheries. My youngest brother is going to the high school in Northfield and it seems to be a very good fit for him and the family.

Mayo: Any tips or lessons learned over the past 6 years to share with other people just starting this journey?

Tyler: Enjoy laughter, even at yourself. Others love to be around happy people, even if you're laughing at yourself. Do not let the TBI define your future. Push yourself outside of your comfort zone. Don't create your own road block in your recovery. I struggle to be great at everything, but I do try every day to be the best Banker on my side of the Mississippi River. The recovery is a never ending process and on that journey there is a crossroads that makes it hard to define recovery over personal growth.

Mayo: Splendid insights, we sincerely appreciate you sharing your story and views with us. It was really nice catching up with you, any chance we could touch base again in another handful of years?

Tyler: I would love to hear back from you, I would greatly enjoy sharing what the ongoing recovery has on the horizon.



“ Do not let the TBI define your future.
Push yourself outside of your comfort zone.”

With ever increasing demands on our personal and professional time in today's busy society, learning to juggle multiple tasks at once is something we all face daily. As a result, a new traffic safety epidemic has emerged on America's roadways that demands immediate attention: distracted driving.

In 2014, 3,179 people were killed in crashes involving a distracted driver. One of the most alarming and widespread forms of distracted driving is cell phone usage. According to a study by the Virginia Tech Transportation Institute (VTTI), sending or receiving a text takes a driver's eyes off the road for an average of 5 seconds, the equivalent of driving blind at 55-mph for the length of an entire football field. And a 2014 special article in the New England Journal of Medicine found that the risk of a crash or near-crash among novice drivers increased with the performance of many secondary tasks, including texting and dialing cell phones.

Text messaging is of heightened concern because it combines three types of distraction – visual, manual and cognitive. In other words, texting involves taking your eyes off the road, your hands off the wheel, and your mind off the task of driving.

To tackle this ever-increasing problem, the National Highway Transportation and Safety Administration (NHTSA) is focusing on ways to change the behavior of drivers through legislation, enforcement, public awareness and

education—the same tactics that have curbed drinking and driving and increased seat belt use.

NHTSA's message is simple – **“One Text or Call Could Wreck it All.”** With supporters ranging from President Obama to Adam Levine and legislation being passed across the nation to discourage distracted driving, we hope drivers get the message loud and clear.

So the next time you are pressed for time, and it seems like multitasking in the car is the best decision, remember those 3,179 lives that were taken because someone decided they could do two things at once. A text or call is not worth your life, or anyone else's.

Distraction.gov is your resource for learning more about distracted driving. Get the facts, get involved, and help us keep America's roadways safe.

The fight to end distracted driving starts with you. Make the commitment to drive phone-free today. Download and sign the Pledge to:

- Protect lives by never texting or talking on the phone while driving
- Be a good passenger and speak out if the driver in my car is distracted
- Encourage my friends and family to drive phone-free

From: <http://www.distraction.gov/take-action/downloads.html>



Mayo Clinic TBI Regional Advisory Council – Featured Members

In recognition of the Mayo Clinic TBI Regional Advisory Council gathering for 25 years, esteemed Council members will continue to be featured in The Messenger. This month we'd like readers to meet the Executive Directors of the Brain Injury Alliances (BIA) of Iowa, Minnesota, and Wisconsin. Mayo Brain Rehabilitation and Research staff have a long and storied history with the regional Brain Injury Alliances (formerly "Associations"). We turn to the BIAs to support individuals/families affected by acquired brain injury as they leave the hospital through education, resource facilitation, peer support programs, and legislative and other advocacy activities, among other services. It has been our privilege to collaborate with these prized organizations through membership on their Boards of Directors, attending and presenting

at annual conferences, sharing resources, and otherwise joining forces on various projects, grants, committees, and research endeavors. If you have yet to interact with your state BIA, please considering doing so; it only takes one click or call to learn more. To Geoffrey, David, and Karl may we publicly and humbly thank you for your leadership, compassion, wit, determination, and foresight as you continue to enlighten us research types about the needs of those we serve. You were right, you are still right - the hospital phase of care and recovery after TBI is but a short (albeit highly important) one but in the grand scheme of things, "the community is where it's at" so let's focus some research on what happens there, on what happens over the long run. Here's to decades more of spirited and fruitful collaboration!



Geoffrey M. Lauer, MA

Chief Executive Officer, Brain Injury Alliance of Iowa
Mayo TBI Regional Advisory Council member since 1999

Geoffrey Lauer attributes his 30 year career in the non-profit human services sector to an insightful comment from an undergraduate mentor who opined: "Lauer, you better stay out of the for-profit sector, as you would likely end up quite wealthy but at the cost of your mortal soul".

Both predictions have come to pass as Geoff has little to show in wealth (but hopefully a bit of soul) as he traveled a path in the Brain Injury advocacy and services realm. This has ranged from serving as a substitute brain injury support group facilitator in the 1980s, through co-founding and directing programming in a SE Iowa non-profit human services agency into volunteer Board service and then President of the Board of the Brain Injury Alliance of Iowa. In 1997 Geoff was recruited to join the staff of the Brain Injury Association of America and served for a decade as a Regional and National Director of State Affairs. Since 2006 Geoff has guided the Brain Injury Alliance of Iowa as its Chief Executive Officer. In that time he has also been a founding board member of the United States Brain Injury Alliance where he currently serves on the National Board of Trustees.

Geoff has his Bachelor's Degree in Psychology and Anthropology from Luther College in Decorah, Iowa, and a Master's Degree in Health Communications from the University of Iowa. He has been appointed by Iowa Governors to the State Advisory Council on Brain Injuries and Mental Health and Disability Services Commission. Geoff has presented before the United States Senate Health, Education, Labor and Pensions (HELPS) Committee regarding barriers to economic self-sufficiency for people with disabilities. He is a recipient of the National Public Policy Award from the North American Brain Injury Society and his efforts have led to the Brain Injury Alliance of Iowa being recognized by the Iowa Association for Justice for Exceptional Public Service and as the 2016 Iowa Childhood Injury Prevention Champion. Lauer now also holds the dubious honor as the longest serving member of the Mayo Clinic's Traumatic Brain Injury Regional Advisory Council.

Geoff still walks far too much with his eyes on the ground as a result of an early and aborted career as an archaeologist. However he is regularly forced to look up to navigate the exploits of the six children that he and his wife Erika herd in his natal home of Iowa City, Iowa.

Brain Injury Alliance of Iowa contact information:

Web Site: biaia.org

Toll free phone number: 1-855-444-6443

Email: info@biaia.org



Karl Curtis, BA

Executive Director, Brain Injury Alliance of Wisconsin

Mayo TBI Regional Advisory Council member since 2016

Karl Curtis celebrated his first anniversary working for the Brain Injury Alliance of Wisconsin in October, 2016. Prior to his current position, Karl spent ten years at the helm of a Chamber of Commerce in one of Wisconsin's fastest growing communities and eight years as a newspaper editor. Karl first learned of the position at the Brain Injury Alliance of Wisconsin through a fortunate accident. He was helping his son, a childhood brain cancer survivor, search for jobs that might accommodate his brain injury, and wound up finding new work himself.

A native of New Hampshire, Karl attended Beloit College in Beloit, Wisconsin, where he a) Graduated in 1986, b) Majored in both government and creative writing and c) Met his future wife, Carmen. Karl and Carmen have been married for 30 years and live in Verona, Wisconsin. They have two adult children, Cameron and Keenan. When not advocating for the brain injury community, Karl enjoys playing golf, reading, creative writing, and performing in Community Theater. He has written both the best mystery novel and the best stage musical you have never read or seen. He also writes an occasional column for his local newspaper, serves on his city's Canvassing Board, and sits on the Board of Directors for the Verona Area Education Foundation.

Brain Injury Alliance of Wisconsin contact information:

Web Site: www.biaw.org

Phone numbers: 1-800-882-9282 (toll free) or 262-790-9660 or 608-206-6426

Email: admin@biaw.org



David King, MBA

Executive Director, Minnesota Brain Injury Alliance and
Minnesota Stroke Association

Mayo TBI Regional Advisory Council member since 2008

David King joined the Minnesota Brain Injury Alliance as the Executive Director in 2008 after working for 27 years in various aspects of vocational rehabilitation. David has a Bachelor's Degree in Social Work from Elizabethtown College in Pennsylvania and a Master's Degree in Business Administration from the University of Maryland, College Park. In 2009, David led the operational merger between the Minnesota Brain Injury Alliance and the Minnesota Stroke Association. As a result of that merger, he now serves as the Executive Director of both 501(c)3 organizations. David is a founding member of the United States Brain Injury Alliance and currently serves on their Board as Treasurer, is the Chair of the Membership and Development Committee, and Chairs the Finance and Audit Committee. He also serves as a member of the Brain Injury Interagency Leadership Council, the Mayo Clinic Traumatic Brain Injury Regional Advisory Council and the Minnesota Department of Human Services Partners Panel. In his spare time David serves as Chair of the Finance Committee of New Life Presbyterian Church and the Chair of the Shoreview YMCA Advisory Board.

David describes his role as Executive Director with the Minnesota Brain Injury Alliance and Minnesota Stroke Association as a dream job. He feels fortunate to be able to get up every day and look forward to going to work. David's connection to brain injury started in 1977 when he met a friend at college who sustained a brain injury as a result of encephalitis. Subsequently, David spent his entire career working with individuals with brain injury. However, things took a more personal turn when David's father had a stroke at age 70 and sustained a TBI as a result of a fall following that stroke.

David grew up on the East Coast and was living and working in Washington, DC when he met and married Carolyn, his wife of 27 years. They migrated to the Midwest in 1990. Their son Ian, 23, is a Business Analyst with 3M. Their daughter Janie, 19, is a sophomore at the University of Wisconsin, Eau Claire. David loves swimming and working out. He is an avid reader, gardener and loves all kinds of music. Last year David and his wife rescued Mabel, an American Pit Bull Terrier. Despite a very unfortunate first year of life, Mabel has discovered her capacity to trust people, love life and entertain the people who love her. Mabel recently completed her second class and now has a repertoire of over 40 tricks she loves to show off!

Brain Injury Alliance of Minnesota contact information:

Web Site: braininjurymn.org

Toll free phone number: 1-800-669-6442

Email: info@braininjurymn.org

Mayo Clinic honored to be ranked No.1 on *U.S. News & World Report* Honor Roll

Thank You!
Ranked #1
in the Nation

U.S. News 2016-17

In August, 2016, Mayo Clinic was named the best hospital in the nation in *U.S. News & World Report's* annual list of top hospitals. Mayo Clinic took the No. 1 spot in Arizona, Florida and Minnesota. In addition, Mayo Clinic is currently ranked No. 1 in more specialties than any other hospital in the country, based on factors such as reputation, mortality index, patient safety, nurse staffing and Magnet status, patient services and technology. Mayo Clinic physicians, scientists, researchers, educators and allied health staff members work together in a team-based model to deliver the highest standards of care and transform scientific discoveries into critical advances for unmet

patient needs. "We are honored to be recognized in this way, as it reflects the tremendous work of our staff every day in caring for our patients and their families," says John Noseworthy, M.D., president and CEO of Mayo Clinic. "This ranking is a testament to the dedication and excellence of all of our Mayo Clinic staff."

Mayo Clinic is part of a select group on the U.S. News Honor Roll recognized for "breadth of excellence," according to the magazine. To make the "honor roll," a medical center must rank at or near the top in at least six of 16 specialties. Mayo Clinic was first overall in the magazine's annual honor roll ranking of its Best Hospitals list and was ranked No. 1 in eight specialties and No. 2 in three more specialties.

American Congress of Rehabilitation Medicine Edward Lowman Award

The American Congress of Rehabilitation Medicine (ACRM) Awards Committee presented the prestigious Edward Lowman Award to Dr. Allen Brown, M.D. for his significant contributions to the field of Physical Medicine and Rehabilitation. He received this award at the Henry B. Betts Awards Dinner & Gala during the ACRM 2016 Annual Conference in Chicago in November.

Dr. Brown's research team studies the process of providing medical rehabilitation care to individuals after their brain function has been altered by injury or disease. The long-term goal of this research is to improve participation in roles meaningful to these individuals through testing of rehabilitation models of care in the real world. Dr. Brown's research team works within the communities of the upper Midwest to study population-based epidemiology of brain injury, new interventions for improving walking after stroke and negotiating public transportation using smart phone technology,

and community-based randomized clinical trials of complex clinical interventions to improve advocacy skill and quality of life after brain injury. Dr. Brown has led the development of an acquired brain disorders service line at Mayo Clinic which integrates acute care and team-based rehabilitation consultative services that provides efficient, patient-focused care across the continuum of need and recovery.



Dr. Allen Brown and his wife Suzi, ACRM meeting, Chicago, IL.

TBI Model System National Database Reaches 15,000 Participants

In the last issue of The Messenger we highlighted some of the accomplishments of the Traumatic Brain Injury Model Systems (TBIMS) program which began in 1987 to improve care and outcomes for individuals with TBI. Currently, there are 16 TBIMS Centers, each providing a multidisciplinary system of rehabilitation care, including emergency medical, acute medical and post-acute services.

The NIDILRR-funded TBIMS National Data and Statistical Center announced enrollment of its 15,000th participant in the TBIMS National Database on July 7, 2016. The TBIMS

National Database contains data collected from participants in the TBIMS Program and is the largest longitudinal database of TBI in the world. The network of TBIMS Centers work together to collect information for research on outcomes after TBI, following participants up to 20 years post-injury. Individuals enrolled in the TBIMS National Database are critical to advancing understanding in the field of the lifetime impact of TBI.

For more information go to tbindsc.org.

Publications

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Philippus, A, Mellick, D, O'Neil-Pirozzi, T, Bergquist, T, Guller Bodien, T, Sander, A, Dreer, L, Giacino, J, Novack, T. **Impact of religious attendance on psychosocial outcomes for individuals with traumatic brain injury: A NIDILRR funded TBI Model Systems study.** Brain Injury. Received 14 Dec 2015, Accepted 06 Jun 2016, Published online: 13 Sep 2016.

Ritter AC, Wagner AK, Szaflarski JP, Brooks MM, Zafonte RD, Pugh MJ, Fabio A, Hammond FM, Dreer LE, Bushnik T, Walker WC, Brown AW, Johnson-Greene D, Shea T, Krellman JW, Rosenthal JA. **Prognostic models for predicting posttraumatic seizures during acute hospitalization, and at 1 and 2 years following traumatic brain injury.** Epilepsia 2016 Sep; 57 (9):1503-14 Epub 2016 July 19 PMID:27430564

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OUR MISSION:

The primary mission of the Mayo Clinic TBI Model System Center 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.

Mayo Clinic Traumatic Brain Injury Model System Center

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The Mayo Traumatic Brain Injury Model System Center has been funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) since 1998.

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