Mayo Clinic’s Traumatic Brain Injury (TBI) Model System Center awarded $2.2 million

Mayo Clinic’s Traumatic Brain Injury Model System (TBIMS) Center has been awarded a $2.2 million federal grant by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), within the Administration for Community Living under the Department of Health and Human Services, to sustain its research through 2022. This is the Center’s 5th consecutive 5-year award since 1998. Led by Allen Brown, MD, Anne Moessner, APRN, and Tom Bergquist, PhD, Mayo Clinic has contributed data to the longitudinal TBI Model System National Database – the largest non-proprietary TBI data set in the world tracking outcomes for over 16,000 individuals – for nearly 20 years. Mayo Clinic has completed numerous analyses using these data to understand outcome prediction and the natural history of recovery after TBI. The Center has focused its site-specific research on studying population-based epidemiology of TBI, increasing healthcare delivery system capacity and access to specialized brain rehabilitation care, and using information communication technology to improve participation and quality of life after TBI.

This funding award further strengthens Mayo Clinic’s established reputation as a leading Center of innovative brain rehabilitation research and clinical practice, supporting continued collaboration with the other 15 TBI Model System Centers around the nation.

http://www.mayo.edu/research/centers-programs/traumatic-brain-injury-model-system
Testing an integrated Medical and Resource Facilitation Intervention (MRFI) after Traumatic Brain Injury: A Community-based Pragmatic Clinical Trial

The Center’s immediate work will capitalize on longstanding collaborations with the Minnesota Brain Injury Alliance and Minnesota Department of Health in a community-based pragmatic clinical trial. Unmet needs persist for individuals with TBI and their families related to making reliable and lasting connections to medical, social, and community services after hospital-based care despite their repeated identification and large scale efforts to address them. MRFI is supported by research evidence and previous experience and will address: 1) the ineffective connection of individuals with TBI and their families to specialized medical and community resources after hospital-based care; 2) limited access to TBI experts; 3) variable knowledge by primary care providers about the complex needs of individuals with TBI.

This clinical trial will test a behavioral intervention to determine whether outcomes over time are better in a group receiving the MRFI model of care compared to a group who receives usual care in their communities. MRFI group participants will have access to the remotely provided supportive, educational, care coordination, and direct clinical services, including therapy, of the Mayo Brain Rehabilitation Clinic. Services will be delivered by a multi-disciplinary team via telemedicine (live two-way audiovisual interaction between providers and participants in their homes) and information communication technology (e.g. web- and phone-based services). There will be no face-to-face visits. The specific modes used to interact with MRFI participants and the specific services provided will be determined by individual need, preference, and technology.

At the outset and throughout the 18 month study period, Mayo Brain Rehabilitation Clinic services will be integrated with the highly developed Minnesota Brain Injury Alliance Resource Facilitation program - a free two-year telephone support service offering assistance in navigating life after brain injury. Target populations for MRFI are up to 500 Minnesotans with a history of TBI who are at least 18 years old, less than one year post-injury, and eligible for Resource Facilitation and equal numbers of their family members and primary care providers. Fundamental to MRFI is the family-centered nature of the intervention, which also relies on the involvement of the participant’s primary care provider. Families in the MRFI group will have access to an array of supportive and educational services; primary care providers will have access to medical and rehabilitation expertise and related resources.
This integrated intervention appears essential to address the complex, intertwined, and long lasting medical and social problems faced by individuals with TBI. An existing collaboration with the Minnesota Department of Health and the expertise of analysts in Mayo Clinic’s Center for the Science of Health Care Delivery will allow for a comparison of costs between groups. Other Mayo Clinic partners include the Center for Connected Care, Center for the Science of Health Care Delivery, and the Mayo Clinic Social Media Network. The trial will build on previous work done with CareHubs, Inc., a leading online community engagement platform for the healthcare industry. Mayo Clinic’s TBI Regional Advisory Council participated in this trial’s design and will provide research oversight.

The anticipated long-term results of this research are development of a sustainable model of care that uses technology to integrate medical-rehabilitation with community expertise to improve TBI care and outcomes. Other expected outcomes include building TBI knowledge among primary care providers and families.

Minnesota Brain Injury Alliance: https://www.braininjurymn.org/

Minnesota Department of Health: http://www.health.state.mn.us/

Mayo Clinic Center for Connected Care (CCC): http://www.mayoclinic.org/about-mayo-clinic/care-network/about

Mayo Clinic’s Social Media Network (MCSMN): https://socialmedia.mayoclinic.org/


CareHubs, Inc.: https://carehubs.com/

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**Medical and Resource Facilitation Integration (MRFI) Grant Consultants**

To further strengthen our grant we have supplemented our team with three grant consultants. James F. Malec, PhD will oversee the use of participation measures and their analysis for this trial, and the integration of Resource Facilitation into its intervention. Joan Griffin, PhD will lend her expertise on implementation and family engagement and outcomes to the project. Geoffrey Lauer, MA will assist with project sustainability, advocate for the concerns of traditionally underserved populations, and provide guidance with analyzing health policy.
James F. Malec, PhD, ABPP-Cn, Rp, FACRM is Professor Emeritus of Psychology at Mayo Clinic-Rochester and Senior Research Professor Emeritus, Department of Physical Medicine and Rehabilitation, Indiana University School of Medicine. He is Board Certified in Clinical Neuropsychology and in Rehabilitation Psychology through the American Board of Professional Psychology. He has been active in research and the clinical practice of brain injury rehabilitation for over 35 years. He has received a number of professional recognitions, including the Lowman Award for interdisciplinary contributions to rehabilitation from the American Congress of Rehabilitation Medicine, the Research Award of the North American Brain Injury Society, the Sheldon Berrol, MD, Clinical Service Award from the Brain Injury Association of America, the Fürst Donnersmarck Foundation Neurorehabilitation Research Award, and the prestigious Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation. He has over 155 peer-reviewed publications as well as other professional publications and continues to conduct research in brain rehabilitation and outcome measurement.

Joan M. Griffin, PhD is an Associate Professor of Health Sciences Research at Mayo Clinic and Scientific Director for the Care Experiences Program at Mayo’s Robert D. and Patricia E. Kern Center for the Science of Health Care Delivery. Dr. Griffin has a long-time research interest in the health effects of family caregiving on both caregiver and care recipient health. Using both qualitative and quantitative methods, she studies how to reduce the physical and mental health risks faced by caregivers providing care and strategies to engage caregivers in their loved one’s health care in order to improve care recipients’ transitions in care, assure their safety, and optimize their health outcomes and quality of life. Her work has focused on the impact of caring for people with cancer, traumatic brain injury, dementia, and heart failure.

Geoffrey M. Lauer, MA is the longest running member of the Mayo TBI Regional Advisory Council. Since 2006 he has guided the Brain Injury Alliance of Iowa as its Chief Executive Officer. Prior to that Lauer served for a decade as a Regional and National Director of State Affairs for the Brain Injury Association of America. Lauer is a founding board member of the United States Brain Injury Alliance where he currently serves on the National Board of Trustees. He has been appointed by Iowa Governors to the State Advisory Council on Brain Injuries and Mental Health and Disability Services Commission. Lauer has presented before the US Senate Health, Education, Labor, and Pensions 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.
The TBI Model System Centers Program – An Overview

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) supports the collection of data from participants in the TBI Model System Centers Program, a network of institutions across the country collecting data for research on outcomes after a TBI. The result of this collaboration is a unique, well-characterized population of subjects with uniformly collected data compiled in the TBI National Database.

The Traumatic Brain Injury Model System Centers Program

February 2017

The Traumatic Brain Injury Model System (TBIMS) Centers program, begun in 1987, currently consists of 16 centers across the US that are competitively funded for 5 years by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The TBIMS Centers are situated in centers of excellence for clinical care and innovative research focused on improving the lives of people with TBI, their families, and close others. The primary focus is on moderate to severe TBI, as patients are recruited from inpatient rehabilitation to participate in research; however, many TBIMS investigators are also interested in mild TBI, or concussion.

The National Database (NDB), managed by the TBIMS National Data and Statistical Center, is at the core of the TBIMS Centers program. More than 15,000 individuals are currently enrolled in the NDB. Each TBIMS center collects and enters into the NDB an identical data set on each individual, which captures:

- Emergency and acute care information such as CT scan findings and depth/duration of loss or alteration of consciousness;
- Status and progress during inpatient rehabilitation;
- Pre-injury social and demographic data;
- Findings from a battery of measures assessing functional, social, emotional, and medical outcomes at 1, 2, 5, 10, 15 years after the TBI and every five years thereafter. The TBIMS is unique in the scope of its longitudinal data on the outcomes of persons with complex mild/moderate/severe TBI.

Recent research has confirmed that the TBIMS NDB is representative of persons receiving inpatient rehabilitation for TBI in the US.

In addition to the enrollment and data capture for the NDB, NIDILRR funding supports the following types of TBI research within TBIMS Centers:

- Data mining studies, which examine relationships among existing data elements in the NDB;
- Local research projects, which are site-specific studies proposed for each 5-year grant cycle;
- Module research projects, which are time-limited, multi-center studies designed to capitalize on the TBIMS infrastructure to address focused research questions that cannot feasibly be answered by a single center. In each 5-year cycle, centers propose and participate in modular studies of interest to them. Module projects have produced new knowledge on (e.g.) the natural history and typology of headache after TBI, the prevalence and outcomes of treatments for deep venous thrombosis, and the feasibility and utility of assessing cognitive function via telephone.

The TBIMS centers work in collaboration with the separately-funded Model Systems Knowledge Translation Center to provide scientific results and information for dissemination to stakeholders, including persons with TBI and their families, researchers, clinicians, and policymakers.

Source

This is a publication of the TBIMS Centers and the Model Systems Knowledge Translation Center at American Institutes for Research, Washington, DC (Grant Number 90DP0082). These centers are funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, an agency within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).

https://tbims.tbindsc.org/StaticFiles/Documents/TBIMS_Center_Description.pdf
The following Centers were also funded for 2017-2022; congratulations are in order and we look forward to collaborating in many ways over the coming years.

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<tr>
<th>Center Description</th>
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<td>The Virginia Commonwealth TBI Model System</td>
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<td>The Institute for Rehabilitation and Research (TIRR Memorial Hermann)</td>
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<td>Southeastern Michigan Traumatic Brain Injury System (SEMTBIS)</td>
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<td>The Ohio Regional TBI Model System</td>
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<td>Moss TBI Model System</td>
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<td>University of Alabama at Birmingham Traumatic Brain Injury Care System</td>
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<td>Rocky Mountain Regional Brain Injury System</td>
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<td>Spaulding-Harvard Traumatic Brain Injury Model System</td>
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<td>Mayo Clinic Traumatic Brain Injury Model System</td>
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<td>Northern New Jersey Traumatic Brain Injury System (NNJTBIS)</td>
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<td>University of Washington Traumatic Brain Injury Model System</td>
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<td>JFK-Johnson Rehabilitation Institute Traumatic Brain Injury Model System</td>
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<td>North Texas Traumatic Brain Injury Model System</td>
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<td>New York Traumatic Brain Injury Model System</td>
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<td>Rusk Rehabilitation TBIMS at NYU</td>
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<td>Indiana University / Rehabilitation Hospital of Indiana</td>
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https://tbims.tbindsc.org/Centers.aspx

Module Research

All Traumatic Brain Injury Model System Centers are required to also participate in at least one multi-center Module study per funding cycle. Mayo Clinic will participate in four Modules during 2017-2022:

- Trajectories of cognitive functioning years after TBI (Lead Center: New York Traumatic Brain Injury Model System)
- Return to driving after moderate-severe TBI (Lead Center: University of Alabama at Birmingham Traumatic Brain Injury Care System)
- Physical activity and its relationship with disabling secondary conditions (Lead Center: University of Washington Traumatic Brain Injury Model System)
- Caregiver resilience: A longitudinal investigation (Lead Center: the Virginia Commonwealth TBI Model System)

During the 2012-2017 funding cycle, Mayo Clinic participated in the following Modules:

- Internet use and online social participation among individuals with TBI (Lead Center: Rocky Mountain Regional Brain Injury System)
- Resilience after TBI (Lead Center: the Virginia Commonwealth TBI Model System)
- Test-retest reliability of Traumatic Brain Injury Model System Center form II measures with people with TBI (Lead Center: the Ohio Regional TBI Model System)
- Understanding causes of death in the TBI Model Systems (Lead Center: New York Traumatic Brain Injury Model System)
- Incorporating TBI Model System data into the Federal Interagency TBI Research (FITBIR) informatics system (Lead Center: Rocky Mountain Regional Brain Injury System)
CONNECT Trial Update

The CONNECT Trial formed the foundation for the MRFI Trial. Enrollment in the CONNECT Trial has ended. Lack of access to specialized TBI care is a common need identified by individuals hospitalized for TBI. Explosive advances in communication technology have brought telemedicine to the forefront of health care. The CONNECT Trial aims to remotely connect the following groups to Mayo TBI rehabilitation specialists and to each other using traditional (telephone, mail) and other (web based, email, smart phone, text, social media, Skype) communication technology:

- Individuals at least 18 years old recently hospitalized with TBI
- Their families
- Their local providers (primary care providers, other doctors, therapists, social service providers, job counselors, case managers, etc.)

We are testing the extent to which remotely partnering with the individual with brain injury, their family, and their local providers to offer TBI specific education, consult on management of common TBI problems, and help coordinate care to promote recovery and return to work, school, and family life is feasible, effective, and satisfying for everybody involved. We are conducting this first-of-its-kind study in Minnesota, Iowa, North Dakota, and South Dakota. Potential research subjects were identified through collaboration with the Departments of Health in Minnesota and Iowa, Altru Health System in Grand Forks, North Dakota, and Regional Health in Rapid City, South Dakota. The long term outcome of this study is to reduce barriers to accessing specialized TBI rehabilitation care faced by individuals with TBI and their families.

The intervention and data collection phase of the study will continue through 2018. An article describing the project was recently published in Brain Injury Professionals, an issue which featured practice innovations. Future data analyses and publications are planned upon completion of data collection.

http://www.internationalbrain.org/media/files/files/34ec9ab8/bip50.pdf
Mayo Clinic was again named the best hospital in the country in U.S. News & World Report’s annual list of top hospitals. Their 28th-annual Best Hospitals (https://www.usnews.com/info/blogs/press-room/articles/2017-08-08/us-news-announces-2017-18-best-hospitals) issue was released in August. Mayo Clinic also ranked No. 1 in Arizona, Florida and Minnesota and No. 1 in the Jacksonville, Florida, and Phoenix, Arizona metro areas. In addition, Mayo Clinic’s Arizona campus ranked No. 20 among hospitals nationwide and is the first Arizona hospital to rank on the Honor Roll. U.S. News & World Report ranks specialties on various factors including safety, mortality, nursing Magnet status, patient services, and reputation with other specialists. Mayo Clinic has more No. 1 rankings than any other provider.

The Rehabilitation Unit Recognized for Excellence

The inpatient Rehabilitation Unit at Mayo Clinic Hospital — Rochester was selected to receive the 2017 Service Excellence and Patient Experience Award for being one of the top performers across the Mayo Clinic Enterprise in patient satisfaction. The Rehabilitation Unit was selected from 156 Mayo Clinic Rochester Medical Practice sites and 54 inpatient units. Top performers were identified based upon overall percentile rank in the 2016 Press Ganey survey returns. An institution-wide recognition event celebrating the unparalleled service that the Rehabilitation Unit provides to our patients every day was held in June 2017. As the acute arm of the Mayo Clinic TBI Model System Center, this award underscores the quality of care the inpatient team provides and highlights the fact they always go above-and-beyond for the needs of our patients. Congratulations!
This story originally appeared in In the Loop on July 31, 2017. To see more stories like this, visit the In the Loop blog or write to intheloop@mayo.edu to subscribe the newsletter.

In 1996, 22-year-old Joe Oppold had the world by the tail. He’d just graduated from the U.S. Military Academy at West Point and was at home in Waterloo, Iowa, preparing to set off and make his mark. Two weeks later, however, Joe began experiencing an increasingly severe headache.

“It was very, very painful,” he tells us.

Joe initially tried to sleep away the pain. “But it was so intense that I just couldn’t sleep,” he tells us. His mother drove him to their local Emergency Department, where doctors suspected Joe had a cerebral aneurysm. Doctors told his mother that, given the circumstances, Joe’s best hope would be to get treatment elsewhere. “They didn’t have the neurological equipment and capabilities that a place like Mayo Clinic has,” Joe tells us. Moments later, Joe was put in an ambulance and driven to Mayo Clinic’s Rochester campus, where neurosurgeon David Piepgras, M.D., and his surgical team were waiting.

After confirming Joe’s diagnosis, Dr. Piepgras and team spent the next 16-plus hours trying to surgically repair the aneurysm. It was a high-risk procedure. “I knew in my heart that the risks for major stroke, possibly even fatal stroke, with such an operation were relatively high,” Dr. Piepgras tells us, “but at that time in 1996, there were no other treatment options.”

Part-way through the operation, Dr. Piepgras’ worst fears materialized. Joe’s aneurysm suddenly ruptured, causing a massive stroke that would leave Joe paralyzed on the right side of his body and unable to speak.

Although Dr. Piepgras was able to bring him out of surgery alive, Joe was told it was unlikely he’d ever walk or talk again. Joe, however, refused to accept that prognosis. And with the help of regular physical, occupational, and speech therapy, he has spent the past 21 years defying those odds.

Last December, Joe published a detailed account of exactly how he did it in an autobiographical tell-all titled, “That’s a Great Haircut!” And when it came time to write the book’s foreword, he knew just who to ask: Dr. Piepgras. “He’s seen firsthand how I’ve improved over the years,” Joe says. “He knows exactly where I was at the beginning of all of this, and he knows exactly where I am today.”

Joe tells us there was one more reason he wanted Dr. Piepgras to contribute to his book. “He saved my life,” he says. “I barely survived my aneurysm, and I don’t believe that I would have if he hadn’t been my neurosurgeon.”

As to why he agreed to contribute to Joe’s book, Dr. Piepgras tells us it’s all right there in the foreword. “Young man, peak of physical and mental conditioning, struck down by an intracranial vascular disruption and left with a major disability, yet he has persevered, maintained a positive attitude and is succeeding in life more than many folks without disability,” Dr. Piepgras says. “Joe is a remarkable guy and as I write in the foreword, an unforgettable person and case for this neurosurgeon.”

You can read that entire foreword in Joe’s book, which is available from Amazon (https://www.amazon.com/Thats-Great-Haircut-Joe-Oppold/dp/1635247314) and Barnes & Noble.
New Website for Rehabilitation Measures Database

The Shirley Ryan Ability Lab has launched a new website for the Rehabilitation Measures Database (RMD). RMD is a free, publicly accessible, online resource that provides summaries of research evidence to support implementation of standardized assessments into clinical practice. RMD helps clinicians select valid and sensitive instruments to screen patients, monitor their progress, and assess rehabilitation outcomes. The new website includes summaries for 400+ instruments that are suitable for use in rehabilitation settings and includes additional educational content. Measures are available as they pertain to the following medical diagnoses: brain injury, stroke, spine injury, Parkinson’s Disease, neuromuscular conditions, vestibular disorders, cancer, older adults and geriatric care, musculoskeletal conditions, and arthritis.

Access the new website at https://www.sralab.org/rehabilitation-measures

Model System Knowledge Translation Center – TBI and Memory Resources

This Hot Topic Module from the Model System Knowledge Translation Center (MSKTC) consists of a suite of resources to help individuals with TBI understand changes in memory and offers strategies that can help people who experience this function more effectively.

VIDEOS: Changes in Memory After Traumatic Brain Injury

The featured video and brief video clips explain changes in memory after TBI. Jason Cowper and Tonya Howell share their stories of coming to terms with changes in their memory, and strategies they use to compensate for these changes. The video also includes the perspectives of TBI experts at the Texas TBI Model System of TIRR Memorial Hermann, who provide clinical insight on the changes in memory that some people experience after sustaining a TBI.

View the featured video here: http://www.msktc.org/tbi/Hot-Topics/Memory/TBI_and_Memory

View additional video clips here: http://www.msktc.org/tbi/videos
FACTSHEET: Memory and Moderate to Severe Traumatic Brain Injury

This fact sheet explains memory problems that may affect people with moderate to severe TBI. By understanding the new limits on their memory and ways to help overcome those limits, people with TBI can still get things done every day.

View the factsheet here: http://www.msktc.org/tbi/factsheets/Memory-And-Traumatic-Brain-Injury

SLIDESHOW: Memory and Moderate to Severe Traumatic Brain Injury

Memory problems are very common in people with moderate to severe TBI. The information in this slideshow explains memory problems that may affect people with moderate to severe TBI.

View the slideshow here: http://www.msktc.org/tbi/slideshows/Memory-And-Traumatic-Brain-Injury

Publications


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.

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

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