

# Traumatic Brain Injury

## *Facts and Figures*

## New Research Initiatives Focus on Novel Interventions and Long-Term Outcomes

*Steve Flanagan, M.D.*

*New York Traumatic Brain Injury Model System*

The primary purpose of the Traumatic Brain Injury Model Systems of Care is to conduct a prospective multi-center evaluation of the course of recovery and outcomes of individuals with traumatic brain injury throughout their life spans. This is largely achieved by the collection of a prescribed set of variables on subjects enrolled in the centers funded as a model system, which constitutes the TBI National Database. This data set provides an important source of information for research and public policy development in accordance with the overall vision of the model systems.

However, local research projects conducted by the individual model system centers provide additional information that advances the understanding and treatment of TBI. Over 40 research projects are planned by individual centers during this 5-year funding cycle, with many more collaborative studies currently in the planning and implementation phases. While the proposed research will address several longstanding issues, such as prediction of outcomes, mood and behavioral disorders, cognitive impairments, and impact on caregivers, other less well studied topics will be explored, often with new technologies and treatments. There is a strong focus on well designed pharmacological trials, while other projects will examine the utility of advanced neuroimaging techniques to predict outcomes, characterize specific impairments, and enhance treatments. Technological advances will also be examined as a means to enhance care and quality of life following TBI. Finally, several poorly understood conditions will be explored,

including post-TBI fatigue, motor disorders, seizures and irritability.

This article will briefly review and describe the local research in this funding cycle. To better conceptualize the plethora of research, the trials can be categorized into 5 broad categories:

- Pharmacological studies
- Technological studies
- Outcomes studies
- Studies examining the impact on caregivers and society
- Studies on specific conditions

### Pharmacology Studies

Seven centers will engage in at least one study examining the impact of various drugs on several TBI-related conditions, including fatigue, depression, irritability, confusion, and spasticity. The Rocky Mountain Regional and New York model systems will study the effectiveness of modafinil for the treatment of excessive daytime somnolence, both in double-blinded, placebo-controlled trials. Modafinil is a relatively new drug approved to treat the symptoms of narcolepsy that has recently been shown to be beneficial in other neurological conditions. Three centers, the University of Alabama, New York and Virginia will each separately study the effectiveness of antidepressant medications for the treatment of post-TBI mood disorders. Despite the prevalence of depression following TBI, surprisingly little research has examined treatment strategies, underscoring the importance of these projects. The Carolinas system will examine the

## Inside This Issue

<i>New Research Initiatives</i> . . . . .	1
<i>Center Spotlights</i> . . . . .	2
<i>Database Update</i> . . . . .	8
<i>TBIMS Contact List</i> . . . . .	11

## Carolinas Traumatic Brain Injury Rehabilitation and Research System Charlotte Institute of Rehabilitation Charlotte, NC



The Charlotte Institute of Rehabilitation was originally opened in 1950 as the Charlotte Spastics Hospital, primarily serving children with physical handicaps. In those early years, with only 16 beds and a tenacious commitment to serve the community, the hospital was laying the foundation of a proud legacy. Over the next three decades the facility would go through 2 major additions/renovations, its first name change, and both the (then) JCAH and CARF accreditation processes. During that time the “Charlotte Rehabilitation Hospital” also joined forces with the Charlotte-Mecklenburg Hospital Authority and its nearby 320-bed general hospital. A 400-foot underground tunnel was constructed to provide a dry and direct route between the 2 facilities, laying the proverbial “groundwork” for the strong connections and collaborations that exist between the facilities today. The Charlotte-Mecklenburg Hospital Authority is now known as the Carolinas HealthCare System (CHS), and is the nation’s 4th largest publicly owned healthcare system. Carolinas Medical Center (CMC), the 777-bed acute care hospital next door, is the largest of North Carolina’s five Level I Trauma Centers and the only such facility in the Western NC region. Carolinas Medical Center is one of five medical centers in the state designated as an Academic Medical Center Teaching Hospital. Carolinas Medical Center offers comprehensive, state of the art emergency medical, trauma and surgical care rivaling that of even the most elite academic centers.

In the early 1990’s, the academic department of Physical

Medicine and Rehabilitation was established, most of the current faculty was hired, and we became the Charlotte Institute of Rehabilitation (CIR). The residency program in Physical Medicine was also established, and currently carries 5-year accreditation, the highest possible. Since those humble beginnings, the now 133-bed Charlotte Institute of Rehabilitation has been meeting the rehabilitation needs of adults and children with brain injury, spinal cord injury, stroke, cancer and orthopedic issues from the Carolinas, Tennessee, Virginia, West Virginia, Georgia and beyond.

### Model System of Care for Traumatic Brain Injury

The Carolinas Traumatic Brain Injury Rehabilitation and Research System (CTBIRRS) is the name of the Traumatic Brain Injury Model System based at the Charlotte Institute of Rehabilitation. The System activates the moment the primary traumatic event occurs, when emergency medical services are initiated. A state-of-the-art communications center enables crews to consult physicians, rapidly develop a care plan, and expedite transport to the emergency department at Carolinas Medical Center (CMC). In addition to MEDIC, the county’s ambulance system, CMC operates MedCenter Air, a fleet that includes fixed wing aircraft and helicopters custom-equipped to serve as airborne critical care units. With flight ranges of 300 miles, multidisciplinary teams can effectively enter and exit scenes in remote locations. CMC has the busiest emergency department in the state caring for over 3,500 traumas annually, approximately 1,500 of those being acute TBI’s. Weekly multidisciplinary trauma rounds include physiatric (doctors specializing in physical medicine and rehabilitation) representation, which facilitates early rehabilitation interventions and enhances coordinated care. Continuity between acute care and rehabilitation is enhanced further through multidisciplinary involvement in Trauma quality assurance and program process review. Our system of care also includes a strong prevention program through the Carolinas Center for Injury Prevention based at Carolinas Medical Center. Program-related activities are conducted through the Mecklenburg Safe Communities Program, a coalition of more than 40 members representing more than 30 organizations and individuals in the community.

Charlotte Institute of Rehabilitation (CIR) provides the comprehensive acute medical rehabilitation for the CTBIRRS. The Commission on Accreditation of Rehabilitation Facilities (CARF) has accredited 12 CIR programs, including Comprehensive Inpatient Rehabilitation, Brain Injury Program

*continued on page 3*

## Charlotte Institute

*continued from page 2*

(both acute and outpatient day treatment), and Vocational Evaluation. CIR is the largest rehabilitation hospital in the region and houses the Carolinas' most comprehensive brain injury unit, with 42 beds, including the state's only neuro-behavioral unit. Community transition and support services are offered through vocational services, which includes evaluation, work adjustment and long-term supported employment. Project STAR is a state-supported program at CIR that offers community-based support groups throughout the county as well coordination and facilitation of linkage with community agencies. Project STAR also provides technical support and on-site planning and evaluation of community programs that are or hope to serve individuals with TBI. Project STAR offers a compensatory education and community leisure class for individuals with TBI in collaboration with Central Piedmont Community College. The Adaptive Sports and Adventures Program of CIR offers outings, adventures and team sport opportunities to individuals with both cognitive and physical disabilities.

## Our Mission

The mission of Carolinas Traumatic Brain Injury Rehabilitation and Research System is *"Improve care and outcome for survivors of TBI through a model system of care using research and dissemination to expand and enhance services throughout their lifetime."* For the last 5 years, the primary funding for this project has come from the National Institute on Disability and Rehabilitation Research, but over the years we have had many partners who have supported our commitment to improve outcomes of people with TBI. The Carolinas HealthCare Foundation, the State of North Carolina, the Health Resources Services Administration (HRSA), and the Brain Injury Association of North Carolina are some of the agency partners in our research of innovative treatments and services. Because of this support and the hard work and dedication of our faculty and staff, Charlotte Institute of Rehabilitation has become one of the country's premier rehabilitation centers for traumatic brain injury.

## Excellence in Research

Research efforts of the CTBIRRS have focused on generating new knowledge that will support the full inclusion and integration of individuals with disabilities due to TBI in their communities and society. Research programs can only produce such long-term outcomes when they are multi-faceted, comprehensive and rigorous, and span many years. For this reason, CTBIRRS is committed to active participation in investigator-initiated and pharmaceutically sponsored trials of new medications in both the acute and community settings that seek to mitigate the effects of TBI. We also engage in longitudinal research of natural recovery and outcomes as well as cross-sectional surveys to better understand impact of TBI on community and family life.

Researchers of CTBIRRS have engaged in systematic study of factors associated with outcomes following TBI for some time. One particular outcome currently under study is the per-

sistent irritability that occurs in up to 70% of people with TBI. Current research projects are aimed at addressing treatment needs and understanding environmental factors related to the presence of irritability. CTBIRRS is currently enrolling subjects in a randomized controlled trial of the safety and efficacy of amantadine hydrochloride for treating irritability. A survey study of caregivers that report post-traumatic irritability in the subject with TBI is also underway.

## Innovative Services and Community-based Supports

CTBIRRS work closely with discharge planners and nurses in the acute center, and service providers in the community to build capacity for educating and supporting those experiencing TBI. Through work done in conjunction with a Health Resources and Services Administration project and funds from the state, we learned that families experiencing traumatic brain injury need consistent, understandable and repeated education regarding TBI. After conducting many focus groups, interviews and collaborative sessions, we learned that the timing, content and amount of information offered must be consumer-driven. The need for consumer-driven education and support continues through acute rehabilitation and long after discharge. We also learned that capacity to deliver such support must be built and that materials were lacking. One product of this knowledge is the "Skill Pack for Families and Providers" which is now used throughout our state and has been made available for broad dissemination through the Brain Injury Association of North Carolina.

Every patient with TBI admitted for care at CIR receives personalized education for themselves and their family members. Based on information from both consumers and service providers, a variety of materials and formats were developed to meet the needs identified. The Family and Community Education Coordinator visits patients early in the rehabilitation stay. During this time, families have a chance to voice their questions and concerns, and learn more about TBI and the rehabilitation process. They are invited to participate in our hospital's TBI registry designed to facilitate ongoing education, support and community linkages especially after discharge. Participation in the registry also will ensure that patients and families are notified of new services, as they become available and are contacted regarding research for which they may be eligible. They are also encouraged to participate in the weekly Family Education Group. The TBI Resource Library at CIR, developed for the Central Piedmont Center of BIA of NC, provides a treasure trove of books, video, pamphlets and fact sheets to meet any informational need that arises. Each person discharging from the Charlotte Institute of Rehabilitation with TBI receives community follow-up from CTBIRRS staff at both 6 and 12 months post injury to address educational, support, and service needs.

For more information on Carolinas Traumatic Brain Injury Rehabilitation and Research System, visit us at [www.carolinashealthcare.org](http://www.carolinashealthcare.org) or call us at 704-355-1502.

## Mayo Clinic Traumatic Brain Injury Model System Rochester, Minnesota

The Mayo Clinic Traumatic Brain Injury Model System (TBIMS) is part of the Mayo Clinic College of Medicine. With over 23,000 health care providers (including 1,384 doctoral staff and 1,548 residents, fellows, and medical students), extensive outpatient facilities, and nearly 2,000 hospital-beds, Mayo Clinic-Rochester is a world resource that hosts 1.5 million patient visits each year from people of highly diverse ethnic, racial, cultural, and religious backgrounds. Despite Mayo-Rochester's status as a world class medical center, nearly 80% of its patients come from Minnesota and adjoining states. Mayo Clinic provides tertiary care to a network of affiliated primary care centers in 60 other communities throughout southern Minnesota, northern Iowa, and western Wisconsin. Most people with brain injury served at Mayo come from this largely rural region in the upper Midwest.



### Rehabilitation

Mayo rehabilitation programs consistently rank among the top programs in the USNews annual report on the best hospitals in America, and are JCAHO- and CARF-accredited for General Rehabilitation, Spinal Cord Injury Rehabilitation, Inpatient Brain Injury Rehabilitation, and Outpatient Brain Injury Rehabilitation. The Department of Physical Medicine and Rehabilitation (PM&R) provides comprehensive and long term rehabilitation services to people with TBI served through the Mayo Clinic TBIMS. The Department of PM&R occupies approximately 60,000 square feet in Mayo-Clinic Rochester facilities that include a 42-bed inpatient unit, group and individual treatment areas, patient kitchens, a patient apartment, fully equipped gyms and treatment areas, and patient computers.

Outpatient brain injury rehabilitation includes the **Brain Rehabilitation Clinic**, the **Comprehensive Day Treatment program**, **Specialized Vocational Services**, and cognitive and other individual and group rehabilitation services. The **Comprehensive Day Treatment** program is a 5 day per week, 4 to 5 hour per day program that engages participants in group-oriented interventions provided by a transdisciplinary team. Participants learn to maximize strengths and reduce disability associated with pervasive cognitive, behavioral, and emotional impairments after TBI including impaired self-awareness. **Specialized Vocational Services** are also provided to assist outpatients with vocational goals to return to full participation in community life and work. One year after completing brain injury vocational services through Mayo, 70-80% of those served maintain community-based employment.

### Mayo Clinic TBIMS

As a Level I Trauma Center, Mayo-Rochester serves virtually all people with moderate to severe TBI in the region. Mayo Clinic's extensive and comprehensive medical and rehabilitation services—including highly respected Emergency, Neurosurgical, Neurology, and PM&R Departments—meet the clinical needs of people with TBI served through the Mayo Clinic TBIMS.

All patients with significant TBI admitted through the Mayo Clinic Level I Trauma Center are followed by Anne M. Moessner, RN, MSN who serves as the TBI Clinical Nurse Specialist and Project Coordinator for the Mayo Clinic TBIMS. She reviews the medical record, meets with the patient, provides education to the patient and family or significant other, facilitates early PM&R consultation and additional services to the primary medical service, obtains consent for TBIMS studies, and assures that data from participants are entered into the research database. The TBI Clinical Nurse Specialist follows the patient after dismissal from acute care and maintains contact with the patient and significant others while on the rehabilitation unit by attending Patient Care Conferences and serving as a primary resource for dismissal planning. After hospital dismissal, she again follows up personally and by telephone.

Within the Mayo system, services for people with TBI at Mayo are overseen by the **Mayo Acquired Brain Disorders Committee**. Since 1992, this Committee has provided oversight to assure quality and coordination of the clinical care of people with brain injury served at Mayo-Rochester. The Mayo Acquired Brain Disorders Committee is chaired by Allen W. Brown, MD (Medical Director of the Mayo Clinic TBIMS) and consists of physicians from Physical Medicine and Rehabilitation, Neurology, Neurosurgery, Emergency Medicine, Psychiatry, and representatives from Rehabilitation Nursing, Emergency Nursing, Neuropsychology and Rehabilitation Psychology, Vocational Rehabilitation, Medical Social Service, and Administration.

The **Mayo TBI Regional Advisory Council** has counseled Mayo TBI Rehabilitation staff about needs and services and has worked with Mayo to develop regional resources for people with TBI since 1991. The Council includes people and families with brain injuries and representatives of the Brain Injury Associations, including the Indigenous Peoples Brain Injury Association, Social Service, and Vocational Service agencies from the 5-state region surrounding Mayo. The Council provided oversight and direction to the Mayo Clinic TBIMS during its initial funding cycle, and assisted in developing the proposal for the second funding cycle. The Council continues to provide oversight and direction to the Mayo Clinic TBIMS in the current funding cycle.

*continued on page 5*

## Mayo Clinic

continued from page 4

### Dissemination

During its initial funding cycle (1998-2002), the Mayo Clinic TBIMS produced:

- 11 articles in peer-reviewed journals
- 15 book chapters and other publications
- 32 national/international, 36 regional, and 41 local presentations.
- *Living with Brain Injury: A Guide for Employers* (over 7,600 copies distributed)
- *Living with Brain Injury: A Guide for Families* (over 4,500 copies distributed)
- Mayo Clinic TBIMS web site ([www.mayo.edu/model-system](http://www.mayo.edu/model-system))

### Ongoing research and activities

In the 2002-2007 funding cycle, the Mayo Clinic TBIMS continues to work with other TBIMS and the TBI National Data Center in developing the National TBI Database and in collaborative research projects. Additionally three primary research projects are being conducted at Mayo Clinic-Rochester.

#### Rehabilitation Pathways

James F. Malec, Ph.D., Mayo Clinic TBIMS Project Director, serves as Principal Investigator for this study which will follow all people (approximately 100 per year) hospitalized with moderate-to-severe TBI through the first two years post-injury, and will follow another cohort of outpatients who complete an evaluation and subsequently receive outpatient rehabilitation and vocational services at Mayo. Goals of the project are to: (1) identify factors which affect decisions made by people with TBI, significant others, and health care providers regarding pathways of rehabilitative services; (2) identify factors associated with positive outcomes (i.e., living independently; community-based employment) following service along various rehabilitation pathways; (3) compare outcomes of various rehabilitation pathways, for instance, long term outcomes of those participating in inpatient rehabilitation compared to those who were discharged to home from acute care.

#### Very Long Term Process and Outcome of TBI

Allen W. Brown, M. D., Medical Director, Mayo Clinic TBIMS, is Principal Investigator for this study. This project capitalizes on the unique opportunity afforded by the longstanding Rochester Epidemiology Project to examine long term outcome in people diagnosed with significant TBI from 1935 to 2000. The Rochester Epidemiology Project provides centralized access to medical diagnoses and medical records for all residents of Olmsted County, Minnesota. This study is designed to investigate factors which create supports or barriers to successful community and vocational reintegration after TBI through questionnaire and telephone interview follow-up of a population-based sample of people with TBI sustained 5 to 20 or more years previously. Specific goals of the project are to (1) identify a population-based sample of people surviving TBI in Olmsted County for injuries that occurred during the period from 1935 to 2000, stratified by injury severity; (2) identify factors associated with positive outcomes such as successful employment, sustaining relationships, successful ageing, independ-

ent living, and satisfaction with current living status in the identified population-based sample; (3) examine the relationship of outcomes to age, gender, and injury severity.

#### Telehealth Cognitive Rehabilitation

Thomas Bergquist, Ph.D., Program Director, Mayo Brain Injury Outpatient Services, serves as Principal Investigator of this study which will be conducted to two phases: Phase I (first two years) involves a pre-post comparison of effects of internet/email-based cognitive rehabilitation to identify characteristics of people able to participate in and potentially benefit from such interventions. The Phase I trial will also provide data and experience needed to refine intervention and measurement tools in absence of a substantial body of previous research literature. During the last three years of the project (Phase II), a randomized controlled trial of internet-based cognitive rehabilitation based on experience in the Phase I trial will be conducted. Primary goals of the study are to (1) identify factors (such as, severity of injury, cognitive impairment, level of emotional distress) that predict which individuals with TBI will be able to participate in and potentially benefit from telehealth cognitive rehabilitation, and (2) evaluate the effects of telehealth cognitive rehabilitation on both subjective and objective measures of emotional and cognitive functions in people with TBI.

#### Advocacy Training Project

Another element of the Mayo Clinic TBIMS is the **Advocacy Training Project** which was launched in 2003 in collaboration with the Fairhaven Institute, Advocating Change Together (ACT), and regional BIAs. The Fairhaven Institute is a consumer-directed research, information, and advocacy program directed by and for people with brain injury. ACT is a Minnesota-based nonprofit group with 15 years experience in assisting people with disabilities in developing self-advocacy skills. Goals of ACT are to: (1) assist people with brain injury and significant others to maximize access to quality services, and to increase governmental and public awareness of brain injury; (2) provide information and education about brain injury to participants and significant others that will improve their ability to live successfully after brain injury and obtain full access to community life and work; (3) obtain feedback from participants and significant others about the impact and role of the Mayo Clinic TBIMS in the region.

### Mayo Clinic TBIMS and Its Region

TBI annual incidence rates for rural areas (464 per 100,000) are similar to rates for urban communities (461 per 100,000; Sosin et al, *Brain Injury* 1996;10:47-54). Annegers's (*Neurology* 1980;30:912-9) seminal work almost 20 years ago indicated a rate of 386 per 100,000 in Mayo's home of Olmsted County, Minnesota. People with TBI in rural regions of the U. S.—unlike their urban counterparts—often live long distances from major medical and rehabilitation centers that provide specialized services for people with TBI, and arguably constitute an overlooked and under-served minority. The Mayo Clinic TBI Model System (TBIMS) is designed to continue to address the needs of people with TBI in our region...to open doors through practice, research, and education to full participation in work and community life.

## New Research Initiatives

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effectiveness of amantadine on the treatment of irritability, while the Mississippi system will investigate the effects of two separate drugs with distinct neurotransmitter effects on post-TBI confusional states. The Moss system will examine the utility of botulinum toxin injections for the treatment of severe spasticity and will also work to validate an observational rating scale of attention in a trial using a psychostimulant medication. These well-designed pharmacology trials have great potential to advance the field of evidence based medicine in TBI rehabilitation and represents a new focus in model system research.

## Technological Studies

Recent advances in functional neuroimaging, telemedicine, and assistive technology will be explored as potential means to better understand TBI-related impairments, improve treatments, and enhance quality of life. The Johnson Rehabilitation Institute, Spaulding, and North Texas Centers will each examine the potential utility of functional magnetic resonance imaging (fMRI). Research at Spaulding includes the development of functional neuroimaging as a tool to guide cognitive therapy. Both the Spaulding and North Texas systems will use fMRI data to predict and monitor outcomes; Spaulding in response to a cognitive retraining program and North Texas for functional recovery. The Johnson Institute will investigate the relationship between fMRI and neurobehavioral indices obtained from a standardized rating scale in individuals in the minimally conscious state.

In other technological studies, the Mayo Clinic will examine an internet cognitive rehabilitation system, a potentially important innovation in rural regions where large geographic distances often limit healthcare accessibility. Internet medicine also holds promise for those with limited or no health insurance benefits. Moss will utilize assistive technology to assist individuals with cognitive and behavioral disabilities, while the Mississippi system will investigate the use of transcranial magnetic stimulation to improve the understanding of post-TBI motor disorders; an important step towards improved treatment interventions.

The University of Pittsburgh will focus all of its local research on innovations in rehabilitation technology, examining its role on service delivery, functional outcome and therapeutic interventions. Research will include evaluating limitations in wheelchair design, a randomized trial investigating the efficacy of virtual reality and robotics, and implementation and evaluation of a web-based virtual case manager for persons with TBI and their families.

## Outcome Studies

Several systems will investigate various factors that impact long term outcomes. The Rocky Mountain Regional system will investigate the environmental and clinical conditions that influenced outcomes over a 40-year time frame to better understand the process

Table 1 – Areas of Research Focus and TBI Model Systems Involvement
<b>Pharmacological Studies</b>
Modafinil for treatment of fatigue (RMR, NY)
Management of depression (AL, NY, VA)
Amantadine for treatment of irritability (CAR)
Treatment of confusional states (MS)
Botulinum Toxin for spasticity management (MOSS)
Validation of a rating scale in psychostimulant trials (MOSS)
<b>Technology Studies</b>
Functional neuroimaging to guide cognitive therapy (SP)
fMRI to predict outcomes (SP, NT)
Relationship between fMRI and neurobehavioral indices (JRI)
Internet based cognitive rehabilitation systems (Mayo)
Assistive technologies for cognitive and behavioral disabilities (MOSS)
Transcranial magnetic stimulation in motor disorders (MS)
Innovations in rehabilitation technologies (UP)
<b>Outcome Studies</b>
Factors impacting on long term outcomes (RMR, MAYO)
Quality of life at various stages (JRI)
Genetic Impact (NT)
<b>Impact on Caregiver and Society</b>
Impact of irritability of caregivers and society (CAR)
Distress, family dysfunction and social modifiers (SEM)
Characteristic of successful return to stable employment (UW)
Therapeutic alliance between health providers, families and persons with TBI (MS)
Training program in problem solving for caregivers (AL)
Impact of PPS on brain injury rehabilitation (UW)
Rehabilitation Pathways (MAYO)
<b>Specific Conditions</b>
Exercise and mood (UW)
Factors impacting fatigue (NC, NY)
Impact of seizures (NC)
Effectiveness of cognitive remediation (JRI)
Structured approach to cognitive and neurobehavioral problems (VA)
Group treatment for social pragmatic skills (RMR)
Promoting retention in substance abuse treatment (OH)
Validity of a tool detecting prior TBI and impact on substance abuse treatment (OH)
<b>LEGEND</b>
<i>AL = Alabama; CAR = Carolinas; JRI = Johnson Rehabilitation Institute; MAYO = Mayo Clinic; MOSS = Moss; MS = Mississippi; NC = Northern California; NT = Northern Texas; NY = New York; OH = Ohio; RMR = Rocky Mountain Regional; SEM = Southeastern Michigan; SP = Spaulding; UP = University of Pittsburgh; UW = University of Washington; VA = Virginia</i>

of living and aging in individuals with TBI. Using a different approach, the Johnson Rehabilitation Institute will use qualitative inquiry to describe quality of life after TBI from the perspective of persons at various stages after their injury. Finally, the Mayo Clinic will utilize regional data to examine the very long-term outcome for people with TBI.

In a separate outcome study, the impact of genetics will be

*continued on page 7*

## New Research Initiatives

*continued from page 6*

explored by the North Texas system. Several candidate alleles will be examined as potential determinants of poorer outcome.

### Impact on Caregivers and Society

The Carolinas system will investigate several aspects of irritability. In addition to the previously mentioned investigation of amantadine, the relationship of post-TBI irritability on the caregiver and the nature of the problem as experienced by those in the community will be explored. The Southeastern Michigan system will examine the relationship of survivor-caregiver situations with survivor distress and family dysfunction and whether social supports act as a moderating influence on the well-being of the person with TBI. This system will also assess a peer-mentoring intervention program for persons with TBI and their caregivers as well as explore correlates of driving after TBI. The University of Washington will utilize data from their own system as well as from the TBI National Database to examine what characteristics enable persons with TBI to return to and maintain employment that is both stable and complex. Mississippi will develop and conduct a trial on an intervention to improve the therapeutic alliance between persons with TBI and their family members with professional staff in a post-acute brain injury program. The University of Alabama will study the impact of a training program in problem solving for caregivers.

The effect of various influences on inpatient brain injury rehabilitation will be explored by two systems. The University of Washington will study the impact of the Medicare prospective payment system on persons with TBI receiving acute rehabilitation services, while The Mayo Clinic will examine decision-making and outcomes of both inpatient and outpatient rehabilitation pathways.

### Specific Conditions

As in the past, many systems will investigate the development, treatment, and impact of numerous TBI-related conditions. Many previously described projects, using either drug or technology interventions, will address such diverse problems as depression, spasticity, motor disorders, and behavioral and attention impairments. Numerous other approaches to these and other conditions will also be undertaken by the individual centers.

In addition to the antidepressant studies by the Alabama, Virginia, and New York systems, the University of Washington will study the effect of exercise on mood by employing it as a means to promote socialization as well as to improve emotional and physical functioning. The Northern California and New York system will explore a multitude of factors that may contribute to post-TBI fatigue. The Northern California system will also continue its work on the impact of post-traumatic seizures in two projects. In one study, the TBI National Database will be used to compare the func-

tional, vocational and medical outcomes of those individuals with and without late post-traumatic seizures. In the second study, they will collaborate with the Denver Hospital Medical Center to explore the barriers to the environment, transportation and seizure control of seizures caused by late post-traumatic seizures.

Several systems will examine the impact of various cognitive and behavioral treatments. The Johnson Rehabilitation Institute will examine the current clinical and methodological concerns regarding the effectiveness of cognitive rehabilitation on cognitive functioning, community integration, social participation, return to school and work, and quality of life. The Virginia system will examine a structured approach to the treatment of acute cognitive and neurobehavioral problems. Lastly, the Rocky Mountain Regional system will explore the effectiveness of a group therapy intervention on social pragmatic communication.

As part of a two part study on substance abuse, the Ohio Regional system will conduct a randomized clinical trial examining interventions that promote retention in substance abuse treatment. The second study will investigate the validity on an instrument that objectively documents the extent of a person's prior history of TBI, in order to examine brain injury as a mediating factor in substance abuse treatment.

In summary, these projects reflect efforts to advance the understanding, impact and treatment of TBI in accordance with the priorities established by NIDRR. Much of this research is groundbreaking, and will ultimately lead to new treatments as well as new questions. A strong focus has been placed on interventional projects, which will advance evidenced-based care for individuals with TBI. Although not reviewed here, additional collaboration studies are planned, taking advantage of the wealth of subjects available in the model system.

**For more information,  
please visit the following websites:**

- Traumatic Brain Injury (TBI) Model Systems  
[www.tbincd.org](http://www.tbincd.org)
- Center for Outcome Measurement in Brain Injury (COMBI)  
[www.tbims.org/combi/](http://www.tbims.org/combi/)
- Brain Injury Association of America (BIAA)  
[http://www.biausa.org/Pages/tbi\\_model\\_systems.html](http://www.biausa.org/Pages/tbi_model_systems.html)

# Database Update

Scott Millis, Ph.D.

Traumatic Brain Injury National Data Center

Persons sustaining moderate to severe traumatic brain injury (TBI) may experience many changes in their lives that are attributable to the brain injury. For example, the cognitive and physical impairments associated with the brain injury may preclude returning to work or cause stress on interpersonal relationships. Although significant recovery occurs for most persons during the first year after the injury, less is known about longer term outcomes. In this issue of Facts and Figures, we examine outcomes at 1, 5, and 10 years post-injury on several variables and compare them with pre-injury status: marital status, residence, and employment status. We also examine global outcome (Glasgow Outcome Scale) and patients' subjective rating of satisfaction with life. Given the nature of data collection, we were not able to obtain information on all patients for all time periods. Hence, these data are cross-sectional.

## Marital Status

At 1-year post-injury, 87% of persons married at time of injury remained married. At 5 and 10 years, there was a decline in the percentage of patients still married, 70% and 74%, respectively. However, given the high rate of divorce in the general population, it is not clear whether the findings in this TBI sample reflect the disruptive impact of a brain injury on the family or other factors.

## Residence

In some cases, persons with severe brain injuries require help and supervision in carrying out activities of daily living. These handicaps can impose tremendous burden on families. At times, families may not be able to take care of the person with TBI in the home. We were surprised to find that 96% of persons discharged to home remained at home at 1-year post-injury. Similar rates were found at 5 and 10 years, 94% and 93%, respectively.

## Employment

Returning to competitive employment continues to be a major challenge following TBI. Even for persons employed at time of injury, only a little more than one-third has returned to work at 1-year, 5-years, and 10-years post-injury.

## Global Outcome

Global outcome, as measured by the Glasgow Outcome Scale – Extended appeared to be relatively stable over time. About one-third of the sample had good recovery while a similar proportion had severe disability. Although the purpose of the GOS-E was not to provide a detailed assessment of outcome, it is interesting to note that it shows the marked heterogeneity in outcome following moderate to severe TBI.

### GOS Year 1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	dead	11	.3	.6	.6
	vegetative state (vs)	12	.3	.7	1.3
	lower severe disability (lower sd)	252	6.9	14.5	15.9
	upper severe disability (upper sd)	273	7.4	15.8	31.6
	lower moderate disability (lower md)	273	7.4	15.8	47.4
	upper moderate disability (upper md)	347	9.5	2.0	67.4
	lower good recovery (lower gr)	267	7.3	15.4	82.9
	upper good recovery (upper gr)	297	8.1	17.1	100.0
	Total	1731	47.2	100.0	
Missing	System	1937	52.8		
<b>Total</b>		<b>3669</b>	<b>100.0</b>		

## Database Update

continued from page 8

## GOS Year 5

		Frequency	Percent	Valid Percent	Cumulative Percent	
Valid	dead	4	.1	1.3	1.3	
	lower severe disability (lower sd)	40	1.1	13.2	14.5	
	upper severe disability (upper sd)	42	1.1	13.9	28.4	
	lower moderate disability (lower md)	49	1.3	16.2	44.6	
	upper moderate disability (upper md)	66	1.8	21.8	66.3	
	lower good recovery (lower gr)	40	1.1	13.2	79.5	
	upper good recovery (upper gr)	62	1.7	20.5	100.0	
	Total	303	8.3	100.0		
	Missing	System	3366	91.7		
	<b>Total</b>		<b>3669</b>	<b>100.0</b>		

## GOS Year 10

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	dead	2	.1	1.1	1.1
	vegetative state (vs)	2	.1	1.1	2.3
	lower severe disability (lower sd)	30	.8	16.9	19.2
	upper severe disability (upper sd)	22	.6	12.4	31.6
	lower moderate disability (lower md)	28	.8	15.8	47.5
	upper moderate disability (upper md)	39	1.1	22.0	69.5
	lower good recovery (lower gr)	19	.5	10.7	80.2
	upper good recovery (upper gr)	35	1.0	19.8	100.0
	Total	177	4.8	100.0	
	Missing	System	3492	95.2	
<b>Total</b>		<b>3669</b>	<b>100.0</b>		

continued on page 10

## Database Update

continued from page 9

## Satisfaction With Life

The Satisfaction With Life Scale (SWLS) measures people's subjective global judgment of satisfaction with their lives. Normative data for the SWLS are available for a broad range of populations, including psychotherapy clients, older adults, and persons with physical disabilities. Overall, the mean scores on the SWLS were quite stable at 1, 2, and 5 years following TBI.

Normatively, the means lie within the "neutral" range, however the scores in our sample range from "extremely dissatisfied" to "extremely satisfied." Higher scores on the SWLS denote higher levels of life satisfaction. Our sample's mean score is similar in magnitude to a sample of students with physical disabilities (Pavot & Diener, 1993). Mean SWLS for psychotherapy clients and a VA hospital inpatient sample were 14.4 and 11.8, respectively.

## Conclusion

Several notable findings emerge from these data. Persons with moderate to severe TBI who have received inpatient medical rehabilitation have a very high likelihood of returning home and are likely to stay there. Persons who were married at time of injury are likely to stay married. Finally, there is a great deal of variability in outcome and subjective assessment of life satisfaction in person with moderate to severe TBI. A substantial portion showed good recovery while an equally substantial portion continued to have severe disability. Identifying those factors associated with good outcome will be important for treatment planning and resource allocation.

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## Satisfaction With Life Scale

	N	Minimum	Maximum	Mean	Std. Deviation
Year 1	1851	5.00	35.00	20.2037	8.2828
Year 2	1289	5.00	35.00	20.7091	8.2063
Year 5	353	5.00	35.00	20.5552	8.4617

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