

# Traumatic Brain Injury

## *Facts and Figures*

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The Traumatic Brain Injury Model Systems National Data Center

## 2nd Federal Traumatic Brain Injury Interagency Conference:

### Integrating Models of Research and Service Delivery

*Tamara Bushnik, Ph.D.  
Santa Clara Valley Medical Center*

In December 1999, the 1st Federal Interagency Conference on Traumatic Brain Injury was convened at the Hyatt Regency Bethesda in Bethesda, Maryland. Over 300 individuals, including approximately 25% consumers, were in attendance at this 2.5 day meeting. Feedback, both from participants and sponsors, indicated substantial satisfaction with this conference and a desire to repeat it in the future. Several specific spin-off collaborations between agencies resulted from this conference.

Due to the success of the inaugural conference and the significant advances that have occurred in TBI research and service delivery since that time, from March 9 to 11, 2006 the 2nd Federal Traumatic Brain Injury Interagency Conference will be held once again at the Hyatt Regency in Bethesda MD. The theme of this educational conference is ***“Integrating Models of Research and Service Delivery.”*** As in 1999, the upcoming conference is being led by the National Institute on Disability and Rehabilitation Research (NIDRR) Traumatic Brain Injury Model Systems of Care and coordinated by the TBI National Data Center (located at Kessler Medical Rehabilitation Research and Education Corporation (KMRREC).

The Program Planning Committee (chaired by Dr. Mitchell Rosenthal, TBINDC, and co-chaired by Tamara Bushnik, PhD, Santa Clara Valley Medical Center), was selected to reflect the interagency spirit of cooperation by involving representatives from the 6 sponsoring/supporting federal agencies: the Brain Injury Association of

America; the Centers for Disease Control and Prevention; the Defense and Veterans Brain Injury Center; the National Association of State Head Injury Administrators; NIDRR; and the Veterans Affairs Rehabilitation Research and Development Service. Additional sponsorship is being provided by the American Academy of Physical Medicine and Rehabilitation, the American Congress of Rehabilitation Medicine, and the Association of Academic Physiatrists.

The planning process kicked off with a face-to-face meeting of the Planning Committee in December 2004. At that meeting, committee members were challenged to create a program that was dynamic, interactive, and engaging in order to foster the exchange of ideas and cross-walk between agencies, grantees, and consumers. It was critical, from the committee’s perspective, that each set of thematic presentations (aka breakout sessions or workshops) have cross-agency representation and allow enough time for interaction and discussion with the ultimate goal of problem-solving and creating recommendations for next steps. During the ensuing brainstorming session, three primary Outcome tracks were identified:

- 1) Effective Practices That Improve Community Integration and Long-Term Outcomes for Individuals with TBI
- 2) Research Since the NIH Consensus Conference – Examining the Gaps in Carrying Out the Research Agenda and Identifying and Responding to Emerging Issues
- 3) Role of Technology in Expanding Rehabilitation and Community Services to Individuals with TBI

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## NIDRR Collaborative Studies of Rehabilitation Interventions for TBI

*John Whyte, M.D., Ph.D.*

*Moss Traumatic Brain Injury System*

Research on treatment efficacy and effectiveness is essential to guide advances in rehabilitation care for individuals with TBI. Yet there is consensus that the evidence base for most treatments provided to individuals with TBI is inadequate. This has implications not only for the care received by individuals with TBI, but also for healthcare coverage for treatments that can be argued to be of unproven value. NIDRR's TBI Model System program has traditionally focused more on descriptive research that characterizes the outcomes experienced by individuals with TBI. In recent years, however, through its collaborative research program, NIDRR has increasingly supported treatment-oriented research. This article describes currently funded collaborative studies that focus on the effectiveness of two treatments focused at very different levels: brain neurotransmitters, and psychosocial adaptation.

The first of these projects, "A Multicenter Randomized Controlled Trial of the Effectiveness of Amantadine Hydrochloride in Promoting Recovery of Function Following Severe Traumatic Brain Injury," is led by Joseph Giacino, Ph.D. at JFK Johnson Rehabilitation Institute, and John Whyte, M.D., Ph.D. at Moss Rehabilitation Research Institute, with collaborators at 6 additional clinical sites and a data coordinating center at Columbia University. The primary aim of this project is to determine whether 4 weeks of treatment of individuals in the vegetative (VS) or minimally conscious (MCS) state with the medication amantadine hydrochloride (AH), enhances functional outcome. If so, the investigators also wish to know whether the improved outcome lasts beyond the duration of medication treatment.

Over the last 20 years, many treatments have been recommended to enhance recovery from VS and MCS, including intensive "coma stimulation", various pharmacologic agents, deep brain stimulation, and hyperbaric oxygen treatment. Unfortunately, the evidence to support or refute these treatments has changed little during that time. Very few controlled studies have been done on any of these interventions, and those that have been done have been too small to rule out random variations in recovery as the source of group differences found.

This present study is a randomized double-blind placebo-controlled multi-center trial which aims to enroll a much larger sample of 180 participants. Individuals in the VS or MCS as a result of TBI are recruited between 4 and 16 weeks post injury, and randomized to a starting dose of 200 mg/day of AH or placebo. The primary outcome is change in score on the Disability Rating Scale, with secondary outcomes of change in diagnosis (VS or MCS) on the Coma Recovery Scale – Revised, improvement in a family-centered outcome of interest, and adverse effects. Randomization is stratified by treatment center, time post-injury, and VS vs. MCS. Those failing to improve after 2 weeks of treatment have a dose increase to 300 mg and then 400 mg/day of AH. Following com-

pletion of 4 weeks of treatment, the final outcome rating is obtained and the medication is withdrawn to see whether any treatment-related improvements are sustained.

This study is relatively straightforward in terms of study design. However, considerable preliminary work was required by the research collaborators to prepare for the study. This included pilot work to track variability of and predictors of spontaneous recovery,<sup>[1]</sup> and focus groups and interviews with rehabilitation staff and family members to identify study designs that would be ethically acceptable in the context of this catastrophic and stressful disability. The relatively short treatment duration was chosen in recognition that neither caregivers nor clinicians would accept a prolonged period of placebo treatment despite the unproven effects of the alternative treatments that would be foregone during the study.

The second study, "The Effect of Scheduled Telephone Intervention on Outcomes After Traumatic Brain Injury: A Multi-Center Randomized Controlled Trial," is led by Dr. Kathleen Bell at the University of Washington, with collaborators at Moss Rehabilitation Research Institute in Philadelphia, and Methodist Rehabilitation Center in Jackson, MS. This is also a randomized controlled multi-center trial, with blinded outcome assessment, but open label treatment.

The potentially life-long process of community reintegration and coping with TBI has barely begun at the completion of inpatient rehabilitation. Yet the resources available for subsequent services are increasingly limited. This limitation is compounded by geographic variations in the availability of skilled TBI rehabilitation professionals. Moreover, the ultimate goal of the rehabilitation process is to enhance the ability of individuals and their families to address their own future needs.

Taking these issues together, Dr. Bell and colleagues completed a single-site study during the previous funding cycle of the TBI Model System program, in which they showed that a service of scheduled telephone intervention following discharge from acute inpatient rehabilitation, enhanced a broad range of functional and psychosocial outcomes, in comparison to the usual post-discharge care system.<sup>[2]</sup> The results of this study were limited by the fact that it was confined to one specific system of care. In addition, the impact of the experimental service appeared to be weaker in patients who were members of ethnic minorities, although the sample size was too small to be sure that this was not a chance occurrence. Consequently, the current study aims to explore the same telephone intervention across 3 geographically and ethnically diverse treatment systems, and to examine whether the effectiveness of this treatment differs by ethnicity.

Upon completion of inpatient rehabilitation following moderate to severe TBI, consenting patients and their caregivers are randomized to receive a set of scheduled telephone contacts over the

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### Collaborative Studies

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ensuing 2 years from a Research Care Manager (RCM), or to continue with the routine follow up care provided by each treatment facility. Randomization is stratified by treatment center and discharge FIM score. Those receiving the experimental intervention are called with gradually decreasing frequency and interviewed about problems they may be having at home and in the community in a range of areas including medical, physical, cognitive, interpersonal, and vocational areas. Calls are ideally made to both the individual with TBI, and the identified caregiver, in order to ensure a full picture of the problems identified, and to enlist the caregiver's support in helping to address them. The telephone interventions are targeted toward helping the individual and caregiver to become increasingly effective in advocating for themselves and solving their own problems, though specific referrals for treatment and services are provided when necessary. Study participants are interviewed at 1 and 2 years post-injury about a range of functional, psychosocial, and community outcomes by a staff member unaware of which treatment they received. The impact of the treatment will be judged with respect to a composite score of this set of outcomes.

This study's challenges are quite different from the previous one, in that it raises fewer ethical concerns or difficulties in participant recruitment. But, whereas defining and standardizing a drug treatment is straightforward, defining and standardizing telephone interactions between different RCMs and a set of varied clients is

much more challenging. If this treatment trial demonstrates the value of structured telephone intervention, it will be critical to be able to clarify what is contained inside the "black box" of treatment. Thus, the study team has worked long and hard to develop a treatment manual and training and supervision process that are intended to distill the active ingredients of the intervention and facilitate subsequent dissemination. If the value of this treatment is replicated, it should be a relatively low-cost method for enhancing TBI outcomes more generally.

With the completion of these 2 studies, NIDRR will have helped, through its program of collaborative research, to advance the state of treatment effectiveness research in two important areas.

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### Brain Injury Interagency Conference

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Within each of these tracks, five essential questions were selected to further focus the solicitation and selection of presentations:

- 1) What do we know about the area?
- 2) What don't we know about the area?
- 3) How do we go about addressing the knowledge gap in the short-term?
- 4) How do we go about addressing the knowledge gap in the long-term?
- 5) Who should be working on the short-term and long-term gaps (agency funding, initiatives)?

Each of the Outcome tracks was championed by a subset of the Program Committee who took primary responsibility for formulating the program within that Outcome track. Workshop ideas were solicited from all of the federal agencies' grantees and constituents; gaps within each track were identified and further workshops were developed in order to create a program that reflects the newest program and research initiatives relevant to TBI. To further the goal of creating an interactive and challenging program, a discussant has been identified for each workshop; each discussant will be asked to provide his/her own perspective on the information presented and to identify key points and recommendations for the needed next steps in developing the program and/or research initiative.

The results of the Program Committee's work have come to fruition. The 2.5 day conference is comprised of 6 plenary sessions reflecting the three Outcome tracks, 35 workshops involving over 125 faculty members, and 58 scientific poster presentations that were solicited through an open call for submission in the fall of 2005. The conference syllabus will contain one-page abstracts for all of the plenaries, workshops, and posters. Each of the plenary sessions will result in a manuscript to be published in a special issue of *Journal of Head Trauma Rehabilitation*. Finally, the key points and recommendations identified by the discussants will be compiled into an executive summary, also to be published in the *Journal of Head Trauma Rehabilitation*, which can be used as a roadmap for continued development and progress towards our joint goal of improving the lives of individuals with TBI.

Registration for this exciting conference is currently open. Early registration, with a fee discount, is being accepted until February 10, 2006. Students, with proof of student status, can register for a significantly reduced fee. Special discounted rates are available for students and consumers. Continuing Education Credits will be available for physicians, psychologists, speech-language pathologists and audiologists, certified case managers, and certified disability management specialists. For further information and registration materials, please go to [www.tbi-interagency.org](http://www.tbi-interagency.org) or call 973-243-6812.

## The University of Pittsburgh TBI Model System of Care Pittsburgh, Pennsylvania

Founded in 1787, the University of Pittsburgh (a.k.a., "Pitt") is a state-affiliated university system with 5 campuses located throughout western Pennsylvania. The medical school (currently ranked 7th nationally in NIH funding) and University of Pittsburgh Medical Center (UPMC) are located on the main campus in the city of Pittsburgh, providing health care and research for much of western Pennsylvania, neighboring states, and persons seeking highly specialized care (e.g., complex multi-organ transplantations and unique forms of cancer treatments) from throughout the world. UPMC consists of 19 hospitals and a network of other care sites spanning a 29-county service area and includes inpatients and outpatient facilities, cancer centers, specialized imaging and surgery facilities, in-home care, rehabilitation units and clinics, behavioral health care, and nursing homes. With over 40,000 employees and a \$5 billion annual operating budget, UPMC is the region's largest employer and has tremendous influence on the local economy. Historically, the University has had strong rehabilitation and brain injury research, primarily from neuroscience, neurosurgical, and bioengineering perspectives. In 2000, a formal Department of Physical Medicine & Rehabilitation was established, which has capitalized upon — and greatly expanded — research and clinical care for persons with TBI. The University of Pittsburgh TBI Model System (UPTBIMS) was launched in October 2002.



### Acute TBI Care

**Pre-Hospital and Trauma Care:** Emergency trauma services for UPTBIMS are provided through the Center for Emergency Medicine (CEM). The CEM is a multi-hospital consortium dedicated to the advancement of emergency medicine through research, education, air medical transport and quality care, and provides a catchment that includes most of western Pennsylvania, northern West Virginia, and much of eastern Ohio. Pitt's Emergency Medicine residents work with the City of Pittsburgh Bureau of Emergency Medical Services and fly on STAT MedEvac helicopters. STAT MedEvac, a service of the CEM, provides air medical transport to patients with critical illnesses and/or injuries. The mean transport time from the estimated time of injury to arrival to our trauma center is 35 minutes. All pre-hospital providers adhere to head injury protocols developed at the University of Pittsburgh, which recommend the use of short acting neuromuscular paralytic agents when needed for pre-hospital intubation of patients, and conservative use of hyperventilation. The emergency department has three fully equipped trauma resuscita-

tion areas, with full monitoring and overhead radiographic capabilities, and four other treatment rooms in the trauma resuscitation area for patients with less severe injuries. One of the nine computed tomography (CT) units in the hospital is housed within the trauma resuscitation area to facilitate care of the trauma patients requiring urgent CT imaging. Four MRI units are also located within the hospital. A unique aspect of the system is the utilization of an all-digital imaging system that allows

for rapid collection and transfer of neuroimaging data in a rapid and confidential manner.

**Neurotrauma care:** Neurotrauma intensive care is provided in two neurotrauma intensive care units with state of the art monitoring capabilities. The total bed count is 20. Three neurotrauma research nurses help to facilitate care protocols. Capabilities include automated recording of hemodynamic parameters, intracranial pressure, and somatosensory evoked potentials, along with portable cerebral blood flow measurements. This information is directly downloaded to an informatics system that allows for collection, graphing and tracking. A physiatrist evaluates each TBI patient within 24 hours of admission, and PM&R faculty and staff meet each week with the neurotrauma team.

### Brain Injury Rehabilitation at the University of Pittsburgh

**Comprehensive Rehabilitation:** The University of Pittsburgh has a total of 180 inpatient rehabilitation beds located throughout its system. The UPMC Institute for Rehabilitation and Research (IRR) serves as the hub of this network and includes both inpatient and outpatient services. The IRR has dedicated rehabilitation units in two hospitals (one in UPMC South Side Hospital and one in UPMC Montefiore Hospital). At UPMC South Side, there is a 20-bed dedicated TBI unit; at UPMC Montefiore there is a 30-bed rehabilitation unit with up to 9 designated TBI beds. On both units, inpatient rehabilitation care is provided by multidisciplinary teams. Both clinical units were renovated and upgraded in mid-2005, providing patients with state-of-the-art facilities and access to novel technologies. The rehabilitation team consists of experienced professionals focused on treating this population. Standardized treatment and evaluation programs have been established in a multidisciplinary fashion. A unique informatics network allows for tracking and graphic representations of outcome parameters and acquisition of data from an electronic medical record. The clinical team consists of three physiatrists; a physiatric TBI Fellow; PM&R residents; rehabilitation nurses; occupational, physical, and speech

therapists; neuropsychologists & rehabilitation psychologists; an orthotist; case managers; vocational rehabilitation counselor; a rehabilitation engineer, and a therapeutic recreation staff.

**Post-Acute Rehabilitation:** Outpatient TBI services are under the direction of Drs. Lisa Lombard and Ross Zafonte. They are centered at UPMC IRR at South Side Hospital, but are also available at regional sites within our network. The program includes over 15 clinicians experienced in brain injury rehabilitation. The treatment plan addresses all aspects of cognitive, physical, social-behavioral function. Acute TBI patients are closely followed and seen within 1 month of rehabilitation discharge. It has been our policy to continue to follow such persons on an on going basis at 3, 6, 12, and 24 months post injury. The UPTBI Community Re-Entry Program aims to restore persons with TBI to the highest possible level of independent functioning at home, work, and in the community. A key component to successful community integration is transportation. The OT department at UPMC IRR provides a state-certified program for drivers with disabilities. The program provides driving pre-assessments and on-the-road evaluations. After discharge from the day treatment program, follow-up vocational and psychosocial services are provided, as needed. In conjunction with the State Office of Vocational Rehabilitation, our supported employment program places persons with TBI in programs facilitating return to work.

### University of Pittsburgh TBI Model System

The University of Pittsburgh TBI Model System (UPTBIMS) represents the efforts of dedicated consumers, clinicians and researchers. UPTBIMS's research focus is on innovations in rehabilitation engineering and technology for persons with TBI. Our center's three local projects ("Rehabilitation by Distortion," "Personal Powered Mobility," and "The Virtual Case Manager") capitalize on the University's strong background and capacities in such technologies.

**Rehabilitation by Distortion:** The University of Pittsburgh is located immediately adjacent to the campus of Carnegie Mellon University (CMU) and has a long collaborative history. Our close collaboration with Yoky Matsuoka, PhD, and Roberta Klatsky, PhD, of the Robotics Institute at CMU is allowing us to perform a randomized trial evaluating the efficacy of virtual reality and robotics ("Rehabilitation by Distortion") for persons with TBI. The overall objective of the project is to develop and evaluate a robotic rehabilitation system that employs virtual reality to produce rehabilitation by distortion effect. Goals for this project include the quantification of just-noticeable-differences (JNDs) for this system in non-injured individuals; evaluation of tolerable distortions in vision and force position mappings; the influence of feedback on sense of effort; and, the development and refinement of this technology for persons with TBI.

**Personal Powered Mobility:** The goal of this project is to address shortcomings in wheelchair design for persons with TBI by evaluating a unique personalized powered mobility system. This is being accomplished in conjunction with Rory Cooper, PhD, and Don Spaeth, PhD, of our Rehabilitation Engineering program through

the development of a novel control wheelchair control system that combines a programmable isometric (force-sensing) joystick and a head position monitor (HPM) that is customized to address each individual's motor and perceptual deficits, leading to improved independent mobility. In addition, the benefit of these controls will be assessed through examining participants' wheelchair navigation through a virtual reality environment that replicates real-world mobility challenges (e.g., maneuver around furniture and bathroom fixtures, driving across carpet and pavement, and driving up and down curb cuts and ramps).

**The Virtual Case Manager:** One of NIDRR's priorities asks for projects that evaluate the impact of selected innovations on service delivery to persons with TBI. Thus, we are using intelligent navigation technology to implement and evaluate a web-based virtual case management support structure ("The Virtual Case Manager," or VCM; PI: Armando Rotondi, PhD) for persons with TBI and their families. The primary objective of this proposal is to address this issue by using state of the art Internet website technology to enhance service support and delivery for individuals with TBI and their families. This objective will be achieved through development of a Virtual Case Manager (VCM) website, specifically focused on the needs of individuals with TBI and their family caregivers. The VCM will guide individuals to educational resources, provide a framework to have their questions answered, and will specifically enhance utilization of healthcare and community services.

### Additional TBI Rehabilitation Research

In addition to those projects under the NIDRR-funded TBI Model System, there are many other TBI research projects within the Department of Physical Medicine & Rehabilitation at the University of Pittsburgh. In the past 5 years, our department has received eight research grants from the NIH that address various aspects of TBI rehabilitation. We are one of the eight sites for the NIH-funded TBI Clinical Trials Network (site PI: Ross Zafonte, DO). We currently have several R01-funded projects, investigating diverse topics such as dopamine genetic variants and their role in mediating recovery in human TBI (PI: Amy Wagner, MD), biochemical and immunohistochemical mediators of cholinergic and serotonergic neurotransmission in an animal model of TBI (PI: Anthony Kline, PhD), and the use of FMRI to examine cerebral substrates of human learning and memory after TBI (PI: Joseph Ricker, PhD). Drs. Wagner, Kline and Ricker also each have smaller pilot grants funded through the R03 mechanism. In addition, Dr. Wagner has a K08 grant, which examines dopamine function in TBI and its relation to therapeutic intervention, and she is the PI on a grant from the Centers for Disease Control (CDC) that examines the impact of neuroendocrine hormones and pathophysiology on outcomes after TBI.

Researchers from PM&R are also very active in collaborative TBI research with faculty from other departments. We have participated in the Brain Trauma Research Center (PI: C. Edward Dixon, PhD, Department of Neurosurgery), and numerous laboratory and applied projects examining acute management of adult and pediatric TBI through the University of Pittsburgh's Safar Center for Resuscitation Research and Children's Hospital of Pittsburgh.

## New York Traumatic Brain Injury Model System of Care Mount Sinai Medical Center New York, New York

The New York TBI Model System (NYTBIMS) is centered within the Mount Sinai Medical Center (MSMC), comprising Mount Sinai Hospital and the Mount Sinai School of Medicine in New York City. Wayne A. Gordon, Ph.D., is project director, and Steven Flanagan, M.D., is project co-director. Joshua Cantor, Ph.D., is project coordinator. Senior staff also includes Mary Hibbard, Ph.D., Marcel Dijkers, Ph.D., Brian Greenwald, M.D., Margaret Brown, Ph.D. and Teresa Ashman, Ph.D. Timothy Pruce is coordinator of advocacy and peer support.

The clinical program of the NYTBIMS brings together several elements of MSMC and affiliated institutions, as well as other entities. NY City Emergency Medical Services, which is part of the NYC Fire Department, ensures speedy transfer of patients from point of injury to the Level I trauma center at Elmhurst Hospital Center (EHC) in Queens as well as to MSMC's Level II trauma center in Manhattan. Acute care and inpatient medical rehabilitation services are provided at MSMC and at EHC. The former has a 25-bed CARF-accredited unit specializing in brain injury, the latter also has a 25-bed unit. In both settings, specialized rehabilitation programs are tailored to the needs of the person, and typically include individual physical, occupational, speech and neuropsychological therapies. Group cognitive treatment is also provided, which was developed to meet the varying emerging needs of individuals as they recover from injury. Support for family members is made readily available through the peer support and advocacy program of the NYTBIMS.

If needed, long-term care is provided at the Park Terrace Care Center and Queens Nassau Nursing Home. The relationship between Mount Sinai and these two facilities encourages continuity of care as Dr. Steven Flanagan provides regular consultations at both facilities and serves as medical director of brain injury rehab at Park Terrace.

Outpatient rehabilitation may initially be provided within the Phase II program, a structured day treatment program at MSMC. One of the only programs of its kind in New York State, Phase II sets its goals on improving participants' awareness of their strengths and challenges, use of compensatory strategies for everyday living, abilities for community travel and participation in leisure and social activities, emotional adjustment to brain injury, social and communication skills as well as vocational readiness. Phase II is organized around group activities addressing a variety of life issues, including coping skills, socializing and emotional well-being. Outpatient rehabilitation care is provided through TBI clinics, and through physical, occupational, speech, vocational and neuropsychological therapies at EHC and at MSMC. These services are provided concurrent with as well as following successful completion of the Phase II program.

The Mount Sinai Hospital, founded in 1852, serves the community of Upper East Harlem, as well as a broad spectrum of patients



from diverse urban and suburban areas in the NYC metropolitan region. EHC serves a population in Queens characterized by large numbers of new immigrants to the U.S. as well as long-time residents from many parts of the world. As a result, a culturally diverse population of individuals reflective of the metropolitan New York area is routinely seen for treatment (in fact, NYTBIMS patients are predominately Hispanic [55%]). Mount Sinai Hospital is one of the oldest and largest voluntary hospitals in the country, with more than 1,200 beds and approximately 150 outpatient clinics. Many institutions across the metropolitan area are direct affiliates of the MSMC: EHC, Queens Hospital Center, Jewish Home and Hospital for the Aged, North General Hospital in Manhattan, Department of Veteran Affairs Medical Center in the Bronx, and Englewood Hospital and Meadowlands Hospital in New Jersey.

MSMC's Department of Rehabilitation Medicine provides comprehensive interdisciplinary rehabilitation, with specialty programs in TBI and spinal cord injury. Approximately 3,500 square feet are allocated for administration and research, and more than 20,000 square feet for outpatient and inpatient rehabilitation. The Department has a large portfolio of funded research, including the New York TBI Model System, the NY Spinal Cord Injury Model System, and the Rehabilitation Research and Training Center on TBI Interventions, in addition to several grants from foundations and pharmaceutical companies.

In addition to our participating in four model system collaborative research projects, two research projects are being implemented by the NYTBIMS:

- **Treatment of Post-TBI Depression** is designed to document the efficacy of Zoloft in the treatment of major depressive disorder and anxiety disorders after TBI, in terms of reduction of emotional distress and improved quality of life. This study is

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## NYTBIMS

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important, as information on the impact on post-TBI depression and anxiety of SSRIs such as Zoloft, based on randomized, double-blind studies, is unavailable.

Approximately 50 volunteers diagnosed with major depressive disorder are being randomly assigned to a 12-week period of Zoloft or a placebo.

- **Post-TBI Fatigue and Its Treatment** is a two-phase study, the first phase of which is aimed at developing a better understanding of post-TBI fatigue and its correlates. The goal is to try to delineate the “topography” of pain, depression, mental fatigue, physical fatigue and related phenomena. Little is known about fatigue in people with TBI, as prior studies have been inadequate in clarifying how fatigue is triggered and its impact on people’s lives. Because fatigue is one of the most common complaints after brain injury (as documented in our work and that of many others), this study is aimed at filling major gaps in the knowledge base. In the second phase of the study, a randomized clinical trial will document the efficacy of Modafinil, as a treatment for fatigue after brain injury. The study of Modafinil, has been preceded by studies of fatigue in people with other chronic conditions that suggest that Modafinil, helps relieve fatigue and has fewer side effects than most other available drugs. The use of Modafinil, has not yet been tested in people with TBI.

Many elements of the NY TBI Model System are unique. For example, individuals with TBI are deeply involved in all components of NYTBIMS activity – clinical, research and training. One physician providing clinical care is a person with a TBI, as is another physician who assists in training medical residents – sharing the perspective of a former patient who also wears the clinical cap. A third person with a brain injury has been hired to provide one-on-one contact with families of newly injured patients, whether model system patients or not, to provide them information, support and a point of continuing contact with the NYTBIMS.

Additionally, two adjunctive programs are aimed at involving individuals with TBI in center activities. The first is the *Support and Info-Share for Women with Brain Injuries*, which meets once a month and is co-led by a brain injury survivor and a psychologist. The second is *Write Your Way to Freedom*, an opportunity for people with TBI to explore creative writing. This group meets once a week for two hours at MSMC and is led by a person with a TBI.

Also unique is our involvement in developing not only a typical model system center newsletter, but also *TBI Research Review*, a newsletter covering policy implications of research done on TBI by all model system centers as well as other researchers. The first issue focused on post-TBI depression. This publication and many others are available for downloading at [www.tbicentral.org](http://www.tbicentral.org), a website shared by the NYTBIMS and MSMC’s RRTC on TBI Interventions.

## ***The 2nd Federal Interagency Conference on Traumatic Brain Injury: Integrating Models of Research and Service Delivery***

[www.tbi-interagency.org](http://www.tbi-interagency.org)

### **The Definitive Conference for**

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# TBI National Database Update

## Compiled by: TBI National Database Center

**The Traumatic Brain Injury Model System Database** has been in existence since 1989. Since its inception, 21 federally-funded TBI Model Systems of Care throughout the United States have contributed data on patients 16 years of age and older with primarily moderate to severe TBI. As of September 2005, the database contained information on 5756 persons with TBI. (All the remaining statistics on this summary are derived from the national database, except for statistics on incidence and prevalence, which are from the CDC)

**Incidence & Prevalence:** Traumatic brain injuries contribute to a substantial number of deaths and cases of permanent disability annually. Each year in the United States, an estimated 1.4 million people sustain a TBI. Of those, 230,000 are hospitalized and survive, which is more than 20 times the number of hospitalizations for spinal cord injury, another key disabling injury. In addition, 50,000 people die from a TBI and 80,000 to 90,000 people experience the onset of long-term of lifelong disability associated with a TBI. At least 5.3 million Americans - 2% of the U. S. population - currently live with disabilities resulting from TBI.

**Age at Injury:** Within the national sample of adolescents and adults, there has been an increase in the average age at time of injury. Prior to 1997, the mean age was 35.6 years. After that period, the mean age was 38.6 years. This difference may reflect the fact that the median age of the general population of the United States has increased by approximately 8 years since the mid-1970s. Alternative explanations for the observed trend toward older age at injury include changes in either referral patterns to model systems, the locations of model systems, survival rates of older persons at the scene of the accident, or age-specific incidence rates.

**Gender:** Over the life of the Model Systems, men have consistently composed about three quarters of the database, similar to population-based studies which have previously been published.

**Ethnicity:** Among persons injured between 1988 and 1996, 49.2% were Caucasian, 38.2% were African-American, 8.1% were Hispanic, and 2.3% were from other racial/ethnic groups. However, among those injured since 1997, 69.0% are non-Hispanic Caucasian, 20.0% are African-American, 7.0% are Hispanic, and 2.7% are Asian/Pacific Islander. This change in the ethnicity mix reflects modifications in sampling. In 1998, there was an increase in the number of Model System centers and a subsequent expansion in the diversity of persons sampled.

The current sample to date is over-representative of the African-American population and under-representative of the Hispanic and Asian-American/Pacific Islander populations (12%, 13.3% and 3.6% respectively according to the 2000 U.S. Census).

**Etiology:** Since 1997, motor vehicle crashes accounted for 46.9% of Model System cases. The next most common cause of TBI is falls (19.5%). Prior to 1997, the second most common cause of TBI in the database was blunt assaults (22.2%), which declined to 7.7% in the period of 1997-2005. During the former period, the Model Systems recruited persons with brain injuries from predominantly urban settings. Within the past year, fall as an etiology has increased significantly, while violence-related TBI has decreased within the TBIMS sample.

**Injury Severity:** Our sample continues to be characterized by more severe brain injuries. Over 62% had Glasgow Coma Scale scores ranging from 3 to 8, were intubated, or were in chemical coma. This level of severity has remained relatively consistent over time.

**Occupational Status:** More than half (63.0%) of those persons with TBI admitted to a Model System reported being employed at the time of their injury. By post-injury year 10, only 29% of person within our sample were employed. Rate of pre-injury unemployment was 15%.

**Residence:** The overwhelming majority of persons with TBI in the Model System (85%) are sent to a private, noninstitutional residence (in most cases their homes before injury).

**Marital Status:** At the time of injury, 31% of persons with TBI in our sample were married. The proportion of the sample that is married remains at about one-third at 1 year follow-up, but drops to about one-quarter at 10 year follow-up.

**Length of Stay:** Not surprisingly, average days hospitalized in the acute care unit for those who enter a Model System immediately following injury has declined from 23.3 days in the period 1988-1996 and 20.0 days for the period 1997-2005. A similar downward trend was noted for days in rehabilitation, from 38.4 to 26.3 days. When focusing on more recent history, we found that the declines in length of stay have continued but at a much slower rate. Mean acute length of stay was 20.9 for the period 1997-2000 versus 20.0 for the period 2001-2005. Rehabilitation LOS declined from 28.4 days to 26.3 days.

## Database Update

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## PRE-INJURY STATUS and INJURY DATA

Enrollment: Last year (July 2004 - June 2005)

n = 719\*

Total n = 5756

Variable	Last year	Total		Last year	Total
<b>PREINJURY STATUS</b>			<b>MEDICAL</b>		
Age (mean)	41	38	Cause of injury		
Gender (% male)	74	74	Motor vehicle (including motorcycle) (%)	51	53
Ethnicity			Violence (%)	10	15
Non-Hispanic Caucasian (%)	71	66	Sports/recreation (%)	1	1
African-American (%)	19	23	Pedestrian (%)	7	8
Hispanic (%)	7	7	Falls/flying objects (%)	26	19
Asian/Pacific Islander (%)	2	3	GCS total (mean)	11	11
Marital status			PTA (mean # of days)	22	27
Single, never married (%)	44	49	LOS – acute hospital (mean)	19	21
Married/common law (%)	34	31	LOS – inpatient rehab (mean)	23	31
Divorced/separated/widowed (%)	22	20	LOS – acute & rehab combined (mean)	42	52
Living status			Charges – acute hospital (mean)	178,802	132,009
Alone (%)	17	18	Charges – inpatient rehab (mean)	55,364	47,895
w/ Related adults (%)	65	65	Charges – combined (mean)	234,116	179,904
w/ Unrelated adults (%)	16	17	<b>FUNCTIONAL OUTCOMES</b>		
Education Years (median)	12	12	DRS at rehab admission (mean)	13	12
Employment status			DRS at rehab discharge (mean)	6	6
Full time student (%)	6	7	FIM at rehab admission (mean)	50	51
Employed (%)	64	63	FIM at rehab discharge (mean)	92	92
Unemployed (%)	13	15	FIM gain (mean)	42	41
Retired (%)	14	10	FIM gain per day (mean)	2.4	2.3
Drug use (% yes)	22	25	Residence at discharge (% to private residence)	84	85
Alcohol use (% drank)	60	61			

\* Cases with date of injury in this time period.

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## Database Update

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## CONDITION AT FOLLOW-UP

Variable	1yr		2yr		5yr		10yr	
	year	total	year	total	year	total	year	total
	n=608	n=4910	n=403	n=3802	n=307	n=1724	n=63	n=507
Deceased* (%)	2.0	1.7	1.2	2.0	2.1	2.7	4.8	5.3
DRS (mean)	3.0	2.8	2.7	2.4	2.0	2.4	2.9	2.5
FIM (mean)	114	114	114	116	116	116	114	115
GOSE (mean)	5.5	5.6	5.7	5.8	6.0	5.8	5.2	5.4
Marital status								
Single, never married (%)	48	47	46	47	44	44	51	47
Married/common law (%)	31	31	28	29	28	27	21	26
Living status								
Alone (%)	12	11	16	14	26	20	17	17
w/ Related adults (%)	70	70	68	66	55	60	66	63
w/ Unrelated adults (%)	18	17	15	17	19	17	15	17
Residence (% in private residence)	93	91	93	91	94	90	96	90
Employment status								
Full time student (%)	6	5	8	5	3	2	0	0
Employed (%)	25	27	27	31	40	34	13	29
Unemployed (%)	32	38	26	32	13	26	34	31
Retired (%)	29	19	32	21	36	25	51	29
Drug use (%yes)	9	12	10	13	15	12	8	15
Alcohol use (% drank)	32	34	32	40	48	29	38	41
Drives own vehicle (%)	42	41	46	49	59	50	33	48
Satisfaction with life (mean)	21	20	21	21	21	21	21	21

\* "Deceased" reported by data collector as reason for no follow-up data. Figures do not include cases deceased at previous follow-up.

**National Institute on Disability and Rehabilitation Research (NIDRR)****Washington, DC**

Program Manager.....Ruth Brannon, MSPH  
Ph: .....202-245-7278  
E-Mail: .....ruth.brannon@ed.gov

Project Officer: .....Phillip Beatty, PhD  
Ph: .....202-245-7267  
E-Mail: .....phillip.beatty@ed.gov

Project Officer: .....A. Cate Miller, PhD  
Ph: .....202-245-7449  
E-Mail: .....cate.miller@ed.gov

Project Officer: .....Theresa San Agustin, MD  
Ph: .....202-245-7516  
E-Mail: .....theresa.sanagustin@ed.gov

Project Officer: .....Delores Watkins  
Ph: .....202-245-7568  
E-Mail: .....delores.watkins@ed.gov

**Traumatic Brain Injury National Data Center (TBINDC)****West Orange, New Jersey**

Project Director: .....Mitchell Rosenthal, PhD  
Ph: .....973-243-6971  
E-Mail: .....mrosenthal@kmmrec.org

Manager: .....Ken Wood, PhD  
Ph: .....973-243-6811  
E-Mail: .....kwood@kmmrec.org

<http://www.kmmrec.org>

**University of Alabama Birmingham, Alabama**

Project Director: .....Thomas Novack, PhD  
Ph: .....205-934-3454  
E-Mail: .....novack@uab.edu

<http://www.uab.edu/tbi>

**Santa Clara Valley Medical Center San Jose, California**

Project Director: .....Tamara Bushnik PhD  
Ph: .....408-793-6446  
E-Mail: .....tamara@tbi-sci.org

<http://www.tbi-sci.org>

**Craig Hospital Englewood, Colorado**

Project Director: ....Gale G. Whiteneck, PhD  
Ph: .....303-789-8204  
E-Mail: .....gale@craig-hospital.org

<http://www.craighospital.org>

**The Spaulding Rehabilitation Hospital Boston, Massachusetts**

Project Director: .....Mel Glenn, MD  
Ph: .....617-573-2625  
E-Mail: .....mglen@partners.org

<http://www.spauldingrehab.org>

**Rehabilitation Institute of Michigan (RIM) Detroit, Michigan**

Project Director: .....Robin Hanks, PhD  
Ph: .....313-745-9763  
E-Mail: .....rhanks@dmc.org

<http://www.semtbis.org>

**Mayo Medical Center Rochester, Minnesota**

Project Director: .....James Malec, PhD  
Ph: .....507-255-3116  
E-Mail: .....malec.james@mayo.edu

<http://www.mayo.edu/model-system>

**TBI Model System of Mississippi Jackson, Mississippi**

Project Director: ....Mark Sherer, PhD, ABPP  
Ph: .....601-364-3448  
E-Mail: .....marks@mmcrehab.org

<http://www.methodistonline.org/>

**JFK-Johnson Rehabilitation Institute TBIMS Edison, New Jersey**

Project Director: .....Keith D. Cicerone, PhD  
Ph: .....732-906-2645  
E-Mail: .....kcicerone@solarishs.org

<http://www.njrehab.org>

**Mount Sinai School of Medicine New York, New York**

Project Director: .....Wayne A. Gordon, PhD  
Ph: .....212-659-9372  
E-Mail: .....wayne.gordon@msnyuhealth.org

<http://www.mssm.edu/nytbims>

**Charlotte Institute of Rehabilitation Charlotte, North Carolina**

Project Director: .....Flora Hammond, MD  
Ph: .....704-355-4330  
E-Mail: flora.hammond@carolinashealthcare.org

<http://www.carolinashealthcare.org>

**The Ohio State University Columbus, Ohio**

Project Director: .....John D. Corrigan, PhD  
Ph: .....614-293-3830  
E-Mail: .....corrigan.1@osu.edu

<http://www.ohiovalley.org>

**Moss Rehabilitation Research Institute Philadelphia, Pennsylvania**

Project Director: .....Tessa Hart, PhD  
Ph: .....215-456-6544  
E-Mail: .....thart@einstein.edu

<http://www.einstein.edu/e3front.dll?durki=11440>

**University of Pittsburgh Pittsburgh, Pennsylvania**

Project Director: .....Ross D. Zafonte, DO  
Ph: .....412-648-6848  
E-Mail: .....zafonterd@msx.upmc.edu

<http://www.upmc.edu>

**University of Texas Southwestern Medical Center Dallas, Texas**

Project Director: Ramon Diaz-Arrastia, MD, PhD  
Ph: .....214-648-6409  
E-Mail: ramon.diaz-arrastia@UTSouthwestern.edu

<http://www.utsouthwestern.edu>

**Virginia Commonwealth University/ Medical College of Virginia Richmond, Virginia**

Project Director: .....Jeffrey Kreutzer, PhD  
Ph: .....804-838-9055  
E-Mail: .....jskreutz@hsc.vcu.edu

<http://www.neuro.pmr.vcu.edu>

**University of Washington Seattle, Washington**

Project Director: .....Kathleen Bell, MD  
Ph: .....206-685-0935  
E-Mail: .....krbell@u.washington.edu

<http://depts.washington.edu/rehab/tb>

# Traumatic Brain Injury

## Facts and Figures

*Editorial Staff:*

*Mitchell Rosenthal, Ph.D., ABPP, Editor*

*Katherine Clawson*

*Slava Gavurin*

*Ken Wood, Ph.D.*

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1199 Pleasant Valley, West Orange, NJ 07052  
 Traumatic Brain Injury Model Systems  
 National Data Center  
 www.tbindc.org



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