



# Traumatic Brain Injury

## Facts and Figures

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United States Department of Education • National Institute on Disability and Rehabilitation Research  
Traumatic Brain Injury Model Systems National Data Center



## TBI Model Systems Activity Update

### 1st TBI Inter-Agency Conference Held

With the sponsorship of the National Institute on Disability and Rehabilitation Research (NIDRR), an exciting conference entitled “TBI in the 21st Century” was held on December 2-4, 1999 in Bethesda, Maryland. This conference was the 1st Federal Interagency on Traumatic Brain Injury and was co-sponsored by the Brain Injury Association, Centers for Disease Control and Prevention, Defense and Veterans Head Injury Program, National Association of State Head Injury Administrators and the Health Resources and Services Administration. The program was designed to educate participants about the latest advances in federally sponsored research and service delivery.

Highlights of the conferences included addresses from Katherine Seelman, PhD, Director of NIDRR, who discussed how the “New Paradigm of Disability” and NIDRR Long Range Plan might impact research in TBI; Allan Bergman, President & CEO, Brain Injury Association, who discussed future opportunities and risks of managed health care and long-term support, person-centered planning, and the need for new technology in brain injury rehabilitation (e.g. telemedicine); David Thurman, MD, MPH, who spoke about the latest epidemiologic data from CDC and the relationship between population-based surveillance and prevention. Over 100 group workshops and scientific poster presentations brought together researchers from TBI Model Systems, CDC, NIDRR and HRSA state demonstration projects. Finally, an outstanding dance performance by the “Rhythms of Hope Dance Company,” which included members of the brain injury community, provided a dramatic and uplifting tone to the conference.

All of the sponsors were impressed with the conference and hoped it would foster greater inter-agency collaboration in the future.

*Selected abstract from this conference start on page 5.*

### National Data Center Moves to New Jersey

As of January 1, 2000, the TBIMS National Data Center (NDC) was transferred to the Kessler Medical Rehabilitation Research and Education Corporation (KMRREC) in West Orange, New Jersey, the site of the Northern New Jersey Traumatic Brain Injury System. Formerly based at the Rehabilitation Institute of Michigan and Wayne State University, the grant was transferred to KMRREC due to the relocation of the project director, Mitchell Rosenthal, PhD, ABPP.

KMRREC has affiliations with the Kessler Institute for Rehabilitation and the Department of Physical Medicine and Rehabilitation at the University of Medicine and Dentistry of New Jersey – The New Jersey Medical School. Joel A. DeLisa, MD, MS, serves as President of KMRREC and Chair of Physical Medicine and Rehabilitation at UMDNJ.

Joining Dr. Rosenthal at the NDC is Neil Grant, MS, MBA, recently hired to assume the responsibilities of the Manager of the National Data Center. His background is in epidemiology, healthcare consulting and infection control surveillance. Mr. Slava Gavurin, BS, was also recently hired as the TBIMS database programmer. He will provide technical support and develop new programs to ensure that data management aspects of the model systems project are enhanced. In addition, Scott Millis, PhD, ABPP, has also moved from the Rehabilitation Institute of Michigan to KMRREC as Senior Research Scientist. Dr. Millis will serve as the Statistical Consultant for the National Data Center.

We appreciate the excellent work of Cynthia Harrison-Felix, MS, who served as National Data Center manager for seven years and has relocated to Craig Hospital in Colorado, as well as Debbie Wood, MS, who filled in for Cindy after she left in September, 1999.

Finally, thanks to National Institute on Disability and Rehabilitation Research, the Rehabilitation Institute of Michigan / Wayne State University and the other Model Systems centers who assisted in the transition process.

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## Center Spotlight: Santa Clara Valley Medical Center

San Jose, CA

Santa Clara Valley Medical Center (SCVMC) is a county-owned hospital which provides services to all residents of Santa Clara County as well as most of Northern California. The 70-bed Rehabilitation Center was established 26 years ago. Soon thereafter, Dr. Sheldon Berrol established the dedicated traumatic brain injury (TBI) program within the rehabilitation center. Essential elements of an ideal rehabilitation model were identified at that time and are still in place.

This includes an identifiable bed allocation in a specially organized and adapted environment that demonstrates commitment to the physical, cognitive, and behavioral deficits and needs of the individual with TBI, as well as the psychosocial needs of both the client and family. Presently three full-time physiatrists who are experienced in caring for individuals with TBI are on staff: Jeffrey Englander, MD, who is the Vice-Chairman of the PM&R department and Principal

Investigator of the TBIMS grant. Freda Dreher, MD, and Malcolm Lawton, MD, are Associate Chiefs and work with the inpatient and outpatient programs, respectively. An integrated treatment philosophy is followed that has neurophysiological, neuropsychological, sociobehavioral, and interdisciplinary foundations that guide the delivery of care.

As the health care system has evolved to managed care models, the flow of patients from trauma systems to acute rehabilitation to outpatient programs is at least twice as fast as it was 10 years ago. Individuals with mild TBI are often seen only in the emergency department or admitted overnight. They receive informational brochures about the immediate effects of TBI as well as the expected course of recovery. Individuals with moderate to severe TBI are seen by a rehabilitation team within 2-3 days of injury, usually in the ICU or neurological observation unit. Initial rehabilitation interventions are started and plans made for their transition to rehabilitation services in the hospital or community as appropriate. If they are admitted to acute rehabilitation, a simultaneous interdisciplinary team evaluation occurs within the first 24 hours, followed by the first team conference within 48 hours of admission. This facilitates the consolidation of discharge goals with the patient, family, and treatment team in important functional areas: health, behavior, communication and cognition, mobility, self care, and toileting. Plans for transition to the next level of care, be it home and community based, day

treatment, transitional living or other levels of inpatient care can be started immediately and communicated with third party payers. The TBI rehabilitation team has a commitment to long-term follow-up care for the client and a commitment to community interagency communication and cooperation to ensure a reasonable continuum of care and vocational training.

SCVMC has been a member of the TBI Model Systems (TBIMS) Program since its inception as a

demonstration program in 1978 and a Spinal Cord Injury Model System for over 20 years. The local TBIMS grant staff have established a tradition of working closely with the clinical staff to enhance the care offered during the inpatient rehabilitation stay, develop continuity of care after discharge, and continue to conduct TBI-related research. Past accomplishments have included the development and testing of the Disability Rating Scale by Maurice Rappaport, MD, Karyl Hall, EdD, and Nathaniel

Cope, MD, at SCVMC. It is one of the most widely used scales in TBI rehabilitation research.

In the present grant cycle, we have again addressed these three areas of activity. A series of informational brochures have been developed and are available on the inpatient unit as supplements to the *Head Injury and Stroke: A Manual for Family and Friends*. These brochures are written in easy-to-understand language and contain essential information on such topics as "Medical Issues: Seizures & Stroke Risk" and "Financial Issues: Medical & Financial Benefits". Individuals with TBI and their family members helped grant staff develop a peer support program to address questions that can best be understood by individuals who have themselves experienced a TBI or supported a family member through the recovery process. Our peer support network consists of trained volunteers, most of whom have had a TBI themselves, who visit patients and their families three times a week. The peer supporters provide an opportunity for the person with a TBI and their family to talk openly about the effects of the injury and to begin to plan for the future after discharge. Post-discharge contact with the peer supporters is also offered to answer questions, provide resource information, and spend time listening to the concerns of both the person with a TBI and their family. The Very Important Person (VIP) Brain Injury Support Group meets monthly at SCVMC during which time individuals with TBI and their families help each other in coping with their



Santa Clara Valley Medical Center

Continues from previous page

## Center Spotlight: SCVMC

injuries. The VIP group is facilitated by a licensed psychologist and is open to individuals and their families during the inpatient stay and also post-discharge.

The community programs and services offered through the TBIMS Grant provide important support and resource referral after discharge. A compilation of resource information for northern California, the TBIRD (Traumatic Brain Injury Resource Directory), is a comprehensive directory of services in the community for those with TBI and their families. A total of 25 categories of information, such as health care providers, accessible housing and transportation, and service and advocacy agencies, are available in a user-friendly format. The TBIRD is made available to all former patients, inpatients and their families prior to discharge, and to the general public. A ResourceLine, accessed by calling a toll-free number, has been developed to facilitate access to information in the TBIRD; alternatively, the TBIRD is also available on-line at [www.tbi-sci.org](http://www.tbi-sci.org). A Mild Brain Injury (MBI) Support Group meets monthly in the community, is facilitated by a licensed psychologist, and is open to any person who has sustained a mild brain injury or has made substantial recovery from a more severe traumatic brain injury.

Running concurrently, a support group for spouses of individuals with TBI is also available. We have had great success with our quarterly education series, "Brain Matters", which features speakers who address issues suggested by individuals with TBI and their families. For example, Dr. Claudia Osborn, a physician who is a survivor of a TBI, gave a talk about her difficulties and triumphs to an audience of over 270 survivors, family members, and health care professionals.

The projects on which we are the lead center investigate the relationship between a wide range of factors and functional outcomes following TBI. Two studies are designed to define key predictors of rehabilitation outcome at the time of hospital discharge and at long-term follow-up. The first study examines the predictive value of CT scans for individuals with TBI, particularly with regard to disability and handicap. The second study investigates the ability of premorbid factors, such as psychosocial history, and functional measures assessed at admission to inpatient rehabilitation, such as the Disability Rating Scale and Functional Independence Measure, to predict status at discharge and at one-year post-injury.

As we approach the beginning of the new millennium, it is becoming clear that external pressures over which, to date, we have little control, will

continue to decrease lengths of inpatient rehabilitation stay. Of pressing concern to health care professionals, clients, and families is whether the decreases in length of stay may have an effect on short- and long-term outcomes in individuals with TBI. We have designed a study to investigate the association between length of inpatient rehabilitation stay on functional outcomes at discharge and one year post-injury in groups comparable on severity of injury and other factors known to impact outcomes. The major hypothesis is that those individuals with longer lengths of stay will show significantly better outcomes on such measures as the Disability Rating Scale and FIM.

Another concerning area for the TBIMS Project is the role that violence plays as an etiology of TBI. Violence is the second leading cause of injury for patients treated in the TBIMS. We are lead center on two studies, and are collaborating on six others that are examining the impact of violence on all aspects of TBI medical sequelae, treatment, and outcomes. Our emphases will be on investigating the impact of violent versus non-violent etiologies on functional outcome in TBI at one, two, and five years post-injury. Within the violence-related TBI group, they will be further subdivided to examine the implications of blunt versus penetrating violent injury on outcomes.

### Online Resources from SCVMC

- The Traumatic Brain Injury Resource Directory (TBIRD)  
[www.tbi-sci.org/tbird](http://www.tbi-sci.org/tbird)
- The TBI Model Systems Website  
[www.tbims.org](http://www.tbims.org)
- The Center for Outcome Measurement in Brain Injury (COMBI)  
[www.tbims.org/combi](http://www.tbims.org/combi)

The last collaborative project for which we are lead center involves our commitment to using the Internet as an essential tool for communicating with and disseminating information to clients, families, health care professionals, and other interested parties. We are currently responsible for maintaining the TBIMS Projects website which is "Bobby-approved", certifying that it meets current ADA standards for websites; this website can be found at [www.tbims.org](http://www.tbims.org). This site links to descriptions of the TBIMS program, news, publications by the TBIMS members, information about the National Database, current and back issues of the Facts and Figures newsletter, and links to the websites of all of the TBIMS centers. Our own center's

website, found at [www.tbi-sci.org](http://www.tbi-sci.org), contains information about our peer support programs, our quarterly educational series "Brain Matters", easy e-mail links to contact our TBI staff, and on-line copies of the TBIRD and our InterAct newsletter.

Both the TBIMS Projects and our own websites contain links to the Center for Outcome Measurement in Brain Injury (COMBI), which is a collaborative effort among eight TBIMS for which we are the lead center. The COMBI is a resource center available for those who need information on brain injury outcome and assessment scales and can be found at [www.tbims.org/combi](http://www.tbims.org/combi). There are 12 scales currently covered; check out the COMBI to see scales such as the Agitated Behavior Scale, Disability Rating Scale, and Patient Competency Rating Scale to name a few. The information for each scale includes background materials, rating scales and forms, syllabi or administration guidelines, training and testing materials, information on scale properties, references, and frequently asked questions. Additional characteristics of the COMBI website are: 1) all rating forms can be downloaded and printed in a usable format; 2) a survey is available online to characterize the individuals accessing the COMBI, the scales used, and opinions on the utility of the scales; and 3) a COMBI newsletter is available online describing recent additions/changes, current research using scales contained in the COMBI, and usage information. Currently, the COMBI receives an average of 50-75 daily visits of which 20% are international. The appeal of the COMBI is that it is dynamic and reaches a wide range of individuals both from a geographical as well as a professional perspective.

Our commitment is to the professional and client/family communities. We are working to achieve these goals by participating in the TBIMS Project group; at present, Jeffrey Englander, MD, co-chairs the Medical committee, Tamara Bushnik, PhD, co-chairs the Dissemination committee, and Jerry Wright, BA, co-chairs the Data committee. We are also conducting research defining the current outcomes for individuals with TBI and their families. Finally, we are actively working to make an immediate difference in the lives of our clients and their families in SCVMC's community through our links to community programs and services.

## Center Spotlight: Virginia Commonwealth University Medical College of Virginia

Richmond Virginia

In 1987, Virginia Commonwealth University (VCU) was among the first five recipients of funding from NIDRR for a brain injury model systems center. Since then, the program has been based at the Medical College of Virginia campus, centrally located in Virginia's capital city, Richmond. With the benefit of funding from NIDRR, the university also serves as a Model Spinal Cord Injury center, a Rehabilitation Research and Training Center (RRTC) for employment, and as a training center for brain injury research fellows. The Virginia Commonwealth Model System has developed a wide variety of clinical programs relating to comprehensive inpatient and outpatient rehabilitative care. The center has also been home to innovative programs providing day rehabilitation, vocational rehabilitation, community outreach, psychotherapy, and family support. Emphasis has been placed on promoting close working relationships between interdisciplinary staff members who have clinical and research interests. The need for long-term supports has long been recognized by our center, and our programs have been developed to help persons well beyond the first few years after injury.

The Virginia center is devoted to developing and presenting high quality educational programs for professionals, survivors, and family members. A number of programs highlight our commitment to providing educational resources. First, the Virginia model systems program has co-sponsored the annual postgraduate course entitled "Rehabilitation of the Adult and Child with Brain Injury." Each year, the course is attended by an international audience of interdisciplinary professionals. In the year 2000, the 24th annual conference will be held in Williamsburg on June 2- 4. The conference will focus on effective interventions with an emphasis on evidence-based practice.

During the last several years, we have taken a series of steps to extend outreach to consumers. Our research indicated that many survivors and family members seek information about brain injury outcomes, rehabilitation, and resources to help them effectively address injury-related problems. In the past decade, there has been a proliferation of literature for professionals.

To widely disseminate research and clinical information to consumers, the Virginia Commonwealth model system has developed and hosted the National Resource

Center for Traumatic Brain Injury. The center maintains an active web site ([www.neuro.pmr.vcu.edu](http://www.neuro.pmr.vcu.edu)) which contains resource areas including reference lists, links to other sites, an advice column called "Chat with Pat", and a section for announcements submitted by visitors. The highlight of the web site is a "Frequently Asked Questions" section, with responses compiled by nationally recognized experts who kindly volunteered their time. The Frequently Asked Questions are submitted by

web site visitors and address a wide variety of topics including insurance, medications, pediatrics, return to school, family concerns, vocational rehabilitation, and independent living. Responses to questions also address problems relating to balance, seizures, communication, cognition, behavior, and emotional changes.

During the past year, the Virginia Model System's National Resource Center has

published a series of four books specifically tailored to meet the needs of consumers. Two books were published for survivors: *Living Better and Better after Brain Injury: A Guide for Survivors* (65 pp), and *The Brain Injury Work Book: A Guide to Living and Working Productively* (155 pp). Recently, two additional books were published, one for family members (*Living Better and Better after Brain Injury: A Guide for Family, Friends, and Caregivers*, 190 pp), and another for service providers (*The Brain Injury Handbook: A Guide for Rehabilitation Providers*, 120 pp). In the next month, *The Brain Injury Source Book: Answers to Questions Most Often Asked by Family and Survivors*, will be published and distributed. The book is a compilation of responses to Frequently Asked Questions from the web site.

Past publications for consumers have focused on negative aspects of injury. Some were virtually compilations of lists and descriptions of problems. The new National Resource Center books are part of our *25 Ideas Series*, and sections from each of the books are posted on our web site. Emphasis is placed on positive and practical solutions to commonly encountered challenges. Many of the detailed ideas described in the books were developed from consumers' suggestions. Early feedback about the publications has been very positive and more *25 Ideas Series* books are on the way.



Virginia Commonwealth University  
Medical College of Virginia

## Research Abstracts: 1st TBI Inter-Agency Conference – *TBI in the 21st Century* Bethesda, Maryland December 1999

### Post-Traumatic Hydrocephalus; Incidence, Risk, and Outcome

Corwin Boake, PhD (*The Institute for Rehabilitation and Research*); Stuart Yablon, MD (*Mississippi Methodist Rehabilitation Center*); Cindy Ivanhoe, MD (*The Institute for Rehabilitation and Research*); Flora Hammond, MD (*Charlotte Institute of Rehabilitation*); Ross Zafonte, DO (*Rehabilitation Institute of Michigan*)

#### Objective

To determine incidence, risk factors and outcome associated with post-traumatic hydrocephalus. HYPOTHESES: (1) Post-traumatic hydrocephalus is associated with poorer outcome. (2) There are specific variables (risk factors) associated with the development of post-traumatic hydrocephalus.

#### Measures

A multicenter study was conducted, reviewing the incidence, risk factors, and outcome of patients with post-traumatic hydrocephalus (PTH). This investigation utilized the NIDRR TBI Model Systems Database, a collaborative multicenter study including 809 patients receiving within a coordinated neurotrauma hospital system for acute treatment and rehabilitation of TBI. Outcome measures included the Disability Rating Scale (DRS), the Functional Independence Measure (FIM), and hospital length-of-stay (LOS), as well as disposition, employment, and ability to undergo neuropsychological testing. Follow-up data at one-year postinjury or more were available on 313 subjects. PTH, defined as enlargement of the ventricles requiring shunting, was identified in 45 patients (5.6%) during their initial hospitalization. Six patients received shunting procedures after discharge, two of which were revisions of prior procedures. Injury severity was significantly associated with risk for development of PTH. Other predictors for PTH included FIM admission, DRS admission, subdural hematoma (relative risk ratio 2.915; 95% CI=1.524-5.200) and epidural hematoma (relative risk ratio 2.018; 95% CI=0.999-4.076). PTH independently correlated with adverse discharge outcome, as measured by the discharge FIM ( $p=0.0001$ ) and DRS ( $p=0.0014$ ), and significantly prolonged rehabilitation LOS ( $p=0.0003$ ). This effect, however, no longer was apparent at the time of first follow-up.

### Evaluation of a Medical/Vocational Case Coordination System for Persons with Brain Injury

James F. Malec, PhD, Angela L. H. Buffington, MA, CRC, Anne M. Moessner, MSN, Lisa Degiorgio, MS, CRC (*Mayo Medical Center and Medical School*)

#### Objective

This project evaluated a Medical/Vocational Case Management System (MVCMS) for persons with brain injury (BI) that provided: (1) early case identification and management, (2) appropriate medical and vocational rehabilitation interventions coordinated by a Nurse Case Coordinator and Vocational Case Coordinator designated for patients with BI, (3) work trials, (4) temporary or long term supported employment including job coaching.

#### Hypotheses

- (1) Vocational outcomes at one-year follow-up will meet or exceed those reported previously in the literature with intensive intervention, i.e., (a) approximately 75% of participants in community-based work or training; and (b) approximately 50% working independently.
- (2) Vocational outcomes will be related to the following factors: (a) severity of injury, (b) severity of impairment/disability (c) impaired self-awareness (ISA), (d) time since injury, (e) presence of additional non-brain injuries, and (f) pre-injury educational/vocational status.

#### Participants

114 Minnesota residents ages 18 to 65 hospitalized after BI, excluding cases in long term residential placements or in which a primary psychiatric or substance abuse diagnosis accounted for all impairments.

#### Measures

The Vocational Independence Scale (VIS) classified vocational outcomes at five levels: Unemployed, Sheltered, Long Term Supported, Transitional, and Independent (Competitive). Potential predictor variables were: preinjury employment status (VIS) and years of education, severity of initial injury (Glasgow Coma Scale, length of unconsciousness), time since injury, current impairment/disability as measured by the Rasch-analyzed Staff Mayo-Portland Adaptability Inventory (MPAI), and ISA as measured by the difference between Staff MPAI and Survivor MPAI and by a specific item for rating ISA by staff.

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## Research Abstracts

### Results

(See Figure) At placement, 46% were in independent work; 25% in transitional placements; 9% in long term supported employment, 10% in sheltered work; and 10% not placed. Outcomes for those with traumatic BI (n = 73) were very similar to those for the entire group: 52% independent; 22% transitional; 7% supported; 8% sheltered; 11% not placed. 39% of those placed returned to previous employment. 92% of placements occurred within 1 year of initiation of services. At 1 year follow-up (n = 101), 53% were in independent work; 19% in transitional placements; 9% in supported work; 6% in sheltered work; and 13% unemployed. At follow-up, the median wage was \$6.75 per hour (semi-interquartile range = \$4.98 to \$9.80 per hour). Stepwise logistic regression analysis showed time since injury ( $\chi^2 = 9.70$ ,  $p < .01$ ) and Rasch Staff MPAI ( $\chi^2 = 8.30$ ,  $p < .01$ ) predicted VIS at placement. Only VIS at placement ( $\chi^2 = 53.30$ ,  $p < .0001$ ) independently predicted VIS at one-year follow-up. In a stepwise linear regression analysis to predict time to placement, Rasch Staff MPAI accounted for 16% of the variance and preinjury education for an additional 3%.

### Conclusions

The MVCMS resulted in community based employment for 80% of persons served with 53% working independently 1-year after placement. Time since injury and overall level of impairment/disability were the best predictors of vocational placement. The best predictor of employment status at one year was the level of initial placement. Persons with greater disability required more extensive time and rehabilitation services for successful placement.

## Relating NIDRR's TBI Model Systems and CDC's TBI Surveillance Systems: Strengths and Weaknesses of Each System

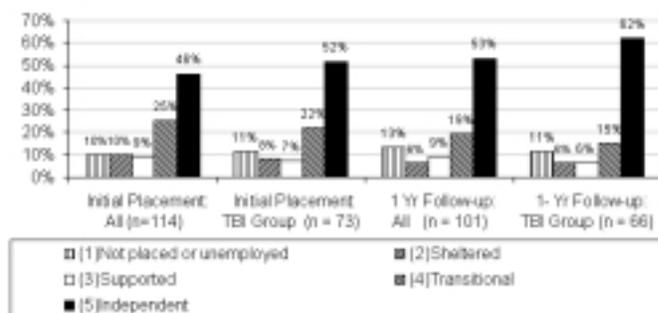
John D. Corrigan, PhD (Ohio TBI Model System, Ohio State University); David J. Thurman, MD, MPH (National Center for Injury Prevention and Control, Centers for Disease Control and Prevention)

The Traumatic Brain Injury Model Systems (TBIMS) Project has been funded by the National Institute on Disability and Rehabilitation Research since 1987. At the core of this project is a prospective, longitudinal, multi-center study examining the course of recovery and long-term outcomes following traumatic brain injury (TBI). Until 1999, no more than five centers were funded for participation in the TBIMS database and approximately 1,000 cases were accumulated. However, in the past year, twelve new centers have been added, which is anticipated to allow enrollment of approximately 300 new cases per year.

By the end of the current funding cycle in 2002, the number of subjects in the database is expected to more than double. The TBIMS dataset contains almost 400 variables describing the initial hospitalization, both acute and rehabilitation, and an equal number assessing outcomes annually for up to 20 years following the initial injury. More than 160 publications in professional journals have grown out of the TBIMS Project, and there are more than 140 discrete research or demonstration projects currently being conducted by the 17 funded centers.

The National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention (CDC) supports a multi-state system for surveillance of traumatic brain injury (TBI). Currently, 15 participating state health departments collect statewide information on TBI-related hospital

### Vocational Independence Scale at Placement and 1 Year Follow-up



admissions and deaths, in order to describe the epidemiology of these injuries and improve TBI prevention efforts. In addition, CDC supports the development of follow-up TBI registries in two of these states. The purpose of these registries is to study longer-term outcomes among people with TBI and needs for services among the population of people with TBI.

Data compiled from the Multi-State TBI Surveillance System indicate that during 1995 and 1996, the annual incidence rate of TBI resulting in hospitalization or death was 95 per 100,000 population, of which 22% resulted in death. TBI occurs most frequently among adolescents, young adults, and people older than 75 years of age; it is principally due to motor vehicle crashes, violence, and falls. Based on preliminary follow-up data, we estimate that 80,000 Americans incur significant disability consequent to TBI each year. Data such as these are important for the development of effective TBI prevention programs and also to ensure adequate services for those who experience TBI.

The TBI Model Systems program and the CDC Multi-State Surveillance program were evaluated and compared according to several criteria: population basis (e.g., the extent to which system data allow estimates of the incidence of TBI and prevalence of TBI-related disability, and the extent to which data are representative of the population of people with TBI); outcome risk factor identification (i.e., the extent to which systems identify predictors of outcome including demographics, premorbid health, cause of injury, injury pathophysiology, and time post-injury); susceptibility to bias (e.g., selection bias, misclassification, recall bias, and confounding by associated health conditions); ability to characterize service needs and access (both for individuals and for the population of persons with TBI); ability to evaluate efficacy of services and interventions; and value of findings for making these criteria, a detailed comparison revealed a complementary pattern of strengths and weaknesses among these systems.

Because of the complementary nature of the TBI Model Systems program and CDC-supported TBI surveillance and follow-up studies, it is important to integrate the information derived from each. Methodologic considerations in such integration were described. To the extent that the two systems overlap, comparisons of data from both systems may enable evaluation of the validity and representativeness of each system..

## Scheduled Telephone Follow-up: A Model for Post-Acute Intervention for Traumatic Brain Injury

*Kathleen R. Bell, MD, Peter J. Esselman, MD, Sureyya Dikmen, PhD, Jason Doctor, PhD, Robert Fraser, PhD, CRC, Kurt Johnson, PhD, Nancy Temkin, PhD (University of Washington, Department of Rehabilitation Medicine)*

Provision of Services after traumatic brain injury during the post-acute period continues to be a challenge because of financial considerations, urban locations of treatment programs, and other barriers to access. Distance telemedicine offers a possible solution to the existing limitations. We propose a model that utilizes telephone follow-ups scheduled weeks 1 and 2 and 1, 2, 3, 5, 7, and 9 months after discharge from acute rehabilitation to provide mentoring, triage, service referral, and support to the person with TBI and his/her community support system. A structured interview (Psychosocial Activity Interview Plus) is used to probe for concerns from both the subject and a caregiver. This explores areas such as ambulation and self-care, return to work/school, cognitive disorders, financial stresses, legal issues, alcohol and drug use, behavioral and emotional concerns, and spiritual or religious questions. Problems are graded by severity by the subject, caregiver, and telephone mentor. In addition to support and reinforcement, the telephone mentor provides guidance in problem solving and behavioral change techniques. For identified problems that require further assessment and intervention, the telephone mentor provides referrals within the local community, or in complex cases requiring expertise not available locally, referrals to a tertiary care center. A summary of the encounter and actions taken is then mailed to the subject and caregiver to reinforce the outcome. The development of a Web-based consultation site to allow the telephone mentor to consult with experts in a variety of areas and a Web-based resource directory of state and regional resources for referrals is vital to the success of the project. In addition, a toll-free number is available to participants.

To date, 61 subjects have been enrolled in the project (30 receiving the telephone intervention and 31 in a control group). Average age of participants is 33.5 years. Subjects have been overwhelmingly male (5:1) and are living at home with spouse or parents as opposed to institutions(9:1). Of the intervention group, 2/3 live in urban or suburban areas and 1/3 in a rural setting. The most significant change from pre-injury status are in return to work, community travel, leisure and recreation, financial independence, home management and cognition and behavior. Interventions have been primarily mentoring and teaching, with some referrals to local agencies and health care providers. Outcome assessment at one year is still pending. Results so far indicate that few calls are initiated even when subjects and caregiver have active concerns and that the written summary reinforces positive change. At least one emergency situation was handled by the telephone mentor. We believe that this model offers an effective means of providing practical support and direction to persons with limited access to more traditional post-acute rehabilitation programs because of finances or geographic distance.

## Family Response to Traumatic Brain Injury: Implications for Research and Treatment

*Angelle M. Sander, PhD (Baylor College of Medicine, The Institute for Rehabilitation and Research)*

Traumatic brain injury (TBI) results in substantial emotional distress for many family members (Brooks, 1991). Researchers have documented persisting emotional distress, as well as, and disrupted family role functioning and communication (Kreutzer et al., 1994). The ability to predict which family members will experience distress and coping difficulties is crucial for developing family interventions. Over the past 5 years, we have extensively investigated individual characteristics that predict how family members adjust to TBI. The results of these studies have guided our plans for developing and testing empirically-based family interventions.

Our research has been guided by a model of family adjustment to crisis that was adapted from family therapy research (McCubbin & Patterson, 1983). The model proposes that family members' reactions to TBI are impacted by how they think about the injury, their coping strategies, and their social support. In a study investigating caregivers' adjustment to TBI, we found that coping style and satisfaction with social support were more predictive of psychological health than was the disability level of the person for whom they provided care (Sander et al., 1997). We found that after controlling for injury severity and family demographics, the best predictors of emotional functioning were the number of unmet needs and the frequency of using the coping strategy Escape-Avoidance. We are now investigating the contribution of family functioning to the long-term outcome of persons with TBI. Preliminary results indicate that family functioning is related to the social integration of persons with TBI.

Our studies have demonstrated that family members' coping strategies and perceptions of support impact their adjustments to injury. Family functioning can also have an impact on the outcome of persons with injury. The results suggest that family interventions should include guidance in developing effective coping strategies and in getting support needs met. As part of a Model System collaborative project, we will be developing and conducting a 3-center, randomized clinical trial comparing the effectiveness of a structured cognitive-behavioral family intervention to a traditional family support group and a no treatment control group. Components of the intervention include: education in brain injury and expected outcomes; discussion of coping strategies; training in structured problem-solving and relaxation; cognitive restructuring of perceptions of the injury and the caregiving role; discussion of relationship issues including roles and communication; and training in accessing community and national resources. The outcome measures employed will assess coping strategies, perceived social support, family systems functioning, and emotional distress. Another project focuses on developing a community-based family outreach program to provide brief education and cognitive-behavioral intervention to a population of underserved family members who receive little to no rehabilitation services.

## Photo Gallery: 1st Federal Inter-Agency Conference on Traumatic Brain Injury

December 2–4, 1999

Hyatt Regency

Bethesda, Maryland

**Left:** John Corrigan, PhD, Program Co-Chair, addresses the TBI Inter-Agency conference. Dr. Corrigan is the project director of the Ohio TBI Model System. From left, Ruth Brannon, MSPH, Katherine Seelman, PhD, NIDRR, and Mitchell Rosenthal, PhD, Program Chair, look on.

**Right:** Constance Miller, founder of the Head Injury Hotline, speaks to the audience.



**Left:** Allan Bergman, president of the Brain Injury Association, and Dr. Katherine Seelman, director of the National Institute on Disability and Rehabilitation Research (NIDRR).

**Right:** KMRREC staff distribute registration materials.



**Left:** Rhythms of Hope Dance Company entertains the audience. The talented troupe includes individuals with TBI.

**Right:** David Thurman, MD, MPH (left) and Rick Waxweiler, PhD discussing the program. Drs. Thurman and Waxweiler are medical epidemiologists with the Centers for Disease Control and Prevention.



**Left:** Robert Fraser, PhD, and Peter Esselman, MD, from the University Of Washington Model System visit the Defense and Veterans Head Injury Program exhibition booth.

**Right:** Mark Sherer, PhD, Mississippi Model System and Jean Langlois, ScD, of the Centers for Disease Control discuss TBI research.



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## Data From the Traumatic Brain Injury Model Systems of Care 1989-1999

The Traumatic Brain Injury Model Systems (TBIMS) Project is a prospective, longitudinal multi-center study examining the course of recovery and outcomes following traumatic brain injury (TBI). The Seventeen Model System centers (11 new centers just beginning to collect data), funded by the National Institute on Disability and Rehabilitation Research, provide coordinated emergency care, acute neurotrauma management, comprehensive inpatient rehabilitation and long-term interdisciplinary follow-up services.

Information contained in the database is collected during initial hospitalization and annually thereafter on

the anniversary of injury. The database contains 391 variables describing the initial hospitalization period, and 419 variables relevant to the follow-up period. The Database Syllabus contains detailed information about the database and is available for purchase from the TBIMS National Data Center.

Presently, the database contains 1861 cases discharged from the TBIMS between March, 1989 and December, 1999; with annual follow-up information extending, thus far, to nine years post injury. The table below summarizes several key characteristics of the TBIMS population, which have been updated from previous issues of *TBI Facts and Figures*:

Number of Cases	1861
Mean Age in Years	36
% Male	75
% White	57
% African American	31
% Unmarried at Injury	71
% w/o High School Graduation at Injury	36
% Employed at Injury/1 yr. Post-Injury	56/24
Mean Lowest GCS	7
% with Post-traumatic Amnesia	97
% Vehicle-related Injury	53
% Violence-related Injury	22
**% Positive Blood Alcohol Level at Injury	53
Mean Acute Length of Stay 1990 & 1999	29/19
Mean Rehab. Length of Stay 1990 & 1999	48/28
Mean Acute Charge Per Day 1990* & 1999*	4210/4847
Mean Rehab. Charge Per Day 1990* & 1999*	1532/1356
% with Medicaid Payer (primary)	27
Mean Disability Rating Scale Score at Rehab. Admit and D/C	15/8
Mean Functional Independence Measure Score at Rehab. Admit and D/C	56/97
% Living in Private Residences at Rehab. D/C	14
Mean Community Integration Questionnaire Score at 1 year post injury	14

\* all figures adjusted to 1999 dollars, according to U.S. Bureau of Labor Statistics' Consumer Price Indexes for medical costs

\*\* any alcohol detected; only includes those tested

## Now Available: The 2000 Traumatic Brain Injury Model Systems National Database Syllabus

In 1987, the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) provided funding to establish the Traumatic Brain Injury (TBI) Model Systems of Care. These research and demonstration projects (currently there are 17 in the U.S.) focus primarily on:

- 1 Developing and demonstrating a model system of care for persons with TBI, stressing continuity and comprehensiveness; and
- 2 Establishing a standardized national database for innovative analyses of TBI research data.

The TBI Model Systems National Database Syllabus is available for public sale. This syllabus (also referred to

as a data dictionary or codebook) contains:

- 1 Introduction to the TBI Model Systems and the National Data base;
- 2 Case definition and inclusion criteria;
- 3 A detailed description of each data item, including codes;
- 4 Data collection forms and guidelines for data collection; and
- 5 Detailed information on standardized tests and measures used in the data base.

*The Syllabus may be ordered by returning a copy of this completed order form, accompanied by the correct payment.*

*Please copy and mail this form to:*

Neil J. Grant, M.S., M.B.A.  
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1199 Pleasant Valley Way  
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### 2000 Syllabus prices: \$100.<sup>00</sup> (USA) OR \$125.<sup>00</sup> (International)

- 1) Payment in U.S. funds must accompany all orders
- 2) Checks or Money Orders should be made payable to: KMRREC
- 3) Shipping and handling charges are included in the charge
- 4) *Sorry ~ we cannot accept credit card or purchase orders.*

Please send me \_\_\_\_\_ copies of the **2000 TBI Model Systems National Data Base Syllabus.**

Enclosed is my check / money order for \$\_\_\_\_\_.

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*Name*

\_\_\_\_\_  
*Title/Department*

\_\_\_\_\_  
*Facility/Organization*

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TBIMS Syllabus

# Traumatic Brain Injury

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## Traumatic Brain Injury Model Systems National Database

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