

Brain Waves

Volume 3, 2005

UPDATE ON CUTTING EDGE RESEARCH IN TBI

THOMAS NOVACK, PHD, UAB-TBIMS DIRECTOR

We often read in the newspaper about new medical discoveries and treatments. Although traumatic brain injury (TBI) is rarely mentioned, there is ongoing research in TBI. There have been many studies over the past 15 years that have examined the impact of various interventions, usually medications, on outcomes following the injury. Unfortunately, these past studies have yielded no positive results.

Because of the expense involved in developing new drugs, attention has now shifted to utilizing existing medications that may have an impact on neural recovery. These include drugs such as the statins (which are intended to control cholesterol), natural steroids (such as progesterone) and drugs that increase the availability of acetylcholine (such as those intended for people experiencing dementia). Although not yet focusing on TBI, there are ongoing studies examining the possibility of insertion of immature neural cells into areas of brain disorder in hopes that those cells will replace lost neurons. Finally, there are very promising developments in the area of neuroimaging that hold the promise of being able to monitor closely a person's recovery from a brain disorder by measuring the utilization of oxygen and glucose within the brain.

There are also studies in behavioral interventions. There is increasing emphasis on home-based programs that are likely to be more intensive than what professional therapists can provide as well as less expensive. Constraint Induced Therapy is an intense, repetitive physical therapy treatment that aims to re-wire the brain, which might help individuals with TBI regain functional use of arms or legs.

TBI Research is more difficult for several reasons. First, there is tremendous diversity within the population with TBI. People are very different in their skills and abilities before brain injury, which will impact their outcome. There may also be genetic factors that impact the brain's response to injury. The severity and extent of injury also differs from person to person. Treatment for TBI also varies in many cases from center to center. Careful examination of treatment protocols indicates that there are substantial differences across sites in terms of the care provided in intensive care, acute rehabilitation, and post-acute rehabilitation. Finally, there are substantial differences in family support and other psychosocial factors that people experience following an injury. Lack of family support, for instance, can have a tremendous impact on outcomes following a TBI.

Unfortunately, recovery from TBI is a complex process. In fact, there will likely be no single "magic bullet" that will reverse the effects of TBI. It will likely include a combination of factors such as proper medication management, consistent rehabilitation, and ongoing support following hospital discharge. Rather than being discouraged by this news, it is better to remember that new discoveries about the nervous system are occurring every year. There is no doubt that some of those discoveries will benefit TBI. Thus, there is hope that the proper combination of factors will be discovered that will soon have benefits in improving outcomes following TBI.

ALABAMA HEAD INJURY HELPLINE

SANDY KOPLON, ALABAMA HEAD INJURY FOUNDATION
DIRECTOR OF COMMUNITY OUTREACH

The Alabama Head Injury Foundation (AHIF) Helpline, mainly funded by the Alabama Impaired

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Drivers Trust Fund, is an information and referral source for individuals with TBI, their families, professionals and the general public.

A typical Helpline phone conversation from a consumer might begin with the caller saying, "I don't know what questions I should ask, or what I need, but..." A knowledgeable staff person in the state office listens patiently, asks questions to explore the caller's needs, offers emotional support when necessary, refers to resources, and might suggest strategies for dealing with issues. The staff person will often refer the caller to one of our eight Resource Coordinators serving the area in which the caller resides. A local Coordinator is usually familiar with resources and services in the caller's community. This Coordinator can give the caller information on how to sign up for Resource Coordination, Respite Care, Support/Recreational programs, and other AHIF programs and services. The AHIF Helpline can also provide callers with referrals to community services and information on volunteering.

The AHIF Helpline utilizes an extensive library of books, audio and video tapes, CDs and DVDs and disseminates the AHIF information and products developed by various Grants. The AHIF can be contacted by mail, email or phone.



INTERACTIVE COMMUNITY BASED MODEL

MARIA CROWLEY, COORDINATOR, ALABAMA HEAD AND SPINAL CORD INJURY REGISTRY

Individuals with TBI and their families often endure physical, emotional, intellectual, and social changes. While many individuals and their families return to activities without consequence, returning to activities is impossible for many without intensive, hands-on assistance.

ADRS implemented a service delivery system to address this need. The Interactive Community Based Model (ICBM), funded by the Impaired Drivers Trust Fund, provides a structured, progressive approach to assist individuals with TBI and their families as they transition from the hospital

to the home and community, and ultimately to the workplace. The overall goal of the ICBM is to improve the individual's readiness for services that lead to employment. The program is interactive and incorporates activities of daily living, cognitive retraining, recreational and social skill development and other activities to promote endurance.

The ICBM helps addresses employability, independence, and community reintegration for individuals who:

- ◆ have sustained a traumatic brain injury as a result of neurotrauma;
- ◆ are less than 2 years post-injury;
- ◆ are not ready for Vocational Rehabilitation Services at the time of referral; and
- ◆ can benefit from a cognitive and/or behavioral rehabilitation program.

As one family member stated:

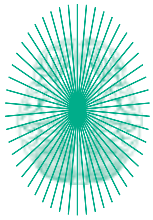
"... Without help from family, friends and ADRS, I do not know if we could have seen such a quick and remarkable recovery."

Services are provided through a statewide network of Care Coordinators. They work with individuals with TBI and their families to ensure that program goals are tailored to meet the individual's needs. The ICBM empowers consumers by involving them in individualized assessment, plan development, monitoring of activities, goal setting and recovery. This participation helps consumers develop a realistic view of their potential for employment after injury.

The overall impact of the ICBM has been significant. It has reduced the cost of post-acute care services and the time of referral to vocational rehabilitation by more than two-thirds of the national average. ICBM has increased the average income of consumers who participate by 15%.

If you or someone you know needs TBI information or services offered by the Alabama Department of Rehabilitation Services, please call the toll-free help line at 888-879-4706 or visit their website at www.rehab.state.al.us.





CONNECTIONS

C A R E G I V E R S S P E A K O U T

“My son has a TBI, and he has been physically abusive for years. I knew that I needed to protect myself, but I felt guilty about worrying more about myself and not enough about my son. I was afraid that he would severely injure or kill me and end up in jail. I participated in Project CLUES, and received assistance in addressing this problem. I first made a list of all I had done to care for my son. I also made a second list of all that my son would lose if I was dead or impaired. These lists helped me realize that I have always made sacrifices to provide my son with the best of care. I also realized that I was now elderly and had approached the limit of what I could physically continue to give him. After I prayed on the situation and consulted with my minister, I decided that I would not consent to have my son released back to me the next time he assaulted someone and ended up in jail. This decision has caused me much grief, but putting my faith in God’s hands has eased my guilt.”

- Lucy

“I knew I needed help for depression when I decided to participate in Project CLUES. I agreed to get help for my depression, but I faced a number of hurdles such as a lack of money, lack of reliable transportation, and a lack of relief from my role as a caregiver. The Project CLUES educator and I looked at possible solutions to each barrier. I had been saving money for a rainy day, and I realized that it was “raining now” and that the counseling fees were a worthwhile investment. Plus, I found a mental health clinic that based its fees on my income. To address the problem of my unreliable transportation, I agreed to call the clinic to cancel my appointments as soon as it was evident that I would not make my appointment. Regarding my need for respite, I decided to ask my neighbor to keep an eye on my daughter [with TBI] when she usually took a nap mid-afternoon. I now see that I was able to get the help that I needed to manage my depression by learning to overcome one barrier at a time.”

- Ally

“When I first enrolled in Project CLUES I was asked what caregiver problem I wanted to address. I was not sure what kind of problem they wanted me to talk about but I realized that I was very worried about long-term care for my son. He has a TBI, and my daughters are not able to care for their brother once my husband and I become unable to do so any longer. I could find no federally funded programs that would provide care for our son, so my husband and I decided to consult a financial planner. We wanted to set up a trust fund with our family assets, but we felt guilty about not being able to share the family assets with all three of the children. My husband and I talked to our daughters, and they assured us that they held no resentment and were very supportive of our long term care plans for their brother. We resolved a family concern that had been weighing heavily on all our minds for many years”

- Ellen

Editor’s Note: Project **CLUES** (Caregiver Links to Understanding, Education and Support) is a research project conducted by the University of Alabama at Birmingham (UAB) TBI Model System. Contact Dr. Patricia Rivera for more information on Project CLUES at 800-405-2640.

“Connections” is an ongoing column in **Brain Waves**. The problems described are real problems faced by real caregivers. The caregivers’ names have been changed to maintain confidentiality.

The next “Connections” column will focus on issues of behavior management. If you are interested in sharing your comments with others in the TBI community, please follow these instructions:

- 1 As briefly as possible, please describe the nature of the brain injury, the problems with behavior that you faced, and how you have solved the problem.
- 2 Send your typed story to Phil Klebine by email at tbi@uab.edu or mail to

619 19th Street South - SRC 529
Birmingham, AL 35249-7330



EDUCATIONAL RESOURCES

NEWSLETTERS FROM THE TBI MODEL SYSTEMS

TBI NEWSCASTER

Annual newsletter for the Spaulding Rehabilitation Hospital Traumatic Brain Injury Model Systems, Boston, Massachusetts.

www.SpauldingRehab.org/TBIMS
617-573-2625

TBI RESEARCH REVIEW

Annual review of current research from New York Traumatic Brain Injury Model System at The Mount Sinai Medical Center.

www.mssm.edu/tbicentral
212-659-9372

THINKING CAP

Annual newsletter by the Southeastern Michigan Traumatic Brain Injury System.

www.semtbis.org/semtbis
313-745-9737

TBI UPDATES

Bi-Monthly newsletter of the University of Washington Traumatic Brain Injury Model System.

depts.washington.edu/rehab/tbi/
206-685-0935

TBI TODAY

Quarterly newsletter by the Virginia Commonwealth University TBI Model System.

www.tbi.pmr.vcu.edu/newsletters.htm
804-828-8797

TALKING HEADS

Newsletter published by the Rehabilitation Research Center for TBI at the Santa Clara Valley Medical Center in San Jose, California.

www.tbimatters.org/talking.html
800-352-1956

The University of Alabama at Birmingham Traumatic Brain Injury Model System is an excellent community resource for educational materials on brain injury. All educational materials are available **FREE** on the Internet at www.uab.edu/tbi, by phone at 205-934-3283, or request through mail.

Research Services
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JOIN THE TBI EMAIL DISTRIBUTION LIST and be notified via email as new and updated TBI materials become available. Email tbi@uab.edu and type "subscribe to TBI email distribution list" in the subject line.



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