

Brain Waves

Volume 2, 2004



CAREGIVERS RECEIVING TRAINING AT UAB

PATRICIA RIVERA, PhD, PROJECT CLUES DIRECTOR

Caregivers of adults with traumatic brain injury (TBI) are invited to participate in Project **CLUES**, which stands for **C**aregiver **L**inks to **U**nderstanding, **E**ducation and **S**upport. Project **CLUES** is one of two research activities currently being conducted by the University of Alabama at Birmingham (UAB) TBI Model System.

Previous research has shown that caregivers who understand how to manage the challenges they face, and who receive the information and support they need, can better care for themselves and the person with TBI who relies on them. The Project **CLUES** staff is dedicated and committed to conducting research that will improve the quality of life of persons with TBI and those who care for them. Your participation in Project **CLUES** and other research activities is an important way to provide very valuable information that is used to improve the lives of future generations.

Persons who enroll in the study will meet with a Project **CLUES** staff member four times during a one year period to talk about their experiences as a caregiver. These meetings will take place in the home or in a convenient location. Participants will be asked questions about their health, mood, how they solve problems, and how they get along with others. Caregiver participants will also receive a monthly follow-up call from Project **CLUES** staff who will be available to answer any questions or serve as a resource to help out with any concerns. Finally, at the end of the study, all participants will receive \$25 in appreciation for their contribution to the study.

For more information, visit the Project **CLUES** website at www.uab.edu/cargiverprojects or call Dr. Patricia Rivera at 1-800-405-2640.



PROVIDING TIME OFF FOR ALABAMA CAREGIVERS

SANDY KOPLON, ALABAMA HEAD INJURY FOUNDATION
DIRECTOR OF COMMUNITY OUTREACH

Anytime there is a person with a traumatic brain injury (TBI) in the home who requires constant supervision and/or custodial care, family activity revolves around the needs of that person. In most cases, caregivers are parents or spouses who provide in-home care for their loved one, around the clock, and without a break or rest. Often, caregivers provide care for other family members as well. These may include young children, spouses and relatives. The stresses and demands of providing such care are overwhelming. Most of the time caregivers give little or no thought to their own physical or emotional needs. This lack of self care often results in extremely high levels of physical and emotional stress for caregivers.

The Alabama Head Injury Foundation (AHIF) Respite Services provide over 75 caregivers in Alabama with much needed breaks from the demands of providing care. AHIF contracts with Home Health agencies statewide to provide qualified personnel to perform the caregiving duties usually carried out by the primary caregiver. Recipients of AHIF Respite Services may choose a home health provider from our list of vendor agencies. These agencies meet the AHIF's standard of training and insurance. Hours are scheduled by the caregiver directly with the Home Health Agency providing the respite services. The funding for the AHIF Respite Services is provided by the Alabama Impaired Drivers Trust Fund, United Way of Central Alabama and private donations.

Each year recipients of Respite Services are asked how they used their respite. The following are a few examples of their responses:

continued on page 2

"I was able to spend a weekend with my daughter and her family without worrying about my husband's care."

- Susan

"The respite gave me an opportunity to just get away for a few hours to do things that most people take for granted. The break is also good for my son, to see other people and not just me all the time!"

- Anonymous

"There are times when you wonder if you can keep on going. With Respite Services, it does give me a break for myself, even if it is only for a long bath or a trip to WalMart!"

- Pam

The AHIF Crisis Respite is now available for caregivers who need assistance due to their own time for medical needs. After the caregiver's physician documents the need for a necessary treatment or procedure, caregivers can rely on Crisis Respite to provide emergency respite from the contracted Home Health Agency. This respite enables caregivers to refrain from medically restricted activities during recuperation while, at the same time, insuring that their loved one is receiving the care he/she needs.

AHIF Respite Services are available for caregivers of persons with TBI and spinal cord injury. Contact Janice Waters, Respite Coordinator, at 205-328-3818 or 1-800-433-8002 for further information.



ALABAMA INDEPENDENT LIVING/HOMEBOUND AT WORK
BETH CREECH, SAIL INDEPENDENT LIVING SPECIALIST

The Alabama Department of Rehabilitation Services (ADRS) State of Alabama Independent Living/Homebound (SAIL/Homebound) Services are to enhance and promote the independence of individuals in the home, community and workplace. SAIL/Homebound offers people with severe disabilities a wide range of home-based support services such as family education, peer counseling, guidance and referrals, counseling, nursing management, home modifications, prescribed medical equipment, supplies, independent living skills training, attendant care and advocacy.

The impact of these services is seen in the daily lives of many like Mike and his mother, Marie. Mike lived a dream life throughout most of his adulthood. He was extremely active – swimming, exercising, running, and cycling when his life took a dramatic turn. He was hit by a car and sustained a severe traumatic brain injury (TBI).

Mike did not qualify for Medicare or Medicaid because he had been employed outside of the United States for most of his working life. However, Mike needed rehabilitation, medical services and supplies, home modification, social services, personal care, and other assistance.

With help from strong family support, Spain Rehabilitation Center and SAIL/Homebound services, Mike began a rigorous physical therapy regimen, which he still follows today. As he grew stronger physically, he also improved his cognitive skills, processing speed, and memory strategies to assist him in becoming more independent – all in preparation for his ultimate goal of moving from his parent's home into his own apartment.

"Before SAIL and ADRS entered the picture, we were at a complete loss. They've done so much."

- Marie

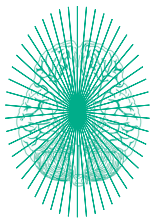
To qualify for SAIL/Homebound services, individuals must be at least 16 years old, live in Alabama, have TBI or tetraplegia, require assistance of others in performing daily activities, demonstrate a financial need and there must be evidence that services will improve an individual's potential to achieve independence. Call 1-800-441-7607 for information.

For more information on the Alabama Head Injury Foundation, please call 1-800-433-8002 or visit the AHIF website at www.ahif.org.

Alabama Head Injury Foundation
AHIF
Improving Life After Traumatic Brain Injury



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 1-888-879-4706 or visit their website at www.rehab.state.al.us.



CONNECTIONS

THE TBI COMMUNITY SPEAKS ON DRIVING ISSUES

"My son suffered a "moderate" head injury in a soccer game at the age of 15. He has been blessed with his recovery. He's almost 17 years old now, and he wants to drive. All of his friends keep telling him that he should be driving because he seems "normal" to them. My son knows the doctors don't want him driving right now because his reaction time is slower than normal and he doesn't do well with multiple tasks. We both hope that he'll be able to drive one day, so I've started taking him to an open lot on weekends to practice his driving. I told him that I'm going to work with him until he can drive safely."

- Steve

"It wasn't long after my husband's car accident before he wanted to go back to work in spite of the fact that he couldn't remember how to actually get to work. The doctors warned me that he might think that he can still drive even though he can't. One of the most common problems I have is that my husband often thinks he's fine and still has a job, so he's always searching for his car keys in order to drive to work. The car keys are well hidden, but I've had to come up with dozens of ways to distract him from thinking that he needs to go to work. I might tell him he's on vacation or give him a small task to get his mind off going to work."

- Rebecca

"My son was seriously injured in a car accident while he was in his last year of college. He can't walk or use his hands very well. He doesn't understand that he has a head injury. He thinks he can drive. He has mood swings too. Sometimes he gets very angry because he thinks I'm keeping him from going to see his friends. I do my best to explain things to him, but he doesn't understand."

- Lynn

"I was so afraid of my son driving again because he got a head injury when he had a wreck. He still drives, and I worry about him wrecking again."

- Linda

"When I was injured back in 1995, my doctors told me that I shouldn't drive because I sometimes get distracted. I went to Spain Rehab Center for my driving evaluation about 6 years ago. I passed, but I can't drive at night, during high traffic times, and during bad weather. I can drive other times, and I think I'm a good driver. I've been driving for 6 years and never had an accident. I'm very careful when I drive because I drive slow and even took the car radio out to keep me from getting distracted."

- Bobby

"At first I thought I couldn't drive again after I got a head injury. But my wife says I'm a safer driver now than I ever was before I had my wreck."

- John

Editor's Note: There is some research suggesting that populations with mobility impairments are not at greater risk for future accidents when compared to similar groups of individuals without disabilities. The reasons behind the findings are unknown, but it may be that some individuals with disabilities make more of an effort to be safer drivers. However, specific research has not been done to determine risk factors within different populations with TBI.

"Connections" is an ongoing column in **Brain Waves**. The comments provided in this column are from individuals with TBI and their families. All names are changed to protect privacy.

The next "Connections" column will focus on issues of caregiver issues. 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 driving 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



CHANGES IN EMOTIONS FOLLOWING TBI

How TBI changes the experience and expression of one's emotions and what might be expected.

COGNITIVE DIFFICULTIES FOLLOWING TBI

Explains cognitive deficits such as the ability to attend and concentrate, communicate, learn and recall new information, organize materials spatially, and reason effectively.

COGNITIVE REMEDIATION FOLLOWING TBI

Exploring the idea of interventions to address areas of deficit either by retraining the areas important to recovery in a direct manner or providing compensation strategies.

POST TRAUMATIC SEIZURES FOLLOWING TBI

Discusses post traumatic seizure types, risk factors, medications, and suggested treatments.

TEMPER OUTBURSTS FOLLOWING TBI

Discusses the causes of temper outbursts in individuals following brain injury along with some of the common characteristics seen and intervention in handling these outbursts.

HOME-BASED COGNITIVE STIMULATION PROGRAM

A workbook providing activities for individuals with TBI to assist recovery of their thinking skills. Each activity provides a group of tasks listed by their level of difficulty. The tasks range from the least challenging (Level 1) to higher levels that are progressively more challenging. You can select activities that you believe are appropriate and increase the level of difficulty by selecting appropriate tasks as progress warrants.

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

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.



Brain Waves is an annual publication of the University of Alabama at Birmingham Traumatic Brain Injury Model System (UAB-TBIMS) and supported by grant #H133A021927 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed are not necessarily those of the granting agency.

UAB-TBIMS Director: Thomas A Novack, PhD
Professor, UAB Department of Physical Medicine & Rehabilitation.

Content information for **Brain Waves** has been provided by the UAB-TBIMS, Alabama Department of Rehabilitation Services, and Alabama Head Injury Foundation. Reprints are encouraged for educational purposes only. All other reprint inquiries are to be made to the Editor.

Alternate formats are available upon request.

Editor: Phil Klebine, MA
Project Coordinator, UAB Department of Physical Medicine & Rehabilitation
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
Phone: 205-934-3283 or TDD 205-934-4642
Fax: 205-975-4691
Email: tbi@uab.edu

© 2004 Board of Trustees, University of AL
The University of Alabama at Birmingham provides equal opportunity in education and employment.

Alabama Head Injury Foundation
3100 Lorna Road, Suite 226
Hoover, Alabama 35216

NONPROFIT
U.S. POSTAGE
PAID
PERMIT NO. 3246
BIRMINGHAM, AL