

Brain Waves

Volume 1, 2003



HELLO, ALL!

PHIL KLEBINE, EDITOR

This is a new newsletter from the University of Alabama at Birmingham Traumatic Brain Injury Model System (UAB-TBIMS). The UAB-TBIMS is 1 of 15 federally funded Model Systems in the country. This honor is given to centers of excellence that demonstrate outstanding care for individuals with TBI during emergency medical services, acute care and through rehabilitation. The UAB-TBIMS also conducts TBI research, disseminates research findings, collaborates with other research programs and participates in the TBI Model Systems Database.

Brain Waves is published annually in cooperation with the Alabama Department of Rehabilitation Services (ADRS) and the Alabama Head Injury Foundation (AHIF). Our goals are to

- 1) provide information on medical, research and social issues of importance to individuals with TBI and their families; and
- 2) offer a forum for individuals with TBI and their families to share their experiences and concerns with everyday issues associated with TBI.



ALABAMA STATE SERVICES

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

ADRS is a proud source of information, education and resources for individuals with TBI, their families, professionals, agencies and organizations. Because brain injury is often a hidden disability, most people in the general community are not familiar with the consequences of injury. However, ADRS has been working with individuals with TBI

and their families for the past 20 years. ADRS understands that TBI has lifelong, far-reaching effects for individuals of all physical, social, economic and cultural lines.

ADRS collaborates with numerous partners such as the AHIF, the Alabama Department of Public Health and the UAB-TBIMS. Together with its partners, ADRS helps to improve the quality of life for many Alabamians affected by TBI.

Although ADRS funds many state-wide services, some state TBI services are funded in whole or in part by the Alabama Impaired Drivers Trust Fund. This special initiative assisted over 1,900 individuals with TBI in the last year alone. This assistance has come in the form of community re-integration, service linkage, housing, respite care, independent living services, resource coordination, attendant care, medical supplies, assistive equipment, cognitive, recreational, and vocational rehabilitation, and for many, ultimately, employment.

Vocational Rehabilitation Services (VRS): The goal of VRS is to assist individuals with disabilities in gaining meaningful employment. VRS offers a customized approach to employment. It incorporates the traditional vocational rehabilitation process, and it also addresses the individual needs of the individual. This process involves an employment evaluation, service plan development, training, assistive technology, job placement, and post-employment follow-up.

Supported Employment: This individualized service is offered to insure the success of securing and retaining employment. A personalized trainer, or job coach, accompanies the person with TBI to the work site and assists with completion of tasks and adjustment to the work environment.

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Passages: This is a structured, progressive approach to assist children and youth with TBI and their families in the transition from the hospital to the home and then to the community. After identification of needs and strengths, resources and services are individualized to enhance the child's function at home, school, and community settings.

Alabama Head and Spinal Cord Injury Registry: The registry is a system for identifying and collecting information on reported cases of head and spinal trauma throughout Alabama. The registry is designed to link individuals with TBI and their families to much needed services as soon as possible after discharge from the hospital. In addition, the registry provides information to professionals working with TBI and collaborates with the Alabama Department of Public Health to develop and implement TBI safety and prevention programs.

Interactive-Community Based Model: This is a unique five phase pre-vocational program designed to evaluate a person's ability to work, live independently and re-integrate into the community after injury. This model has been successful in reducing the time of consumer referral to Vocational Rehabilitation by more than two-thirds of the national average.



DEVELOPING COMMUNITY SUPPORT NETWORKS

CHARLES PRIEST, EXECUTIVE DIRECTOR, AHIF

The ongoing mission of the Alabama Head Injury Foundation (AHIF) is to improve the quality of life for individuals with traumatic brain injury and their families. The AHIF is the primary consumer advocacy organization stimulating the development of TBI support services in Alabama. Over the last 20 years, the AHIF has been a leader behind the passage of numerous legislative acts including Alabama's Head and Spinal Cord Injury Registry and Impaired Drivers Trust Fund, which funds many of the AHIF services. The Foundation's efforts have resulted in enhanced educational services for students with TBI, improved opportunities for community re-integration, and developed an array of consumer support services to help provide for previously unmet needs.

Information & Referral: The AHIF coordinates the state's largest repository of consumer information on brain injury. Consumers seeking information can contact a knowledgeable professional by email, telephone or general correspondence (see contact information on page 3). Foundation professionals will research your questions/requests and respond within 24 hours, often immediately. Over 800 callers receive about 1,000 referrals and 1,250 bits of information per year.

Support Groups: There are over 30 TBI related support groups throughout Alabama hosted by, or affiliated with, the AHIF. Whether the group is therapeutic in nature, informational, social-recreational, or a combination, these support groups continue to meet the needs of individuals with TBI and their families.

Resource Coordination: This program serves over 1,200 people each year and provides local help through information/referral, emotional support, education and resource development. The Resource Coordinators are highly trained and caring professionals – most of whom are consumers or family members – based throughout Alabama. Their work has resulted in over \$500,000 worth of donated or discounted goods and services secured each year. Food, medicines, shelter and related needs are met through the compassion and generosity of local communities. Resource Coordinators also assist clients in "navigating the maze" of federal, state and local assistance programs.

Respite Care: Studies show that many families providing around-the-clock care for loved ones with severe disabilities often go up to 7 years without a substantial break. This is likely to result in extremely high levels of physical and emotional stress. The AHIF's respite care program provides over 75 caregivers with a much needed break from the demands of providing care. Through contracts with home healthcare agencies, AHIF clients may select the service and the dates of respite needed. Emergency care is also available on a limited basis in the event the caregiver becomes ill, which provides peace of mind for everyone.

Socialization/Recreation: The Foundation's

Recreation Department provides many social and/or recreational opportunities for individuals with brain injury. Activities are designed and supervised by Recreational Therapists, and services such as Small Places – a day recreational program now offered in Birmingham, Tuscaloosa, Florence, Huntsville, Cullman, Mobile and Calhoun County - give individuals with TBI the opportunity to participate in stimulating activities in an age appropriate, supportive environment.

Camp programs are also held throughout the year. There is a Spring Camp Weekend and a week-long Summer Camp held at Camp ASCCA in Jackson's Gap, Alabama. Teen Camps are held in the winter at the new Lakeshore facility in Birmingham. Although there is a modest fee charged for attending recreational programs, the AHIF programs have served over 200 people every year.

Housing Programs: Accessibility to one's home often means the difference between a person living at home or in an assisted living facility. Therefore, the AHIF and local volunteers provide accessible home renovations and structural repairs at no charge to consumers.

The AHIF is also an advocate for accessibility in the community. Dogwood Terrace is a 20 unit apartment complex that is scheduled to open in the winter of 2003 in Florence, Alabama. The complex offers affordable one and two bedroom barrier-free apartments. It is a collaborative project between AHIF, Accessible Space, Incorporated, the United States Department of Housing and Urban Development, the Federal Home Loan Bank of Atlanta, the city of Florence and many other individuals and groups. Rocky Ridge Place is a similar project under development in Hoover, Alabama.

The Future: The Alabama Head Injury Foundation is working very hard to increase its number of volunteers to continually provide and expand much needed community-based services for individuals with TBI and their families. As the Foundation continues to grow, the hope is to increase the public's awareness of both the AHIF and the impact of brain injury on individuals, families and communities.



Great Expectations

Phil Klebine, Editor

Each future edition of **Brain Waves** will offer you more detailed information on state services of the AHIF and ADRS. In addition, this newsletter will focus on topics of interests to individuals with traumatic brain injury and their families.

TBI Model Systems Information Update: Each issue will include a list of available educational materials produced by the UAB-TBIMS (see page 4). The update will also include a brief summary of ongoing research activities of the UAB-TBIMS and information on participating in research.

"Connections": This is a column that will appear in all future editions of **Brain Waves**. This column will be for everyone in the TBI community and written by individuals with TBI and their families. In each edition, they will write about a selected topic of importance. They will share their thoughts, feelings and experiences in dealing with TBI related issues.

The first "Connections" column will focus on issues of driving after injury. If you are interested in sharing your story 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
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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.



RESEARCH & YOU

TBI Inform discusses data collection and research at the UAB-TBIMS.

INTRODUCTION TO BRAIN INJURY: FACTS & STATS

TBI Inform explains types of brain injuries, how severity is measured and statistics about individuals with TBI and causes of injury.

WHAT TO EXPECT AFTER TBI AND REHABILITATION

TBI Inform reviews the cognitive, behavioral and emotional difficulties individuals may have after injury; the role of rehabilitation; outcomes following TBI; and rehabilitation services.

MANAGING BEHAVIORAL PROBLEMS AFTER TBI

TBI Inform offers family member and caregiver information on behavioral problems that often occur after TBI as well as suggestions on managing problems.

SPASTIC HYPERTONIA FOLLOWING TBI

TBI Inform discusses spastic hypertonia in individuals with TBI and its management.

HOME-BASED COGNITIVE STIMULATION PROGRAM

by Tom Novack, PhD

& Jacqueline Blankenship, MCD, CCC-SLP

This workbook provides activities for individuals with brain injury 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 materials are available on the Internet at www.uab.edu/tbi, by phone at 205-934-3283, or request through mail.

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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.



Brain Waves is published annually and provides information for individuals with traumatic brain injury, their family, and rehabilitation service providers. It is distributed free of charge. Reprints are permitted with prior approval. Alternate formats available on request.

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