



# President's Report



As in every year, 2002 was a time of challenges and opportunities. In spite of the revenue shortfalls in a post "9/11" environment, the Association worked diligently to pursue its mission: "***To create a better future through brain injury prevention, research, education and advocacy.***" We have much for which we are grateful, yet still have a ways to go to reach our quest.

According to the Centers for Disease Control and Prevention, *at least* 1.5 million American children and adults sustain a traumatic brain injury every year. That number is larger than the annual incidence of spinal cord injury, multiple sclerosis, HIV/AIDS and breast cancer combined. From that 1.5 million, most will recover from a "mild" TBI, yet 50,000 will die, 230,000 will be hospitalized and over 80,000 will live with lifetime disability (cognitive, behavioral and/or physical). That's 219 individuals per day who became disabled in 2002; and another 219 children and adults per day who will become severely disabled as a result of a traumatic brain injury in 2003. TBI does not discriminate. Each one of us is potentially only a second away from a devastating and life-altering experience.

In spite of major advances in emergency medical services, trauma centers, life saving and life improving neurosurgical and rehabilitation techniques that have increased the survivor rate, many children and adults with disability attributable to a TBI receive little to no information or support or lifelong services to reenter and maintain a role in their family, home, school, work place and community. Individuals with TBI represent the most unserved and underserved populations across the disability and chronic illness spectrum by far. Therefore, it is imperative for the Association and its chartered State Affiliates, working with individuals with brain injury, their families and circles of support, researchers, clinicians, providers, government and the private sector to make our voices heard in the halls of government. Policy makers must recognize and support the needs of this invisible population of the so-called "silent epidemic" of TBI.

At the same time, we must also reach out to the general public to increase education and awareness about TBI as well as its prevention, since it's still today's best cure. As you will read in this Annual Report, the Association continues to develop new prevention programs targeted at preschoolers. We believe that if we teach and "insititutionalize" prevention behaviors early in life, these lessons will carry over into childhood and adolescence. We have also begun to refine concepts for a major national public awareness campaign aimed at adolescents and young adults with billboards and bus shelter/mall/restaurant poster boards to raise the public's awareness and consciousness of TBI and the Association.

All of our initiatives would not be possible without the support of dedicated individuals such as yourself, as well as the multiple collaborations developed between government and the private sector. These partnerships allow us to pursue our mission and work to achieve our vision: "A world where all preventable brain injuries are prevented, all unpreventable brain injuries are minimized and all persons who have a brain injury experience quality of life."

Allan I. Bergman  
President and CEO

# Public Policy and Advocacy Efforts

The Brain Injury Association of America and its strong grassroots network continue to fight for the rights of persons with brain injury and their families and friends on Capitol Hill. With a unified voice, advocates from across the country have forced Congress to face the critical issues facing the “silent epidemic” of brain injury. The Association empowers its advocates to make a difference by effecting critical changes in public policy at the state and federal level.

## **Public Policy Conference**

A key program in this effort is the Association’s annual Public Policy Conference. The Conference attracts attendees from across the country and focuses on key health and disability policy issues such as the TBI Act, patients’ rights, managed care, Medicaid/Medicare, personal assistance, housing, transportation, family supports and major Supreme Court cases that deal with the Americans with Disabilities Act (ADA) affecting the disability community. In addition to presentations by highly qualified individuals in the field of public policy, including Members of Congress, the Conference culminates with a visit to Capitol Hill where participants meet with their Congressional Members.

In 2002, over 100 people attended the Association’s Policy Conference, despite the tragic events of September 11<sup>th</sup> and the understandable reluctance of many Americans to travel to Washington, DC. Highlights from the 2002 Conference *Reaching for the Gold* include: the debut performance of the Kids on the Block, Inc. puppet “Justin Campbell” who teaches children and adults awareness and sensitivity to brain injury; a White House briefing luncheon on disability policy from the Office of Domestic Policy; a federal panel comprised of leaders in various federal agencies discussing disability perspectives from the George W. Bush Administration and concurrent sessions on the TBI Act, Education Reform, Long-term Services and Supports and Patients’ Rights legislation.

## **Policy Corner and TBI Act Update**

The Association distributes a weekly policy newsletter via email to nearly one thousand individuals across the country – from grassroots advocates to professionals in the field of brain injury. Recipients of this free electronic service include: the Association's chartered State Affiliates, federal agency staff including HRSA, the CDC and NIH, persons with brain injury and their family members, advocates, federal and state governmental employees, physicians, researchers, social workers, rehabilitation counselors, academicians and others. The "Policy Corner" e-letter analyzes current legislation and health policy related to the silent epidemic of brain injury in the U.S., and tracks relevant bills moving through Congress that advocates are encouraged to support.

Advocates also receive a free monthly email subscription to the *TBI Act Update*, which provides information and action alerts about the Traumatic Brain Injury Act and the status of fiscal year appropriations.

## **Legislative Action Center**

The Association's "Legislative Action Center" (LAC) — accessible via our website at [www.biausa.org](http://www.biausa.org), is an interactive online advocacy tool that allows advocates to identify and learn how to contact their elected officials on Capitol Hill, as well as to stay abreast of legislative and health policy issues. The LAC helps the Association and its constituency realize critical legislative goals by effecting positive changes in health policy. By logging on to this free online service, advocates are able to identify their Congressional Members simply by typing in their home zip code. Advocates are empowered to communicate directly with their elected officials by sending targeted emails, letters and facsimiles. The Association also utilizes the LAC to send out grassroots "Action Alerts" regarding key legislation such as the Traumatic Brain Injury Act of 2000 and related appropriations bills, the Elder Fall Prevention Act, the Lifespan Respite Care Act, Mental Health Parity legislation, and legislation designating October as "Brain Injury Awareness" month. To date, there are nearly one thousand members signed on to the LAC.

### **The Consortium for Citizens with Disabilities**

The Consortium for Citizens with Disabilities (CCD) is a coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

### **Congressional Brain Injury Task Force**

In March 2001, the offices of James C. Greenwood (R-PA) and Congressman Bill Pascrell, Jr. (D-NJ) contacted staff of the Association's Government Relations Department regarding the formation of the bipartisan Congressional Brain Injury Task Force. In a letter dated March 22, 2001, the Congressmen wrote: "As Members of Congress concerned with the health of all Americans, we share your deep interest in increasing awareness of the incidence and prevalence of brain injury in the United States," adding "Your national leadership in addressing various aspects of brain injury is most important to us." Due in large part to the work of the Association's grassroots network from across the country, the Congressional Brain Injury Task Force has grown to include approximately 68 Congressional Members.

### **Olmstead Training**

In February 2002, through a contract with the Center for Medicare and Medicaid Services, the Association conducted a "train the trainer" series on the Supreme Court decision *Olmstead*, entitled *Olmstead Decision 101*. In this 1999 Supreme Court decision, the Court stated that the unjustified isolation of persons with disabilities in institutions constitutes discrimination under the Americans with Disabilities Act. The Association recognizes that numerous persons with brain injury continue to be placed inappropriately in institutional settings without appropriate treatment, rehabilitation or access to the community.

Participants were trained to be trainers within their own states. Each participant was provided with a training binder and toolkit that contained resources for use in their home states. Resources included: expert presentations, the *Olmstead* decision and background information, perspective from the George W. Bush Administration, *Olmstead* Advocacy information and State Medicaid Letters, transparencies, a CD Rom and a hard-copy version of a template *Olmstead* training, as well as camera-ready *Olmstead* fact sheet for reproduction.

### **TBI Act Appropriations**

In 2002, the Association's Government Relations team and extensive grassroots advocacy network successfully urged the House and Senate to include critical report language on brain injury into its Labor, Health and Human Services and Education appropriations bill for fiscal year 2003 to fund the TBI Act. Critical report language was included for the HRSA, CDC and NIH sections of the Act. Further, the Association was able to increase funding levels for the TBI Act in fiscal year 2003

### **Blue Ribbon Panel Reviews Brain Injury Risk of Amusement Park Rides**

In response to a request from U.S. Representatives Edward Markey (MA) and Bill Pascrell, Jr. (NJ), along with 12 additional Members of Congress who expressed concern over the apparent increase in incidence of roller coaster related brain injuries and fatalities, the Association, under the leadership of its Medical Director, Dr. Gregory J. O'Shanick, assembled a dispassionate panel of experts from a variety of disciplines to review the literature and case studies regarding the potential risks of brain injury from high speed amusement park rides. The panel met throughout the year by teleconference and e-mail and culminated its work with a two-day meeting in November in Alexandria, Virginia. The National Institutes of Health, National Center for Medical Rehabilitation and Research, provided funding to the Association for travel and expenses of the members of the Blue Ribbon Panel.

Although the final report will not be released until 2003 at a press conference at the National Press Club, the bottom line conclusion is captured in the following statement: "the risk is in the rider and not the ride." Simply stated, there was no evidence that the rides caused the brain injury. The riders who experienced brain injury were individuals with undetectable preexisting conditions such as an artery about to rupture from an aneurysm, which could occur at any time, and the individual would have no advance knowledge. The Panel also made a number of recommendations, which are posted on the Association's web site.

# Education and Research Efforts

## Symposium

The Association held its 21<sup>st</sup> Annual National Symposium in Minneapolis, Minnesota in July of 2002. More than 400 people from all sectors of the brain injury community attended the meeting, titled *WIDENING THE CIRCLES: Constituencies, Collaborators and Communities*. Featured plenary speakers included Allan I. Bergman, President and CEO of the Association, Susan Horn, PhD, Gale Whiteneck, PhD, Karen Schwab, PhD, Charles Christensen, PhD, Alta Bruce, BA, and Pricilla Sanderson, PhD. Over 60 concurrent technical sessions were held in major areas of research and education. Workshops were held for educators and the AACBIS program. Overall participant evaluations rated the conference very high.

## American Academy for the Certification of Brain Injury Specialists (AACBIS)



Founded in 1996, The American Academy for the Certification of Brain Injury Specialists, a program of the Association, continued the expansion and implementation of its national certification program for people who specialize in working in the field of brain injury and the development of a strategic plan for the future (state specific curricula and testing, restructuring to conform to NOCA, new manual in winter of 2003).

### *Highlights of the Year:*

There are currently 650 Certified Brain Injury Specialist and over 500 people involved in various stages of the testing and training process for certification.

## **Information and Resource Department: National Toll-Free Helpline 800#**



The Information and Resource Managers, funded by the Defense and Veterans Brain Injury Center through the Department of Defense, provide accurate and current information about traumatic brain injury and resources in a supportive manner, while simultaneously facilitating individual choice, decision-making, and personal advocacy. In 2002, the Information and Resource Managers had nearly 17,000 dialogue contacts with individuals with brain injuries, their family and friends, professionals, military personnel and veterans, students, the general public, and the Association's State Affiliates via the Association's national toll-free Family Helpline, emails to the Family Helpline mailbox and other correspondence.

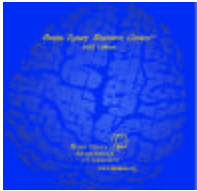
The Information and Resource Managers have specialized education and experience that enables them to assemble, create, and disseminate information on the wide range of issues that traumatic brain injury encompasses—from in-depth medical questions to complex emotional issues. In addition to responding to the Family Helpline inquiries, the Information and Resource Managers regularly wrote reports, special topic handouts, content for the Association's website, content for other departmental projects, and for the Association's publications. The Information and Resource Managers presented nationally as invited keynote or guest speakers at a variety of conferences in the health care arena, including conferences held by other national disability and health advocacy organizations.

In 2002, the Information and Resource Managers mailed 2,700 requested packets of general and complex information about traumatic brain injury. During this year, the Information and Resource Managers consistently received superior ratings from random surveys regarding their job performance and the quality of information provided. Furthermore, hundreds of unsolicited positive feedback responses received from inquirers reported that the Information and Resource Manager's contributed positively to their lives.

## Brain Injury Resource Center™ (BIRC™)



After several years of development, the Brain Injury Association's interactive multimedia information center has been reorganized from a kiosk version into an easy to use and distribute CD-ROM. The BIRC™ provides access to information at the click of a mouse, where and when people need it. It is readily available in emergency departments, trauma centers, hospitals, rehabilitation programs, attorney's offices and Brain Injury Association State Affiliate offices.



Family members are thrust into situations that require them to make decisions with no preparation and scarce information. And once the immediate crisis has passed, more questions arise and more decisions must be made. Through the BIRC™, users can find:

- ◆ Answers to the most common questions about brain injury
- ◆ A glossary defining technical terms
- ◆ Information about available programs and services throughout the United States and abroad
- ◆ Descriptions of professionals and the services they offer
- ◆ Interviews with people with brain injury, family members, and professionals at various stages throughout the recovery process
- ◆ Education and informational materials, including information about secondary injury

Through the combination of still and motion video, graphics, text, and sound, the *Brain Injury Resource Center™* provides easy to understand information for individuals with a friend or family member who has sustained a brain injury. At the same time, it provides education and information of a more technical nature for medical professionals. Individuals using the *Brain Injury Resource Center™* are able to control the rate at which information is presented, the nature of the information, and the depth in which it is explored, allowing them to learn at their own pace.

# TBI Model Systems



In the early 1970s, it became apparent that the complex nature of some injuries and the disabilities that followed required special attention by the federal government. Care provided for these injuries varied from region to region and even between care providers in the same region. Basic questions about these injuries and their treatment could not be answered because there was no mechanism for systematically investigating these issues and collecting consistent data. Without a central storehouse for that information, there was no way to tell who the injured were, how they were treated or which treatments worked.

The TBI Model Systems (TBIMS) were established in 1987 through a grant from the United States Department of Education, National Institute on Disability Rehabilitation and Research (NIDRR) with two major goals: (1) development of an exemplary system of care and (2) uniform data collection related to important research questions. TBIMS sites actively pursue a wide variety of interesting research questions and publish articles in peer-reviewed journals. All TBIMS, located across the country, are housed in strong and well-established medical centers that provide care from the onset of injury through the post-acute phase. Overall they have provided care and collected information on 2,600 individuals with TBI during the acute hospital stay and in the community after discharge.

Unfortunately, individuals with brain injury, their family members, advocates and professionals do not always have the time or resources to review all relevant journals. In order to enhance the dissemination of this research and to provide it in a "user friendly context," the Association has entered into an agreement with the TBIMS to develop and publish 40 to 50 abstracts of TBIMS published research articles per year and to post them on the Association's web site as well as in the Association's newsletter, TBI Challenge! The abstracts on the web site also will be linked to the original journal article for the reader who desires more in-depth information. Preliminary feedback on the abstracts from the public, TBIMS researchers and the federal government has been favorable, and it is the Association's goal to expand this program by adding a full-time staff member to review all relevant scientific data and disseminate the information to those who need it most.

# Public Awareness Initiatives

## National Brain Injury Awareness Month



October is National Brain Injury Awareness Month, a critical time when the Brain Injury Association strives to build public awareness and education by producing and distributing important education and prevention tools in the form of unique and eye-catching public awareness kits. Thanks to the generous support of the Defense Brain and Spinal Cord Injury Program, and the efforts of many individuals, the Association has been able to effectively expand this effort each year.



The 2002 Brain Injury Awareness Kit featured:

- ◆ A new poster titled, Break the Cycle; it stops with me
- ◆ A set of five distinct information clue cards designed to placed in physician offices or emergency rooms to educate people about violence prevention, shaken baby syndrome, penetrating brain injury, domestic violence and violence in the military.
- ◆ A set of five distinct bookmarks about violence prevention, shaken baby syndrome, penetrating brain injury, domestic violence and violence in the military.
- ◆ A CD-Rom with sample press releases and other information on how to utilize the tools contained within the kit to procure media placement and organize events in local areas.

More than 5,000 kits were mailed to chartered state affiliates, individuals with traumatic brain injury, family members, state and federal agencies, service providers and teachers.

## National Public Awareness Campaign



In 2001-2002, the Association expanded its partnership with the nationally known advertising agency BVK/McDonald, based in Milwaukee, WI to create a national public awareness campaign. The CDC provided funding to assess the feasibility of three creative concepts developed by BVK. All of the concepts contained images that drew attention, comments, and reactions to the prevention message. Focus groups in Los Angeles, CA and Birmingham, AL as well as Internet responders provided opinions and represented a varied demographic base across age, gender, race, ethnicity and geographic region. The creative concepts help to further the Association's vision.

The Association required that the research study (focus groups) meet the following criteria:

- ◆ Determine the degree to which each campaign is effective in communicating a specific strategic message
- ◆ Assess the likelihood of each campaign to grab consumer attention
- ◆ Ascertain the level of message retention for each campaign

The demographic specifications were:

- ◆ Age 18 to 32, 300 interviews and age 33+, 300 interviews
- ◆ Mix of African American, Caucasian, Hispanic
- ◆ Mix of male and female

The results of the focus group tests were published in 2002. From the results of the focus group the Association along with BVK/McDonald decided to peruse the "Safe World" campaign. Feedback from the focus group about this campaign are as follows:

- ◆ 61% agreed Safe World would capture their attention
- ◆ 62% believed they would remember the campaign
- ◆ Interesting and clever
- ◆ Message of "need to wear a helmet" is clear
- ◆ 76% believed the campaign was easy to understand

The Association plans to launch the Safe World campaign in 2003.

# The Internet and Technology



In an effort to better serve its constituents, the Brain Injury Association of America has re-designed its web site – [www.biausa.org](http://www.biausa.org). The re-design of the Association's award-winning web site has resulted in improved navigation and search possibilities, as well as allowing for a better and more logical flow of information. The new web site has tabs that carry over to every page, allowing the user to find his/her way around [www.biausa.org](http://www.biausa.org) even quicker and easier.

The new homepage features a set of horizontal tabs, which are now found at the top of each page – enhancing the ease with which visitors can navigate within the web site. The new and improved homepage also includes the most up-to-date information about the Association, an “Act Now” section that will feature time sensitive material and a jobs section.

Since our redesigned web site has been launched, visitors have been enjoying a much more user-friendly and accessible web site, including downloadable files offered as both pdf files and as text-only files and eye-catching graphics download quickly. The improved web site not only has appealed to our repeat visitors, but has also lured new visitors to the most comprehensive web site on brain injury.

## **New – Spanish Materials added to the Association's Website in 2002:**



- 1) Road to Rehab
- 2) Guide to Selecting and Monitoring Brain Injury Rehabilitation Services
- 3) Brain Injury Fact Sheet
- 4) TBI Incidence Fact Sheet

## **Articles**

- 1) Neuropsychological Evaluation and the Schools
- 2) Planning School Transitions for Students with TBI
- 3) Selecting a Neuro-lawyer
- 4) Back to work: A personal perspective
- 5) Personality changes after TBI
- 6) Shaken Baby Syndrome
- 7) Substance Abuse and TBI
- 8) Brain Injury Association of America Background
- 9) Survivor's Voice

## **Other Materials**

- 1) Concussion Poster
- 2) Concussion Clue Card
- 3) Spanish Family Help line PSA

# Assistive Technology and Devices for Individuals with Cognitive Impairments



During the past twenty years the lives of most Americans have been improved as a result of innovations in technology. In 1988 the federal government began making investments in assistive technology through devices for people with disabilities with an emphasis on people with physical and sensory disabilities. In 2001, the National Institute for Disability and Rehabilitation Research (NIDRR), upon urging by the Association and other advocates, proposed funding for projects to conduct research on assistive technology and devices for individuals with cognitive impairments. The Association assembled an exemplary cadre of partners with interest and expertise in this area, including the University of Akron, Moss Rehabilitation Hospital Temple University in Pennsylvania and Spaulding Rehabilitation Hospital in Massachusetts to develop a collaborative proposal for five years. The proposal was funded in 2001 and work began in 2002.

The project's focus is on the use of digital memory organizers (DMO's) by children and adults with brain injury or mental retardation. Researchers focused on three questions: (1) What technology for memory and organization is currently available? (2) What are important features of technology for memory and organization for persons with cognitive disabilities? and (3) How well do current DMO's serve the perceived needs, and what are the perceived gaps for users and non-users? During 2002, a survey was completed, a catalogue of devices was assembled and placed on the Association's web site and a research design was established for the research trials to begin in 2003. We expect that the research and the dialogue with manufacturers will result in modifications of the devices, and that the research will justify changes in third party reimbursement. Lastly, and most importantly, we expect assistive technology may be one of the last frontiers of compensatory strategies for individuals who have sustained a TBI to enhance their independence and personal dignity by relying less on paid caregivers and family members as well as reducing the paid support costs for personal care workers. We are confident the next four years will yield promising results and practices

# Preventing Brain Injuries

The Association develops and disseminates materials that are designed to promote practices that will help prevent new brain injuries. Several projects and publications are geared to nationally promote that prevention matters.

## *Prevention Matters*



In 2002, two issues of *Prevention Matters* were circulated through the Association's website and email. To access a copy of *Prevention Matters* please visit [www.biausa.org](http://www.biausa.org).

## The Medtronic Foundation - I.M. Brainy



**Medtronic**

The Association continued its successful partnership with the Medtronic Foundation - a leading medical technology company. The Association



is in the process of developing a prevention-oriented curriculum, which will be tailored to early elementary aged children. A 36-inch "I.M. Brainy" puppet, properly attired in a helmet, will be the prop that will aid teachers and their aids in telling the I.M. Brainy prevention story.

This product is built around a bear puppet designed in active collaboration with Playful Puppets, Inc., named I. M. Brainy, for use by teaching assistants, parents, or other non-educational professionals in a large classroom or small auditorium setting. The I. M. Brainy concept was tested extensively, going through seven redesigns before a final version was adopted. The puppet itself was named with the help of preschool teachers, who approved this choice because it could be personalized to each student (for example, "Alex M. Brainy" ...Why is Alex brainy? Because he wears a helmet!)

While year one activities were concentrated on evaluation to determine the types of materials and information that are most needed, Year Two activities focused on the development of these materials. Following the study's completion, the Association began the development of an introductory presentation for school groups of 20 to 125 children. Intended to raise awareness of brain injury prevention in schools and other venues and to establish the Brain Injury Association as a source of additional information, the product includes:

- ◆ A movable-mouth hand puppet
- ◆ A presenter's guide

Finally, the Association's project team, in consultation with teachers and educational experts, refined the program concept to focus specifically on children enrolled in pre-school. This refinement takes into consideration:

- ◆ Children at this age are most receptive to the I. M. Brainy concept;
- ◆ Studies show conclusively that early exposure to concepts of safety has the best results;
- ◆ The Association program staffing will permit us to most effectively focus on fewer age groups;
- ◆ Other safety curricula targeting grades 1 through 12 adequately reinforce concepts taught through the I. M. Brainy Preschool Awareness and Prevention Kit.

To be implemented over a five-day period, the program begins with a simple introduction to the brain. The next three days are devoted to high-risk transportation issues: motor vehicle safety, pedestrian safety and helmet safety. A final assessment and review on the last day ensures that children have understood and absorbed the messages of prevention and basic safety techniques.

All of the materials were created in collaboration with a team of preschool teachers. Their combined experience with both traditional school settings and Montessori classrooms has produced lessons incorporating many teaching methods and accessible to a wide range of learning styles.

The activity kit will include lessons, a song, illustrated activity sheets, which the children can color, resource web links for teachers, and letters of instruction for teachers and parents.

Based on information gathered from interviews with teachers and administrators, the Association changed its dissemination strategy. Since schools are being held to more stringent requirements regarding core learning objectives and standards set by state systems, it is becoming more difficult for them to integrate curriculum that is not sanctioned by State Departments of Education. For this reason, the Association staff determined that it would be more effective to post the downloadable products on the Association's website and promote them through the website and locally through the Association's state affiliates. In this way, teachers will have easy access to the lessons and the Association staff will be able to update them more easily.

# The Association's Premier Publications

## ***The National Directory of Brain Injury Rehabilitation Services***

The *Directory* contains information about rehabilitation facilities and programs as well as individual service providers and community-based services across the country. The Association has continued to improve the *Directory* to make it easier for individuals, particularly those with brain injury, to utilize the information presented. The 2003 printed *Directory* also included a CD-ROM version providing access choices to the users. More than 5,000 Directories were distributed free of charge to individuals with brain injury, advocates and professionals in the field.

## ***Brain Injury Source***



Approximately 28,000 copies of the Association's professional magazine, funded by the DBSCIP program, were circulated.

The 3 issues created in 2002 covered the following topics:

- ◆ New Therapies and Treatment in Brain Injury: The Challenges and Successes
- ◆ Understanding the Epidemiology of TBI
- ◆ Brain Injury and Children – A Silent and Ignored Epidemic

## ***TBI Challenge!***



Also funded by DBSCIP, the Association's quarterly newspaper has a primary audience of individuals with brain injury, family members and others interested in brain injury. *TBI Challenge!* has a circulation of 25,000 and is provided to every member of a chartered state affiliate. In addition to its featured columns of "Information and Resources", "Ask the Lawyer", "Public Policy Update" and Symposium notes, the Challenge now features abstracted articles written by researchers from the TBI Model Systems Projects. The purpose of this newest feature is to assist people with brain injury and their families to learn about the latest research findings in a user-friendly context.

The issues covered in 2002 covered the following topics:

- ◆ The September 11<sup>th</sup> tragedy
- ◆ Research findings in the field of brain injury
- ◆ Managing Behavioral Issues in Community Settings
- ◆ The TBI Model Systems
- ◆ Communication vs. Conflicts: Helping Parents and Education
- ◆ Reaching Out to Families of People with Chronic Pain
- ◆ The NEW Spanish Language Component of the Brain Injury Association's of America's web site
- ◆ Impact of TBI on the Family
- ◆ Planning for the Future

# Health Resources and Services Administration (HRSA) Partnership for Information and Communication Cooperative Agreement



In 2002, the Association completed its fourth year of a five-year cooperative agreement known as the Partnership for Information and Communication (PIC) with Health Resources and Service Administration (HRSA), Maternal and Child Health Bureau. The Association completed numerous products and services for the PIC. They include:

## **Regional Meetings:**

A training was held in November, 2002, in New Orleans, LA, in collaboration with the National Association of State Head Injury Administrators. At this meeting, Association Staff provided training in TBI Advocacy & Systems Development. In attendance were State Affiliate leaders and state government leaders from Georgia, Kansas, Louisiana, Maine, Mississippi, Texas and Washington.

## **Policy Corner:**

The Association nationally distributes Policy Corner, a weekly email policy brief to nearly 1000 individuals, including the Association's chartered State Affiliates, HRSA staff, TBI survivors and their families, advocates, federal and state employees, physicians and academicians. The policy brief analyzes weekly activities related to brain injury targeted by Congress and other federal agencies.

## **Fact Sheets:**

In 2002, the Association updated its fact sheets on the Association; Brain Injury; TBI Incidence; Scooter Safety; Transportation Safety; Sports and Recreation; Shaken Baby Syndrome; Falls; Bicycle Safety; and Violence Prevention. The Association also created two new fact sheets, Violence in Youth and Domestic Abuse in Military Families. The fact sheets are available on the Association's website for public awareness efforts, as well as for media inquiries. The fact sheets are also distributed to Affiliates to assist with their information dissemination.

### **The State Affiliate Resource Site (STAR) Site- [www.brain-injury.org](http://www.brain-injury.org):**

In 2002, the Association continued to host the STAR Site as a password-protected web site providing up-to-date information to the State Affiliates. The site contains information on brain injury, governance, federal and state policy, advocacy and technology, and provides resources, such as articles, document templates and sample presentations. Through the STAR Site, Affiliates can also exchange best practices. The Delta Foundation makes the STAR Site possible through a generous donation for Rehabilitation and Research.

### **Currents:**

The Association's Affiliate Relations Department distributes an email newsletter titled Currents to State Affiliates to encourage frequent communication. The newsletter contains information on conferences, training seminars, grant announcements, legislative action alerts, and news briefs from Affiliates.

## **Leadership Conference:**

November 2002 - New Orleans, Louisiana



Supported by the Association, HRSA and DBSCIP, the conference attracted 70 association leaders, members, staff volunteers and guests from thirty-five states. The Leadership Program featured sessions on financial survival in the 21st Century, TBI advocacy and systems development. Membership and State Affiliate assembly meetings were also held, and multiple networking opportunities were offered.

## **U. S. Department of Education, National Institute on Disability and Rehabilitation Research Field Initiated Research Project**

In October 2002, the Association, responding to the significant unemployment of individuals with brain injury, launched a three-year self-employment project for people with Traumatic Brain Injury (TBI) in partnership with the Montana Rural Institute's Adult Community Services and Supports Department. The Self-Employment Development for Individuals with Traumatic Brain Injury Project will create replicable self-employment options for people with TBI through inventive capacity building that focus on the skills and interests of the potential business owner. The project will focus its activities in collaboration with its affiliate in Utah and with advocates in the state of Virginia.

# Development and Fundraising

## **The Lynn A. Chiaverotti Memorial Fund – a very special tribute**

The Lynn A. Chiaverotti Memorial Fund (“The Lynn Fund”), founded in November 1997 by Naval Captain Gary R. Chiaverotti and his family, continues to celebrate the life of his wife, Lynn, who passed away as a result of injuries sustained in an automobile crash while they were stationed in Singapore.

Events sponsored by the fund focus on awareness of potential causes of brain injury, methods of prevention as well as information and assistance available to individuals with brain injury, their family and friends.

## **Devon Struck**

Devon Struck, a 27-year-old Columbia, Maryland woman, began preparing to backpack the 2,170-mile Appalachian Trail to raise money for the Brain Injury Association of America for traumatic brain injury (TBI) research.

“Devon's Walk in the Woods,” as Struck calls her mission, was inspired by Stephanie Gianfagna, a 34-year-old Columbia Maryland woman who sustained a severe brain injury at the age of 21 in a head-on collision with a vehicle. Stephanie, who was enrolled in the nursing program at the University of Maryland and engaged to be married, was left comatose by the accident and has needed around-the-clock care in a nursing home for the past 13 years.

Struck's goal is to raise \$10 for each of the 2,170 miles of the Appalachian Trail, which begins in Georgia in March, 2003, and ends in Maine. All funds will be donated to promote research via the Brain Injury Association of America.

Donations can be mailed to Devon's Walk, #276, 5430 Lynx Lane, Columbia, MD 21044. Checks should be made payable to the Brain Injury Association of America. All donations are tax-deductible.

## Statement of Activities for the Year Ended December 31, 2002

### Revenue and Other Support:

Grants Revenue	\$1,759,095
Contributions	369,719
Special Events, Net	29,101
Products, Publications and Related Items	246,302
Contributed Services	78,650
Conferences and Meetings	355,637
State Affiliation Fees	221,230
Rental Revenue	23,920
Net Investment Revenue	359
Other Revenue	14,046
Total Revenue and Other Support	<u>\$3,098,059</u>

### Expenses:

#### Program Services:

Public Awareness	\$670,484
Education and Training	442,531
Information and Resources	560,860
Prevention	181,629
Government Relations	469,247
Affiliate Relations	291,533
Research	268,712
Total Program Services	<u>\$2,884,996</u>
Management and General	154,189
Fundraising	382,159
Total Expenses	<u>\$3,421,344</u>

Change in Net Assets: \$ (323,285)

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<b>*Colorado</b> (303) 355-9969( 800) 955-2443	<b>Nat'l Kentucky</b> (502) 493-0609 (800) 592-1117	<b>New Jersey</b> (732) 738-1002 (800) 669-4323	<b>Tennessee</b> (865) 982-4455
<b>Connecticut</b> (860) 721-8111 (800) 278-8242	<b>*Maine</b> (207) 861-9900 (800) 275-1233	<b>New Mexico</b> (505) 292-7414 (888) 292-7415	<b>Texas</b> (512) 326-1212 (800) 392-0040
<b>Delaware</b> (302) 537-5770 (800) 411-0505	<b>Maryland</b> (410) 448-2924 (800) 221-6443	<b>New York</b> (518) 459-7911 (800) 228-8201	Utah (801) 484-2240 (800) 281-8442
<b>Florida</b> (954) 786-2400 (800) 992-3442	<b>Massachusetts</b> (508) 795-0244 (800) 242-0030	<b>North Carolina</b> (919) 833-9634 (800) 377-1464	<b>Vermont</b> (802) 453-6456
<b>Georgia</b> (404) 467-9367 (888) 334-2424	<b>Michigan</b> (810) 229-5880 (800) 772-4323	<b>Ohio</b> (614) 481-7100 (866) 644-6242 ("Ohio BIA")	<b>Virginia</b> (804) 355-5748 (800) 334-8443
<b>Hawaii</b> (808) 941-0372	<b>Minnesota</b> (612) 378-2742 (800) 669-6442	<b>Oklahoma</b> (580) 233-4363 (800) 765-6809	<b>Washington</b> (425) 895-0047 (800) 523-5438
<b>Idaho</b> (208) 342-0999 (888) 374-3447	<b>Mississippi</b> (601) 981-1021 (800) 641-6442	<b>Oregon</b> (503) 585-0855 (800) 544-5243	<b>*West Virginia</b> (304) 766-4892 (800) 356-6443
<b>Illinois</b> (708) 344-4646 (800) 699-6443	<b>*Missouri</b> (314) 426-4024 (800) 377-6442	<b>Pennsylvania</b> (717) 657-3601 (866) 635-7097	<b>Wisconsin</b> (414) 778-4144 (800) 882-9282
<b>Indiana</b> (317) 356-7722 (800) 407-4246			<b>Wyoming</b> (307) 473-1767 (800) 643-6457 *

# Board of Directors

Chairperson  
Chairperson-Elect  
President and CEO  
Vice-Chairperson for Program Outcomes  
Vice-Chairperson for Finances and Records  
National Medical Director

James T. McDeavitt, MD  
Maureen Alterman, MS  
Allan I. Bergman  
John D. Corrigan, Ph.D.  
Dianne J. Weaver, Esq.  
Gregory O'Shanick, MD

Maureen Alterman, MS  
Howell, MI  
Term ends: December 31, 2004 (2nd term)

James T. McDeavitt, M.D.  
Charlotte Institute of Rehabilitation  
Charlotte, NC  
Term ends: December 31, 2003 (2nd term)

Mark J. Ashley, Sc.D., CCC-SLP, CCM  
Centre for Neuro Skills  
Bakersfield, CA  
Term ends: December 31, 2005 (1st term)

Gregory J. O'Shanick, M.D.  
Midlothian, VA

Allan I. Bergman  
Brain Injury Association of America  
Alexandria, VA

Jay Rosenberg, M.D.  
LaJolla, CA  
Term ends: December 31, 2003 (2nd term)

Debra Braunling-McMorrow, Ph.D.  
Center for Comprehensive Services  
Carbondale, IL  
Term ends: December 31, 2005 (2nd term)

Andres Salazar, M.D.  
Washington, D.C.  
Term ends: December 31, 2003 (2nd term)

John D. Corrigan, Ph.D.  
The Ohio State University  
Columbus, OH  
Term ends: December 31, 2002 (2nd term)

Ralph William Shields  
Advocate for Disability Rights  
Albany, NY  
Term ends: December 31, 2003 (2nd term)

Wayne A. Gordon, Ph.D.  
Mount Sinai School of Medicine  
New York, NY  
Term ends: December 31, 2005 (1st term)

Ellen Shillinglaw  
Bethesda, MD  
Term ends: December 31, 2002 (1st term)

Marilyn Hern  
Boise, ID  
Term ends: December 31, 2005

Karen R. Voogt, RPT  
Virginia Beach, VA  
Term ends: December 31, 2003 (2nd term)

Tim Imhoff  
State Wide Community Support Services  
St. Louis, MO

Wally Walsh  
Delta Foundation  
Snohomish, WA  
Term ends: December 31, 2004 (2nd term)

Douglas I. Katz, M.D.  
Braintree Rehabilitation Hospital  
Braintree, MA  
Term ends: December 31, 2004 (2nd term)

Dianne J. Weaver, Esq.  
Harrell & Johnson, P.A.  
Jacksonville, FL  
Term ends: December 31, 2004 (2nd term)

**2001 Board of Directors Meeting List –**

- February 21 - Association Offices, Alexandria, VA
- May 31 - Association Offices, Alexandria, VA
- July 24 - Hyatt Regency Hotel, Minneapolis, MN
- November 8 - Hilton Hotel, Alexandria, VA

# Association Staff & Volunteers

The Association employed the following staff in 2002:

Allan Bergman	President and CEO
Karen Flippo	Vice- President

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Greg Ayotte	Director of Information Resources (I&R)
Polly Berry	Administrative Assistant
Nancy Blethen	Chief Financial Officer
Michele Burnett	Director of Development
Dr. Mary Car	I&R Specialist
Tom Coffey	Government Relations Specialist
Viki Cucciardo	Development Specialist
Danita Davis	Administrative Assistant
Roxane Dean	I&R Specialist
Mary Beth Diehl	State Affiliate Specialist
Robert Demichelis	Volunteer
Alice Demichelis	Volunteer
Rachel Egner	Prevention Specialist
Amy Fitzgerald	Policy Analyst
Chris Fuller	Communications Specialist
Karen James	Education Specialist
Dan Keslar	Director of MIS
Geoffrey Lauer	Director of State Affiliates
Craig Levin	Librarian
Monique Marino	Communication Specialist
Tony McNeil	Accounting Specialist
Rebecca Mosher	Jr. Graphics Designer / Admin. Assistant
Hillary Norton	Administrative Assistant
Scott Peterson	Director of Operations
Sonia Quintero	I&R Specialist – Spanish Help line
Tina Radenberg	Graphic Designer

Linda Robinson	Director of Education and Research
Anne Rohall	Director of Government Relations
Margaret Roller	Accounting Assistant
Donna Scott-Martin	Executive Assistant
Alice Marie Stevens	Director of Prevention
Jean Wellman	Event Coordinator

