



2003 Annual Report

Public Policy

The Brain Injury Association of America and its grassroots network continue to educate policy makers on Capitol Hill and across federal agencies in support of the rights of persons with brain injury and their families. The Association's Department of Government Relations actively promotes the need for services for all individuals with brain injury and supports efforts to obtain such services through governmental agencies at the federal, state and local level as well as in the private sector.

In 2003 the Government Relations Department primarily focused its efforts on increasing federal appropriations for the TBI Act, the only federal law that specifically addresses the issues faced by people with TBI. The Department aimed to accomplish this goal through many avenues. First, the Department educated policy makers directly by having meetings with key Congressional offices, providing these offices with information from their states and districts and demonstrating the way the TBI Act can and has made a difference to their constituencies.

Next, monthly TBI Act "Updates" and/or "Action Alerts" were e-mailed to a grassroots list of over 1000 individuals from across the country explaining recent developments and suggesting action steps for moving legislation forward.

Additionally, web casts and targeted plans were developed with specific State Affiliates and individuals to reach their Senators and Representatives. These efforts were successful in increasing some key appropriations. For example, Congress provided an increase of \$1.2 million for TBI Programs under the Centers for Disease Control and Prevention in a year when increases were very rare and remarkable.

Finally, the Department maintained an active presence in the general disability community by signing on to letters of support for important legislation, attending meetings and testimonies, and providing advice and a voice where policy could affect people with TBI.

Education and Research Efforts

Leadership Conference:

September 2003 - San Antonio, Texas

Supported by the Association and Health Resources and Services Administration the conference attracted 60 association leaders, members, staff volunteers and guests from thirty-five states. The Leadership Program featured training on association management and policy issues. Membership and State Affiliate assembly meetings were also held, and multiple networking opportunities were offered.

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.

Highlights of the Year:

There are currently 650 Certified Brain Injury Specialist and over 1200 people involved in various stages of the testing and training process for certification.

The Corporate Advisory Council (CAC):

The AACBIS board developed the CAC to expand the reach of AACBIS, to strengthen its financial foundation, and to gain knowledge of the needs of facilities that serve people with brain injuries to provide better and more accessible training and testing tools. The CAC was led by Dr. Jeff Victoroff and in 2003 had charter members from The May institute, Casa Colina Centers for Rehabilitation, Gentiva Rehab Without Walls, The Center of Neuro Skills, the Mentor ABI Group, Lakeview NeuroRehabilitation Centers, Bancroft NeuroHealth, Rainbow Rehabilitation Centers, Robert Voogt and Associates and Remed.

The following were members of the AACBIS Board in 2003:

Dr. Deborah Braunling-McMorrow, Ph.D. - *Board Chairperson*
Terri Antoinette, MHSA, RNC - *Vice Chairperson*
Mike Davis - *President of BIA West Virginia*
Matt Garlove, Ed.D
Harvey Jacobs
Linda Mackay
Ann Pereia-Ogan
Debra M. Russell, Ph.D.
Lisa Selznick Gurdin, MS, BCBA - *Board Chair Elect*
Tina Trudel, Ph.D.
Janet S. Tyler, Ph.D.
Jeff Victoroff, M.A., M.D.

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, work began in 2002, and continued through 2003.

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 and research trials 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 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 two years will yield promising results and practices.

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

The Centers for Disease Control and Prevention awarded the Brain Injury Association of America a three-year Cooperative Agreement to create, implement and evaluate a National Brain Injury Information Center. This information center will incorporate the Association's current toll-free 800 number and connect it to the Association's State Affiliate offices, creating a nation-wide, one-call center for traumatic brain injury. The Association's National and State Information and Resources staff will handle and process all inquiries and provide information and linkage to services regarding brain injury issues. The National Brain Injury Information Center will provide a standardized protocol for handling calls, a customized packet of information on brain injury topics, and a linkage to brain injury services in the caller's local community.

The Information and Resource Managers 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. Communications and materials are provided in both English and Spanish Languages. In 2003, the Information and Resource Managers had over 12,000 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. In 2003, the Information and Resource Managers mailed 2,700 requested packets of general and complex information about traumatic brain injury.

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 wrote content for the Association's publications. The Information and Resource Managers presented nationally as invited keynote or guest speakers at conferences held by national disability and health advocacy organizations.

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.

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 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 produced over 40 abstracts of TBIMS published research articles, which are posted on the Association's web site. Additionally, a featured article based on the TBIMS' research was published in the Association's newsletter, TBI Challenge! Feedback on the abstracts from the public, TBIMS researchers and the federal government has been favorable.

Public Awareness Initiatives

Brain Injury Awareness Month

The Brain Injury Association of America leads the national effort to raise awareness about brain injury. During Brain Injury Awareness Month (October, 2003), the Association distributed approximately 6,000 awareness kits to the Association's State Affiliates, schools, medical facilities, doctors' offices and individuals interested in raising awareness about brain injury.

The Medtronic Foundation - I.M. Brainy

The Association continued its successful partnership with the Medtronic Foundation - a leading medical technology company. The Association developed and distributed a prevention-oriented curriculum, tailored to elementary-aged children. A 36-inch "I.M. Brainy" bear puppet, properly attired in a helmet, was a prop that aided educators, and other professionals in teaching prevention tips to children.

The Association's Prevention Department developed a curriculum in collaboration with a team of preschool teachers to produce an activity kit that included lessons, a song, illustrated activity sheets, resource web links for educators, and letters of instruction.

The bears and the kits were distributed to the Association's State Affiliates, many of whom had great successes in garnering attention for the bears, including media exposure in their communities.

National Public Awareness Campaign

As part of a continued partnership with the Health Resources Services Administration (HRSA), in 2002-2003, the Association continued its work with the communications firm BVK/McDonald, based in Milwaukee, Wisconsin. The firm produced an outdoor advertising campaign titled "Until the World's This Safe Wear a Helmet, " combining prevention and public awareness message. The Association worked with Clear Channel Outdoor in Chicago, Illinois and Washington, DC to have the campaign displayed in public. This pilot public awareness campaign utilized bus and train transit shelter postings as well as indoor mall kiosks. In addition, the communications firm "All Over Media" also posted the campaign in public restroom facilities across the country pro bono.

The Internet and Technology

In 2003 improvements and additions were made to the Association's web site. New sections were added and pre-existing information was updated to keep all materials and information current.

The Association added a section to the web site for the quarterly newsletter, the TBI Challenge! The section includes: general information about the TBI Challenge! including features and columns consistent throughout each issue, guidelines, sizes, rates for advertising, and contact information to submit comments and articles.

The Association also added a Legislative Action Center (LAC). The LAC is a comprehensive tool for online grassroots advocates. With this addition, the Association now has the ability to list alerts and other pertinent information to constituents to inform them of ways to take legislative action. Visitors to the LAC may also look up information on elected officials, candidates, election issues, as well as national and local media by entering their zip code or state.

The Association assembled an exemplary cadre of partners with interest and expertise in the area of assistive technologies, 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 purpose of this project is to examine how electronic organizers (PDAs, handheld computers, voice organizers, watches, cell phones and Smartphones) can be used to promote the independence of people with cognitive disabilities. In April of 2003, the searchable online version of the Assistive Technologies Catalogue was added to the Brain Injury Association of America's web site. This Catalog provides a partial listing of commercially available portable electronic devices that may have potential to be used as memory and organizational aids. In several categories of devices, which were recommended by persons with cognitive disabilities, the Association has included names and descriptions of devices, web-links and other manufacturer contact information, and selected information on device features identified by "consumer panels" as especially important.

Also added to web site include the addition of many TBI Model Systems abstracts, a new and improved Brain Injury Bookstore, the I.M. Brainsy educational materials created for Brain Injury Awareness Month 2003, and updates to AACBIS section.

Since our redesigned web site was launched in 2002, 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 that 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.

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The Association's Premier Publications

The National Directory of Brain Injury Rehabilitation Services

The Directory contains information on over 3000 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 a brain injury, to utilize the information presented. The 2003 printed Directory included a CD-ROM version providing electronic access choices for users. More than 2,500 Directories were distributed to individuals with brain injury, advocates and professionals in the field.

Brain Injury Source

The Association published one issue of *Brain Injury Source* in 2003, the Association's professional magazine. The summer issue was titled "Mapping the Moral Landscape, for Families and Persons with Traumatic Brain Injury." Approximately 28,000 copies of the magazine were circulated. The writings in this issue are a culmination of a three-year project spanning 199-2001 between the Hastings Center of Garrison, New York and the Rehabilitation Institute of Chicago Center for the Study of Disability Ethics (CDSE). *TBI Challenge!*

Funded by the defense and Veterans Brain Injury Center (DVBIC), 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 the Association's chartered State Affiliate. In addition to its featured columns of "Survivor's Voice," "State Spotlight" and "Public Policy Update" 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.

Health Resources and Services Administration (HRSA)

Partnership for Information and Communication Cooperative Agreement

In 2003, the Association completed its final 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:

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; Sports and Recreation; Shaken Baby Syndrome; Falls; Bicycle Safety; and Violence Prevention. 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: In 2003, 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.

Waves:

The Association's Affiliate Relations Department distributes an email newsletter titled Waves 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.

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

In October 2003, the Association continued to respond to the significant unemployment of individuals with brain injury, with its self-employment project for people with Traumatic Brain Injury (TBI) in partnership. In Association with the Montana Rural Institute's Adult Community Services and Supports Department The Self-Employment Development for Individuals with Traumatic Brain Injury Project is working to 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.

Statement of Activities for the Year Ended December 31, 2003

Revenue and Other Support:	
Grants Revenue	\$1,344,422
Contributions	312,755
Special Events, Net	23,208
Products, Publications and Related Items	172,581
Contributed Services	67,375
Conferences and Meetings	43,175
State Affiliation Fees	132,545
Rental Revenue	2,804
Net Investment Revenue	7,669
Other Revenue	5,523
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Total Revenue and Other Support	\$2,112,057
Expenses:	
Program Services:	
Public Awareness	\$392,187
Education and Training	117,606
Information and Resources	362,262
Prevention	34,310
Government Relations	207,724
Affiliate Relations	301,825
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Research	360,287
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Total Program Services	\$1,776,201
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Management and General	183,759
Fundraising	228,954
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Total Expenses	\$2,188,914
Operating Income (Loss)	\$ (76,857)
Other Revenue:	
Gain on Sale of Building	\$554,742
Change in Net Assets:	<u>\$477,885</u>