

SUMMER 2012 • VOLUME 6, ISSUE 3

THE *Challenge!*

A yellow liquid is being dropped from a glass tube into a petri dish. A magnifying glass is positioned over the petri dish, focusing on the liquid drop. The background is a solid blue color.

MW151–

A New Drug for Brain Swelling

Neuron Growth

Dual Use for Diabetes Drug

Guide to Clinical Trials

Who can participate?

RESEARCH= **PROGRESS**

SUMMER 2012

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From my Desk

Individuals with brain injury, their families and others who care about people with disabilities and chronic conditions had an important victory on June 26, 2012, when the Supreme Court of the United States issued key rulings on the constitutionality of the Patient Protection and Affordable Care Act (Public Law 111-148, “the Affordable Care Act” or ACA).

The Court kept the Affordable Care Act largely intact, upholding the mandate for individuals to obtain health insurance by 2014 and allowing the federal government to incentivize states to expand Medicaid eligibility to persons at or below 133 percent of the federal poverty level (about \$14,404 for a single adult or \$29,327 for a family of four). This means that insurance market protections, such as anti-discrimination and pre-existing condition rules, will remain in place. It also means the elimination of annual and lifetime limits in health plans and the inclusion of rehabilitation and habilitation services and devices as an essential health benefit in all individual and small-group plans beginning 2014.

Most Americans agree that the Affordable Care Act is not perfect and that the legislation will be amended many times in the years to come, but the law lays the groundwork for better access to care, which is a primary goal of the Brain Injury Association of America (BIAA) and why we worked so hard to ensure that rehabilitation was included in the health reform law.

As *THE Challenge!* readers know, federal advocacy is a cornerstone of BIAA’s efforts, but it is not the only thing we do. Earlier this year, BIAA’s Board of Directors revised our mission statement to better explain the broad scope of our work. The new mission statement is:

The mission of the Brain Injury Association of America is to advance prevention, research, treatment, and education to improve the quality of life for all people affected by brain injury.

We are continuing our awareness campaign, introduced in March this year, to teach all Americans that brain injuries can happen anytime, anywhere to anyone, and we’ve dedicated this issue of *THE Challenge!* to research efforts. As always, we report news from our state affiliates and gratefully acknowledge the donors who make our accomplishments possible.

Have a cool summer!

Susan H. Connors, President/CEO
Brain Injury Association of America

2012 Moody Prize Winner: Keith D. Cicerone, Ph.D.

By Thomas Felicetti, Ph.D.

The 2012 Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation, which honors individuals or a team of individuals who have made significant contributions in applied brain injury research and rehabilitation, was awarded to Keith Cicerone, Ph.D., director of Neuropsychology at the JFK Johnson Rehabilitation Institute & New Jersey Neuroscience Institute in Edison, N.J. The award was presented during the Galveston Brain Injury Conference in May.

Dr. Cicerone has been a seminal figure in brain injury rehabilitation, making significant contributions to the field during the past 30 years. He began working in brain injury rehabilitation in the late 1970s, when, due to improved emergency response systems and neurosurgical techniques, individuals began to survive severe brain injuries. He began to develop and engage others in the development of psychological and learning-based interventions to rehabilitate the cognitive, affective, behavioral and social impairments that frequently result from brain injury. He maintained an active clinical practice as his research career progressed. Dr. Cicerone's work consistently focused on developing and testing methods to improve the functioning and quality of life for individuals with brain injury.

In addition to being an exceptional clinician and clinical researcher, Dr. Cicerone has also been an outstanding teacher, mentor and leader in the field. He

has trained students, junior faculty and members of his rehabilitation team and has been a TBI Model Systems project director for more than 13 years. He served as president of the American Congress of Rehabilitation Medicine and played a leadership role in other professional organizations.

Dr. Cicerone has been a strong advocate for brain injury rehabilitation services. In 2011, he testified at the Institute of Medicine meetings to support the availability of cognitive rehabilitation services to returning soldiers affected by brain injury. He also participated in a press conference held by the Congressional Brain Injury Task Force, office of Rep. Gabrielle Giffords and the Brain Injury Association of America about the importance of access to comprehensive rehabilitation after brain injury.

Of his many significant contributions, Dr. Cicerone's work with the Cognitive Rehabilitation Committee of the Brain Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine has perhaps had the broadest impact. He led this group through three evidence-based reviews of the literature in cognitive rehabilitation, which were published in the *Archives of Physical Medicine and Rehabilitation* and are among the most frequently cited articles in that journal. These critical reviews are an important resource for clinicians and researchers working in cognitive rehabilitation. They also serve as advocacy tools to support funding and other policy decisions for the provision of these types of services.

The Moody prize is presented annually by the University of Texas Medical Branch School of Health Professions and the Transitional Learning Center of Galveston. The prize, named for Robert L. Moody, is administered by a board of governors; candidates are considered by a panel of experts. Criteria include the total impact of a candidate's work, achievements and unique contributions, and recognition by peers within the scientific or rehabilitation communities. ●

The annual award consists of a \$10,000 honorarium, a citation and an inscribed statue, which were presented at the Moody Prize Dinner in Galveston in May.



Moody Prize winner
Keith D. Cicerone, Ph.D.

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New Drug Could Reduce BRAIN INFLAMMATION

A new class of drug developed at Northwestern University Feinberg School of Medicine shows early promise of reducing inflammation in the brain for patients with traumatic brain injury (TBI), stroke and other neurological conditions, including Alzheimer's disease, Parkinson's disease and multiple sclerosis.

In animal studies, the drugs – represented by MW151 and MW189 – reduced the neurological damage by preventing the overproduction of brain proteins called proinflammatory cytokines. Scientists now believe overproduction of these proteins contributes to the neurodegeneration seen after a TBI and in other neurological conditions and diseases.

When too many of the cytokines are produced, the synapses of the brain begin to misfire. The neurons lose their connections with each other and can eventually die. The resulting damage in the cortex and hippocampus can compromise memory and decision-making, according to D. Martin Watterson, John G. Searle Professor of Molecular Biology and Biochemistry at Northwestern, whose lab developed the drug. He is a coauthor of a study published in July in the *Journal of Neuroscience*.

After a TBI, the glial cells in the brain become hyperactive and release a continuous cascade of proinflammatory cytokines that – in the long term – can result in cognitive impairment and epilepsy. As a result of this hyperactivity, researchers believe the brain is more susceptible to serious damage following a second neurological injury.

In a study with mice, Mark Wainwright, M.D., professor of pediatric neurology at Northwestern's Feinberg School and a physician at the Ann & Robert H. Lurie Children's Hospital of Chicago, showed that when MW151 is given during an early therapeutic window three to six hours after the injury, it blocks glial activation and prevents the flood of proinflammatory cytokines after a TBI.



“If you took a drug like this early on after a TBI or stroke, you could possibly prevent the long-term complications of that injury including the risk of seizures, cognitive impairment and, perhaps, mental health issues,” Wainwright said.

Stroke causes inflammation in the brain that also may be linked to long-term complications including epilepsy and cognitive deficits. As in TBI, this inflammatory response is part of the recovery mechanisms used by the brain, so the use of brief and focused treatments like MW151 could prevent the harmful effects of inflammation while allowing the protective effects to occur unimpeded.

In another study, Wainwright showed MW151, when given after a TBI, prevented the increased risk of epileptic seizures. Northwestern has recently been issued patents to cover this new drug class and has licensed the commercial development to a biotech company that has recently completed the first human Phase 1 clinical trial for the drug.

Content for this article was prepared from a press release issued by Northwestern University. For more information, see www.northwestern.edu.



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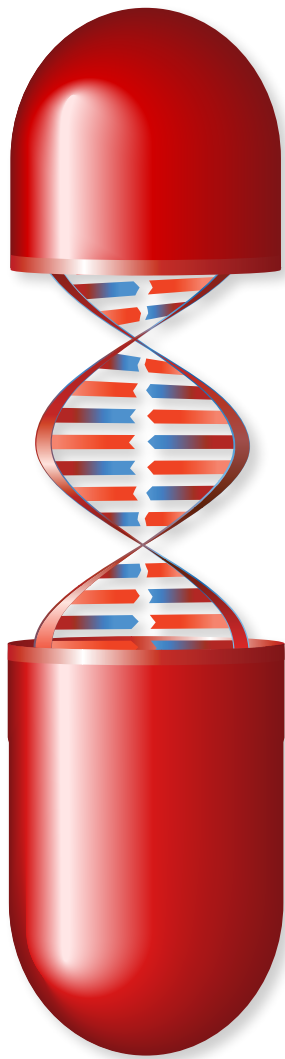
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COOPERATION will Lead to Capacity and Clout

By Susan Connors, President/CEO, Brain Injury Association of America

The Center for Neuroscience and Regenerative Medicine (CNRM) was established by the National Defense Authorization Act of 2008 (Public Law 110-252) as an intramural collaboration between the Uniformed Services University of the Health Sciences in the Department of Defense (DoD) and the Clinical Center within the National Institutes of Health (NIH) to improve diagnosis, treatment and prevention of the long-term consequences of traumatic brain injury (TBI), particularly in the context experienced by servicemen and servicewomen in Operation Iraqi Freedom and Operation Enduring Freedom.

CNRM brings together the expertise of clinicians and scientists across multiple disciplines in six program areas:



- 1** The Diagnostics & Imaging Program will characterize each patient's injury to optimize diagnosis and inform the treatment plan from among the available options. Advanced neuroimaging techniques go beyond standard imaging parameters to interpret injuries from novel combinations of structural measures, metabolic parameters, and indicators of circuitry function and dysfunction.
- 2** The Biomarkers Program will identify molecules with physiological relevance or that can be used as surrogate indicators along with diagnostic and neuroimaging criteria to further improve patient assessment and personalize treatment options, when applicable.
- 3** The Neuroprotection & Models Program will address ways to preserve tissue structure and function, which is especially important relative to the secondary damage in TBI. Limiting the extent of tissue damage is the primary means to preserve functional capacity.
- 4** The Neuroregeneration Program will develop approaches to address damage and dysfunction that cannot be prevented. Neuroregenerative approaches will include stimulation of the repair capacity of existing neural stem and progenitor cell populations, tissue modifications to reduce environmental factors that inhibit repair and stem cell transplantation paradigms.
- 5** The Neuroplasticity Program will study processes that maximize function from existing neural cells as a critical component of promoting recovery from TBI. Neuroplasticity studies will also assist the development of neuroregenerative strategies, since newly generated cells must establish the appropriate neuron-glial interactions and/or integrate into the appropriate circuitry to contribute to the recovery of function.
- 6** The Rehabilitation & Evaluation Program will develop strategies to more accurately characterize injury progression across the TBI spectrum. Researchers will then apply rehabilitative medicine approaches to intervene to prevent disability and enhance functional capacity on an individual basis.

Each program area is led by a DoD researcher with an NIH representative serving as co-leader. Ramon Diaz-Arrastia, M.D., Ph.D., who is a member of the Board of Directors of the Brain Injury Association of America, is director of clinical research.

The CNRM seeks to capitalize on its unique opportunity to develop a set of mutually reinforcing programs among collaborating DoD facilities and the NIH. The Brain Injury Association is pleased to serve in a consumer advisory capacity to the Center.

Diabetes Drug Shows Promise In Treating Brain Injury



By Lissa Hurwitz, Director of Communications,
Brain Injury Association of America

Brain injury is unpredictable in its consequences. It affects who we are and the way we think, act and feel. It can change everything about us in a matter of seconds. Now, findings of a study conducted by Toronto's Hospital for Sick Children indicate that a drug used to treat Type 2 diabetes may also help people with brain injury.

Metformin is the drug of choice to prevent low blood glucose (hypoglycemia) events in people with Type 2 or non-insulin-dependent diabetes. Some scientists believe that the drug may be able to help in repairing brains damaged by diabetes, Alzheimer's and injury.

In the Canadian study using both lab-dish experiments with mouse and human brain stem cells and experiments on live mice, metformin helped to form memories more quickly and improved the brain's ability to learn.

Researchers found that the drug helps the brain to stimulate stem cells that generate neurons and other types of brain cells.

The scientists added metformin to lab dishes containing mouse stem cells and did the same with lab-generated human brain stem cells. Both the mouse and the human stem cells produced new brain cells. They tested the drug in lab mice and found that those given daily doses of metformin for two or three weeks had increased brain cell growth and outperformed untreated mice in learning and memory experiments.

This finding is remarkable, and its implications for developing a treatment that might improve the brain function of people with brain injury are encouraging said James F. Humphries, chairman of the board at the Brain Injury Association of America.

“This finding is remarkable, and its implications for developing a treatment that might improve the brain function of people with brain injury are encouraging”

Published in the journal *Cell Stem Cell*, the study showed that metformin significantly reduced the time required for mice to form new memories. Mice injected with the drug were able to learn and remember the location of an object hidden in a maze much more quickly and easily than did mice in a control group that were injected only with saline. In one experiment, the number of new neurons produced by mice taking the drug was nearly twice those produced by mice in the control group.

Another benefit of metformin is that it has already been in wide use in people of all ages so there is ample data on its safety, dosage and effectiveness, which could considerably accelerate the pace of further metformin research. But researchers cautioned that the findings are preliminary, noting that earlier experiments with growth factor and small molecules that showed early promise ultimately failed

to show any benefit of those substances in brain-cell repair. Another challenge in using metformin to treat older persons is that stem cells age as people age, leaving open the question of whether seniors have enough stem cells to produce an adequate supply of neurons.

The Canadian researchers have been talking with clinicians about creating a pilot study to test metformin in children with acquired brain injury from treatment of a childhood brain tumor or from a traumatic brain injury. Such a study would attempt to determine whether the drug could increase brain cell mass and measure any improvement in cognition and behavior.



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A Guide to Participating in CLINICAL RESEARCH TRIALS

By Greg Ayotte, Director of Consumer Services, Brain Injury Association of America



Clinical trials are research studies in which people volunteer to participate. A clinical study is designed to answer specific scientific questions. An ethics board reviews a clinical study before researchers are allowed to initiate their study. Participants are selected based on pre-determined criteria. A participant chooses freely to participate or not after reviewing the possible risks and benefits of participation. Some studies will pay for people to participate in their research.

A common question people with brain injury and their families ask is: "Where can I find information on clinical trials for brain injury?" Locating clinical trials on brain injury can be challenging. There is not just one answer to this question. Unlike such diseases as AIDS and cancer, there is not a single location where the majority of brain injury clinical trials are listed. A possible reason for this is the nature of brain injury and the level of public awareness. Brain injury is not one disease. There are distinct stages that occur during the recovery process. For example, during the acute stage, pharmacological (medication) interventions are geared toward minimizing additional adverse medical consequences. During the post-acute stage, people with brain injury are medically stable but may have cognitive, physical or emotional impairments. The following information offers suggestions for searching for clinical trials and a listing of a sample of clinical trials currently recruiting volunteers:

- There are no guarantees. You may search the clinical trial databases – and find nothing. There is no guarantee that there is something out there that will help your particular situation. However, you may find that these sites can point you in the right direction.
- The presence of a clinical trial does not automatically mean that you will qualify to participate, receive the treatment offered, benefit from the treatment offered, or be cured of brain injury. Researchers set up a study because they have reason to believe – but are not sure about – an intervention and need more information.
- Discuss the information with your doctor before participating. Research trials are designed to be as risk-free as possible, but by their very nature, research trials are looking into the unknown. Take the time to read through ALL research material and ask questions. A good resource to read is the Patient Guide developed by the National Institutes of Health (www.cc.nih.gov/participate/_pdf/pthandbook.pdf). The publication describes the basics of clinical research, defines the different phases and answers questions you may want to ask before choosing to participate in a research study.
- Participation in clinical trials is a personal choice and may not be for everyone. Choosing to participate or not to participate is an individual decision that should be respected.

The Bill of Rights for Clinical Center Patients

- (www.cc.nih.gov/participate/patientinfo/legal/bill_of_rights.shtml) The Bill of Rights for Clinical Center Patients is designed to protect participants in clinical research trials.

Searching the Web for Research Trials

- Search for local universities or large rehab centers. These are places that might be running clinical trials. Sites listed below will help you identify some of the major research centers associated with universities.
- Some websites offer personal clinical trials notification and will email updates on trials relevant to a person's interest.

(Continued on pg. 10)

A GUIDE TO CLINICAL RESEARCH TRIALS *(Continued from pg. 9)*

- Some websites require user registration prior to a site search. Most sites only require you to register with an e-mail address.
- Some websites may ask for your mailing address, name, area of interest, etc. before they allow you to gather research trial information. Make sure you read their privacy policies before doing so.
- The list of clinical trials provided below is not comprehensive. It is intended to be a helpful resource for persons starting to search for clinical trials.

ACURIAN

- (www.acurian.com) features the capability to develop a personal profile of information. Registration is free, and may be required to search the database.

CenterWatch

- (www.centerwatch.com) offers a listing of clinical trials and a personal clinical trial notification option.

Clinical Trials

- (www.clinicaltrials.gov) This site is provided by the National Institutes of Health in collaboration with the National Library of Medicine and Federal Drug Administration. The site contains a large number of clinical trials conducted in the USA and 70 other countries.

The Warren Grant Magnuson Clinical Center

- (www.cc.nih.gov) 800-411-1222 or 1-866-411-1010 (toll free TTY). The Warren Grant Magnuson Clinical Center has listings for National Institutes of Health (NIH) funded studies. This site is where many NIH research studies are carried out.

The Pharmaceutical Research and Manufacturers of America (PhRMA)

- (www.phrma.org) represents research-based pharmaceutical and biotechnology companies. The site provides information about prescription medication in development and available from member companies. A second website: www.pparx.org lists patient assistance programs available through PhRMA's member companies. These programs can assist people in obtaining prescription medication for free or at reduced costs. ●

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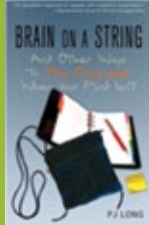
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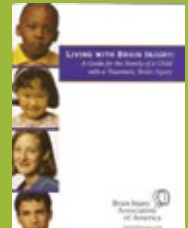
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ADVOCACY UPDATE

By Amy C. Colberg, M.A., Director of Government Affairs, Brain Injury Association of America

HEALTH CARE REFORM UPDATE

On June 28, 2012, the U.S. Supreme Court of the United States upheld the Patient Protection and Affordable Care Act (Public Law 111-152, the “Affordable Care Act” or ACA), finding that the individual mandate is constitutional under congressional taxing authority and that Medicaid expansion is constitutional but limited in terms of how states can be penalized. BIAA is gratified by the decision. We led the fight to include rehabilitation as an essential health benefit under the law. BIAA will continue to advocate on behalf of individuals with brain injury and their families. Please watch our website for further analysis and visit the Advocacy and Government Affairs section to read BIAA’s comments on proposed rules and regulations under the law.

In early 2011, the Agency for Healthcare Research and Quality (AHRQ) announced its intent to study the effectiveness and comparative effectiveness of post-acute rehabilitation for individuals with TBI. AHRQ’s final report is now available and BIAA is pleased that the authors and reviewers adopted seven of eight recommendations that we offered. This extraordinary response rate reaffirms how much influence advocates can exercise through cogent and compelling arguments. Most important, the report clearly states that “The failure to draw broad conclusions {from the available evidence} must not be misunderstood to be evidence of ineffectiveness.” In essence, the statement supports our fight against insurance companies that claim rehabilitation is ineffective, unproven or experimental.

In June, BIAA submitted comments to the Department of Health and Human Services (HHS) Center for Consumer Information and Insurance Oversight (CCIIO) on the newly released *General Guidance on Federally Facilitated Exchanges* (FFE). The Guidance describes the concept of the FFE, which will operate in states that do not have a fully operational state insurance exchange in place by 2014, which was made law under the ACA.

On July 2, 2012, BIAA submitted comments to HHS Centers for Medicare and Medicaid Services (CMS) on the proposed rulemaking amending Medicaid regulations to provide home- and community-based setting requirements. More than 11,000 individuals with brain injury are served in home- and community-based programs supported through Medicaid waivers. In our comments, BIAA expressed deep concern that the new “quality principles” CMS has proposed for home- and community-based settings will displace many of these individuals. Rather than optimizing autonomy, independence,

The Brain Injury Association of America (BIAA) continues to advocate for access to care and the Traumatic Brain Injury (TBI) Act reauthorization as Congress debates across-the-board spending cuts during the summer months. BIAA is committed to showing policymakers that brain injury is a serious public health problem that will not be ignored. As important decisions are made throughout the fall, BIAA will be educating Congress about the needs of people with brain injury.



TBI ACT REAUTHORIZATION 2012

The TBI Act, H.R. 4238, was introduced by Reps. Bill Pascrell, Jr. (D-NJ) and Todd Russell Platts (R-PA) on Wednesday, March 21, 2012, in the House of Representatives.

BIAA urges constituents of the following members to call or email their representative to ask them to cosponsor the bill. The representatives listed below are members of the House Committee on Energy and Commerce, Subcommittee on Health:

Rep. Shimkus (IL-19-R)
Rep. Myrick (NC-9-R)
Rep. Murphy (PA-18-R)
Rep. McMorris Rogers (WA-5-R)
Rep. Bono Mack (CA-45-R)
Rep. DeGette (CO-1-D)
Rep. Doyle (PA-14-D)
Rep. Eshoo (CA-14-D)

**TAKE
ACTION!**

privacy, dignity and engagement in community life, the proposed rules could force individuals with brain injury into institutional settings and/or eliminate access to services and supports altogether.

Also in July, BIAA submitted comments to the CMS on the proposed rulemaking for data collection to support standards related to essential health benefits. The proposed rules pertained to the recognition of entities for the accreditation of qualified health plans under ACA. BIAA's comments strongly stated that it is critical that the regulations explicitly establish appropriate coverage levels for essential health benefits in a manner consistent with the statute's intent and the needs of people with TBI. Habilitative and rehabilitative services and devices are mandated as essential health benefits in ACA Section 1302.

Please visit BIAA's website, www.biausa.org, to read the comments to HHS.

APPROPRIATIONS UPDATE

On April 12, 2012, BIAA submitted Fiscal Year 2013 (FY13) written testimony to the Senate and House Appropriations Subcommittees on Labor, Health and Human Services and related agencies. Both letters proposed the following funding increases for TBI Act programs and the TBI Model Systems of Care Program:

- \$10 million (a proposed increase of \$4 million over FY12) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness
- \$8 million (a proposed increase of \$1 million over FY12) for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program
- \$4 million (a proposed increase of \$1 million over FY12) for the HRSA Federal TBI Protection & Advocacy Systems Grant Program
- \$11 million (a proposed increase of \$1.5 million over FY12) for the TBI Model Systems of Care Program and line-item status within the broader National Institute on Disability and Rehabilitation Research budget

In June, the Senate Appropriations Committee slated \$9,760,000 for the Traumatic Brain Injury Program in the FY13 Labor/HHS/Education funding bill. This amount is the same as the FY12 comparable level and the budget request.

The program supports grants to states for coordination and improvement of services to individuals with TBI and their families. Such services can include pre-hospital care, emergency department care, hospital care, rehabilitation, transitional services, education, employment, long-term

(Continued on pg. 23)



An individual with a neurologic impairment, especially a traumatic brain injury, is the focus of **Success Rehabilitation's** programs.

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STATE AFFILIATE NEWS

LOUISIANA

The Brain Injury Association of Louisiana (BIALA) kicked off its Featured Speakers Tour in May with a presentation featuring Dr. Paul Harch of Harch Hyperbarics. More than 20 professionals, survivors and family members learned more about the use of hyperbaric oxygen therapy in the treatment of brain injury. June's tour, featuring speech pathologist Kimberly Diez, informed attendees about the effects of cognition on daily living following a brain injury. Additional presentations are scheduled monthly through the end of the year. For the most up-to-date information on tour locations and dates, please visit www.biala.org.

MICHIGAN

Spring is a very busy time for the Brain Injury Association of Michigan (BIAMI). Advocacy and recognition are in abundance. Members enjoyed themselves at the 17th annual Spring Fling and annual meeting and on Capitol Day, where 150 BIAMI representatives met with more than 97 percent of Michigan legislators to educate them about the importance of protecting our superb standard of care for those who depend on it. Spring ended with four events that brought together veterans (new and old) to enjoy the outdoors and fish among friends. Summer begins with BIAMI filing a lawsuit against the Michigan Catastrophic Claims Association so that critical financial

records can be released. This information is necessary in preserving no-fault automobile insurance – also known as Auto No-Fault – in Michigan. At the organization's annual meeting in May, Board of Directors Chairperson Debbie Newton recognized Linda Michaels-Gruber with the Chairpersons Award, Dr. Barbara Semakula with the Prevention Award, Brad Jones with the Education/Public Awareness Award, and Michael Radelt with the Volunteer Award. That evening, members enjoyed themselves at a planned dinner. Spring Fling Chair Cindy Fendt reminisced about this event 17 years ago, when only three participated; the event has now grown to dining in a private room. Capitol Day was a huge success with more than 150 advocates participating and meetings with 147 members of the Michigan legislature. Legislators were given packets of information about brain injury in Michigan. Although Auto No-Fault continues to be a priority, it was not the focus of this event. Instead, the Michigan Brain Injury Act and sports concussion facts were discussed. State Rep. Holly Hughes took BIAMI member Andrew Bos down to the House floor for a "photo opportunity." It was Andrew's first time visiting Lansing, where he also took a tour of the Capitol Building.

MI



Awardees Barbara Semakula, Lynn Brouwers, Linda Michaels-Gruber and BIAMI Chair Debbie Newton

MI



Rep. Hughes escorts Andrew Bos to the MI House floor

BIAMI has found that such recreational programs as fishing, hunting and sporting events help melt away the obstacles that military combat has built. Each year, BIAMI hosts four fishing tournaments. This year, more than 500 veterans and military service personnel participated with more than 1,000 crew, volunteers and guests attending. Veterans from more than 145 cities fished and learned about TBI. These events are a great way to thank Michigan veterans! At BIAMI's June 17 Walleyes for Warriors event, a WWII veteran took home first place and brought everyone to tears with his heartfelt thanks for inviting him to the event.

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) has several events planned for late summer/early fall. The 25th Annual BIA-MO Charity Golf Tournament will tee off in St. Louis on August 26. Participants will enjoy an 18-hole golf scramble, lunch, dinner, live and silent auctions and on-course games at the Norman L. Probst Community Golf Course in Forest Park. In beautiful Mount Vernon on September 22, the Brain Injury Awareness Run/Walk will include 10K and 5K runs and a 1-mile walk to raise awareness about brain injury. BIA-MO's 8th Annual Statewide Conference will convene in St. Charles from October 4 through October 6. Anticipated topics include under-identified populations, community reintegration, behavior management, pediatric brain injury, combat injury and more. In addition to the sessions for professionals on Thursday and Friday, there will be a session for survivors of brain injury and family members on Saturday. Please contact Eliza Butcher, BIA-MO program and office coordinator, at (314) 426-4024 or ebutcher@biamo.org if you have any questions.

NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) co-produced the Service Credit Union Boston-Portsmouth Air Show June 30 and July 1 at the Pease International Tradeport in Portsmouth, N.H. More than 75,000 people enjoyed the U.S. Navy Blue Angels jet team and other aerobatic flight demonstrations by Sean D. Tucker, Michael Goulian, and Jane Wicker – Wing Walker, and a fantastic demonstration of WWII aircraft. Beautiful weather, ample parking and large crowds helped to make this air show a success! Over the past three years, the air show has raised more than \$1 million for BIANH and its co-partner, the Boy Scouts of America. The Third Annual VW Pull for Wounded Warriors took place on Sunday morning at the air show, with 16 teams participating in a tug-of-war against a jetliner. The winning team had to be the fastest to pull the 150,000-pound FedEx cargo plane 12 feet. Team Wal-Mart 7814 of Lewiston, Maine, won first place with 6.1 seconds. Team Wal-Mart 6830 won Overall Champion for its speedy pulling time and for raising more than \$7,900 to support the event. In all, more than \$65,000 was raised for Wounded Warriors, which assists servicemen and servicewomen living with TBI. Future BIANH events include the Heads-Up Half Marathon on September 9 and the 26th Annual Walk-By-The-Sea on September 30.

(Continued on pg. 18)



NY Annual Conference Attendees



Dr. Harch talks oxygen therapy

NEW YORK

The Brain Injury Association of New York State (BIANYS) held its 30th anniversary annual conference on June 5 and 6 in Albany, N.Y. Keynote speaker Chris Nowinski set the stage for an exciting conference by using his own personal experience with brain injury and wrestling. He issued a rally call for participants to engage in public advocacy about brain injury and the consequences of brain injury, particularly for children. Mr. Nowinski called on the audience to use their own experiences as part of a more vigorous campaign about living with brain injury. While giving a nod to New York's new Concussion Awareness and Management Law, which went into effect July 1, Mr. Nowinski noted areas that should be strengthened to provide a more comprehensive approach to concussion management. His keynote address was followed by 20 workshops and a plenary that highlighted BIANYS advocates. July 8 was the second annual Brain Injury/Concussion Awareness Day at Citi Field, home of the New York Mets. BIANYS provided a color guard of retired Marines and a special public service announcement broadcast on the stadium's public address system. Ten BIANYS members received a Spirit Award and a great time was had by all! Plans are under way for the 6th Brain Injury in the Community Symposium, Access to Health Care in the Changing Landscape, on October 13, 2012, in New York City. The 5th Journey of Hope Gala will be held on October 23 at the Prince George Hotel, also in New York City.

TENNESSEE

The Brain Injury Association of Tennessee's (BIAT's) Global Picnic was held on Saturday, June 30. There was good food and lots of fun. State Rep. Mark Pody and his wife attended, and several people with brain injuries told inspirational personal stories about their journey living with a brain injury. A big thank you to Greg Costa and Lisa Howser for putting this picnic together and making it a fun event for everyone. Another big thank you to BIAT Board Member Cynthia Zmroczek for her donation as a picnic sponsor and to Kelly Sanders who provided massages for all of the survivors!

VERMONT

Vermont's School Sports Concussion bill contains four critical elements: coaching education, parent and athlete education, return-to-play guidelines and a requirement that an athlete suspected of suffering a concussion be removed from play until cleared by a healthcare professional. A Concussion Task Force (a committee of the TBI Advisory Board) is forming to provide recommendations on protocols for return to play and return to academics. Brain Injury Association of Vermont (BIAVT) staff are

also participating on a committee to develop a report on serious functional impairment in the correctional system for the 2013 legislative session. The Annual Walk for Thought continues to grow in participation and revenue, doubling both in just two years. Staff are also working with VocRehab VT staff on a TBI task force to assist in meeting the needs of individuals with brain injury while optimizing limited funding and staffing resources. BIAVT staff will have a unique opportunity to participate in a Public Television series, Emerging Trends, in which one 20-minute segment will focus on brain injury/concussion. The organization continues its involvement on the Military Family and Community Network and is also working on brain injury legal clinics with Disability Rights VT. The Aging Disability Resources Committee's Options Counseling grant is nearing completion and has been very successful. BIAVT's Annual Brain Injury Conference will be held at the Burlington Sheraton Conference Center on October 9. Please contact Barb Winters, Education & Outreach Coordinator at braininfo1@biavt.org.

VIRGINIA

In June, the Brain Injury Association of Virginia hosted a two-day Virginia Collaborative Policy Summit on Brain Injury and Juvenile Justice in Richmond. The summit was convened in collaboration with the Virginia Department of Rehabilitative Services, the Virginia Department of Juvenile Justice and Virginia Commonwealth University Medical Center's Traumatic Brain Injury Model System. The summit's objective was to discuss mechanisms for and progress toward the development of a systematic, empirically-based process for reliably identifying brain injury among the juvenile justice population, and creating staff training programs and effective intervention techniques. The grant activity brought together Health Resources and Services Administration (HRSA) staff, leading researchers, state agency stakeholders and advocacy professionals from other states – Texas, Nebraska, Utah and Minnesota – engaged in similar projects. Participants discussed each state's policies, practices, successes and challenges related to identification, diagnosis and intervention. Members of the Virginia and Utah legislatures also attended, and their expertise was employed to explore policy initiatives that could be enacted at the state level. The discussion was outstanding, and a white paper of the proceedings will be available for dissemination soon. The summit was conducted as part of the Virginia Department of Rehabilitative Services' federal Traumatic Brain Injury Implementation Partnership Grant from the Department of Health and Human Services' Health Resources & Services Administration. ●

One Mind Seeks Multiple Answers and Overarching Approach to Brain Science and Cures



By Luke Knittig, Director of Development, ONE MIND for Research

Over the next ten years, One Mind's leaders expect to change the way scientists, healthcare professionals, advocacy organizations and government partners think about and conduct scientific and translational research. The group will work to open up research bottlenecks, create new funding sources, embrace and foster public/private partnerships, facilitate the use of new technologies and reduce the stigma of brain disease and injury.



Sgt. First Class Victor L. Medina and his wife, Roxana E. Delgado

One Mind has established the TBI-PTS Knowledge Integration Network to accelerate advancements in diagnosis and treatment. The program intends to increase the rate of large-scale collection of clinical and biomarker information to help identify biological indicators of the causes and effects of diseases or pathology; investigate disease progression for earlier/more accurate diagnosis and treatment; and create new systems and approaches that will enable data sharing between academia, industry, non-profits and governments.

Removal of barriers to effective scientific and clinical research will speed diagnosis and treatment on an unprecedented level. It will empower individuals to take a more active role in their own care and to contribute to the acceleration of research by direct engagement and expanding the use of advanced biosensors and diagnostics.

In partnership with the International Neuroinformatics Coordinating Facility, One Mind is also creating a "brain data exchange portal" where academia, industry, nonprofits and governments can share tools, technology and complex data to support scientific and clinical research that will speed diagnosis and treatment.

"One Mind for Research will serve as the catalyst that promotes cooperation and the sharing of knowledge by advancing and resourcing promising research in brain science and treatment," said General Peter W. Chiarelli (Ret.), former vice chief of staff for the U.S. Army and One Mind's chief executive officer.

Stent-coating Research Holds Promise for Those with Brain Artery Damage

By Lissa Hurwitz, Director of Communications,
Brain Injury Association of America



Researchers at Purdue University, the U.S. Army and neurosurgeons at the Walter Reed National Military Medical Center are teaming up to create a new type of bioactive coating for stents – small, expandable tubes made of mesh that are inserted in a blocked blood vessel. Stents are often used to treat brain aneurysms. An aneurysm is an abnormal widening or ballooning of a portion of an artery due to weakness in the wall of the blood vessel. It can be naturally occurring or the result of a trauma to the head, including aneurysms suffered by military personnel from brain injury due to bomb blasts.

Currently, aneurysms are treated either by surgery to open the skull and clip the aneurysm or by inserting a catheter through an artery into the brain and implanting a metallic coil into the balloon-like sac. Both procedures risk major complications, including massive bleeding or the formation of potentially fatal blood clots. The success rate of the current surgery is 50 percent or less according to researchers at Purdue, and some who undergo the procedure become impaired.

The research team wants to determine whether coating the stents with a bioactive material might help to heal the inside lining of the blood vessel.

“Stents commonly in use today keep vessels open but have no effect on the degree of damage done to the artery wall that produced the aneurysm,” said Brent E. Masel, M.D. and the Brain Injury Association’s national medical director.

“We hope that the new stents’ coating will actually heal the artery wall, attracting cells to reconstruct it.”

The new stents will be designed using bioactive coatings to attract magnetized cells to repair trauma-damaged blood vessels. The stents are made of nonmagnetic materials, such as stainless steel and an alloy of nickel and titanium, except for the area that is intended to attract the cells. Specific areas of the stents are magnetized to precisely direct the cells to repair a blood vessel where it begins bulging to form the aneurysm. Some of the cells are magnetic naturally, and magnetic nanoparticles would be injected into the bloodstream to speed tissue regeneration. The stents are modified in a Purdue facility that uses ion beams to alter the coatings with a magnetic material and to create lifelike, or bionimetric, surface textures designed to promote cellular proliferation and repair damaged vessels.

The research is funded by a three-year, \$1.5 million grant from the U.S. Army.

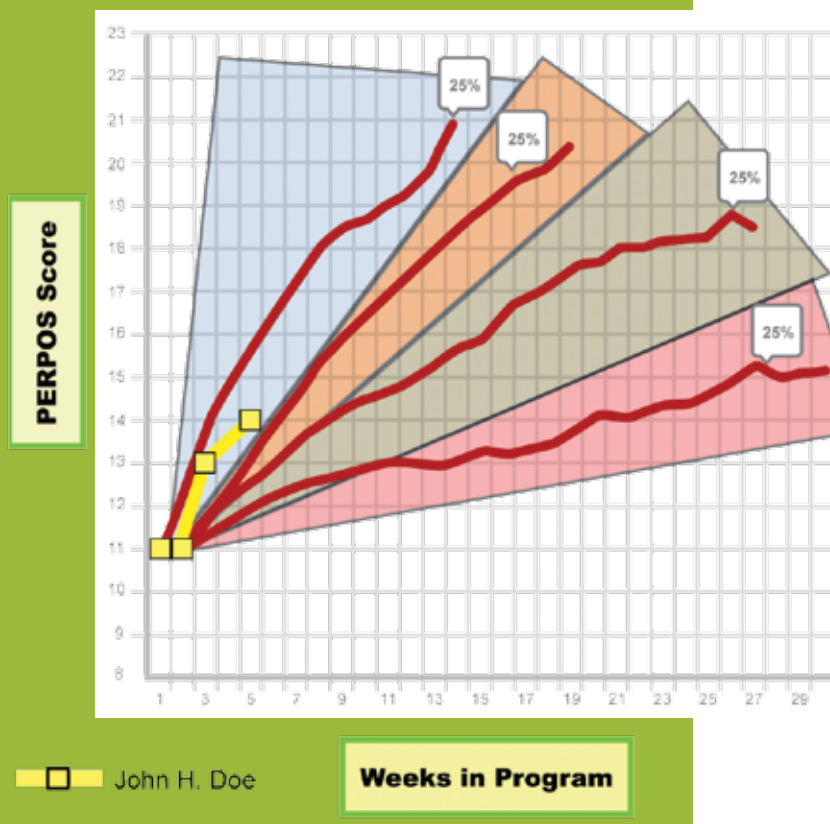


PERPOS Shatters the Plateau Myth

By Kier Bison, Ph.D., Director of Program Development, Pate Rehabilitation

Pate Rehabilitation has developed a valid and reliable measurement tool that demonstrates the anticipated path of recovery after brain injury. The tool is called PERPOS, which stands for Pate Environmentally Relevant Program Outcome System, and it shows patients and payers how much rehabilitative treatment it will take to achieve a functional outcome. Importantly, PERPOS demonstrates that significant gain in functioning can occur as many as four years after injury.

234 TBIs Beginning at PP11
Average Progress History
Each line shows progress of 25% of Patients



Under PERPOS, each patient is rated on structure, distraction and overall functionality. Assessments are made by a multidisciplinary team of professionals at admission, every other week, at discharge and after discharge. Treatment progress is recorded. All data are entered into Pate's database, which has more than 4,000 patients with traumatic brain injury, cerebrovascular accidents and other medical conditions involving the brain.

By combining and studying records of individuals with the same diagnosis, impairments and treatment plan, Pate staff can better estimate which patients can achieve a particular outcome and how long it will take. PERPOS is also useful for payers because the system demonstrates how much more progress can be made with additional treatment time. PERPOS is highly correlated with the Mayo-Portland Adaptability Inventory (MPAI), a commonly used outcome-measurement tool.

PERPOS was originally created as a way to measure and track each patient's ability to perform with varying levels of structure and distraction. Pate Rehabilitation's founder Mary Ellen Hayden, Ph.D. and her colleagues had an opportunity in the 1980s to observe Dr. Yehuda Ben-Yishay's day program at New York University's Rusk Institute. The experience taught Pate's leaders that the most successful treatment is the one that generalizes to each individual's natural environment.

A natural environment has varying levels of structure and distraction. The structure concept is highly related to executive functioning, and monitors the ability to manage time, keep appointments, plan for future needs, follow-up on projects, etc. The distraction segment monitors competing demands on senses as well as internal cognitive states and other diversions. As part of treatment, Pate clinicians gradually decrease structure and increase distractions so that patients can eventually function on a day-to-day basis after discharge. Pate staff continually analyzes PERPOS data to improve treatment practices.

For more information, visit: www.paterehab.com/research/perpos/

NEWS & NOTES

SUMMER 2012

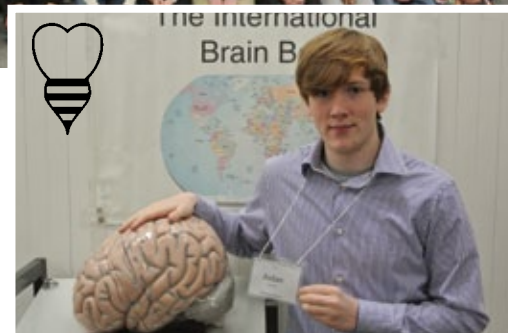
► Pennsylvania Student Represents U.S. at International Brain Bee

The International Brain Bee (IBB) is a neuroscience competition for high school students. Its purpose is to motivate young men and women to learn about the human brain and to inspire them to enter careers in the basic and clinical brain sciences.

Aidan Crank, a senior at Stroudsburg High School in Stroudsburg, PA, won the National Brain Bee in March. He will travel to Cape Town, South Africa to represent the United States in the International Brain Bee.

Dr. Norbert Myslinski founded the IBB at the University of Maryland in 1998, with 12 local chapters in North America. It has now grown to more than 150 chapters in more than 30 countries and six continents. Approximately 30,000 students compete annually, and about 50 websites are devoted to IBB chapters. Winners have been recognized by presidents, ambassadors and other public officials. Many former competitors are now working in neuroscience, neurology, psychology and related fields.

The IBB is funded mainly by private contributions but also helped by dozens of partners, including the Society for Neuroscience, the International Brain Research Organization, and many colleges, universities, foundations, museums, hospitals, libraries, institutes, societies, and commercial companies and businesses. Organizations, such as the American Psychological Association and the Canadian Association for Neuroscience, host the IBB Championship at their annual conventions.



Aidan Crank shows off his brain power at the Brain Bee

► DCoE Releases Clinical Recommendation, Reference Card to Treat Neuroendocrine Dysfunction

The Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury (DCoE) has developed new clinical recommendations and clinical-support tools to guide primary care providers of servicemen and servicewomen who sustain minor traumatic brain injuries. The *Neuroendocrine Dysfunction Screening Post Mild Traumatic Brain Injury Clinical Recommendation and Reference Card* provides medical guidance to evaluate and treat post-injury neuroendocrine dysfunction. The tools clarify the indications for post-injury neuroendocrine screening and provide a reference point for such screening following traumatic brain injury.

► VA to Study Whether Telemedicine Can Boost Brain Injury Treatment



The Department of Veterans Affairs plans to launch a five-hospital pilot program to determine how telemedicine can improve care for veterans with mild traumatic brain injuries or concussions. The increase in combat casualties with TBI from current conflicts has spurred demand for telemedicine solutions that can extend such clinical activities as neurological assessment, acute medical and neurosurgical treatment, psychiatric intervention, behavioral therapies, occupational and physical rehabilitation, and overall service coordination between the military, Veterans Administration and communities. An estimated 180,000 veterans are returning from military service with mild to moderate brain injuries, according to data from the Indiana University School of Medicine in Indianapolis.

The institutions participating in the telemedicine pilot program are Brooke Army Medical Center in San Antonio; Hunter Holmes McGuire VA Medical Center in Richmond, Va.; Michael E. DeBakey VA Medical Center in Houston; Richard Roudebush VA Medical Center in Indianapolis and Walter Reed National Military Medical Center in Bethesda, Md.

Mesoblast to Develop Stem Cell Therapies for Neurologic Conditions

Mesoblast Limited announced plans to develop adult stem cell therapies for neurodegenerative diseases at the Jefferies Global Healthcare Conference in New York. The company intends to commercially develop its proprietary adult dental pulp stem cells for stroke, spinal cord injury, Parkinson's and Huntington's diseases. These cells produce significantly greater levels of neurotrophic factors and are significantly more effective than other adult stem cell types for neural differentiation and repair of various neural cells and tissues.

Sebelius Creates New Agency for Disability and Aging

Health and Human Services (HHS) Secretary Kathleen Sebelius has announced the creation of the Administration for Community Living (ACL), a new agency within HHS. Bringing together the Office on Disability, the Administration on Developmental Disabilities and the Administration on Aging to form a single agency, ACL was created to increase access to community supports and resources that allow people to live with dignity and respect as fully participating members of their communities. Sebelius envisions a stronger, more coordinated platform to move forward on issues vital to individuals with disabilities. You can find more information on the Administration for Community Living at: www.hhs.gov/acl.

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ADVOCACY UPDATE (Continued from pg. 15)

support, and protection and advocacy services. The Committee includes no less than the FY12 funding level for protection and advocacy services, as authorized under section 1305 of Public Law 106-310.

In the report, the Senate Appropriations Committee notes:

"TBI is a leading cause of death and disability worldwide, especially in children and young adults ages 1 to 44. Due to the high prevalence of TBI, the Committee believes there is a need for multidisciplinary approaches to rapid evaluation and diagnosis of injured patients who have the potential for the development of TBI, as well as the development of early intervention and treatment protocol for use in preventing TBI and improving patient outcomes. The Secretary is encouraged to support a competitively awarded program of academic centers focused on developing and implementing multidisciplinary approaches to the early diagnosis and innovative treatment models for TBI victims."

BIAA and the National Association of State Head Injury Administrators worked with the Congressional Brain Injury Task Force to issue a letter of support to appropriators urging them to preserve funding for both programs authorized by the TBI Act and for the TBI Model Systems of Care Program.

POLICY SUMMIT ON BRAIN INJURY AND JUVENILE JUSTICE

In June, BIAA attended the Virginia Collaborative Policy Summit on Brain Injury and Juveniles in Richmond, Va. The summit's purpose is to develop a systematic, empirically-based process for reliably identifying brain injury; implement staff training programs; and identify effective intervention strategies and techniques. It was organized by the BIA of Virginia and the Virginia Department of Rehabilitative Services and was funded in part by a Federal Traumatic Brain Injury Implementation Partnership Grant from HRSA.

Representatives from Minnesota, Nebraska, Utah and Texas attended the summit to share their work with youth with brain injury in the juvenile justice system. Results of the Policy Summit will be released in the fall of 2012.

TBI ACT PRESS CONFERENCE

On May 30, 2012, BIAA presented Rep. Bill Pascrell, Jr. (NJ-D) with an award to thank him for his tireless work in Congress on behalf of individuals living with brain injury. The press event was held at the Kessler Institute for Rehabilitation in Saddle Brook, N.J., and focused on TBI Act reauthorization introduced by Rep. Pascrell on March 21, 2012.



BRAIN INJURY ASSOCIATION OF AMERICA INFORMATION

UPCOMING BIAA WEBINARS

- Tuesday, October 30, 2012, at 3 p.m. ET
Legal Rights under the ADA
Bobby Silverstein, Esq.
 Bobby Silverstein, Esq., of Powers Pyles Sutter and Verville PC, will discuss the Americans with Disabilities Act and its ramifications for and protections of people with brain injuries.
- Wednesday, November 14, 2012, at 3 p.m. ET
Using Computers to Assist with Cognitive Rehabilitation
Dr. Gerald Voelbel
 Dr. Gerald Voelbel will provide an overview of the best practices in cognitive rehabilitation and discuss how computer-based training programs can help cognitive recovery after brain injury.
- Thursday, November 29, 2012, at 3 p.m. ET
Community Resources
Janet Williams, Ph.D.
 Dr. Williams will discuss resources available in the community for people with brain injury, their families and caregivers, and the professionals who provide services to them.

VISIT www.biausa.org
FOR MORE INFORMATION

Registration for upcoming webinars, as they become available, can be completed online in the Marketplace of the Brain Injury Association of America's website at: www.biausa.org. Recordings of most webinars are available for purchase in the Marketplace.

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**If you or a loved one
has had a brain injury, call
the National Brain Injury
Information Center
toll-free for information at:
1-800-444-6443**

Call for information about:

- Local treatment and rehabilitation options
- Living with brain injury
- Funding for services
- Legal issues
- Veterans information
- Returning to school and work
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For more information on how to become part of Brain Injury Association of America Corporate Sponsors Program, please visit the sponsorship and advertising page at www.biausa.org or contact Susan H. Connors at 703-761-0750 or shconnors@biausa.org.

