

THE CHALLENGE!

RESEARCH



SUMMER 2017

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In Memoriam
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1960 - 2017

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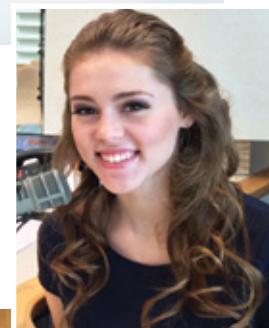
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From my **DESK**

In July the Brain Injury Association of America (BIAA) lost an important member of our family. Alice Demichelis was an extraordinary advocate for her son, Robert, and for all individuals who sustain brain injuries and their families. She participated in virtually every major policy achievement BIAA attained over the past 30 years. Alice, along with her husband, Bob, represented our organization on Capitol Hill and to federal agencies and insurance companies. She also worked to advance state policy through service as a volunteer regional vice president in the early days of our national organization. We will miss her.

This issue of the *THE Challenge!* is always a favorite of mine because it presents a glimpse of research underway in our field. This year we're highlighting a major national initiative on epilepsy, a long-term military/civilian collaboration on the natural time-course of TBI, and a private sector study on the effectiveness of in-home services. Reporting on key research is only one way BIAA works to advance brain injury science. We issue letters of support for grant applications, serve on advisory committees, assist with recruitment efforts, and post research study results to our website. We are also conducting research.

BIAA's project to develop and disseminate Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe TBI is making steady progress. Our partner, the Icahn School of Medicine at Mount Sinai, is leading a team of top researchers who have reviewed nearly 18,000 journal article abstracts to answer more than 50 research questions relating to how much rehabilitation adults who sustain moderate to severe brain injuries should receive, in what setting, and at what time. We expect to report the results of this multi-year project in about 18 months, so watch this space for updates!



Last, but definitely not least, BIAA has re-introduced Brown-Bag-It for Brain Injury. You can read all about this FUNdraiser on page 29! I hope you'll participate.



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

P.S. You can remember Alice with a tribute at www.mossfeaster.com or with a memorial gift to BIAA at <http://weblink.donorperfect.com/AliceDemichelis>.

BRIDGING THE BRAIN INJURY DIVIDE:

Working Together to Understand and Prevent Epilepsy After Traumatic Brain Injury



By Daniel J. Correa, M.D.¹; Karen Osiowy, M.Sc.², Solomon Moshé, M.D.¹, and Nathalie Jetté, M.D.²

Throughout the traumatic brain injury (TBI) rehabilitation process, small victories can be offset by frightening setbacks. For example, “K,” a 24 year-old man recovering from a severe brain injury after a motorcycle crash, is finally gaining strength and coordination in his arm after months of physical therapy. Today, he is able to take out his wallet, count out bills, and pay for his coffee. After a few sips, however, his arm begins flailing uncontrollably, and he is unable to speak to ask for help. Suddenly, his world goes black. When he wakes confused, scared, and embarrassed, a paramedic explains that he’s had a seizure and is on his way to the hospital.

A seizure is a surge of abnormal electrical activity in the brain that can affect how a person appears or acts for a short time. Symptoms of a seizure can vary and include brief changes in movements, sensation, thinking, speech, or awareness. Epilepsy is a chronic condition that causes a person to have repeated seizures over time.

Brain injury occurs when brain cells known as neurons are destroyed. When the damage is related to an external physical trauma, the term TBI is used. Motor vehicle accidents, firearms, falls, sports, and physical violence are the leading causes of TBI that can bring significant disability and mortality.

There are roughly 2.9 million people in the United States with epilepsy. TBIs are the most significant cause of epilepsy in people aged 15 to 24, but the condition can occur at any age. Epilepsy after TBI is referred to as Post-Traumatic Epilepsy (PTE). It occurs in 15 to 55 percent of persons with severe TBI. The time between the TBI and onset of recurrent seizures (epilepsy) can be from six months to two years or longer. PTE is a significant public health burden, and there are currently no treatments to prevent it.

The process whereby a person’s brain begins to develop recurrent seizures is called epileptogenesis. The goal of anti-epileptogenesis (epilepsy prevention)

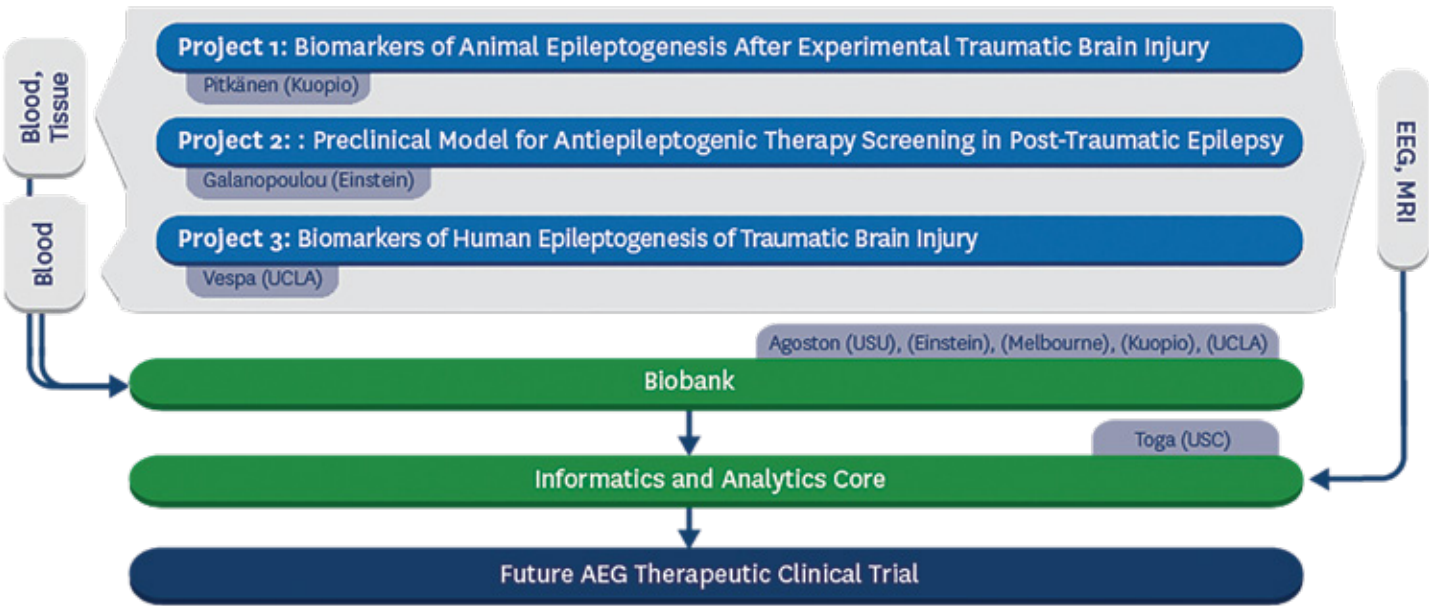
is to identify new treatments to improve brain healing after TBI and to decrease a person’s risk of future seizures. Unfortunately, anti-seizure medications have failed to prevent epilepsy, promote healing, or improve recovery after severe TBI.

Recognizing that the development of strategies to “prevent epilepsy and its progression” is a top priority, the National Institutes of Health (NIH) funded a Center Without Walls, the Epilepsy Bioinformatics Study for Anti-epileptogenic Therapy (EpiBioS4Rx), dedicated to identifying ways to prevent epilepsy after TBI. This \$21 million project is a collaboration of multiple university medical centers to develop ways to prevent epilepsy in persons with TBI. This project includes University of California Los Angeles (UCLA), Albert Einstein College of Medicine,

and scientists to design early treatments that affect these biomarkers and prevent the progression of the disease.

EpiBios4RX has three parallel projects to develop biomarkers that reliably predict epilepsy following TBI in both animals and humans. The projects will identify specific treatments to be used in a future treatment trial.

In Project 1, animal studies will be done using a rat model of PTE to identify biomarkers that are most useful in predicting epilepsy after TBI. Using the results from Project 1, Project 2 will utilize these biomarkers to guide new therapies that may impact the biomarkers and prevent PTE in animal models. In coordination with experienced TBI centers,



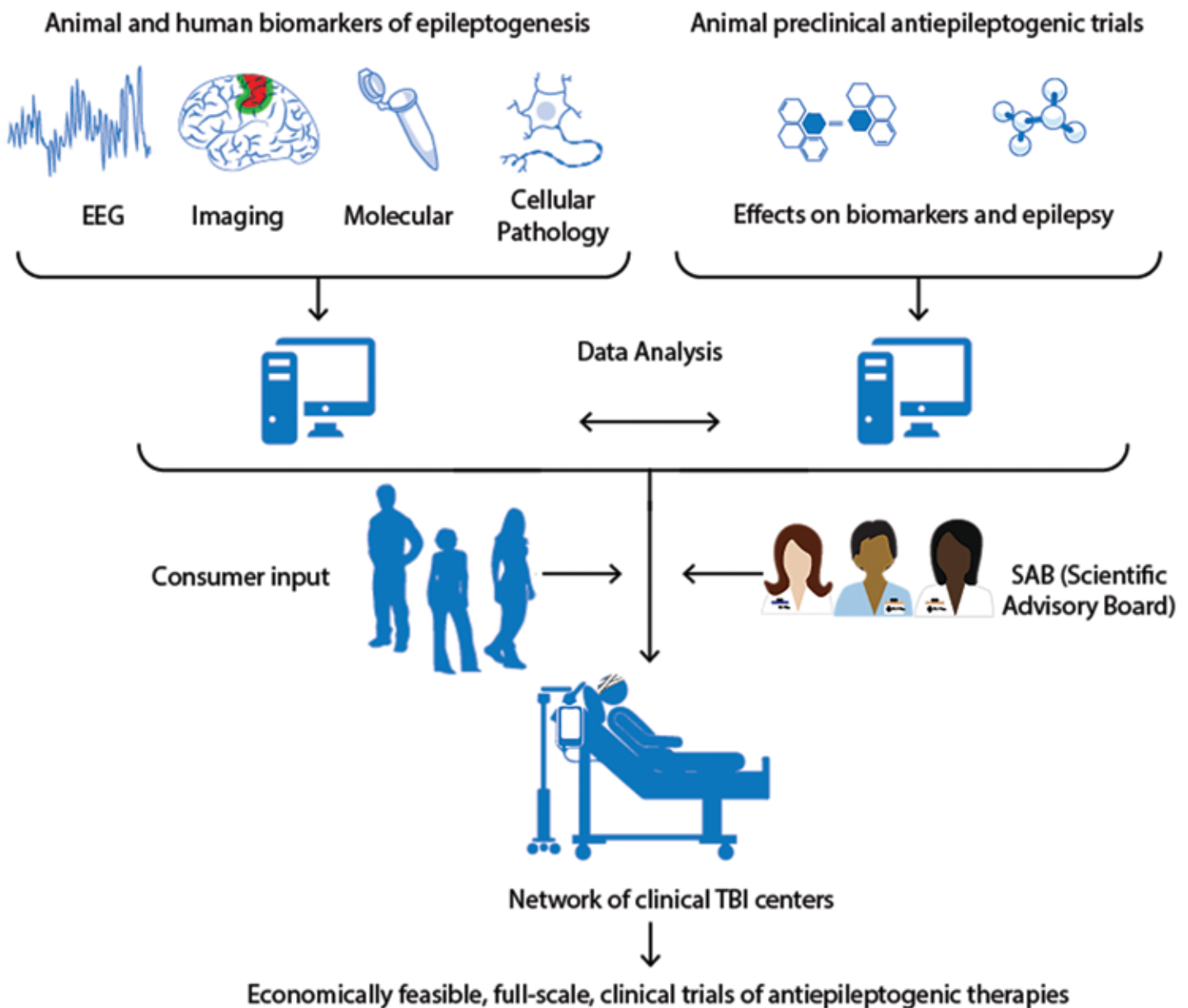
University of Calgary, University of Eastern Finland, University of Royal Melbourne, and a network of TBI centers worldwide.

The goal of EpiBioS4Rx is to identify the key biomarkers that predict that a person is likely to develop epilepsy and to propose new treatments to prevent or delay the onset of seizures. Biomarkers are the measurable indicators that occur with a medical condition or injury. They predict how the condition/injury progresses. Such biomarkers can include changes in blood, brain wave recordings (EEGs), or brain imaging. It is possible for doctors

Project 3 will identify and confirm blood-, brain wave recording-, or imaging-based biomarkers in persons who recently experienced a TBI and are currently living with PTE. These results will culminate in the development of a future treatment trial.

A Public Engagement Core (PEC) will facilitate the successful completion of a future treatment trial through partnership with consumer and scientific groups. The PEC will bring together consumer advocacy groups and will involve persons living with PTE and those living with TBI who are at risk

(continued on page 6)



for developing PTE. The Brain Injury Association of America (BIAA), the Epilepsy Foundation of America, veterans' groups, and many others are working together to identify ways to prevent epilepsy after TBI. The inclusion of international organizations will make sure this approach can be applied worldwide and will address cultural differences in attitudes toward epilepsy and TBI.

The PEC will also use and develop programs to educate individuals and their families about the importance of research on epileptogenic mechanisms. To do this, the PEC will listen and learn from individuals and their families about their most pressing needs and concerns. In collaboration with

BIAA, the PEC hopes to encourage participation in research studies to prevent PTE.

Over the next five years, EpiBioS4Rx will develop the first biomarker testing that can be used in anti-epileptogenesis research and future medical screening to prevent the onset of epilepsy after TBI. EpiBioS4Rx will speed up the process from lab testing to treatment trial for persons with TBI. ●

1. Albert Einstein College of Medicine
2. University of Calgary, Department of Clinical Neurosciences and Community Health Sciences, Hotchkiss Brain Institute and of the O'Brien Institute for Public Health



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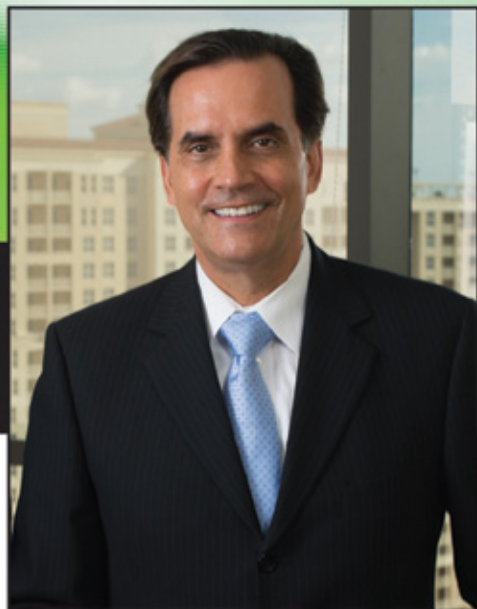
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The Center for Neuroscience and Regenerative Medicine:

Teaming up with Patients and Caregivers to Forge New Directions for TBI Research

By Julie Wilberding, Ph.D., M.A., Center for Neuroscience and Regenerative Medicine

The Uniformed Services University's (USU) Center for Neuroscience and Regenerative Medicine (CNRM), a federal research collaboration between the Department of Defense (DoD) and the National Institutes of Health (NIH), has the overarching goal of accelerating traumatic brain injury (TBI) research and improving the recovery of our nation's service members. "The Center addresses the full spectrum of TBI, with a special focus on military-related TBI, and has been driving TBI translational research for the DoD since 2008," said Dr. Regina Armstrong, CNRM Director.

Research at CNRM includes basic, preclinical, and clinical research, including clinical trials. In collaboration with researchers from Walter Reed National Military Medical Center, Fort Belvoir, and NIH, CNRM is focused on six major areas of TBI research:

- Neuroregeneration (repairing damage to brain cells)
- Neuroplasticity (optimizing ways to help brain circuits function)
- Diagnostics and Imaging (finding ways to quickly diagnose TBI through brain imaging, such as MRI)
- Neuroprotection (preventing tissue damage and cell death)
- Biomarkers (identifying molecules that can inform TBI diagnosis and treatment)
- Rehabilitation (evaluating and improving function after TBI)

Scientists conduct research in these focus areas with the help of special research staff, tools, and

equipment within the CNRM core facilities. These core facilities assist in analyzing the injured brain through imaging and the use of special microscopes as well as studying animals with TBI to determine what happens to the brain when it is injured. They also assist in collecting blood and health information from TBI research volunteers, recruiting people for studies, performing cognitive and behavioral testing of research participants, studying patients immediately after injury, and looking at effects of TBI on the brain after death.

CNRM could not have developed its strong research program without the help of the research participants. Recruitment of research participants from both the military and civilian populations has been instrumental in key discoveries as well as in CNRM's ability to follow the natural time-course of TBI from hours after injury to several years post-injury. Studying the time-course of brain injury allows scientists to delineate the order of biological and chemical steps that occur within the brain as a result of injury. Knowing these steps and when they occur is critical for treatment design and testing. Collection of blood and other biological fluids, along with health information from study participants, allows scientists to search for valuable biological signals of TBI and, in some cases, predict who will recover quickly from a TBI and who will not.

Research participants choose which CNRM study they are interested in joining and are also contacted as opportunities from additional studies become available. Involvement in research studies has the advantage of providing the participants with a greater knowledge and awareness of TBI and its co-



morbidities. To help participants better understand TBI research and some of the procedures they may encounter, the CNRM Recruitment Core has created a collection of YouTube videos that explain what participants will encounter in the studies and why the studies are being done. A link to these videos can be found at <http://www.cnrmmstudies.org/>.

Forging New Directions for TBI Research

A new initiative at CNRM is the involvement of people with TBI, caregivers, and advocates as partners in the research program. Our vision is that these individuals will provide input in multiple areas of the research and work with CNRM program leaders on specific TBI topics, including reviewing the impact during the planning of research studies, providing feedback on the design of clinical trials, serving on steering committees, and assisting with recruitment in CNRM studies. CNRM views this partnership with patients and patient advocates as essential in moving forward the research that is directly relevant to individuals with TBI and their caregivers on a day-to-day basis as they recover, rehabilitate, and accommodate for the chronic effects of TBI. Through consultation with the Brain Injury Association of America, CNRM is working to identify individuals to serve in this capacity.

Another new initiative is an enhanced focus on clinical trials in TBI and its co-morbidities. This initiative coincides with a leadership change within the organization. Dr. Regina Armstrong, who has lead CNRM from its inception, is stepping down from her role as Director as of Aug. 1, 2017. Dr. Armstrong leaves behind a legacy of strong collaborative interdisciplinary research across two federal agencies and a state-of-the-art infrastructure in addition to her own exemplary research program in TBI. She will remain involved with CNRM in her role as Director of Translational Research, a position critical in

identifying promising therapeutics being tested at CNRM and moving these therapeutics to clinical trials.

To continue to advance our research program and to build new capabilities, Dr. David Brody will assume leadership of CNRM. Dr. Brody will develop a clinical trial network centered at CNRM, in partnership with NIH and involving collaborations with DoD treatment facilities, which will be devoted specifically to TBI and its co-morbidities in the military. Dr. Brody is internationally-recognized for his expertise in TBI clinical care as a neurologist and for his outstanding research as a neuroscientist. Leading the CNRM is a continuation of Dr. Brody's work in multiple advisory roles for the DoD and his deep interest in preventing and mitigating the effects of TBI and its co-morbidities in service members. To learn more about Dr. Brody, watch his TEDTalk on YouTube. ●

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Evaluating the Effectiveness of an In-Home Service Program for People with TBI

The Safe@Home Program Aims to Provide Safety and Independence for People with TBI and their Families.

By Amanda Crowe, M.A., M.P.H., Shepherd Center

Recovering from a traumatic brain injury (TBI) and transitioning back home can be challenging. Balancing supervision needs, independent return to activities, and personal safety is complicated. While individuals with brain injury may not have a good perception of what happened or how the injury has changed their lives, their goal is nevertheless to be independent and return to prior activities.

Families, however, have vivid memories of their loved ones' injuries, so keeping them safe is often paramount. In some cases, families follow providers' full-time supervision recommendations to the letter, so they may not know how or when to help their loved ones to safely and independently re-engage in activities. In other cases, families may have limited support systems and need to return to work, which may mean individuals with brain injury are left on their own despite being at risk in such contexts. Consequently, many people with TBI who are at high risk for injury or harm are undersupervised and at increased risk, while others who are low-risk may be overly restricted.

According to the Centers for Disease Control and Prevention (CDC), unintentional injuries and medical events are the leading causes of death following TBI once a patient has been discharged from the hospital. Accurately assessing and mitigating safety risk, as well as designing interventions to set patients and families up for success, is an active area of research at Shepherd Center in Atlanta, Georgia.

"After formal rehabilitation has ended, the main goal of many individuals with TBI is to get their life back while the families' main goal is to keep the individual safe," explains Ron Seel, Ph.D., the O. Wayne Rollins Director of Acquired Brain Injury Research at Shepherd Center. "Survivors and families both seek

next-step recommendations to improve a safe return to independent activities."

Dr. Seel and his team are close to completing a multi-year research project evaluating a novel, in-home service program called Safe@Home. This research program has been developed with input from at least 200 people with brain injury or family members and 35 interdisciplinary clinicians. Dr. Seel provided insight on the study and how it might impact practice.

Q: *How was the study conducted?*

A: This is a quasi-experimental clinical trial in which 60 dyads (patient-caregiver pairs) were either assigned to usual care or enrolled in the Safe@Home program. Safe@Home is designed to increase activity and independence while reducing risk.

People were assigned to a treatment group based on how far away they live from Shepherd Center, given the practical considerations for how far our life skills coaches can travel to peoples' homes. Those within 75 miles of Shepherd Center were assigned to Safe@Home, and people farther away were in the usual care group.

Both groups completed surveys and received a computer-generated, personalized assessment of abilities, risks and recommended next steps. The Safe@Home group received, on average, 10 in-home visits with a life skills coach to work on self-selected goals while members of the usual care group selected and pursued goals on their own. Data was collected at baseline, after three months (corresponding to the end of the Safe@Home program), and at six months to see if any progress from the intervention was sustained.

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Shepherd Center's Safety and Independent Living Survey provides a comprehensive picture of someone's risk of harm after TBI. Included in this survey is the Safety Assessment Measure, which asks a family member the likelihood that the person with TBI will be unsafe in a variety of everyday activities to predict the overall risk of unsafe events related to: (1) carrying out activities, (2) walking/wheelchair mobility, (3) judgment, and (4) self-control.

"It means therapists and coaches have much more information at their disposal from the beginning," Dr. Seel said. "Instead of spending lots of time on assessments, they can walk in with a feel for what the person can do, their challenges, what kind of assistive devices they use, and the like."

(continued from page 11)

Q: *Who was included in this study?*

A: Our sample tended to be a younger group – 35 years of age on average – whose brain injuries most often stemmed from motor vehicle crashes. Some of the inclusion criteria included:

- Being 18 years and older and within two years post-TBI;
- Having a safety risk based on the hospital's safety assessment measure;
- Being fairly proficient with self-care; i.e., being able to feed themselves, dress themselves, and manage their bowel and bladder on their own; and
- Living with an adult family member (a parent, partner, or adult child) who was willing to participate.

Q: *What does the Safe@Home program entail?*

A: Life skills coaches make between six and 14, two-hour in-home visits over a three-month period, depending on an individual's goals and progress.

The first visit or two is primarily spent on goal-setting and making sure the patient and family are on the same page. Participants choose to work on skills in two of five modules focusing on:

- Managing health and wellness
- Improving mobility, balance and strength
- Independence in the home
- Getting out in the community
- Maintaining the home

If someone wants to be independent in the home, the participant might set up a daily schedule and practice safely preparing a favorite meal, doing chores, or handling situations like dealing

with strangers who come to the door or call on the phone. If the person chooses the goal of managing health and wellness, the focus might be how to take medications on a regular schedule. If the goal is to get out in the community, activities might include practice in arranging transportation, going for a walk, or completing a six- to 10-item grocery store run.

Coaches record what the patient does in each session and make note of his or her progress, adjusting strategies as needed.

Q: *How were coaches trained so that all patients received a consistent experience?*

A: Our life skills coaches received about 30 hours of training on this semi-structured intervention, which gave them leeway to tailor their approaches to each individual. We wanted to make it "real-world" and adaptable because we can't predict all situations.

As part of the training, there is a detailed manual that outlines the research behind Safe@Home and our automated Safety Assessment Measures as well as standard instruction for goal-setting, motivational interviewing, problem-solving, and suggested activities to meet goals within each of the five focus areas. It serves as a guide and could be adapted to home health and other care delivery settings.

Q: *What outcomes are you most interested in?*

A: First, reducing the number of unsafe events, including near-misses. We developed a standard format to measure unsafe events with substantial feedback from CDC, which has served as an adviser on the project for 10 years.

Second, we used the Mayo-Portland Participation Index to measure independence in home and community activities. We hope to have final analyses completed by the end of 2017, but anecdotal evidence so far supports the value of the program.

Q: *What's the potential gain from this kind of program?*

A: We are finding that if you can help individuals become more safe and independent, not only does personal safety improve, but their emotional outlook and how they feel about themselves also improves. For the family member, the potential burden and relationship friction that accompanies providing supervision is reduced. There are also significant potential gains to society, such as avoiding setbacks and rehospitalizations that impact health payer costs, as well as the potential for a family member to be able to return to work.

Q: *How does this intervention fill an unmet need?*

A: This research has taken a practical approach to setting up an intervention by addressing the families' primary goal, which is safety, and the primary goal of persons with brain injury, which is independence. Staff members deliver individualized in-home services that are specific to each person's and family's circumstances.

Q: *Could this be a model for other hospitals?*

A: Yes. The timing is right in terms of payers moving to a more population-based payment system where investing some money upfront reduces the risk for injury and other negative outcomes that cost a lot of money. This intervention is cost-efficient, provides a practical way to assess risk, gives next-step recommendations, and empowers individuals and their families to self-manage their own situations in the long term.

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Lessening the Impact of Concussion



By Stephanie Cohen, M.S., Development Manager, Brain Injury Association of America

Ever since she sustained a severe concussion in her freshman year of high school, Brooke Mills has been on a mission to raise awareness of concussion throughout the nation. During her own recovery, Brooke felt isolated, discouraged, frustrated, and angry, largely due to other's people's attitudes and misconceptions about concussion. She doesn't want other people to go through what she did.

Brooke's concussion occurred when she was kicked in the head during gym class. She experienced a variety of symptoms, including headaches, eye tracking problems, light sensitivity, sleeping issues, memory loss, mood changes, and dizziness. Brooke followed all of her doctor's recommendations, including



Brooke Mills, right, discusses concussion symptoms, treatment, and return to play guidelines on Open Mic with Pat Kelly at the WEMJ 1490 radio station in New Hampshire January 22, 2016.

“The chance to help others through the BIAA has helped me turn a negative situation in my life into a more positive one.”

getting plenty of physical and cognitive rest, and assumed she would be back to normal within two weeks. However, months passed with little improvement and she began to lose hope. Her mother and sister supported her and, as a family, they searched for answers. Brooke describes her experience during this time, “I lost memories. I felt isolated from friends because I couldn't remember our inside jokes. I wasn't myself and they simply could not relate or understand what was happening to me. It affected every part of my life.”



Brooke runs the Concussion Awareness booth at the New Hampshire Technical Institute's Community Wellness Fair March 28, 2017.

Immediately after her injury, Brooke and her family were overwhelmed and did not know where to turn. The Brain Injury Association provided them with the resources, education, and support they needed to navigate what to do and where to go for help. The Mills family was impressed by the daily efforts of staff and volunteers as they advocated for individuals with brain injury. Brook was inspired by the way the huge network of people across the country worked together to provide community education, raise funds, promote research, create legislation, and support those affected by brain injury.

Though she's making significant improvements, Brooke still has post-concussion headaches and memory issues. Despite this, she remains committed to educating people about concussion. "No one should let an injury define them or rob them of their aspirations," Brooke explains. To increase awareness and understanding, she speaks about her experience at middle schools and high schools. She explains what a concussion is, its causes, the associated symptoms and diagnosis, and the social and emotional effects. Brooke credits her volunteer advocacy experience with being a major part of her healing process. She recently graduated high school – a year early and with honors! She is now a student at New Hampshire's Technical Institute and looks forward to receiving her Doctor of Chiropractic degree.

Hoping to spread the word further and to create a national conversation about concussion, Brooke started a volunteer program called Lessen the Impact in 2015. She knew that partnering with the Brain Injury Association of America (BIAA) was the most logical step and subsequently launched National Concussion Awareness Day in 2016 to raise funds to support the brain injury community. In addition to increasing education and awareness, she uses this annual event to encourage others to donate to BIAA. "The chance to help others through the BIAA has helped me turn a negative situation in my life into a more positive one," Brooke explains. ●

For information on
National Concussion Awareness Day
and concussion in general, please visit
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Thank You!

Advocacy UPDATE

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

Advocates Savor Health Care Reform Victory

The Brain Injury Association of America (BIAA) joins other health and disability organizations in celebrating the preservation of the Patient Protection and Affordable Care Act (ACA). In late July, senators considered multiple bills to repeal and/or repeal and replace the ACA. The final measure that was considered, known as the “skinny repeal” bill, would have done away with the ACA’s individual mandate, employer mandate, and medical device tax. The proposal failed in a 49-to-51 vote. Senator John McCain of Arizona cast the decisive vote, joining Sens. Susan Collins (R-Maine) and Lisa Murkowski (R-Ala.), in opposing the bill. BIAA sincerely thanks all of the grassroots advocates who fought for this important victory.

BIAA Sponsors Washington, D.C., Fly-In to Advocate for Rehabilitation

BIAA jointly hosted a bipartisan congressional briefing, “The Value Of Rehabilitation and Habilitation Services and Devices in America’s Health Care System,” in collaboration with the Coalition to Preserve Rehabilitation, the Habilitation Benefits Coalition, and the Independence Through Enhancement of Medicare and Medicaid Coalition. The briefing, held June 27, attracted over 200 attendees, including House and Senate staffers. The event included marquis speakers Sen. Tammy Duckworth (D-Ill.), Rep. Glenn Thompson (R-Pa.), Gregory J. O’Shanick, M.D., BIAA’s medical director emeritus, and others. BIAA greatly appreciates the brain injury advocates who traveled to Washington, D.C., to meet with their legislators.



Brain injury advocates support the disability community during the congressional fly-in and briefing June 27 on Capitol Hill.



Speakers Lisa Smith (left), Gregory J. O'Shanick, M.D., and Peter Thomas listen as Rep. Glenn Thompson (R-Pa.) discusses rehabilitation at the June 27 congressional briefing.

BIAA Submits Testimony to Congress on Therapy Caps

The House Energy and Commerce's Subcommittee on Health, chaired by Rep. Michael C. Burgess, M.D. (R-Tex.), held a hearing July 21 on 11 bipartisan bills relating to Medicare. BIAA submitted testimony in support of proposals to eliminate the cap or, alternatively, maintain the existing exceptions process and manual medical review required under the Medicare program. BIAA asserted that intensive and ongoing rehabilitation care is vital for individuals with brain injury, stroke, other serious disabilities, and chronic conditions. Access to such care must be preserved.

A second bill of interest to BIAA is H.R. 2465, the Steve Gleason Enduring Voices Act of 2017, pertaining to Speech Generating Devices. BIAA submitted a letter of support for the legislation.

House Appropriations Subcommittee Rejects President's Elimination of the TBI State Grant Program

On July 19, 2017, the House Appropriations Committee approved the draft fiscal year 2018 Labor, Health and Human Services, and Education (LHHS) spending bill, which includes federal funding for

research, prevention, health, education, employment, and safety net programs. The bill maintains funding for the Administration for Community Living (ACL) TBI Federal program at \$9.3 million, which is the same as the fiscal year 2017 enacted level for both the state grant and the protection and advocacy grant programs. The House rejected the Administration's proposal to combine the TBI Program with other programs administered by ACL.

The House Appropriations Committee also disagreed with the president's proposal to eliminate funding for the Centers for Disease Control and Prevention's (CDC) National Injury Center's Injury Control Research Centers (\$9 million) and the elder falls prevention program (\$2.05 million). The Committee recommended level funding for both as well as the Injury Center's TBI program (\$6.75 million). For a third consecutive year, the spending bill allocates a significant funding increase of \$1.1 billion for the National Institutes of Health (NIH), which includes additional funding for the BRAIN initiative.

The next step is for the LHHS bill to be considered by the full House of Representatives. Both the House and the Senate will need to pass the 12 spending bills, an omnibus bill combining spending bills, or a continuing resolution by Sept. 30, 2017, to keep the federal government open once the new fiscal year begins.

House Budget Committee Passes Budget Plan

The House Budget Committee approved a budget resolution, "Building a Better America," to pave a path toward a balanced budget within 10 years. The budget blueprint calls for increased military spending, reshaping Medicare into a voucher program, and cutting funding for food stamps, Medicaid, Social Security Disability Insurance (SSDI), and other social programs. There is speculation that the House will delay taking up the resolution until September. In the meantime, BIAA will monitor budget developments closely as cuts or changes to

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these federal programs could significantly impact individuals with brain injury.

BIAA Creates PBA Coalition

BIAA is taking the lead in the neurological space to create a new coalition that will raise awareness about Pseudobulbar Affect (PBA), a neurological condition marked by uncontrollable outbursts of laughing and/or crying in people with brain injuries and the challenges that patients face in accessing treatment. The goal of the coalition is to increase PBA education and advocacy by establishing a digital presence and working with other leaders in the neurological community to grow the coalition.

BIAA Endorses the Disability Integration Act

BIAA joined other member organizations of the Consortium for Citizens with Disabilities in supporting the Disability Integration Act (S. 910, H.R. 2472). This legislation, if passed, would ensure the rights of people with disabilities to live full and independent lives in their communities. This legislation builds on the Americans with Disabilities Act and the Supreme Court's Olmstead decision, asserting that people with disabilities have a right to live in their own homes and communities and to receive the services and supports they need in order to do so.

CMS Issues New Policy on Fees for Complex Rehab Technology

As a member of the Independence Through Enhancement of Medicare and Medicaid Coalition, BIAA has supported efforts to fix the problem of competitive bid pricing being applied to manual and power complex rehabilitation technology (CRT) wheelchair accessories. In June, the Centers for Medicare and Medicaid Services (CMS) issued a new policy on how adjustments to the fee schedule based on information from competitive bidding programs apply to wheelchair accessories and back and seat cushions used with Group 3 CRT power wheelchairs. Section 16005 of the 21st Century Cures Act currently allows higher payments for these items but is set to expire after June 30, 2017. Continuing these higher payments will help protect access to CRT power wheelchair accessories.

A poster for the Brain Injury Summit 2018. At the top, a stylized brain is shown with white lines radiating from it, set against a dark blue background with white stars. Below the brain is a white silhouette of a mountain range. The text "BRAIN INJURY SUMMIT | 2018" is in white, with "A Meeting of the Minds" underneath. The dates "JANUARY 7-10, 2018" and location "VAIL, COLORADO" are in white. A blue banner with white text says "REGISTRATION IS NOW OPEN! Now accepting ABSTRACT SUBMISSIONS!". Below this, white text invites professionals to join in Vail, Colorado, for a multidisciplinary continuing education experience. The website "braininjurysummit.org" is in blue. The host is listed as CRAIG Rocky Mountain Regional Brain Injury System, with the CRAIG logo and tagline "UNYIELDING DETERMINATION. EMPOWERING LIVES." The "Endorsing Organizations" list includes BIAC, BIAA, IBIA, NASHIA, NABIS, and USBIA. At the bottom, it states the activity is jointly provided by Craig Hospital and Medical Education Resources.

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- International Brain Injury Association (IBIA)
- National Association of State Head Injury Administrators (NASHIA)
- North American Brain Injury Society (NABIS)
- United States Brain Injury Alliance (USBIA)

*This activity is jointly provided by Craig
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Brain Injury **ADVISORY COUNCIL CORNER**

Member Spotlight: **PAUL BOSWORTH**

By Amy Zellmer, Brain Injury Association of America Advisory Council member



While living in Washington, D.C., and working for a leading computer manufacturer, Paul Bosworth sustained a mild traumatic brain injury (mTBI) after he choked on chicken fried rice. Alone in his kitchen, he passed out, hitting his head on the floor. When he came to, Paul still had food lodged in his throat, so he went to the bathroom and attempted to remove it. The removal was painful and caused tearing in his throat, so he called his girlfriend to take him to the hospital.

Once the doctors had attended to the tears and bleeding, they told Paul that he had suffered a concussion and sent him home. He went back to work, but eventually it became apparent that he had suffered more brain damage than originally thought. He was having a hard time speaking, was plagued with debilitating headaches, and had a difficult time reading and comprehending things. He eventually went to see a neurologist he'd met at a happy hour who told him he had post-concussion syndrome (PCS).

Paul began to realize he wasn't going to be able to continue working and went on long-term disability. He moved back home to Louisiana to be near friends and family. Friends from his corporate life had been slowly and gradually leaving him – they simply didn't understand what it meant to live with the effects of brain injury, the silent epidemic.

After a conversation with fellow brain injury survivor, Anne Forrest, Paul decided to join the Brain Injury Advisory Council in 2009. He also started a support group called AMAZE. "AMAZE provides a space for caregivers and survivors to take a breath and know that they are not alone. Guest speakers visit our group's monthly meetings to share therapies or activities that add life every time. AMAZE is a place where a member will be understood and not judged," said Paul. Thanks to physician referrals, AMAZE has grown over the past seven years.

Though AMAZE was very fulfilling, Paul knew he needed to do something more to raise awareness and occupy his time. He organized BBQ4TBI, a community barbecue in conjunction with a Jeep ride, and donated the proceeds to the Brain Injury Association. Organizing the barbecue gave Paul a sense



Paul Bosworth, left, assists Greg Ayotte, BIAA's director of consumer services, at Brain Injury Awareness Day 2017.

of belonging and challenged his brain, allowing him to relearn some of the skills he'd lost.

I have to say that Paul has done something spectacular for brain injury awareness, and I want to extend a heartfelt "thank you" to him for all of his efforts. I know what kind of energy it takes to put on an event and run a support group, and I also know that it takes a toll on a brain injury.

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State Affiliate NEWS

GEORGIA

The Brain Injury Association of Georgia (BIAG) has expanded its Information and Resource Program to include consultation services for families and individuals in hospital, with a goal of providing a smooth transition from hospital to home. To increase awareness of brain injury around the state, BIAG hosted its first Walk for Brain Injury. Attendees were grateful that the rain stopped as soon as the walk started. Many thanks to support group members from Augusta and Savannah, who donated proceeds from the walk to Camp BIAG.

Earlier this spring, BIAG participated in the Atlanta Science Festival, held in Centennial Park, and performed a hands-on demonstration using sheep

brains to illustrate the difference between normal and damaged brains. Volunteers conducted surveys on visitors' knowledge of brain injury.

Board Member Kelly Campbell, who leads the Unlimited Possibilities Cobb Support Group, was in a podcast interview. Listen to Episode 5 on <https://handinhandshow.com> to hear her story. The Gwinnett Support Group hosted an Unmasking Brain Injury event and invited area support groups to participate in creating their own unique masks. To see the masks and read their stories, visit <http://unmaskingbraininjury.org/georgia>. Don't forget to like BIAG's Facebook page to view details and photographs of its events.

KANSAS

The Brain Injury Association of Kansas and Greater Kansas City's (BIAKS) hosted the 30th Annual Amy Thompson Run for Brain Injury (ATR) Memorial Day, May 29. More than 1,800 spectators and runners participated in the Walk for Thought and Fun4Kids events held that day.

The honoree for this year's run was Zeke Crozier, a veteran injured in a 2011 helicopter crash in Afghanistan. Zeke founded a small company called Handy-Cappin LLC, which specializes in creating unique art pieces created from bottle caps. NFL Hall of Famer and former Chiefs Offensive Lineman Will Shields served as the honorary chair for Walk for Thought. Larry Moore, anchor emeritus for KMBC television station, served as the master of ceremonies for the 30th time. Featured this year was a new promotion called GeoGo, a pre-race token trail challenge developed by Brandon and Brandon Marketing to encourage race participation and promote local businesses. Race registrants had an opportunity to win valuable prizes by visiting local businesses and collecting tokens. For more information, visit <http://biaks.org>.



◀ GeoGo winner Beth O'Bryan (left) and her daughters are congratulated by the Sporting KC mascot.

2016 ATR honoree Patrick McGinnis (left), Honorary Walk for Thought Chair Will Shields, 2017 ATR honoree Zeke Crozier, and Zeke's son get ready for the Walk for Thought event.



◀ The Thompson Family and Zeke Crozier display a commissioned piece of art, designed and produced by Handy-Cappin LLC, to the Country Club bank.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) recently wrapped up the third year of its TBI State Partnership grant through the Administration for Community Living. This grant enabled BIAA-ME staff to assist nearly 500 individuals and families through Information and Resource Facilitation services, present to 82 percent of Maine’s hospitals, and provide presentations on supports and services to 30 brain injury support groups, providers, and community organizations.

The Eighth Annual Conference on Defining Moments in Brain Injury will take place Tuesday, Oct. 17, 2017.

The conference will have five tracks: medical, clinical/allied health, survivor, community alternative, and youth concussion management training. Tim Feeney, Ph.D., will present the keynote address, “Developing Meaningful Supports for the Successful Integration in School, Work, and Home.” After outgrowing its previous location, the conference will take place at the DoubleTree by Hilton Portland Hotel in South Portland.

BIAA-ME’s third annual Bowling for Brain InjurySM event is scheduled for Sunday, Dec. 3, 2017, at Spare Time Portland.

MICHIGAN

Every year, the Brain Injury Association of Michigan (BIAMI) partners with the Sinas Dramis Law Firm, as well as various local companies and organizations, for Lids for Kids in May and June. Lids for Kids is a series of events in which children are properly fitted with and given bike helmets while they listen to presentations on the importance of bicycle safety.

The events also include fun activities for children and raffles for new bikes and other prizes. Many of the children live in low-income neighborhoods and would not have access to helmets without Lids for Kids.

Many biking-related brain injuries can be prevented by wearing a properly fitted helmet, something the organizers of Lids for Kids recognized in the creation of this program. Brand-new helmets are donated and volunteers are trained to custom-fit each helmet. These events are held in Traverse City, Lansing, and Grand Rapids. This year, the program provided more than 1,000 helmets to children around the state.

Since Lids for Kids began in 2003, more than 8,000 helmets have been distributed. BIAMI is proud to be an integral part of such an important program.



◀ A Lids for Kids volunteer helps to fit a young girl with her new helmet.

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MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual Donald Danforth Jr. Wilderness Camp in June. Nearly 70 survivors of brain injury enjoyed a week of fun, independence, and adventure as they ziplined across the lake, played sports, danced, and walked nature trails. Family members had a week of respite to rejuvenate emotionally and physically. Campers raised \$2,000 through the Walk Float Swim Challenge in which family and friends sponsored each lap they took around the pool or camp ground.

Bowling for Brain InjurySM was held in Springfield and St. Louis, with nearly 200 bowlers and spectators

in attendance. The event raised more than \$17,000 to increase awareness of brain injury and provide support for survivors and families in Missouri.

The BIA-MO Annual Statewide Conference will be held Oct. 5-7, 2017, at the Marriott St. Louis West Hotel. This conference is dedicated to innovative therapeutic strategies, cutting-edge and best practice treatment options, and current research. The Thursday and Friday sessions will be of most interest to professionals, while Saturday sessions will focus on education and support for survivors of brain injury and family members. For more information, visit www.biamo.org.

NEW HAMPSHIRE



◀ Nicole Bingaman presents the keynote address at BIANH's 34th annual Brain Injury and Stroke Conference.

The Brain Injury Association of New Hampshire (BIANH) held its 34th annual Brain Injury and Stroke Conference, featuring keynote speaker Nicole Bingaman. In 2012, Nicole became a student of brain injury when her oldest son sustained a severe TBI after falling down a flight of stairs. In her presentation, Nicole candidly discussed the emotional impact of brain injury on her family as she chronicled the years since her son's TBI. By sharing her story, she has been able to raise awareness for the TBI community as a whole and increase knowledge and compassion for those most affected by brain injury. Nicole's ongoing mantra is "Love Wins."

The 31st annual Walk by the Sea and Picnic was held June 4 at Hampton Beach State Park. The sun was out and the temperature was in the high 60s. It was the best turnout in several years, with almost 500 people in attendance and more than \$31,000 raised in support of the event.



▲ Participants get ready for the 31st annual Walk by the Sea and Picnic.

NEW YORK

The Brain Injury Association of New York State (BIANYS) 35th annual conference and professional symposium, "One Voice for Brain Injury," returned to the Holiday Inn in Saratoga Springs, June 14-16. Nearly 300 survivors of brain injury, family members, professionals, and friends from across the state learned about research trends, innovative treatments, and strategies for not just living, but thriving after brain injury.

The organization's one-day symposium featured sessions led by top medical professionals, and the two-day conference included nearly two dozen sessions led by brain injury survivors as well as interactive panel discussions and the opportunity to network with leading professionals in the field of brain injury. The conference also featured an exciting keynote address from Dr. Joel Goodman, founder of The HUMOR Project, an effort focusing on the positive power of humor.

"The annual conference is a signature event for the organization," said Eileen Reardon, BIANYS executive director. "Annually, this event draws hundreds of survivors, family members and leading medical professionals with different backgrounds. They come together, learn about new strategies and ideas, and forge meaningful connections that provide positive outcomes for all involved."



▲ Attendees enjoy the Neurologic Music Therapy Workshop, presented by MedRhythms, during the "One Voice for Brain Injury" conference.

BIANYS also recently announced the return of its popular March On for Brain Injury events, presented by iHeartMedia, slated to return to both Rochester and the Hudson Valley Aug. 26. This year, March On for Brain Injury will feature an inaugural 5K course, a one-mile family fun walk, and activities for the whole family to enjoy. As part of its statewide effort, BIANYS will also be hosting March On for Brain Injury satellite locations in New York City and Long Island. For more information or to register, visit <https://bianys.org>.

PENNSYLVANIA



▲ Briana Scurry (left) and Christabelle Braden show their support at BIAPA's 17th annual conference.

The Brain Injury Association of Pennsylvania (BIAPA) hosted its 17th annual conference, "Navigating Paths to Hope and Health," June 25-27 in Lancaster. There were 366 people in attendance. The conference included two keynote presentations: Briana Scurry, two-time Olympic Gold Medalist as goalkeeper for the U.S. Women's Soccer team, spoke about her life-changing concussion; and Christabelle Braden, founder of Hope After Head Injury, spoke about the unseen emotional and physical struggles of daily life as a brain injury survivor. The program also included two plenary presentations, 22 workshops, two social receptions, a showing of the movie "Becoming Bulletproof," an Artisan's Showcase, and an Open Mic Coffee House.

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Using a model that combines both professionals and consumers, BIAPA strives to bring people together for a time of learning, reflection, networking, and personal growth. "To us, the conference is spiritual food," explains Holly Irish, who attends each year with her husband. BIAPA and the David Strauss Memorial Scholarship Fund, supported by ReMED and CoBI, provided 126 scholarships for individuals with brain injuries and their families or caregivers to attend.

The Centers for Disease Control and Prevention (CDC) recently recognized the Pennsylvania BrainSTEPS program as one of four promising Return to Learn Programs nationwide. A CDC Evaluation



Team came to Pennsylvania for two days in May to meet with key BrainSTEPS Program stakeholders and conduct an evaluability assessment for the next phase of the project. The goal of the program is to develop Return to Learn best practice guidelines for services to children with TBI that can be disseminated across the country.

RHODE ISLAND

The brain injury community came together May 20 for the annual Brain Injury Association of Rhode Island (BIARI) Keep Your Head Up 5K Walk. In addition to the raffles, great music, and tasty food, the walk was kicked off with the sound of the bagpipes to set the mood. Later in the spring, BIARI hosted an Enchanted Tea Party, offering complimentary reiki, tarot card readings, and a medium.



▲ The team from Marasco & Nesselbush, a Providence-based law firm, gives out sunscreen at the Keep Your Head Up 5K Walk.



▲ 5K Walk Chair Kate Cioe (left) gets ready to walk with her parents, Tim Anderson and Liz Charette.

For the 18th year, BIARI staff and its army of more than 40 volunteers donned CVS Health Classic Charity logoed baseball caps and t-shirts and spread out along the tees and fairways of the scenic Rhode Island Country Club in Barrington. The CVS Health Charity Classic brings world-class professional golf to New England and raises funds for nearly 100 charities. BIARI is thrilled to be included in the festivities. This summer, BIARI will hold its second member appreciation party and picnic at Newport Polo, where the staff pampers members with a catered meal and everyone will enjoy watching a topnotch polo match.

VERMONT

The Brain Injury Association of Vermont (BIAVT) held the 15th annual Walk for Thought May 20. The event consisted of 420 donors helping 108 fundraisers to raise more than \$30,000! BIAVT is grateful for the support of sponsors, donors, families, and friends who attended the event.

BIAVT staff joined the VT Dept. of Health (VDH) Chronic Disease Advisory Group. The purpose of the group is to assist with and advise upon the startup and implementation of a CDC grant received by the VDH.

The Vermont School Concussion Management Toolkit will be updated to reflect the recommendations of the consensus statement on concussion in sport, provided at the Fifth International Conference on Concussion in Sport in Berlin last year. Download the editable toolkit at www.biavt.org.



▲ Kirsten Wiley and Hannah Deene show their enthusiasm at the 15th annual BIAVT Walk for Thought.



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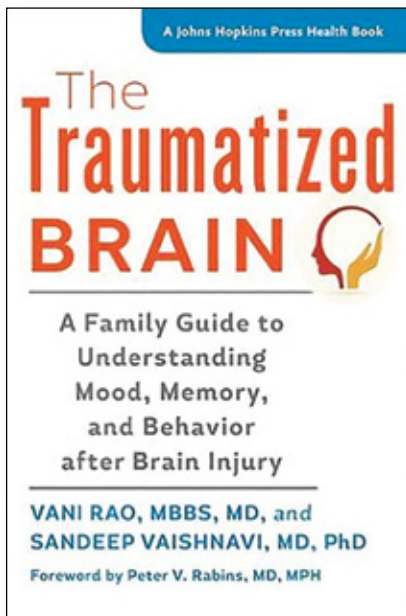
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The BIAA BOOKSHELF

By Roxane M. Dean, Social Worker, Carolinas HealthCare System

Though I usually review stories by persons with brain injury or their family members, I thought it would be interesting to review a more practical book because, sometimes, people just want medical information that they can understand. I chose to read “The Traumatized Brain: A Family Guide to Understanding Mood, Memory, and Behavior,” written by neuropsychiatrists Vani Rao, MBBS, M.D., and Sandeep Vaishnavi, M.D., Ph.D.



The book is divided into five sections. The first section covers the structure and working of the brain, the different types of brain injury, and what factors can influence recovery. Understanding these components helps us understand the complexity of the brain and diagnosing traumatic brain injury (TBI). The next part of the book explores emotional problems that occur after brain injury. It examines how depression, anxiety, mania, and apathy can be caused by the damage the brain has sustained and provides a review of current treatment and therapies to help persons with brain injury and their loved ones to cope with these issues.

The third section deals with behavior problems including psychosis, aggression, impulsivity, and sleep disturbances. Often these changes are of primary concern for family and friends. I found the case examples described and the list of tips for coping with these behaviors to be incredibly helpful. In the following section, Rao and Vaishnavi look at cognitive problems – how and why an injury to the brain can change attention, memory, and reasoning. If we know how certain areas of the brain control our higher levels of thinking, we can begin to understand why these problems occur. This section also includes

practical suggestions for drug treatment and therapies, and the writers take care to present all the medical information in a thoughtful and accessible manner.

The fifth and final section explores common problems such as headaches, seizures, and vision changes. These problems can be very frustrating and can continue for a long time. Learning what can trigger them and what may help alleviate them can greatly benefit those who suffer from their effects.

So many people with brain injury are met with skepticism from friends and other peers when they describe their symptoms. Stressing that symptoms are real and are directly related to the trauma, Rao and Vaishnavi provide comfort to persons with brain injury and encourage them to ask for help. There are no easy answers or quick fixes for the many and varied consequences of brain injury, but this book will provide excellent information and practical guidance. It is a great addition to any library. To purchase your copy, visit BIAA's Online Marketplace at <http://shop.biausa.org>.

News & **NOTES**

BROWN-BAG-IT for Brain Injury Returns

In 1994, the Brain Injury Association of America (then National Head Injury Foundation) launched Brown-Bag-It, a nationwide fundraiser encouraging people to bring their lunch from home and donate what they would have spent on a restaurant lunch to the organization instead. The campaign went on for several years and proved to be a fun way for people to show their support for the brain injury community. This summer, BIAA brought back Brown-Bag-It. Now we need your help to make the event a huge success!

Please join the BIAA staff and members of the brain injury community in bringing lunch to work on the last Wednesday of every month and donate your lunch money to BIAA instead. To make your donation, visit www.biausa.org/brownbagit.



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Beechwood NeuroRehab supports individuals with brain injury to be able to engage in productive and satisfying lives.

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Upcoming **WEBINARS**

Mitchell Rosenthal Memorial Research Webinar – New Treatments for Emotional Deficits after Brain Injury: A Key Common Attribute

September 14, 2017, 3 p.m. ET/12 p.m. PT

*Dawn M. Neumann, Ph.D., Indiana University and
Rehabilitation Hospital of Indiana*

Carolyn Rocchio Caregivers Webinar – Life Care Planning After Brain Injury

September 20, 2017, 3 p.m. ET/12 p.m. PT

Harvey Jacobs, Ph.D., CLCP

Robert Sbordone Memorial mTBI/Concussion Lecture – Return to School after Mild Brain Injury

October 4, 2017, 3 p.m. ET/12 p.m. PT

*Ann Glang, Ph.D., Center on Brain Injury Research and
Training, University of Oregon*

Carolyn Rocchio Caregivers Webinar – "When Can I Drive Again?" Driving Evaluation Services and Assessment Tools

October 19, 2017, 3 p.m. ET/12 p.m. PT

Jan Crye, OTR/L, CDRS, Sinai Rehabilitation Center

Mitchell Rosenthal Memorial Research Webinar – Service Delivery for Children Following TBI: Gaps in Care

November 1, 2017, 3 p.m. ET/12 p.m. PT

*Juliet K. Haarbauer-Krupa, Ph.D.,
Centers for Disease Control and Prevention*

Carolyn Rocchio Caregivers Webinar – Caring for the Brain Injury Caregiver

November 11, 2017, 3 p.m. ET/12 p.m. PT

*Denise Krch, Ph.D., and Peii Chen, Ph.D.,
Kessler Research Foundation*

David Strauss Memorial Clinical Webinar – Cognitive Rehabilitation: Memory Deficits and Rehabilitation

November 15, 2017, 3 p.m. ET/12 p.m. PT

*Thomas Bergquist, Ph.D., L.P., Mayo Clinic and
Mayo Graduate School of Medicine*

To register, please visit

<https://shop.biausa.org/products/livewebinars>

Brain Injury **ADVISORY COUNCIL CORNER**

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When asked how the BIAA has changed his life, Paul said, "BIAA provides me a unique platform so that I am able to connect and learn more about what is being done to positively influence brain injury on several different levels. I am also able to get a sense of what's coming down the pipe to help survivors and caregivers. Each March, I take a stand by showing up in my state lawmaker's office to effectively highlight brain injury from a first-person perspective while I am in Washington, D.C., attending Brain Injury Awareness Day."

"BIAA enables me to gain access to the people with the latest information and statistics, help those who are presenting research findings in public forums as well as what Americans, both civilian and military alike, are doing to move the ball forward at the Brain Injury Awareness Day Fair. After all, we are together in this fight for better brain health."

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The Corporate Sponsors Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and education programs. BIAA is grateful to the Corporate Sponsors for their financial contributions and the many volunteer hours their companies devote to spreading help, hope, and healing nationwide.

For more information on how to become part of the Brain Injury Association of America Corporate Sponsors Program, please visit the sponsorship and advertising page at www.biausa.org or contact Carrie Mosher at 703-761-0750, Ext. 640 or cmosher@biausa.org.

