

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 11, Issue 2

THE CHALLENGE!



TECHNOLOGY

SPRING 2017

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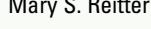
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From my DESK



In April, hundreds of thousands of people marched in the District of Columbia and 600 other cities to support science in all its forms – earth science, life science, social science, and even old standbys like chemistry, physics, and astronomy. While many marchers called for stronger environmental protections, plenty of people rallied for advances in technology. In fact, technology was a core message during the march because it brings people together and allows them to participate in ways that were not possible just a few years ago. As the event organizers put it, “Technology has opened up a new world of ways everyone can be a researcher or part of a research team.”

The Brain Injury Association of America is proud to dedicate this issue of *THE Challenge!* to technology. We've included articles on mobile apps for everyday living after brain injury and assistive technology solutions in acute rehabilitation settings. All of the articles focus on ways to personalize your brain injury experience through the use of technology. We've also taken this opportunity to congratulate Joseph T. Giacino, Ph.D., winner of the prestigious Moody Prize, for his significant contributions in clinical research and rehabilitative medicine.

BREAKING NEWS

Join us for the Capitol Hill Fly-in to protect rehabilitative and habilitative services and devices and other key provisions in the Senate effort to repeal and replace the Affordable Care Act.

Tuesday, June 27, 10 a.m. - 5 p.m.

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I sincerely thank our corporate sponsors and individual donors for their generous support. We could not pursue our mission to increase brain injury awareness, research, treatment, or education without their critical financial support. My hat also goes off to our affiliates and chapters for the important work they accomplish at the state and local level. It is our partnership with affiliates that helps us improve the quality of life for everyone affected by brain injury.

Please enjoy a happy and safe summer.

Susan H. Connors

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

ASSISTIVE TECHNOLOGY Goes Mobile

By Sarah Foley, M.S., CCC-SLP and
Erin Muston-Firsch, M.S., OTR/L, Craig Hospital

Craig Hospital is an inpatient rehabilitation hospital in Englewood, Colorado, specializing in treatment of individuals with traumatic brain injury (TBI) and spinal cord injury.

Technology is more than just a luxury at Craig. As technology becomes a greater part of the world at large, therapists at Craig are finding more and more ways to incorporate it into the acute rehabilitation process for those recovering from TBI. In the Assistive Technology Lab, for example, occupational and speech therapists consider technology a vital tool in the lives of those living with disabilities. Specifically, therapists have found that technology opens up opportunities post-injury for many patients, ranging from increasing engagement in therapeutic tasks to allowing the individual to return to a previous job.

TECHNOLOGY AS A TREATMENT MODALITY

D (first initial used to protect the person's privacy) sustained a severe TBI after a fall. Before his injury, this young man enjoyed playing games on both his computer and video game system. When he initially came to Craig, D was not able to move most of his body, communicate basic needs, or remember things from day to day – let alone play traditional video games. His treatment team also noticed severe left visual neglect, or difficulty looking at and attending to things on his left side. D's initial treatment involved using a device that tracked his eye movements in order to play video games; not only was this a great way to work on scanning and attention on his left



side, but it was also something that he really enjoyed and found motivating. D's family commented that it was one of the first things he was really able to "do" as a part of his rehabilitation. As D progressed and began moving his arms, big button switches were used to play games, encouraging him to move and reach while still challenging his vision. Eventually, D began to gain more control of his hands and fingers, so he was further challenged with video game controllers to practice hand-eye coordination, reaction time, and problem-solving skills. D used technology therapeutically, as a treatment, to work on deficits from his TBI. As he progressed, his therapists were able to adjust the type of technology he could use and the games he could play to provide just the right level of challenge for him.

While we traditionally think of using assistive technology to make access easier, it can also be used to work on physical, cognitive, and even visual skills. There are a variety of options available, including use of eye tracking technology to work on vision and attention, big button switches to work on reach and coordination, mobile applications to provide visual and cognitive challenges, and computer and console-based video game controllers to work on dexterity and reaction/processing time. Virtual reality is an emerging technology with the potential to work on balance, motor skills, dexterity, and cognitive skills in an immersive environment. D's story shows us that technology is a great treatment tool because of its widespread commercial availability and its inherent ability to motivate and engage users through interactive, competitive gameplay.

TECHNOLOGY TO ADDRESS LANGUAGE DEFICITS

M was a young man who sustained a TBI through electrocution. Upon arrival at Craig, he was unable to move most of his body. He was barely able

to communicate "yes" or "no" through his head movements, much less signal any other basic needs. Through the use of technology, M learned how to use his eyes to operate special software on a computer. A camera attached to the computer could track his eye movement – by holding his gaze in a specific part of the screen, M was able to trigger the computer to say what he was thinking. When he was discharged, M was using his eyes to communicate anything and everything he wanted to say. In addition, this technology allowed him to text his friends, engage on Facebook, and surf the web independently.

Speech-generating devices such as these are some of the ways that Craig therapists use technology to assist people with communication. For those who can physically touch a screen, there are iPads and communication apps that can say selected words and phrases for the speaker. For others who have some gross motor movement, switches can be enabled to select a word or phrase as the computer/tablet scans through various options.

(continued on page 6)



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TECHNOLOGY TO ADDRESS COGNITIVE DEFICITS

J was a woman in her 50s, actively involved in her family and community. Before her brain injury, J did much of the organization and planning for her family. Her stroke caused difficulties with her language skills – writing specifically – and she had trouble maintaining attention and performing typical life management. She was determined to be more independent with these things as she returned home.

J's phone became her lifeline. She relied on it for remote communication with her many family members and as a cognitive tool to provide the structure she could no longer maintain herself. Her therapist worked with her to simplify her home screen so that she could more easily locate the apps she used most. She learned how to use voice input for texts and emails, making communication more efficient. She was taught to use her online calendar for visual organization of her days. Alerts were set up to remind her of upcoming tasks, and she used a separate medication app to guide her in filling her pill box each week. A simple emergency alert app provided her and her family with peace of mind if a medical emergency occurred when she was alone. With proper training to use these tools, J was able to return home with less supervision and increase her independence in performing daily tasks.

In addition to the tools mentioned above, individuals with brain injury can benefit from mobile technology at home. Use of call systems, similar to intercoms,

allows families to check on their loved ones when in another room or location. Far-field recognition (such as the Amazon Echo or Google Home) can turn lights on and off using a single voice command. When motor movements are impaired, TV may be more easily accessed using an app on the individual's phone.

TECHNOLOGY FOR RETURN TO WORK AND SCHOOL

Consider these scenarios:

1 N was a young man working at a fast-paced job that demanded efficient computer skills. After his TBI, his language skills were impaired and his left arm did not work at all.

2 T was in her junior year of high school when she sustained a TBI in a car accident. When it was time to return to school, she still had difficulty with multitasking (i.e., taking notes while listening to the teacher) and keeping up with the pace of the class.

What are these individuals to do? How are they to successfully reintegrate into their work and school environments?

As patients move toward the end of inpatient rehabilitation, they are often looking for tools to aid them in returning to work or school. For those like N, who are using computers frequently but lacking the manual dexterity to access the keyboard or mouse, adaptive equipment can be provided to allow for this access. Speech recognition software, such as Dragon NaturallySpeaking, allows speakers to dictate into a microphone and see their words appear on the screen. Others may prefer to learn one-handed typing to increase their efficiency with only one functioning hand. Adaptive mice, such as trackballs and trackpads, can be used in lieu of standard mice to allow for easier movement, scrolling, and clicking. For those like T, who need to take notes during classes or meetings but lack the processing speed to keep up with the presenter's pace, smart pens (i.e., LiveScribe) and notetaking software (i.e., Sonocent Audio Notetaker) are available. These technologies allow users to take brief notes as they take audio recordings of the presentation, and the notes are then timestamped with the audio to make subsequent review quick and easy.

CLOSING THOUGHTS

With so many devices and programs available, there is a lot to consider when selecting the right technology to support someone after a brain injury. Just as no two brain injuries are exactly alike, no two assistive technology solutions are exactly alike either. Consulting with assistive technology professionals can provide expert assessment, education, and training to identify the best use of technology for each individual's needs. With the right tools and training in hand, many individuals with brain injury can experience increased confidence in their daily living. Whether used to communicate with others, assist with memory and organizational support, facilitate return to work and school, or provide a motivating therapeutic challenge, assistive technology is a powerful tool for independence.

For more information on the assistive technology being used at Craig, visit <https://craighospital.org/services/>

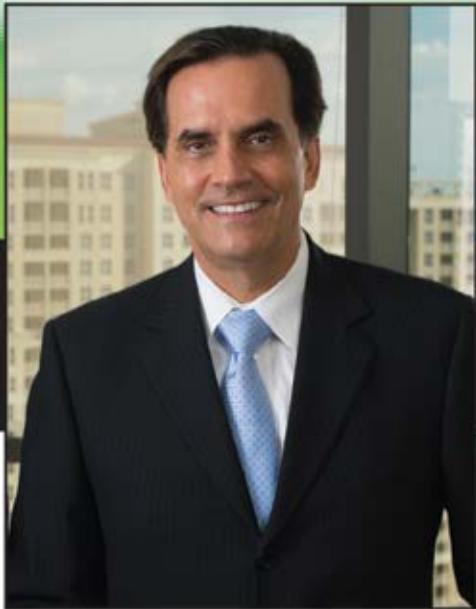


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2017 Moody Prize Awarded to **Joseph T. Giacino, Ph.D.**

Joseph T. Giacino, Ph.D., is the 2017 recipient of the Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation. Dr. Giacino is director of rehabilitation neuropsychology and research associate in the department of physical medicine and rehabilitation at Spaulding Rehabilitation Hospital in Boston, Massachusetts. He is a neuropsychologist who completed his doctorate in clinical/school psychology at Hofstra University in 1986.

Dr. Giacino is also consulting neuropsychologist in the department of psychiatry at Massachusetts General Hospital, associate professor in the department of physical medicine and rehabilitation at Harvard Medical School, and adjunct professor at the MGH Institute of Health Professions. His research has been disseminated via 85 peer-reviewed publications. He has also written 17 book chapters and was co-lead author of the Mohonk Report, a Congressionally-sponsored initiative to establish recommendations for lifelong care of patients with disorders of consciousness (DoC).

Dr. Giacino's clinical and research activities focus largely on the development and application of new assessment and treatment methods for individuals with severe acquired brain injury (ABI) and DoC. He served as co-chair of the Aspen Workgroup, which established the diagnostic criteria for the minimally conscious state (MCS), and currently chairs the DoC Guideline



Development Panel, co-sponsored by the American Academy of Neurology (AAN), American Congress of Rehabilitation Medicine (ACRM), and National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR).

In his clinical role, Dr. Giacino directs the Spaulding Rehabilitation Network DoC Program and maintains a broad array of national and international collaborations aimed at improving care for patients with severe traumatic brain injury (TBI). He has also served a term as president of ACRM and as a subject matter expert of the Department of Veterans Affairs Polytrauma Rehabilitation Centers Emerging Consciousness Program. Currently, he is the project director and principal investigator for the Spaulding-Harvard TBI Model System

(SH-TBIMS), funded by NIDILRR. Dr. Giacino is co-principal investigator on the “Transforming Research and Clinical Knowledge in TBI (TRACK-TBI)” initiative, funded by the National Institutes of Health National Institute of Neurological Disorders and Stroke (NIH-NINDS), and the Department of Defense-funded “TBI Endpoint Development (TED)” projects, both of which are validating clinical, imaging, genomic, and outcome markers to enable more precise TBI diagnosis, prognosis, and treatment.

At a recent SH-TBIMS-organized TBI stakeholder summit, Dr. Giacino demonstrated his concern for persons with brain injury and the barriers impeding their access to care. “Survivors of severe TBI and their families face enormous challenges in coping with the acute and chronic effects of this condition. Unfortunately, access to inpatient rehabilitative care and other post-acute services has progressively declined, increasing the risk of medical complications and poor outcome. Although new data on long-term outcomes show clear cause for optimism in the prospects for meaningful recovery, existing gaps between scientific evidence, clinical practice, and regulatory policies limit access to care and ultimately increase the economic burden to society,” he explained.

Before he was selected for the 2017 Robert L. Moody Prize, Dr. Giacino received local and national awards, including the ACRM Distinguished Member Award (2002). He was also awarded the 2014 Brain Injury Association of America (BIAA) William Fields Caveness Award, which recognizes the individual who, through research on both a national and international level, has made outstanding contributions to bettering the lives of persons with brain injury.

Dr. Giacino is seen as a leader in the field of rehabilitative medicine. “[His] seminal work in the field of disorders of consciousness is some of [the] most important findings we have for treating these patient populations. His tireless advocacy and uncompromising focus on improving the approaches to care has benefited countless patients and families connected to brain injury,” said Dr. Ross Zafonte, senior vice president of medical affairs, research, and education at Spaulding Rehabilitation Network and chair of the department of physical medicine and rehabilitation at Harvard Medical School.

BRAIN INJURY LEADERSHIP ACADEMY

“Leaders who are committed to improving their performance must commit to growing as individuals, becoming increasingly more competent, self-aware, and conscious.” Anderson & Adams, Mastering Leadership

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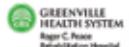
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The Moody Prize is awarded annually by the University of Texas Medical Branch (UTMB) at Galveston, the Transitional Learning Center of Galveston, and the UTMB Center for Rehabilitation Sciences to honor and recognize individuals who have made significant contributions in applied brain injury research and rehabilitation. Candidates are considered by a panel of experts and are evaluated based on (1) their contributions toward advancing clinical research related to disorders of the brain, (2) their development of improved treatment and rehabilitation procedures for persons who must contend with the disabilities associated with congenital or acquired brain disorders, and (3) their work to increase awareness of the need for the rehabilitation of individuals following brain injury. The award recognizes Dr. Giacino’s contributions in clinical research, rehabilitative medicine, patient care, and advocacy in the field of brain injury. Dr. Giacino was nominated for the award by Alan H. Weintraub, M.D., medical director, Brain Injury Program, Craig Hospital and medical director, Rocky Mountain Regional Brain Injury System.

MOBILE TECHNOLOGIES

Nag You Toward Independence

By Tony Gentry, Ph.D., OTR/L, Virginia Commonwealth University

“Since your brain injury, what do people have to nag you to get done?”

This is the first question I ask when assessing whether a mobile technology may support an individual's everyday living after a brain injury. Typical impairments in memory, planning, task-sequencing, and time management often lead caregivers and family members to become *naggers*, nudging a person along to stay on task just to get through the day. A mobile device and a well-chosen application (app) or two can do that job, so the person with a brain injury can rely on the device to do the nagging instead. Nobody likes to be a nag and nobody likes a nagger. Letting a phone or tablet do the work can be a win-win for all!

Support for Everyday Memory

Since the first PalmPilot personal organizer was launched in the 1990s, pocket-sized devices have offered reminder calendars that flash or ring to help people remember appointments and activities. Today, all smart phones come with that capability, and there are also hundreds of reminder apps available for download. Many people with memory impairments rely on alarm reminders – as many as 20 or more each day – to help them stay on task and attend appointments. Specialized medication management apps, such as My Pillbox and Medisafe, remind people to take their medications on time, show pictures of the correct pill, and offer check boxes for people who might forget that they've already taken their medications.



Support for Task-Sequencing

Many people need help performing complex activities, such as meal preparation, wayfinding in the community, interacting with others, and vocational tasks. Fortunately, there are various instructional slide show and video apps that help users create step-by-step guides for their daily tasks that previously may have required supervision. The Can Plan and

Function Planning System apps, for instance, use the phone's camera to record a brief instructional video demonstrating how to perform a task. The video can be linked to a calendar reminder inside the app, so the video pops up along with the reminder alert exactly when the user needs instruction or assistance. When building a slide show or video for a user, it's important to provide the right level of support. These apps allow one to easily produce photographic slide shows that may include audio, video, and/or

text instructions. Some users only need text-based instructions while others prefer audio cues. With these apps, instructional materials can be customized to the user's real needs.

When it's time for users to perform a given task, a tried-and-true three-step instructional method called video modeling is recommended. Users can play slide shows or videos on a mobile device all the way through before attempting to complete tasks. While performing tasks, users can play and pause the material as needed. After completing tasks, users can play the instructional material again to compare what they did to what was shown on the slides or in the video. With repetition, this stepwise Preview/Play and Pause/Review model can help build competence while also providing in-hand support for task completion.

Behavioral Supports

Life after a brain injury can be confusing, leading to anxiety, loss of sleep, and various behavioral challenges. Fortunately, there are apps that can

help. Many people rely on relaxation apps, such as Breathe2Relax, Calm, or Simply Being, to help them pause, take a few deep breaths, and get on with their day when anxiety strikes.

Doctor and therapy appointments can be frustrating for people with memory impairments. It can be hard to generate a useful answer when a health professional asks, "How have you been this past month?" Apps such as MoodTracker and My Pain Diary can help. They can be set to remind a user to tap brief responses to health-related questions in real time, several times a day. The answers are saved in graphic form on the app, so users can illustrate their day-to-day experiences in a meaningful way. This information can help providers adjust medications and therapies more effectively.

Support for Speech Difficulties

Some people with brain injury suffer from dysarthria, making communication difficult. In the past, speech-generating devices could cost thousands of dollars, but now apps such as Speakit! (\$1.99) and Voice4u

(continued on page 12)



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(continued from page 11)

(\$59) allow people to type phrases into their phones or tablets that can then be spoken out loud by the device. Two public speakers with brain injury of my acquaintance use the Speakit! app and an iPad to deliver their speeches! They enter typed content into the app, connect a portable speaker to their iPads, and simply tap to play back the spoken words. Speakit! has a selection of surprisingly natural-sounding speaking voices in both male and female registers.

Drinking from a Fire Hose

The great challenge in using mobile devices as everyday supports for brain injury is selecting and measuring the usefulness of the millions of apps on the market. How do you choose? Overloading a phone with a lot of apps can make it confusing and difficult to use, and the device becomes ineffective. I urge people to select no more than three or four apps to support their everyday activities (see my favorites listed on page 13). For most, these include a good reminder app, an app to support list-making and task-sequencing, and a relaxation

app for managing anxiety and stress. Some may require additional specialized apps for medication management or speech generation.

It may seem odd that only three or four apps can support someone with brain injury, but the important thing to remember is that each app will be used quite often. For instance, a person may record up to 10-20 daily reminders in one app and have a second app for short instructional videos that support task management and wayfinding. Because the reminder and instructional apps recommended here are timed and self-generating, the user doesn't have to navigate the screen to find them – the elements pop up when needed.

Who Programs These Things?

Occupational therapists (OTs) and speech and language pathologists (SLPs) can provide skilled assessment and focused interventions using mobile devices and apps. OTs are trained to support everyday functional activities and assistive technology adaptations; SLPs address speech and cognition

TRAUMATIC BRAIN INJURY

RESEARCH STUDY

If you or someone you care for has experienced a traumatic brain injury (TBI), please consider participating in a 16-week study of an investigational medication designed to reduce TBI-related aggression, agitation and irritability. To qualify, individuals must:

- be 18 to 70 years of age
- have developed TBI more than nine months ago from a physical-force injury
- have a history of TBI-related aggression, agitation and irritability

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VoCal	iOS only	Spoken word alerts	Free
Clock	iOS only	Easy to program	Free
Pill Reminder	iOS, Android	Picture prompt medication manager	Free
Task-Management			
CanPlan	iOS only	Slide shows/videos/alerts	\$14.99
Functional Planning System	iOS only	Slide shows/videos/alerts	\$4.99
Stress Management			
Breathe2Relax	iOS, Android	Deep breathing training	Free
Simply Being	iOS, Android	Relaxation and meditation	\$0.99
Text-to-Speech			
Speakit!	iOS, Android	Speech generation from typed text	\$1.99
Voice4u	iOS only	Speech with picture choices	\$59.99

Tony Gentry, Ph.D., OTR/L, is an associate professor in the occupational therapy department at Virginia Commonwealth University, where he directs the Assistive Technology for Cognition laboratory, which conducts research into the development and utilization of smart homes, handheld devices, body-worn sensors and telehealth applications to support individuals with cognitive-behavioral challenges. With his wife Chris, he co-owns Neurological Expert Therapies, LLC, an outpatient therapy program.

issues related to communication. Once trained to use a device, some people can program reminders and other cues themselves; others need a caregiver to set up the applications. For therapists involved in these interactions, it is important to collaborate with both the client and a caregiver while providing follow-along assistance and training as needs and solutions evolve.

Though mobile technologies cannot address all of the challenges people with brain injuries face, they can be useful tools to help people navigate difficulties in their everyday lives. Among other benefits, they help with remembering to do routine things, performing complex tasks, managing stress, and communicating effectively. Apps are valuable in that they can support individuals who have been injured while taking the burden of nagging away from weary caregivers.

Online Resources

- Assistive Technology for Cognition Facebook page: <https://www.facebook.com/at4cg>
- Neurological Expert Therapies website: <http://www.next-therapy.com>
- Dr. Gentry's Assistive Technology for Cognition Laboratory at Virginia Commonwealth University: <http://www.sahp.vcu.edu/departments/occu/research/assistive-technology-for-cognition-laboratory>

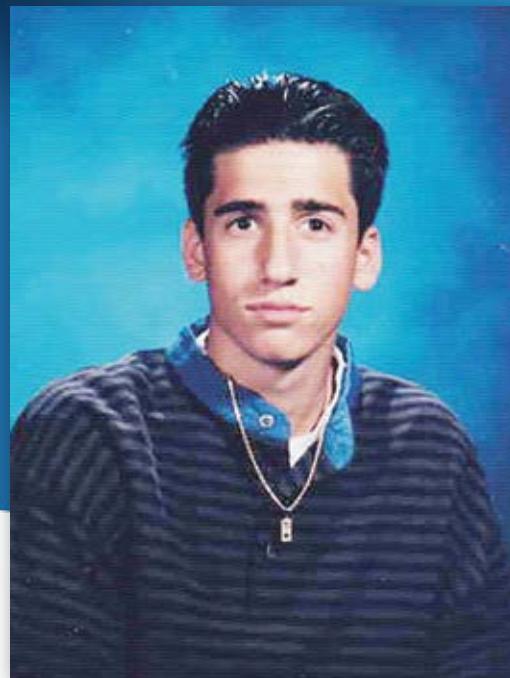
A Family's Support **KEEPS HOPE ALIVE**

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

The Feigenbaums have been loyal donors for more than 10 years. Bob and his wife, Bobbie, discovered the Brain Injury Association of America (BIAA) when their oldest child, Jared, sustained a life-threatening traumatic brain injury (TBI) after being hit by a car.

Jared's accident resulted in cognitive, speech, and physical deficits. With hard work and the help of physicians, nurses, and physical therapists, Jared regained his ability to speak, learned to walk again, and became fully interactive with his surroundings. He made remarkable progress in acute rehabilitation and continued his journey to recovery in outpatient therapy. His sisters, Audrey and Joanna, his parents, and his grandmother, Shirley, were all very involved in his rehabilitation.

Throughout Jared's recovery, the Feigenbaums familiarized themselves with BIAA's print and online materials, which they found to be extremely helpful.



They consulted resources on a wide range of topics, including the nature of brain injury, the psychological and economic impact of injury on patients and their families, and prominent research in the field. THE Challenge! was especially helpful to them because it made them feel connected to the larger community.

With the aid of a tutor and some very special teachers, Jared returned to high school and was able to catch up with the rest of his classmates. He graduated the following year and enrolled at the University of Akron in the fall of 1999. On Jan. 5, 2000, mere weeks before his 19th birthday, Jared had a major seizure and died unexpectedly in his sleep. After the months of hard work and all the progress that Jared had made, it just didn't seem fair that something like this could happen. His family almost felt as though they had lost him twice.

"The ordeal of watching Jared sustain such a devastating injury and seeing his struggle to recover placed enormous psychological stress on our whole family," Bob explains as he remembers this difficult time. Jared was the type of kid who ran out of the house to help an elderly neighbor bring in her groceries. Through everything, he always remained positive and loving, fiercely protective of his sisters and friends, and strikingly optimistic about the future. "To this day, each of us, in our own way, continues to remember and honor Jared, to be influenced by his life, and to remain affected by his passing."

As a result of their son's experience, Bob and Bobbie developed a particular interest in the prevention and treatment of early and late post-traumatic epilepsy – they wanted to find ways to better identify persons with brain injury who were most at risk. Through their financial contributions to BIAA, the Feigenbaums hope to support brain injury research and make life better for all those affected by brain injury.

The Feigenbaums know firsthand that BIAA is an important source of support for those who have lost a family member or friend to brain injury. "Grief ties us together, but in other ways isolates and separates us still. Holidays, family events, and new experiences will forever be tinged with sadness because Jared is not here to share in them. Some of our friendships were lost, but a few were strengthened. We are saddened that our sons-in-law never got to meet him. And, although we are thrilled for Jared's friends who have gone on to successful careers, marriages, and children, it hurts that he will never experience those joys, nor will we experience them with him." In their minds, the Feigenbaums' continued support of BIAA is part of Jared's legacy. ●

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Ms. Jessica Hale

In memory of Andrew Cox
Ms. Terry Cox

In memory of Becky McCleskey
Pate Rehabilitation

In memory of Bradford J. Claeyns
Ms. Patricia Fox

In memory of Cecil Edward Hearn
Ms. Laurie Bailey
Colleen Fields and Renee Bradley
Captain Milton Stanhope,
Austin Chapter of the UDC

In memory of Clara Mae Burton
Ms. Barbara Clay and Ms. Stacie Clay

In memory of Clarke Aaron Spillers
Mr. & Mrs. Edward and Sharon Benson
Ms. Marilee Murray

In memory of Denard Duheart
Mrs. D'Angelique Russ

In memory of Dennis P. Mitchell
Mr. Donald Martin
Ms. Jennifer Pybus
Mr. & Mrs. Michael and Mary Schmidt

In memory of Donald Summer
Mr. Gerry Ginsberg

In memory of Doug Strickland
Mr. & Mrs. John and Robin Howell

In memory of Edmund George Fisher
Mr. Aaron Fisher

In memory of Edna H. Strauss
David Willoughby, DDS

In memory of Evelyn Ruth Wasshem
Ms. Jane Johnston

In memory of Frederick Mortisson Heath
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Ms. Susan Kibler

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Mr. Sam Huang
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In memory of Henry J. "Hank" Figurski

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Mrs. Shirley Feigenbaum

In memory of Jams Keith
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In memory of Jared Harlan Feigenbaum
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Thank You!

Advocacy UPDATE

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

The start of the 115th Congress focused on repeal of the Patient Protect and Affordable Care Act (ACA). Brain injury advocates participated in grassroots efforts to stop the repeal. March was Brain Injury Awareness Month, and the Congressional Brain Injury Task Force hosted Awareness Day on Capitol Hill, March 22. The Brain Injury Association of America (BIAA) thanks all the advocates who urged legislators to increase access to care.

President Trump Commends Task Force for Promoting Brain Injury Awareness Month

President Trump sent a message to the Congressional Brain Injury Task Force (CBITF) Co-chair Tom Rooney (R-Fla.) commending efforts to promote awareness and recognizing the impact on veterans and civilians who have sustained a brain injury. The message was sent to coincide with the Brain Injury Awareness Day events, which included a fair, briefing, and reception. Trump stated,

"Today, we are reminded of the significance of preventing, identifying, and treating brain injuries. American scientists and researchers – whether at private research facilities, universities, VA or military research hospitals – play an integral role in better understanding these injuries, developing prevention protocols, and exploring innovative technologies that help prevent and treat them,"

On Awareness Day, advocates met with their representatives and senators and called for increased funding for the TBI Act programs and the TBI Model Systems for fiscal year 2018. CBITF Co-chairs Bill Pascrell, Jr. (D-N.J.) and Tom Rooney (R-Fla.) are circulating a Dear Colleague letter asking members of congress to support funding for the Administration for Community Living's (ACL) TBI State Grant, Protection

and Advocacy Grant, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) TBI Model Systems programs, and \$5 million in additional funding to support a national surveillance project to determine the number of individuals with TBI, which will be conducted by the Centers for Disease Control and Prevention's (CDC) National Injury Center.

Senate Convenes Work Group on Health Care Reform

The House of Representatives passed the American Health Care Act (AHCA) May 4 to repeal and replace Obamacare. The Senate Republican Leadership convened a special health care reform work group, which includes Sens. Shelley McConnell (R-W. Va.), John Cornyn (R-Texas), John Thune (R-S.D.), Orrin Hatch (R-Utah), Ted Cruz (R-Tex.), and Rob Portman (R-Ohio). Their task is to develop a proposal to replace the health care law that addresses

concerns expressed by various senators, such as continuing Medicaid expansion; cutting Medicaid and transferring its administration to the states; and ensuring individuals with pre-existing conditions continue to have coverage.

Sens. Bill Cassidy (R-La.) and Susan Collins (R-Maine), who are not members of the work group, have introduced the Patient Freedom Act of 2017 for purposes of eliminating



the “one size fits all” approach to health care. This bill would protect individuals with pre-existing conditions, allow young people to remain on a parent’s policy until age 26, and continue to prohibit lifetime or annual limits or caps. BIAA will continue to update brain injury advocates as a bill develops in the Senate.

BIAA Submits Testimony for TBI Funding

BIAA submitted written testimony to the calling for increased fiscal year 2018 appropriations for TBI Act programs, including the state grant program, and for TBI Model Systems research funded by NIDILRR.

Congress Passes FY 2017 Omnibus Appropriations Bill

On May 5, Trump signed the \$1.16 trillion omnibus appropriations bill funding the federal government through the end of this fiscal year, ending Sept. 30. The Federal TBI grant programs administered by ACL and the research and education initiatives at NIDILRR and CDC, respectively, were level-funded.

Trump Releases His “Skinny” Budget Recommendations



Trump released his budget blueprint for fiscal year 2018 with a more detailed budget to be released later. In this initial proposal, the president proposes to cut 18 percent, roughly \$15 billion, from the U.S. Department of Health and Human Services (HHS). The proposed cuts would be from various agencies, including a \$6 billion cut to the National Institutes of Health (NIH) and a \$403 million cut in health

(continued on page 20)

The advertisement features a large image of a lighthouse tower on the left and a modern building with a copper roof on the right. A cherry blossom branch is positioned above the center logo.

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(continued from page 19)

workforce training programs. The plan also proposed to restructure public health, NIH, emergency preparedness and prevention programs, as well as a new \$500 million block grant program to states through the CDC. Trump's budget also proposes:

- A 13.2 percent decrease for the Department of Housing and Urban Development (HUD). Public housing funding would be cut by 30 percent, resulting in the loss of roughly 200,000 housing choice vouchers.
- A 21 percent decrease in the Department of Labor (DOL), including unspecified cuts to job training and employment service formula grants, projected to result in the loss of more than 123,000 supported jobs.
- Elimination of the Low Income Home Energy Assistance Program and the Community Services Block Grant within the Office of Community Services.

The proposed cuts make way for an increase of \$54 billion to the Departments of Defense, Veterans Affairs and Homeland Security. The administration did not propose any cuts or changes in the Medicare and Social Security programs. The administration is expected to release a complete budget by the end of May.

Lawmaker Introduces Return to Work Bill

Rep. Joyce Beatty (D-Ohio) has introduced H.R. 1128, Return to Work Awareness Act of 2017, to assist survivors of stroke and other debilitating health conditions, including TBI, in returning to work. The legislation authorizes the Department of Labor's Job Accommodation Network to disseminate information and promote awareness among survivors of TBI, stroke and other debilitating health occurrences and their families, as well as among private employers, government agencies, employee representatives, and service providers in returning to work after a TBI, as well as to enhance self-employment and entrepreneurship options.

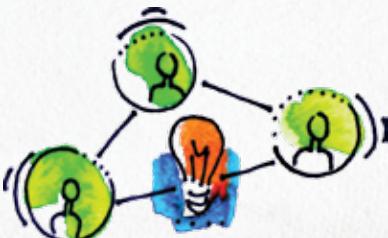


A Year at BIAA

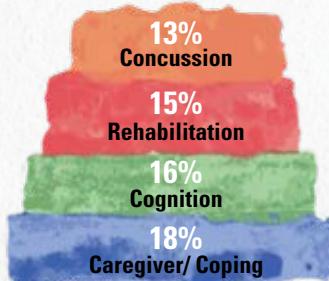
With your help last year,
BIAA accomplished great things.
This year, we can do even more.

SUPPORT

BIAA's National Brain Injury Information Center responded to **more than 30,000** calls for support and resources.



Most common call topics



EDUCATION

24 online webinars educating **more than 1,500** professionals, caregivers, and people with brain injuries.

1,800 newly Certified Brain Injury Specialists, bringing the national total to **7,000**.



ADVOCACY

BIAA is the **only** brain injury organization with **full-time** representation in Washington, D.C.



We're fighting for:

- **Life-Saving Research**
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How to make your gift:

1 mail your check in the enclosed envelope,



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3 support online at www.biausa.org/support



State Affiliate NEWS

INDIANA

The Parkview Brain Injury Support Group and the Fort Wayne community mourn the loss of Kim Klein, who lost her battle with cancer April 4, 2017. Kim and her husband, Andy, were longtime participants of the support group, along with their son, Noel, who



suffered a brain injury more than 15 years ago. From the very beginning, Kim took an active role in the group and constantly suggested ideas to make the group more effective. She helped launch an additional support group, organized multiple social opportunities each month, and even hosted people in her own home. Additionally, Kim led the charge in Fort Wayne in organizing one of the initial Bowling for Brain Injury events to support the Brain Injury Association of America (BIAA) and the Brain Injury Association of Indiana (BIAI).

Kim was a champion for persons with brain injury and their families. Through her loving guidance, she helped turn brain injury victims and caregivers into brain injury survivors and advocates. The Fort Wayne community feels a palpable void without Kim's presence, but her spirit and passion will live on in the lives of everyone she touched.

KANSAS

On March 22, 2017, a delegation from the Brain Injury Association of Kansas and Greater Kansas City (BIAKS) traveled to the state capital for a "Pie Rally." In preparation for the rally, legislators were sent an invitation glued inside an empty pie tin, which could be exchanged for a piece of pie at the Capitol Rotunda during the rally. A display of Unmasking Brain Injury, an exhibit containing masks created by brain injury survivors, was set up in the Rotunda upon their arrival. Several legislators and legislative aides enhanced their awareness of brain injury and heard about the need for services for people affected by brain injury. Approximately 100 people from around the state traveled to Topeka to speak to their legislators about policies impacting those affected by brain injury.



Unmasking Brain Injury volunteer shows her support at the Pie Rally.

LOUISIANA

The Brain Injury Association of Louisiana (BIALA) presented its 10th Annual Conference, "Ten Years of Help, Hope and Healing," March 10-11, 2017, in Kenner. The event brought 220 professionals, caregivers, and survivors together. Professionals and experts in the field of brain and spinal cord injuries gave dynamic presentations on topics such as rehab pharmacology, chronic pain, executive functioning, returning to driving, and clinical research. The attendees enjoyed visiting the booths of 22 exhibitors and nine sponsors, and everyone had a great time at the Survivor Social.

BIALA is currently in the process of developing a peer mentor program. A daylong training will take place in July for all mentors. Many hospitals around Louisiana are supportive of this new program and look forward to the assistance it will provide. Additionally, BIALA has become the state project partner for Unmasking Brain Injury. Masks are being distributed around the state to support groups, rehabilitation facilities, and independent living facilities. Once completed, these masks will be on display at various locations around Louisiana with the aim of providing education and awareness of brain injury.



An individual with brain injury and a caregiver enjoy the Survivor Social sponsored by Howard T. Katz, M.D.



Attendees listen to a presentation at BIALA's 10th Annual Conference.

MAINE

During Brain Injury Awareness Month, the Brain Injury Association of America – Maine Chapter (BIAA-ME) held the Second Annual Maine Brain Injury Resource Fair in Augusta. The event took place March 30, 2017, and was sponsored by NeuroRestorative. There were 35 exhibitors from across the state representing services, resources, and opportunities for individuals with brain injury, family members, caregivers, and professionals. Sadie Tyler, who is a survivor and holds the title of Mrs. Waldo County, was among the distinguished attendees. BIAA-ME staff and support group participants chatted with attendees and distributed copies of the new Maine Brain Injury Resource Directory. The fair was a great success with more than 140 attendees.



Attendees explore the 2017 Maine Brain Injury Resource Fair.
Photo Credit: Sarah Gaffney

BIAA-ME will hold its eighth annual conference on Defining Moments in Brain Injury Oct. 17, 2017, in Portland.

(continued on page 24)

MICHIGAN

The Brain Injury Association of Michigan (BIAMI) organized an active Brain Injury Awareness Month this past March. BIAMI President and CEO Tom Constand made multiple appearances on local access TV alongside survivors, caregivers, and medical professionals. Constand also appeared on WZZM's "My West Michigan" as well as the station's noon news broadcast. A print ad, television PSA, web banner promotions, and various radio PSAs were aired statewide to promote awareness throughout the month. Awareness efforts were further increased through BIAMI booths at both Detroit Red Wings and Grand Rapids Griffins hockey games, helping to highlight proper concussion protocol in hockey.

Partnering with Rainbow Rehabilitation Centers, BIAMI sponsored free movie screenings of "Head Games: The Global Concussion Crisis." The film, based on former college player and WWE wrestler Christopher Nowinski's book "Head Games," highlights neurological findings from studies on rugby and soccer. Following each screening, Tom Constand participated in panel discussions on concussion that featured sports neurologists and industry professionals.

At each BIAMI event, masks created for Unmasking Brain Injury were on display, helping to tell the story of brain injury survivors when words often fail. Additionally, BIAMI had their entire collection of nearly 100 masks in a special exhibit at the Michigan State Capitol in Lansing.



BIAMI President and CEO Tom Constand speaks at the Unmasking Brain Injury exhibit at the Michigan State Capitol.



Available in BIAA's Online Marketplace

<http://shop.biausa.org>

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual Survivor and Family Seminars this spring. Individuals with brain injury and their family members discussed life changes and ways to adjust. State representatives joined the Association for the "Meet Your Elected Officials" seminar to learn more about the brain injury community. The same seminar topics will be offered in St. Louis Oct. 7, 2017.

In March, BIA-MO reached more than 500,000 individuals by sharing a Brain Injury Fact of the Day through radio ads, interviews, social media, and on its website. The daily facts included information about brain injury prevention, causes, impact on life, and the Missouri AgrAbility Project.

Gather your teams and join us for Bowling for Brain Injury-Missouri, a mission-focused fundraiser being held Saturday, June 17, 2017, in St. Louis and Springfield. Sponsorships are available. Later in June, brain injury survivors can enjoy a week of fun, independence, and adventure at the Donald Danforth, Jr. Wilderness Camp June 18-23, 2017. For more information, visit www.biamo.org.

RHODE ISLAND

March was officially declared Brain Injury Awareness Month by Rhode Island's Governor Raimondo, and advocates spent the month working to raise awareness of brain injury all over the state. The Speaker of the House and President of the Senate concurrently entered into the record and read resolutions reinforcing the Brain Injury Association of Rhode Island's (BIARI) education efforts to decrease the number of brain injuries statewide. On Brain Injury Awareness Day, BIARI spent the afternoon "hitting (Smith) hill" with an army of brain injury survivors, community partners, and staff to educate legislators about the consequences of brain injury and to lobby for a bill ensuring that athletic trainers would be available at high schools during games and practices. The day culminated with state leaders introducing BIARI on the floor of the Senate and the House to a standing ovation and promising to meet with us and learn more about our work.

BIARI packed every day in March with activities to raise awareness and educate Rhode Islanders about brain injury. We hosted "Business After-Hours" for our local Chamber of Commerce and our 16th annual Statewide Brain Injury Education Conference, both



Brain injury advocates are all smiles after a standing ovation on the floor of the Rhode Island House of Representatives.

of which were very successful. BIARI was also out in force attending seminars and fairs, including the Brain Bee for children at Brown University, setting the Statehouse dome blue, and placing signage on Interstate 95. Even busier than March were April and May, when we hosted an enchanted tea party and a 5K Walk. For more information about our events, visit www.biari.org.



East Providence Area Chamber of Commerce's Laura A. McNamara learns more about brain injury prevention from Debra Sharpe, BIARI's executive director, at "Business After-Hours."



BIARI board member Nick Cioe, who acted as master of ceremonies at the BIARI Statewide Brain Injury Education Conference, lightens up at a laugh yoga session.

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VIRGINIA

More than 100 advocates attended the Brain Injury Association of Virginia's (BIAV) 14th Annual Brain Injury Awareness Day in February and successfully fought a proposed cut of \$375,000 to community-based brain injury core safety net services.



Anne McDonnell, BIAV executive director, presents the Legislator of the Year Award to Brenda Pogge (right).

In March, BIAV presented several educational events, including its first Professionals Pre-Conference Workshop that focused on advanced practice strategies for cognitive and behavioral challenges and a training session for Support Group Leaders. BIAV's 16th Annual Conference, featuring Stephanie Kolakowsky-Hayner, Ph.D., CBIST, FACRM as the keynote speaker, took place March 11 and was attended by more than 125



Advocates gather at the BIAV Brain Injury Awareness Day rally.

guests. At the event, BIAV's Karen Brown was presented the Weinstock Award for her many years of dedicated service to persons with brain injury, and Del. Brenda Pogge (R-Williamsburg) was presented with our Legislator of the Year Award for her sponsorship of several budget amendments to increase funding benefiting individuals with brain injury, their family caregivers, and the community as a whole.

VERMONT

The Brain Injury Association of Vermont (BIAVT) is participating in an advisory group for a Department of Health grant addressing ways to improve the health of people with mobility limitations and intellectual disabilities through state-based public health programs.

In April, BIAV participated in the "Spring into Summer" fundraising event, which benefited BIAVT and the Vermont Cancer Center. The theme was Movement is Medicine, highlighted by a fun fashion show of athletic wear. The Walk for Thought was held May 20 in Burlington. The 29th Annual Brain Injury Conference will be in Burlington Oct. 10, 2017.

Kirsten Wiley, brain injury survivor and organizer of the "Spring into Summer" fundraiser, joins with others to show that movement is medicine.



Brain Injury ADVISORY COUNCIL CORNER

Member Spotlight: SARAH LEFFERTS

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



When asked how the BIAA has changed her life, Sarah said:

"The group of people I have met through the BIAA is empowering and supportive. BIAA taught me that I am not alone in brain injury and that every injury is different. It blew me away when I realized how many people suffer from concussions and other brain injury. I feel like my responsibility on the other side of this injury is to help other people understand that this injury is often invisible, but you are not – and it's OK to always keep striving to heal."

It started out as an ordinary September day for Sarah Lefferts. As she was walking, she suddenly slipped on wet tile flooring and fell backward, hitting her head on the floor. When she got up, she was upset that she had spilled coffee on her dress, and she had no idea how much her life had changed in that split second.

Over the next several days, her concussion symptoms progressed. At the time of her fall, she was working full time, attending graduate school, and had the active social life of an average twenty-something. She was not OK with her new normal, and was frustrated that the healing wasn't more immediate. She wanted to get back to work and school, and she wanted to push her recovery as quickly as she could.

Sarah, like most of us, didn't understand the recovery that was ahead of her, and neither did anyone around her. She said, "I learned a lot about how it was OK to be broken, and how I needed to communicate that to the people around me so they could understand enough to support me – even when I didn't understand my injury."

Her friends and family would go along to her doctors' appointments and take notes so that she could look back later to remember what they had talked about. Early in her recovery, she used a small notebook so that she could keep her thoughts organized. She made to-do lists for everything, even basic stuff like showering and making food.

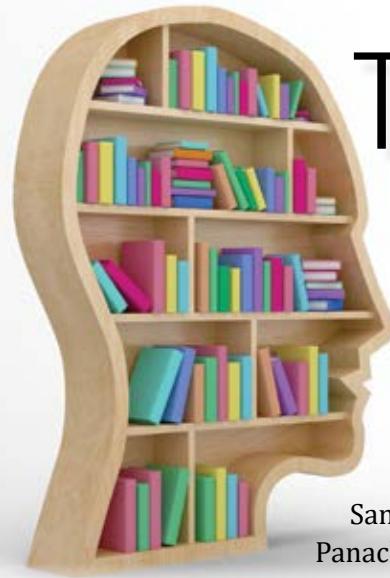
Sarah remembers going to the grocery store, and how she would freeze up as soon as she walked in. It was just too much for her. All of the options bombarded her, and she couldn't focus on what she was there to buy. She learned to make detailed lists and to save up her energy on days she had to go because she knew she would be completely exhausted afterward. So many take this simple task for granted, yet for someone dealing with a brain injury, it is an overwhelming chore to tackle.

Her job was based on an ability to communicate and work with others. After her injury, she wasn't able to maintain conversations or be in groups. She didn't even have the energy to engage with other people, and having one long conversation would wipe her out.

Sarah felt that her identity had been taken away from her and that everything people would have said to describe her was no longer true. It took her a long time to show excitement again, and she now appreciates the ability to show joyful emotions so much more than she had before.

"One of the hardest parts of the recovery wasn't the physical healing but the social support. It's a real challenge to figure out how to communicate to your network about what's wrong and what you need from them. You look fine – you can walk and talk, so it's harder for them to understand what you're going

(continued on page 30)



The BIAA BOOKSHELF

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

I was so excited as I started reading Debra Sanders' book, "A Matter of Panache: A Career in Public Education, A Traumatic Brain

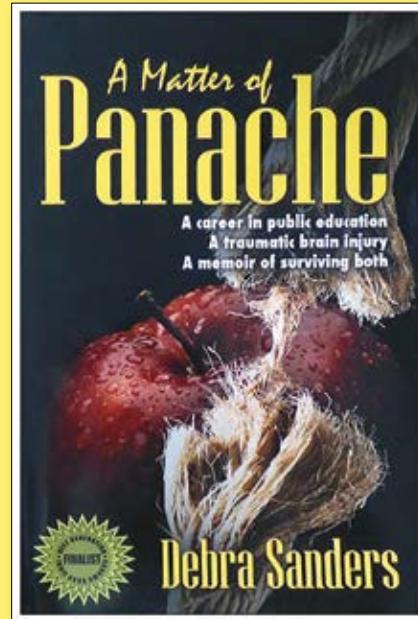
Injury, A Memoir of Surviving Both." Like many people, I have always been fascinated by Alaska – the vast landscape, the glaciers, and the native arts and cultures. I have also heard, as Sanders writes early in the book, "Alaska has a way of burrowing into a person's soul and tethering it there forever."

When Sanders was offered a nine-month paid internship at the end of her graduate studies, she never expected to spend the next 18 years in Alaska. She became a school psychologist for a district that covered 80,000 square miles! Each week, a bush pilot would fly her to a school, where she would usually sleep on the floor of a classroom or library before flying to the next school after a few days. Sanders shares some amazing stories of adventurous trips and the school children with whom she worked. She was a dedicated professional who advocated for the best educational plans for students.

When her best friend and "sister of the heart" was diagnosed with cancer, Sanders moved to Utah so she could support her friend and help her friend's family. Here, one morning, on the way to a meeting, she was involved in a motor vehicle accident, rolling her truck twice. The emergency room staff checked her out and reassured her she had no injuries, just a mild concussion.

Shortly after the accident, Sanders panicked when she tried to do some school work and realized she *could not add*. She was taken to the hospital for observation and was again reassured she just had a mild concussion.

A Matter of Panache



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So began the arduous task of trying to figure out what had broadsided her life. She suffered blinding headaches, fatigue that would sometimes demand 18 to 48 hours of sleep, and the feeling that her head was "stuffed with a mountain of cotton batting." When she returned to her job nine months later, Sanders displayed personality changes that she was unable to comprehend or recognize. She began to have conflicts with staff about student education plans and, eventually, was no longer welcome back at school.

Sanders' advocacy for the rights of children with special needs shines throughout the book. Despite the consequences of her traumatic brain injury, she never lost her ability to write. This is an interesting book with exquisite examples of what can go wrong when your brain just can't process information.

News & NOTES

A National Neuroscience Competition for High School Students

The 10th anniversary USA National Brain Bee Championship, a neuroscience competition for teenagers, was held in Baltimore, March 17-19, 2017. Winners from chapter competitions came to compete at the University of Maryland to test their knowledge of the human brain. The competition included such topics as intelligence, emotions, memory, sleep, vision, hearing, sensations, Alzheimer's disease, Parkinson's disease, schizophrenia, addictions, and brain research. The winner, Sojas Wagle from Arkansas, will represent the United States at the World Brain Bee Championship in Washington, D.C., Aug. 3-6. Dr. Norbert Myslinski founded the competition 18 years ago with the aim of inspiring students to seek careers in the basic and clinical neurosciences to help treat and find cures for brain disorders. In his words, "we build better brains to fight brain disorders."



The top three participants, from left: Amit Kannan from Indiana; winner Sojas Wagle from Arkansas; and Aarthi Vijayakumar from Minnesota.

**“ We build better brains
to fight brain disorders. ”**



Competitors from across the country join together at the USA Brain Bee Championship.

Upcoming WEBINARS

Carolyn Rocchio Caregivers Webinar – Using Technology to Help with Problem Solving After Brain Injury

June 8, 2017, 3 p.m. EST/12 p.m. PST

Michelle Wild, M.A., Coastline Community College, and Laurie Ehlhardt Powell, Ph.D., University of Oregon, Center for Brain Injury Research and Training

Business of Brain Injury Webinar – Learning Systems Management, Training, and Education

June 22, 2017, 3 p.m. ET/12 p.m. PT

Peter Wright, M.B.A., CBIST, ReMed

Carolyn Rocchio Caregivers Webinar – Management of Challenging Behaviors in the Community

July 12, 2017, 3 p.m. ET/12 p.m. PT

Kyle Haggerty, Ph.D., and Sheryl Berardinelli, Ph.D., Bancroft NeuroRehab

David Strauss Memorial Clinical Lecture – Cognitive Rehabilitation: Social and Pragmatic Communication

July 26, 2017, 3 p.m. ET/12 p.m. PT

Rebecca D. Eberle, M.A., CCC-SLP, BC-ANCDS, Indiana University

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Brain Injury ADVISORY COUNCIL CORNER

(continued from page 27)

through and what you need. Yet, it's critical that you seek support from them," explains Sarah.

Under her neurologist's care, Sarah returned to work on a partial schedule after her injury, gradually working her way back to full time within the first year. In 2014, two years after her concussion, she went back to grad school, taking one class at a time, with some academic accommodations to help with the delay in her processing speed. She went on to complete a triathlon in 2015 and graduated with a Master of Arts in May 2016.

Sarah wants others with concussion to understand that they're not alone and that people do heal from this. There are resources and supportive communities out there to help you through it. It's challenging to advocate for yourself the way you need to when part of your brain has been damaged, but you need remember to put your own physical and mental health first, even though that isn't something society teaches us.

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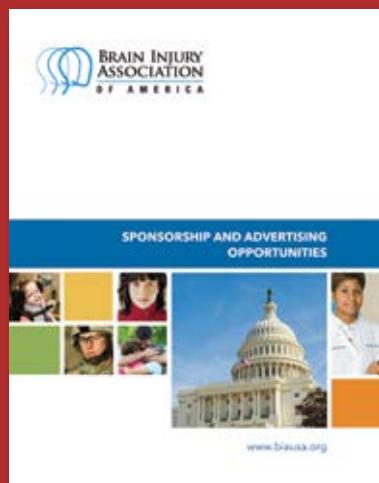
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