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THE CHALLENGE!

Regaining Independence

FALL 2016

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From my DESK

Today my desk is in sunny Florida, where the 21st Annual State Affiliate Leadership Conference is taking place. Once again, volunteer leaders and paid staff professionals from Brain Injury Associations across the country have come together to learn from experts and one another on how to best advance our shared mission to improve the quality of life for individuals who sustain brain injuries and their loved ones.

One of the best parts of the Leadership Conference is the distribution of the Awards of Excellence. These awards recognize chartered state affiliates of the Brain Injury Association of America (BIAA) that deliver exceptional programs and services in their home states. This year's award winners are the Brain Injury Associations of California, Delaware, Kansas and Greater Kansas City, Massachusetts, Michigan, New Hampshire, Rhode Island, and South Carolina. Robin Abramowitz, Executive Director of the BIA of Kansas and Greater Kansas City, received the Chief Staff Professional of the Year award for her extraordinary accomplishments with a small staff and limited resources. The Chief Volunteer Officer of the Year award was presented to Teresa Hayes for her many contributions to the Brain Injury Association of Massachusetts and her dedication to the brain injury community throughout the state.

Readers of *THE Challenge!* may not know that November is National Family Caregivers Month. This is a great time to acknowledge how important caregivers are in helping individuals who have been injured to regain the maximum level of independence possible. If there is a special caregiver in your life, now is a great time to say thank you! BIAA is making it easy by selecting the theme #BrainInjuryHero for our #GivingTuesday campaign, which takes place on November 29. Throughout the month of November, we will be celebrating our heroes on social media. Feel free to post a message about your hero on any one of BIAA's social media platforms – we're on Facebook, Twitter, and Instagram.

Last but definitely not least, by the time this issue of *THE Challenge!* makes its way into mailboxes, voters will have elected a new President of the United States. The results will delight some and disappoint others. Either way, I hope our elected leaders will work cooperatively to solve the serious problems our country faces. Since hope is not a strategy, I plan to write to our policymakers at the start of the New Year to let them know the brain injury community is ready for a little less conversation and a little more action!

In the meantime, I'll take this opportunity to thank the generous contributors who have donated their precious time and money to BIAA throughout 2016 – we couldn't do what we do with you!

You have my best wishes for a happy and safe holiday season.

Susan H Connors

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

Self-Awareness Issues

after Traumatic Brain Injury

By Kayela Robertson, M.S., and Maureen Schmitter-Edgecombe, Ph.D., Washington State University

What is self-awareness?

Self-awareness is the ability to recognize changes in one's cognitive abilities, such as memory and judgment, that are important for completing everyday tasks.

What are self-awareness issues?

Difficulties with self-awareness are quite common, especially in the initial stages of recovery from traumatic brain injury (TBI). Self-awareness issues can result in decreased motivation to work on problem areas due to lack of recognition of the difficulties and compromised safety due to poor decisions or unrealistic goals.

What causes difficulties with self-awareness?

Research has shown that everyone has problems with self-awareness to some extent; we simply are not very good at estimating our own abilities. Self-awareness can worsen following TBI because of damage to structures in the brain that give us the ability to self-monitor. For example, based on prior experiences we can typically judge whether we will perform a task well or whether we will experience difficulties that may require using an organizational strategy (e.g., writing a reminder) or seeking assistance to complete the task. Persons with TBI can lose the ability to monitor their performance of such tasks, resulting in difficulty adjusting their idea of what they can and cannot do. Although damage to the brain is thought to be the main cause of self-awareness difficulties following TBI, emotional coping and adjustment are other issues that can also impact self-awareness.

Can difficulties with self-awareness be improved?

A neuropsychologist, speech therapist, occupational therapist, or other trained professional can facilitate self-awareness training. Inpatient and outpatient therapy have been shown to be helpful in improving self-awareness. It is important to keep in mind that self-awareness training is a slow process, and that the techniques provided may not work for individuals who have significant difficulty learning new information.

Common training techniques:

- Videotaping an individual while he or she performs a task. With the help of a clinician, the individual can evaluate his or her own performance after the fact. The clinician can assist the individual in identifying difficulties that he or she is having and help develop compensatory strategies to use.
- Identifying the individual's strengths and weaknesses. A clinician can help an individual connect his or her strengths and weaknesses to the performance of everyday tasks.
- Having a clinician give direct feedback about performance while the individual does a particular task. Often the individual will be asked to estimate how he or she will perform beforehand and then will be asked to re-evaluate his or her estimation once the task is finished.
- Treatment with a clinician aimed at improving mental health and reducing any emotional problems that may limit self-awareness.

How can caregivers help facilitate self-awareness?

- Be patient and do your best to understand that your loved one's brain injury is causing difficulties with self-awareness; it's not something that the individual can quickly change.
- Remind your loved one multiple times that he or she is not able to do something that could be done prior to injury. Do your best to give direct feedback, but remember that the brain injury makes it challenging for your loved one to understand his or her difficulties and that he or she may not remember the difficulties moments later (especially if there are significant problems with memory).
- As your loved one recovers, you might be surprised at what he or she can do with a little guidance. Allow your loved one to be involved in safe activities as much as possible to build self-confidence. Encourage him or her to do things independently. When a mistake is likely or danger is possible, provide guidance to help correct behavior rather than completing the task for him or her.
- Demonstrate a task before your loved one attempts to complete the activity alone.
- Set realistic goals with your loved one and continually re-evaluate the goals as you see improvement.
- Before completing a task, have your loved one estimate his or her performance. Provide your loved one with gentle corrective feedback as he or she does the task and talk about ways to improve performance in the future.

Things to keep in mind as a family member or caregiver of someone with a TBI:

- Healing takes time and often goes beyond just the initial year of recovery. Issues with self-awareness are usually worst in the beginning stages of recovery and tend to dissipate as the brain heals. Depending on the type and severity of injury, however, difficulties with self-awareness may be a long-lasting problem for some individuals.
- Learn to adjust to a "new normal." When a family member sustains a TBI, a number of adjustments must be made within the family structure. If an individual experiences long-lasting impairments, it will take some time to fully understand these changes and how they impact the person with TBI and the family. Part of this is accepting the changes, grieving the loss of the person you once knew, and getting to know the person as he or she is now.
- Self-care is important to you and to your loved one's recovery process. This is a stressful time for everyone involved, which can result in frustration and impatience. Be sure to take time for yourself. ●

Resources for caregivers:

Brain Injury Association of America, www.biausa.org

National Institute of Neurological Disorders and Stroke, www.ninds.nih.gov/disorders/tbi/tbi.htm

Center of Excellence for Medical Multimedia – Online TBI Caregiver's Program, www.traumaticbraininjuryatoz.org/The-Caregivers-Journey/Caregivers-Program-Introduction

Family Caregiver Alliance – Coping with Behavior Problems after Head Injury, www.caregiver.org/coping-behavior-problems-after-head-injury

Family Caregiver Alliance – Self-Care for Family Caregivers, www.caregiver.org/Taking-Care-You-Self-Care-Family-Caregivers

Nothing About Us Without Us:

Involvement in Research from the Perspective of Persons with TBI and Family Members

By Irene Ziaya[1], Marvel Vena[1,2], Candace Gustafson[1,2], Carolyn Rocchio[1,2], Michelle Maust[1,2], Alan Smiley[3], Bill Smiley[3], John D. Corrigan[4], Susan D. Horn[5], and Jennifer Bogner[4]

How many times have you heard about the results of a research project and thought, “So what? How do those findings affect me?” or “Well, we already knew that… they spent that much money only to confirm what we already knew?!”

These sentiments not only reflect the frustrations of individuals living with the effects of traumatic brain injury (TBI) but are among the most discouraging comments that rehabilitation researchers can hear. Ultimately, the value of research lies in its ability to improve the lives of the people being studied – this is, or should be, the common goal of individuals (or “consumers”), principal investigators, funders, and policymakers.

For more than 50 years, there has been a growing recognition that, in order to maximize the value of research, consumers must be engaged as collaborators. Within the field of rehabilitation research, this evolution was stimulated in the 1990s when the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) began to require that study proposals include plans for Participatory Action Research (PAR). Through participation of consumers, PAR helps to ensure that the questions being addressed are relevant and that the findings will be important to those most affected. Action implies that the results of the studies will be used to spark change that will improve lives. To put it simply, PAR is a process by which consumers and investigators put their heads together to identify a problem, come up with a solution, and act to resolve the problem. More recently, other funding sources, including the Patient-Centered Outcomes Research Institute (PCORI), have chosen to support projects based in part on the extent to which patients contributed to the original idea for the research, helped design the study, and were involved with implementation of the study and its findings.

Beyond the financial incentives offered by funding agencies, investigators have begun to realize that there are many important benefits of consumer involvement. In addition to identifying research questions that are important and relevant, PAR also ensures that: (a) the research is conducted in a way that will be most applicable to real life; (b) the findings are interpreted from the viewpoint of the persons affected by those findings; and (c) the conclusions will be easy to access and usable by persons with brain injury, their family members, and the treatment providers who serve them. Consumers should be an integral part of the research team because they bring a different and extremely valuable perspective to the work.

As with all research methodologies, the value of patient/consumer engagement in research lies in how well their involvement is utilized. The role of the consumer in the research process has been slowly evolving. As experienced research advisors and collaborators, we have observed the changes throughout the years and have accumulated a set of "lessons learned" about what works and what does not work in PAR. The remainder of this article will provide tips for both consumers and investigators describing how to collaborate in the research process to produce findings that affect lives. For investigators and consumers who have been collaborating for many years, perhaps our tips will help improve the process. For investigators and consumers who are approaching PAR for the first time, we hope our tips will help get you off to a good start.

Recommendations for Principal Investigators

① **Avoid tokenism.** Early versions of PAR (which are sometimes observed today) included a single consumer who was expected to represent the viewpoints of all persons with TBI and their family members. It is widely acknowledged that every TBI is different, as is every person who

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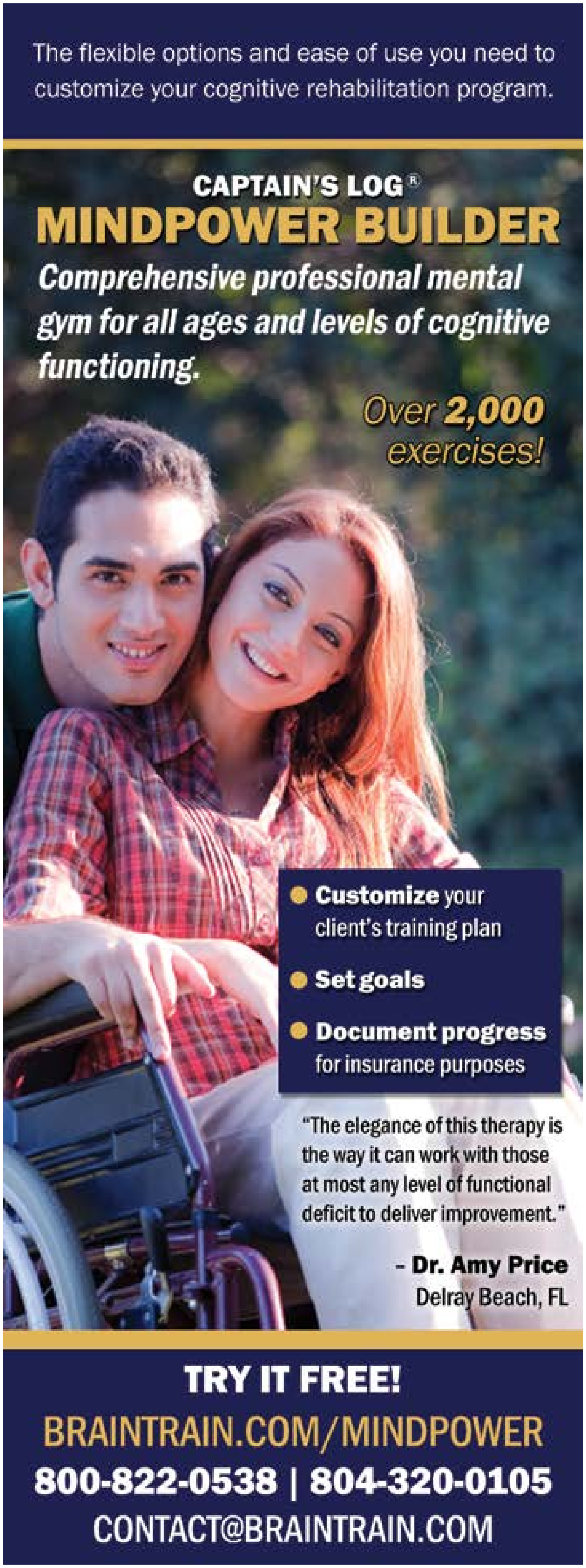

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sustains a TBI. A single stakeholder would not be able to represent the needs and perspectives of persons with TBI and their family members as well as would a group of stakeholders who have had different life experiences and could therefore offer opinions informed by their diverse perspectives.

2. **Consumers must be involved from the beginning, helping to formulate and shape the research question.** Our ideas have the potential to be ground-shifting and may completely change the course of the proposal if we are brought in early enough to affect the actual choice of a research question.

3. **Be aware that everyone has unique strengths and knowledge to bring to the research.** Just as a research team often includes experts in content, statistics, and writing, consumers on the team have a range of expertise that we can offer as well. Expertise and input differ based on life experiences, injury cause or severity, and even the time since injury. Talents will also differ. Some consumers will be particularly gifted in generating ideas, while others may be more helpful in identifying practical applications to real life. Some consumers may be the voice needed to convey the findings to other consumers and the public in general.

4. **Trust the process.** Allow free discussion and brainstorming. While this may initially appear to be a group of disjointed topics, the real issue will eventually rise to the surface. Oftentimes, the best ideas emerge when the process is allowed to unfold naturally. Be flexible in your thinking, remain open-minded, and get ready to be wowed.

5. **Request clarification when you are unsure about what a comment means.** Rephrasing a statement can often help determine what the consumer really meant and can stimulate additional discussion if others in the group were unsure of the consumer's intent as well.

6. **Translate statistics into graphics and real-world examples as often as possible.** Burying participants in numbers can lead them to become disengaged in the project, especially if they do not work with statistics regularly. Charts, graphics, and real-world examples are an easy way to be inclusive and maintain engagement.

7. **Recognize when accommodations are needed to maximize consumer involvement.** Some accommodations may be very subtle, like tolerating a change in the direction of a conversation because a consumer brought up an idea that he or she was afraid to forget if he or she did not speak up right away (see above). Another example could be watching for body language indicating that the consumer has something to say but is having trouble breaking into the conversation. Provide frequent breaks and healthy snacks to help maintain endurance and active participation. Other accommodations may be less subtle and may require input from consumers to be most effective (see Consumer tip 10).

8. **When the research needs consumers who have recently sustained a TBI, consider where potential candidates are in their adjustment to injury, and prepare to accommodate accordingly.** Some people who recently sustained a brain injury may not be able to participate as advisors because they need to focus on their recovery. It is also possible they are unable to consider the needs of the larger brain injury community or are not aware of the impact of their injury on their life or the lives of their family members. Consider including family members who can help to provide input about the challenges experienced after TBI.

9. **Standing advisory boards can be more effective than ad hoc groups for engaging participants in the research process.** Many times, ad hoc meetings, such as focus groups or other one-time opportunities for gathering input from consumers, are held to prepare a grant, but these may not be as effective as an established advisory board. Established groups have the advantage of giving advisors more time to understand the study and to build ideas. As a result of their long-term involvement with the group and with each other, consumers develop an understanding of how each study serves as another piece in the larger puzzle that will ultimately lead to better treatment and outcomes for persons with TBI. For example, since the Ohio Valley Center Advisory Council began in 1991, its members have participated in an envisioning process to guide the course of the Ohio Valley Center's research every five years since that time.

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Their ideas have evolved through the years and, as a result, so have the Center and its research agenda.

10. **Seek diversity in consumer input by including family members and consumers from a variety of genders, racial/ethnic backgrounds, economic circumstances, and lived experiences.** In addition, try to include those residing in different living situations.
11. **Individuals and family members living with the effects of brain injury are an integral part of the research team.** Show respect for our ideas by acknowledging our contributions. Use the same standards as are used with other research team members to determine how we should be acknowledged. If we contributed to the writing of a manuscript, we should be co-authors. If we advised from a greater distance, we should be named in the acknowledgements with others who provided similar contributions. If we are doing the work of a co-investigator, we should be paid for our work.

Recommendations for Consumers

1. **Speak up.** Your input is as critical as that of the other research team members. Your knowledge is unique and you can make a valuable contribution to the research in sharing it with others.
2. **Trust your instincts and opinions.** This is a corollary to Recommendation 1. Sometimes you may not be able to state why you have a specific opinion, but it likely emerged from your lived experiences.
3. **No question is stupid.** If you do not understand some of the information that is presented, ask for clarification. Many times, if you did not understand, others did not understand either. Keep asking for clarification until you understand what is going on.
4. **Help principal investigators to understand, learn, and respect perspectives of consumer advisors and collaborators.** Provide them with resources and input to help them see the perspectives of persons with TBI and family members.
5. **Recognize your assets as well as your limitations.** For example, read the provided written material as many times as you need to in order to absorb new information before a meeting. Recognize the limits of your endurance and take breaks as needed. Meetings are more enjoyable – and you will be able to provide more creative input – when you are well-rested.
6. **Bonding within the collaborative research team is essential.** Collaborators can become a better functioning team through face-to-face meetings and regular communication.
7. **Take time to listen to what others are saying;** it may help you generate new ideas.
8. **Are you ready for involvement of this type?** Most individuals with brain injury experience a "me" phase, when the focus is on regaining one's lost self. It is important to work through this stage of recovery before collaborating on research as an advisor. As consumers get to know others with brain injury and become more involved in the brain injury community through support groups, they will be able to share a more comprehensive experience.
9. **If you are a family member, you are coming from a very different place than a person with brain injury.** Be sure to share your impressions and ideas as a family member. You are needed. You see the individual with TBI in all settings and situations and have developed practical approaches to managing a variety of problems.
10. **Assist with identifying helpful accommodations to maximize your involvement.** Request materials ahead of a meeting and allow ample time to process the information. Review the minutes from previous meetings to assist with recollection of past discussions. Be aware that principal investigators may fall short of their good intentions, so you should provide feedback when accommodations are not working.

Persons with TBI need research in order to improve the care and services received and to ultimately improve lives. Sometimes it may be difficult to understand the value of research. By participating and contributing to research as advisors or

collaborators, family members and persons with TBI will improve their understanding of research and enhance its value. We hope these "lessons learned" will encourage other consumers to contribute to research endeavors and will help principal investigators use consumer input wisely. ●

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Definitions:

Consumers: Persons and family members living with the effects of brain injury

Research team member: Any member of the research team, including consumers, family members, clinicians, statisticians, research methodologists, and principal investigators

Principal Investigator: The leader of the research team

Collaborator: Participant on the research team, often a coinvestigator

National Institute on Disability, Independent Living and Rehabilitation Research: Primary funding body of disability and rehabilitation research, formerly housed in the U.S. Department of Education and now housed in the U.S. Administration for Community Living

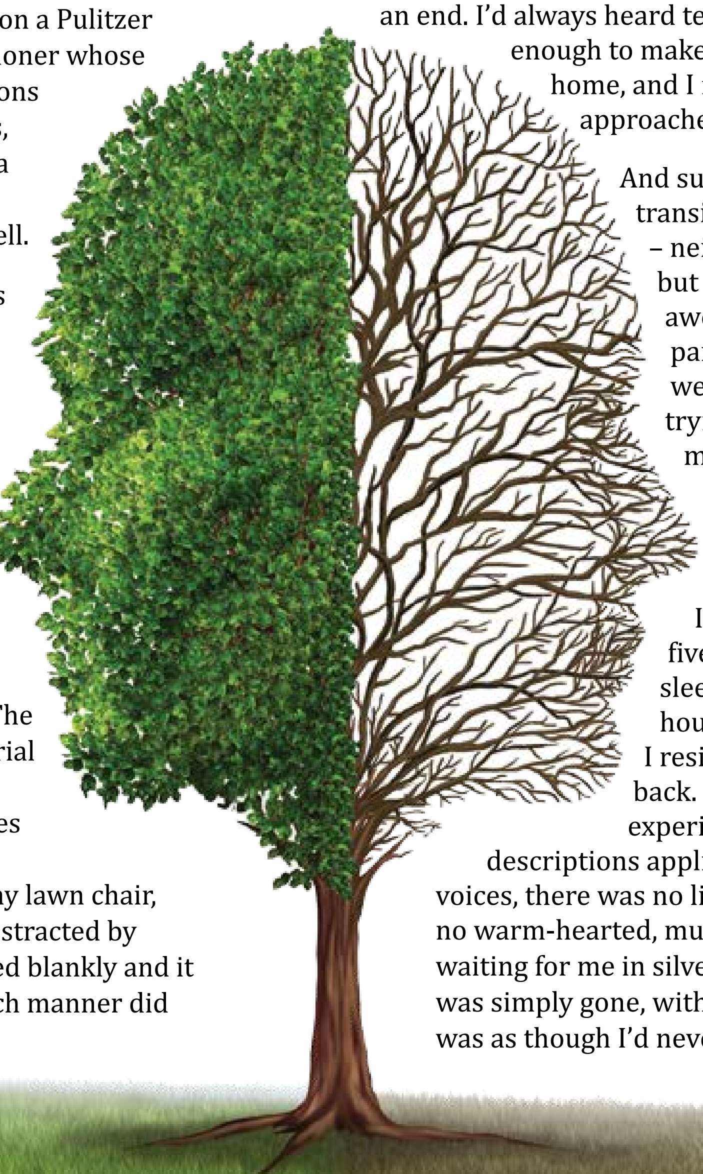
Patient-Centered Outcomes Research Institute (PCORI): Independent, nonprofit, nongovernmental organization authorized by Congress to fund comparative effectiveness research studies

Comparative effectiveness research: Research that compares the effectiveness of various health care options

Letter From the Other Side

Return from a Traumatic Brain Injury

By Tim Page, University of Southern California



When I returned to California, I brought my diaries into the backyard every afternoon and read them through sequentially, with the hope of learning more about the years before my brain injury.

I remembered much of my professional life, and whatever additional information I needed could usually be found in my constantly vandalized Wikipedia page. Here was the story of an awkward, imperious child prodigy who made his own films and became famous much too early; a music explainer (on radio and in print) who won a Pulitzer prize; a driven and obsessive loner whose fascinations led to collaborations with Glenn Gould, Philip Glass, and Thomas Pynchon, and to a large role in the revival of the American novelist Dawn Powell.

In 2000, at the age of 45, I was diagnosed with Asperger's syndrome. In retrospect, the only surprise is that it took so long.

But the diaries promised a more intimate understanding. Reading them was slow going, and I felt as though my nose was pressed up against the windowpane of my own life. The shaggy-dog accretion of material – phone numbers, long-ago concert dates, coded references to secret loves – all seemed to belong to somebody else. In my lawn chair, I flipped through the pages, distracted by everything, as the hours passed blankly and it was time to sleep again. In such manner did I spend the last part of 2015.

My last clear memory was of a muggy, quiet Sunday morning in July, three months earlier, as I waited for a train in New London. It was 11:13 and the train was due to arrive on time two minutes later. I was contented, proud of my punctuality, and expecting an easy ride to New York in the designated "quiet car," with just enough time to finish whatever book I was carrying. There would be dinner in midtown with a magical friend, followed by overnight family visits in Baltimore and Washington, and then a flight back to Los Angeles and the University of Southern California, at which point my sabbatical semester would be at an end. I'd always heard tell of trips away just long enough to make the traveler ready to come home, and I flattered myself that I'd approached this balance.

And suddenly, with no conscious transition, there was nothingness – neither blackout nor whiteout but purest Absence – until I awoke in an ambulance, my pants down, while two medics went through my pockets, trying to find something that might identify me as me, the rumpled, bloodied 60-year old man who had fallen over.

It was like being wakened five minutes into an induced sleep – "Go on, go on, let the house burn; I'll be fine" – and I resisted any effort to bring me back. If this was a "near-death experience," none of the popular descriptions applied. There were no celestial voices, there was no light and no tunnel, and no warm-hearted, much-missed grandmother waiting for me in silvered first-day perm. I was simply gone, without will or memory; it was as though I'd never been, and I'd not been uncomfortable with the dissociation.

The world reassembled in pulsing pixels. Soon I remembered my name, my birthdate, my children, and other people who should probably be told that something had happened. And then, suddenly irritable, I thought of my dinner plans. “Well, I’ve certainly enjoyed this meeting and I’d love to stay and talk,” I said to the attendants with an absurd mustered dignity, “but I have to be in New York in four hours and I really must fly.”

The medics looked at my purpled head and coal-black eye. “I don’t think you’ll make that dinner, Tim,” one said with a wry, apologetic smile. And then I tasted the blood in my mouth and remember nothing until the next morning.

My injury had begun to announce itself a week or two earlier, in the guise of a stabbing headache and piercing sensitivity to light that I foolishly pegged as my first-ever migraine, a pain that simply had to be borne till it went away. I had returned to my hometown of Storrs, Connecticut, to attend a high school reunion for all who graduated between the late 1960s and early 1970s, classes that more or less coincided with the rise and fall of the counterculture. Now the lost, high little hippies were respectably advanced in life, for good and for ill; we were retirees, we were grandparents, too many of us were dead, while others had left Storrs long ago and never looked back.

Still, more than 75 people showed up, and I had planned my summer around the occasion. After all, we were the only ones who knew the legends and vanished topographies of what had once been a tiny, cloistered town. It was a night for laughter and retrospective amazement, and more than a few of us, I’m sure – widowed, divorced or merely storm-tossed in the complicated loneliness of late middle-age – were there to identify a potential companion, somebody we had known for many years and wouldn’t have to start in with all over again, a last love with whom to share a few more trips around the sun.

But I grew increasingly pained, to the point where I could no longer make conversation. I returned to the hotel early and forced myself through the night with Valium and aspirin, before catching a ride the next morning to New London and my appointment with the station floor.

July 28, 2015 – Two days after being admitted to Hartford Hospital with an acute subdural hematoma. The only reason I was able to smile was because my son Johnny was taking the picture.

If I’d made it on to the train, I would likely have passed out in my seat, an old man dozing and not to be disturbed until New York, when I might or might not have awakened. Instead, rushed to Hartford Hospital, I was diagnosed with an acute subdural hematoma, a gathering of blood in the tissues that surround the brain. It was unclear what had brought this on – likely some recent, and already forgotten, minor trauma that ruptured ancient veins – but as it intensified and thickened, the resultant pressure was squeezing my brain as though it was citrus and had displaced the right hemisphere a full two centimeters across the midline. I was unconscious, so calls were made and my brother gave permission for an emergency operation.

Brendan Killory, the surgeon who would save my life, had just finished with a stroke patient when he learned that his night’s work was not yet done. I asked him later to write about the occasion for me, so that I might have some understanding of what had happened. “I introduced myself to you just before the anesthesiologist put you to sleep,” he responded. “You were minimally responsive, but I squeezed your hand and assured you I would take good care of you.

“I studied your brain scans to plan an optimal placement for a small craniotomy – a piece of skull that is removed and then reattached to gain access to

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the brain – to best access the hemorrhage. After you were asleep and a breathing tube had been secured in your throat, I placed your head in a horseshoe-shaped padded cradle and sketched a 6 cm curved incision on your scalp with a purple skin marker. I trimmed your hair around the planned incision and then scrubbed your head with multiple rounds of antiseptic solutions. I injected numbing medicine into your scalp and draped your head in sterile cloths so that only the thin strip of skin around the surgical sight was visible. The operating room team then paused for a "timeout" to confirm your identity and the details of the planned surgery.

"The operation commenced as I incised your scalp and used a power drill to remove a circular piece of your skull. I used a fine scalpel to open your dura, the outermost brain lining, and encountered the hemorrhage, which was predominantly in the form of a solid blood clot. It was under significant pressure and "delivered itself" out of the opening I had created with some gentle prompting using irrigation fluid and suction. I placed a small surgical drain over your brain to remove any fluid that might accumulate around the hours after surgery and reattached your skull with small titanium plates and screws. After I sutured together your scalp, I called your brother to let him know that the surgery had progressed smoothly and that I was cautiously optimistic that you would make a good recovery."

August 2015 – Sitting up at Mansfield Center for Nursing and Rehabilitation, several days after my operation.

I spent the next few days in Hartford Hospital, fuddled and becalmed, thinking mostly about the orange Popsicles from the vending machine outside my room, food of the Gods that I begged from visitors. A lifetime's modesty was quickly lost, as I was poked, prodded, and otherwise explored by earnest young people with bedpans. I received a call from somebody I love and hadn't seen in months. Shocked and protective, she wanted to fly out immediately but I dissuaded her, insisting that Hartford was, well, a bit of a drag just now, not yet realizing that I carried my own "drag" around with me. Instead, I came up with the idea that we meet four days later up in Nova Scotia, where life was invariably cool and un-crowded and I would surely be healthy again. I was exhilarated after we hung up, and I started to raise myself from my bed – at which point an alarm went off, nurses arrived and I fell back into gray confusion.

August will be remembered as The Month of Watching Television, first in Hartford Hospital and then at a rehabilitation center back in Storrs. A presidential race had begun and was already getting strange. I caught up with the early seasons of "Breaking Bad," although it was necessary to watch episodes two or three times to comprehend them. I developed a woozy crush on Mariska Hargitay, a constant presence on my roommate's soundless screen, who had somehow perfected the art of taking suspects into custody and making it erotic.

There were advertisements for a drug called Xarelto as well as from a firm offering legal counsel to those who had already taken Xarelto. Commercials for pharmaceutical products warned of possible side-effects over happy music and visions of scrubbed, smiling, dynamic people in motion: "This drug may cause scurvy, the yaws, the heartbreak of psoriasis, decapitation and crotch rot, often leading to painful death. Discontinue usage if you go blind, if your hands fall off, if your erection knocks over a desk, if your dog becomes rabid or if your 3-year-old shows signs of going through puberty…"

I was especially grateful for Facebook, which allowed me to communicate at whatever level my capacity permitted. Personal letters were out of the question and phone calls exhausted me within two or three grunts: moreover, I didn't want to relay the same story over and over again. Still, distanced, I could type a couple of sentences for general distribution.

The first post, sent out two days after my fall, along with a photograph of my smashed but smiling face, was not very edifying but it was all I could do:

"No idea what happened. Waiting for the 11:15 Sunday train to New York from New London and woke up in an ambulance."

By the time I was awake long enough to sign in again, a couple of days later, there were dozens of alarmed replies and I tried to be specific.

"As some of you will know, I suffered a traumatic brain injury on July 26. I'm sorry for my tardiness in sharing details – it seemed the better idea to wait until I had a steady evaluation and at least some prognosis about what my future might be. I'm happy to say that I'm doing very well indeed, and a complete recovery is anticipated. It's been a shocking couple of weeks, and I'm still somewhat unsteady on my feet – but emergency brain surgery will have that effect, I suppose..."

A rudimentary but easily negotiated system of communication was established: I could simply push the "Like" button to acknowledge notes I received – a way of thanking friends for their care, of reciprocating their affection without wearing myself out. Crafting paragraphs of update took more time and energy than long articles had once demanded.

"Yesterday I walked to the front door of Mansfield Rehab, joined a friend in her car, drove to Tolland for a fine pizza lunch, then returned and walked back to my bedroom," I posted August 21. "This would have been suicide as recently as Tuesday, and impossible to have conceived of last week."

Only as I grew stronger did I realize how badly damaged I'd been.

In the morning, it took me an hour or more to understand that I was actually expected to get up and then at least another hour to dress myself. I could no longer sit in crowded restaurants, follow a multi-party conversation, or stay up even a few minutes longer than body and brain willingly permitted. I reached for words that were not quite there, and some of them never arrived. The cliché about memory and Swiss cheese applied. I could give ad hoc lectures on my pet subjects and write down most of the phone numbers I had dialed more than twice, but I had forgotten the life stories of friends, the names of their children, the funerals of their parents. When it could be accessed, my brain functioned like a capacious hard drive, but my "software" was tangled beyond belief.

Out of rehab but still unable to travel, I went to stay with my friends Wendy, Dudley, and their children at Holiday Hill Recreation Center, 3 miles from the house where I grew up. "Re-creation," indeed: had I been fashioning this article as a work of inspirational

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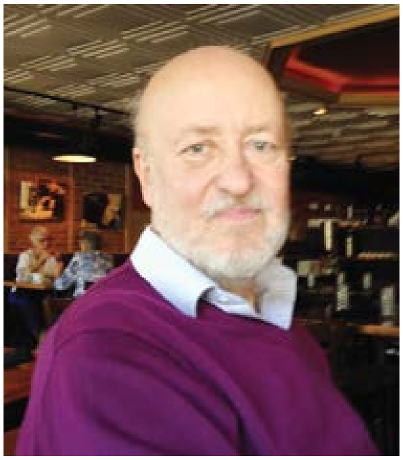
fiction, I couldn't have chosen a more appropriate place to begin again. Holiday Hill is a day camp where generations of Storrs children have spent summers since 1960. It was there that I had learned long ago to swim, to run around a soccer field, to ride a horse and shoot an arrow – and now I was back with the specific intention of getting better, permitted to sleep most of the day, and then to join the dinner table if I was up to it. There, comfortably, I could either participate in the conversation or sit in silence, within a protective aura of love and friendship.

I walked cautiously but unaided with Wendy into Dr. Killory's office at the end of September, where the three of us watched CT-scans of my brain, squiggling and gelatinous, like a horror movie octopus on black and white television. But there was no residual bleeding, and I was cleared to return to California. Dr. Killory gently deflected any expressions of gratitude. "Seeing you recover your personality, intellect, wit and sense of humor has been all the thanks I have needed," he wrote to me later. "As is often the case in neurosurgery, I have the privilege of getting to know my patient's thoughts and feelings weeks after becoming intimately acquainted with the organ of their origin."

In a moment of mad delusion and against all advice, I decided to fly home by myself. Confused and wasted by the check-in process, I forgot why I was in the airport and sat disarrayed, head buzzing and empty, for more than two hours. In the bathroom, I heard my name announced as that of somebody about to miss his plane, and I fled into the crowd while still tucking myself in. By the time I got back to my gate, the door was closed, the counter was deserted and I started banging on the fortified metal, howling wordlessly. Finally on board, it was my turn to be the clumsy, resented last-minute arrival, the overloaded man maneuvering carry-on and computer down the aisle, misjudging distances, banging knees and stepping on the shawls of tidily in-place people who had never forgotten their planes.

I was somehow convinced that the return to my house would envelop and embrace me and make me whole once more. In fact, the mix of comfortable familiarity and my own freshly acquired strangeness made me

feel more dissociated than ever. There was too much “stuff” and I could never find anything that I wanted; trips up and down stairs were plotted like military operations, while coordination of my various remote controls – television, cable, DVD, CD – seemed a sadistic, satanic test of memory. I taught myself to be fearfully conscious of every action whenever I crossed a street or caught a bus. Cockiness might be fatal now: I thought of Garry Trudeau’s Doonesbury character B.D. and wondered hypothetically whether I should travel in a football helmet. One day I got lost on the way to the grocery store, and then, already flustered, forgot to grab a basket and wandered the aisles clutching food to my chest before I made a mess with the register scanners and lights, alarms and the voice of a robot went off – “PLEASE WAIT WHERE YOU ARE! SOMEONE WILL ASSIST YOU SHORTLY!” – and I couldn’t speak for terror.



But now there are days, weeks and even months when life seems sweeter than ever, when the people I love are near, and I will throw a favorite toy to my eager little terrier until she sleeps serenely under my desk.

I thought of my mother, in the days when her Alzheimer’s was still undiagnosed, and the way she announced, without preface or explanation, that no, she didn’t want to prepare a Thanksgiving feast in 1994, although the whole family was coming to town and these dinners had been her pride for 40 years. Most grown children revert when they’re visiting home (until that home is suddenly – amazingly – gone for good) but only now do I understand the doubt and defeat she must have felt.

One of my best methods of self-defense became the simple admission that I didn’t understand. Unexpected travel routes, allusive jokes, sudden interruptions, and emotional outbursts upended me and sometimes I needed to ask questions or even protest. More often, patience and an enigmatic smile carried me through until I was back on familiar ground. I started making very few advance appointments; better to gauge the day’s energy level before committing to anything. How terribly boring it is to be sick, to be thinking always about bedtime!

According to the doctors, my body and brain (the two were always lamentably separate for me) will likely continue to heal for a couple of years. After that, I’ll just have to live in whatever is left. At this point, I am capable of pursuing two, sometimes three, projects every day, no more, and I try to get them all done in the morning, as I slide by late afternoon, and it may be hard to keep a thought in my head by evening. On bad days, I feel like the computer HAL shutting down and wonder when I’ll break into “Daisy.”

Music still astounds and renews me, although it demands more solitary concentration than ever before and I can no longer “swim” in it as I did from earliest childhood. But I’ve found a new therapy: part of each day is spent listening to complicated pieces that I know fairly well but not too well – large amounts of Bach, Beethoven’s “Diabelli” Variations and late quartets, symphonies by Mahler and Bruckner, “Die Meistersinger” – and I concentrate deeply, often with my eyes shut. Well-known, technically “simple” works bring pleasure but don’t seem to be furrowing the same neural paths that I sense from more extended challenges. Such exploration takes me back to my childhood, and the wonder I used to feel when wandering the woods around the University of Connecticut, pushing aside the branches of budding trees, finding out what paths led to what streets and, eventually, which one of those streets would lead me home.

For most of the past year, I’ve likened myself to a car that was permitted exactly so much gasoline a day. When that was used up, I stopped in my tracks. But now there are days, weeks and even months when life seems sweeter than ever, when the people I love are near, and I will throw a favorite toy to my eager little terrier until she sleeps serenely under my desk. In January, I returned to teach my first class at USC, frightened, exhilarated and grateful beyond measure. My students were kindly and interested and I could feel my powers surge as they cheered me on, an exchange of gifts. I’m content with what may come next, whatever it is – and I’ve learned that you can do quite a lot in a few hours with a couple gallons of gas. ●

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Mr. & Mrs. John Dillon and Alice Dillon

Thank You!

Golfing for Brain Injury

By Stephanie Cohen, Development Manager, Brain Injury Association of America

Married for more than 30 years and parents to three children, Gordon and Doris Conklin faced news that changed their world forever. On May 14, 2014, Christopher, their middle child and only son, sustained a traumatic brain injury (TBI) from a fall at work. He passed away later that day.

Christopher Conklin was a kind, caring, and hard-working young man who was known for his captivating smile and prepossessing personality. He enjoyed traveling, sports, and spending time with his family and friends. Christopher was only 26 years old when he died. At the time, he was looking forward to his wedding, which was less than three months away.

After Christopher's death, Gordon and Doris searched for a way to honor their son's memory. They wanted to help other families affected by TBI, so they set about finding a nonprofit organization that would provide the most help to the greatest number of people. In their search, they came across the Brain Injury Association of America (BIAA). As soon as they read BIAA's mission statement, they knew they had found an organization they wanted to support. "The fact that BIAA did research as well as helped people with brain injuries was what we were most interested in," Gordon explained. BIAA's mission, "to advance awareness, research, treatment, and education and to improve the quality of life for all people affected by brain injury," really resonated with the Conklins. They were confident that BIAA was the right organization with which to partner and support.

The Conklins acknowledged their son's love of sports by establishing an annual charitable golfing event where people could join together to celebrate Christopher's life. Three years ago, they launched the inaugural outing in Christopher's memory, with all proceeds benefiting BIAA. This year's event was held Aug. 26 at Holbrook Country Club in Holbrook,

Gordon Conklin (right) presents the proceeds from the 2016 golf outing to the BIAA.

New York. Approximately 200 golfers played in the tournament, and many more joined for the reception that evening. The community's dedicated support of the event is a testament to the impact that Christopher had on the lives of others. Over the past three years, the tournament has attracted hundreds of people and has raised over $15,000 for BIAA.

Christopher Conklin (right) celebrates his sister's wedding with the rest of the Conklin family.

Gordon and Doris want their son's life to make a difference. They don't want other families to face the same tragedy. Funds from their golf tournament have helped support projects like the "Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe TBI," a collaborative research effort between BIAA and the Brain Injury Research Center at the Icahn School of Medicine at Mount Sinai. This research project will tell us how much rehabilitation adults with moderate to severe TBI should receive, in what setting, and at what time, with the hope that treatment decisions could one day be controlled by doctors, patients, and families – rather than payers like insurance companies and public policymakers.

"[We] hope the money we raise can help some other families [...] by funding more research," the Conklins shared. Increasing the quality and volume of research in the field of brain injury is one of BIAA's top priorities, and the essential support of people like the Conklins allows BIAA to continually fight to improve care for individuals with brain injuries and their families. For more information about how you can support BIAA, visit www.biausa.org. ●

Six Tips for Surviving the Holidays with a TBI

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

With the holidays upon us, many traumatic brain injury (TBI) survivors will find themselves facing more overstimulation than normal. This stimulation can cause additional brain fatigue and stress, and in some situations, both fear and panic set in.

Overstimulation is one of the most common consequences of concussion and TBI, and it can be caused by any combination of sounds, images, light, smell, taste, and touch. Because overstimulation can't be seen, it can be a mystery to those who have never experienced it and can also cause frustration for someone who is going through it and for his or her loved ones who don't understand it.

I know about overstimulation from personal experience. I have a hard time dealing with a crowded restaurant or busy malls, especially during the holidays when there is too much noise, too many lights, and lots of scents. I have hard time focusing when there is a lot of background noise, and I am unable to carry on a conversation or make sense of what I am trying to do. I will leave the mall feeling completely exhausted, and I often develop a headache to go with my exhaustion. I usually tire out before my 78-year-old mother, who can shop circles around me.

Here is my list of six simple things you can do to make the holidays easier on yourself or a loved one who is dealing with overstimulation.

➡ **STAY HYDRATED.** The brain functions best when it is fully hydrated. When you are out shopping, it is easy to become dehydrated rather quickly. You can combat this by always having a water bottle with you and refilling it often. As tempting as it is, drinking alcohol and caffeine will cause you to become dehydrated, so it is best to avoid alcohol and caffeine when you know you are going to be faced with overstimulation.

➡ **KEEP ADDITIONAL STIMULATION TO A MINIMUM.** Decrease the amount of stimulation in places where you have control. If you know you're headed to the mall or a crowded restaurant, don't watch television before heading out or listen to the radio on the way there. If you're going with friends or loved ones, explain to them that you might not be able to have a conversation while you're there. Bring your sunglasses and earplugs along, and use them if necessary.

➡ **GET ADDITIONAL REST.** While this one seems obvious, it is sometimes hard to do with the hustle and bustle of the holiday season. Rest is critical to help your brain recover from overstimulation. Take a nap before or after your outing, and do your best to get a good night's sleep each night. Give yourself a designated bedtime, and stick with a schedule throughout the holidays.

- **TAKE SHORTER TRIPS.** If you have a lot to do, you may want to consider breaking it up into smaller trips. I find it easier to do one errand each day rather than trying to cram five things into one outing. It may take longer, but your brain will thank you.
- **WRITE LISTS.** I am the queen of sticky notes and shopping lists. Why add additional stress to the situation by going shopping without a clear list of where you need to go and what you need to buy? Even with a list, it is easy to feel overwhelmed and out of sorts. Having a plan that details exactly where you need to go and what you need to purchase at each location will help keep your stress levels down and keep you organized.
- **ASK FOR HELP.** It can be hard to do, but sometimes you need to ask for help – whether it's asking for someone to drive you somewhere, carry your bags, or even run an errand for you. It's best to know when you've reached your limit (preferably before you've reached your limit) and ask for help. If you are a friend or loved one of a person with a brain injury, offer to help before you are asked – or better yet, do something that's on your loved one's list before you see that he or she needs assistance.

If you are a caregiver, family member, or friend of a brain injury survivor, please understand that overstimulation is very real. Allow us to take the steps needed to ensure our health and sanity this holiday season and all year round.

To all my fellow TBI survivors, I wish you a wonderful holiday season filled with peace, joy, and love. Take care of yourself, and give yourself grace when needed. It is easy to push ourselves because we feel like we have so much to do; however, it is important to know when to step back… and take a nap. ●

Amy Zellmer is an award-winning author, speaker, and advocate of traumatic brain injury (TBI). She sits on the Brain Injury Association of America's Advisory Council (BIAAAC) and travels the country with her Yorkie, Pixxie, to help raise awareness about this silent and invisible injury that affects over 2.5 million Americans each year. She has released one book, "Life With a Traumatic Brain Injury: Finding the Road Back to Normal" which can be purchased from BIAA's Online Marketplace, http://shop.biausa.org.

Advocacy UPDATE

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

With the end of the current administration approaching and a new administration coming in 2017, the Brain Injury Association of America (BIAA) is working hard to protect individuals with brain injury in current and future policy. Through this past election cycle, BIAA was able to impact Federal regulations and legislation that affect our community.

Stroke Guidelines Released

On Oct. 6, BIAA served as a supporting organization as the American Heart Association and the American Stroke Association released their first ever evidence-based guidelines intended to optimize the rehabilitation and recovery of stroke survivors at a briefing on Capitol Hill. Nearly 800,000 Americans have a stroke each year and, as the brain injury community knows, the rehabilitative care and support patients receive can have a significant impact on their recovery. The briefing included information about the latest recommendations for stroke rehabilitation, barriers to the implementation of these recommendations, and policy implications for improving the quality of stroke rehabilitative care. To read the recommended evidence-based guidelines, visit www.strokeassociation.org.

Senate Passes Special Needs Trust Bill

In September, the House of Representatives passed H.R. 670, the Special Needs Trust Fairness Act of 2015, which enables individuals with disabilities to create their own special needs trust accounts to save for the future without losing government benefits. Sponsored by Rep. Glenn Thompson (R-Pa.), the legislation expands on the Achieving a Better Life Experience Act of 2014 (ABLE Act) by empowering families to roll over 529 college savings plans to ABLE accounts for disability-related expenses. The Senate passed this legislation by unanimous consent. BIAA will work to move H.R. 670/S. 349 forward during the lame duck and to the President's desk. For more information, visit the ABLE National Resource Center at www.ablenrc.org.

House Bill Weakens the ADA – BIAA Called Brain Injury Advocates to Action!

In July, the Consortium for Citizens with Disabilities (CCD), of which BIAA is a member, called on advocates to oppose H.R. 3765, which weakens the Americans with Disabilities Act (ADA). Specifically, H.R. 3765, the ADA Education and Reform Act of 2015, would eliminate the responsibility of businesses to know their obligations under the ADA and place the burden of ensuring compliance on people with disabilities themselves. The legislation imposes several additional steps on plaintiffs before they can file a civil action for an accessibility violation in a public accommodation case. It would also impose criminal fines if demand letters or other pre-suit notifications alleging violations of ADA public accommodation requirements are not sufficiently specific.

On July 7, the House Judiciary Committee passed the bill out of committee by a 15-6 vote. Two other bills were also heard by the Committee: H.R. 241, the ACCESS ADA Compliance for Customer Entry to Stores and Services Act of 2015, and H.R. 4719, COMPLI Act. Similar to H.R. 3765, these bills are designed to limit the ability of individuals with disabilities to enforce their rights to public accommodation. Advocates were called upon to contact their House Members to oppose H.R. 3765, noting that businesses have had 26 years to learn the provisions of the ADA and to be in compliance.

House Committee Holds Hearing on National Trauma System

On July 12, the House Energy and Commerce Committee's Subcommittee on Health heard testimony on strengthening the country's trauma system. This hearing follows a June 17 report produced by the National Academies of Sciences, Engineering and Medicine (NASEM) entitled "A National Trauma Care System: Integrating Military and Civilian Trauma Systems to Achieve Zero Preventable Deaths After Injury." The report noted that traumatic injury imposes an incredible burden on the U.S. health care system because it is the third leading cause of death overall and the number one cause of death for Americans under the age of 46.

During the hearing, draft legislation was presented that would authorize a tiered grant program for civilian trauma centers to engage in military-civilian partnerships. The legislation would require the Secretary of Health and Human Service (HHS) to study how trauma care is reimbursed and to study the effect of military-civilian trauma integration on military readiness and the civilian community.

Another proposal, H.R. 4365, Protecting Patient Access to Emergency Medications Act of 2016, sponsored by Rep. Richard Hudson (R-N.C.), would allow medical directors to continue overseeing care provided by paramedics and other emergency medical service (EMS) practitioners through "standing orders." Standing orders allow physicians to establish pre-set protocols for EMS practitioners to follow while delivering emergency medical care. Such protocols are especially important in the administration and delivery of controlled substances.

BIAA and the National Association of State Head Injury Administrators (NASHIA) co-signed a letter supporting a national trauma system of care, which was discussed during the hearing. The letter thanked the subcommittee for focusing on the need for an organized and coordinated trauma care system. The organizations pointed out that a full spectrum of timely and appropriate care – from the time of injury through rehabilitative care – is necessary in order to preserve life and to reduce the debilitating effects of a traumatic brain injury (TBI).

Appropriations

On Sept. 27, Congress passed a short-term spending bill, referred to as a continuing resolution, that will continue to fund the federal government at the current funding levels through Dec. 9, 2016. The continuing resolution included $1.1 billion in emergency funding for Zika. Congress will need to enact an appropriations measure to fund the government for the rest of the fiscal year when lawmakers return to Washington after the elections.

NIDILRR Announces New Research Grant Opportunity on LTSS and TBI

John Tschida, Director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), issued a statement sharing his thoughts about the potential for a new grant opportunity for NIDILRR researchers and invited comments on how NIDILRR can assist in advancing this research agenda. NIDILRR is proposing an expansion of its grant portfolio to develop evidence for community-based, long-term services and supports (LTSS) for individuals with TBI who experience life-long chronic health conditions. As part of this effort, NIDILRR will sponsor research to better understand health service delivery system models that include LTSS. Visit www.grants.gov/web/grants/view-opportunity.html?oppId=284508 to learn more information about this grant opportunity.

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Administration Awards Lifespan Respite Grants

In early September, the Administration for Community Living (ACL) awarded more than $1.1 million in Lifespan Respite Grants to eight states to support lifespan respite care programs and improve the delivery and quality of respite services available to families across the age and disability spectrum. New state grants totaling $400,000 for three-year projects were awarded to Maryland and Mississippi for planning, establishing, and expanding lifespan respite care systems that provide new and planned emergency respite services, train and recruit respite workers and volunteers, and assist caregivers with accessing needed services.

Colorado, Delaware, Massachusetts, Montana, North Carolina, and Washington were awarded one-year expansion supplements, totaling more than $750,000, to build upon their work developing an integrated and sustainable respite care system. All projects will focus on the direct provision of respite services and address unmet needs of family caregivers across the lifespan.

Since 2009, ACL has awarded competitive lifespan respite grants to 35 states and the District of Columbia. Each state collaborates with an Aging and Disability Resource Center System and a public or private nonprofit statewide respite care coalition or organization.

Centers for Disease Control and Prevention (CDC) Awards $30 Million to 23 State Injury and Violence Prevention Programs

In July, the Centers for Disease Control and Prevention (CDC) announced that $30 million has been awarded to 23 state health departments over the next five years as part of the Core State Violence and Prevention Program (Core SVIPP). The program will support states in the implementation, evaluation, and dissemination of strategies to address pressing injury and violence issues, including child abuse and neglect, traumatic brain injury, motor vehicle crash injury and death, and intimate partner/sexual violence. The Core SVIPP program helps states collaborate with other states to share lessons learned, highlight successful strategies, and bring together partners to prevent violence and injury. Awarded through a competitive application process, the Core SVIPP includes a Base component and two optional enhanced components: the *Surveillance Quality Improvement* (SQI) *and the Regional Network Coordinating Organization* (RNCO) components.

The 23 states selected to receive Base funds are: Arizona, Colorado, Georgia, Hawaii, Illinois, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Nebraska, New York, North Carolina, Oklahoma, Ohio, Oregon, Rhode Island, Tennessee, Utah, Virginia, Washington, and Wisconsin. In addition to the *Base* funding, four of the 23 States (Colorado, Kentucky, Maryland, and Massachusetts) received SQI funding to conduct injury data investigations to improve data quality, promote uniform injury case definitions, and explore emerging sources of injury data. Five of the 23 states (Colorado, Maryland, Massachusetts, North Carolina, and Washington) received RNCO funding to coordinate across and between States and to collaborate with injury and violence prevention (IVP) organizations to share scientific evidence and programmatic best practices.

CDC Report on Guideline for Managing Mild TBI

The *Board of Scientific Counselors* (BSC), an advisory board to the CDC, met in early September and accepted the mild traumatic brain injury (mTBI) workgroup report prepared for Congress. The BSC recommended that the CDC move forward with developing the mTBI guideline. More information on the public comment period for this guideline will be forthcoming as that process gets further underway. The TBI Act Reauthorization of 2014 directed the CDC, in consultation with the National Institutes of Health (NIH), to conduct a review of scientific evidence related to brain injury management in children and to submit a report to Congress in 2016. CDC's Injury Center is expecting to release the report around the annual Congressional Brain Injury Task Force Awareness Day in March. To review the report, visit CDC's website at www.cdc.gov/injury/bsc/meetings.html. ●

To follow BIAA's weekly work in Washington, D.C., sign up for BIAA's Policy Corner at www.biausa.org/biaa-advocacy.htm Policy Corner is distributed via email every Friday afternoon while Congress is in session.

Have you or someone you know been diagnosed with Traumatic Brain Injury (TBI)?

The University of California, San Francisco (UCSF) seeks individuals diagnosed with traumatic brain injury (TBI) to participate in current and future research studies for the treatment of TBI

The Participant Recruitment Registry for TBI Research at UCSF

What is a Participant Registry?

A participant registry is a listing of people interested in participating in research studies

Who is eligible for the registry?

You may enroll in the Participant Recruitment Registry for TBI Research if you:

- Are age 18 or older
- Have been diagnosed with a TBI
- Have ongoing symptoms from your TBI

How do I sign up for the registry?

Submit an online questionnaire at **TBIStemCellStudy.ucsf.edu**

What can I expect?

Once you complete the online questionnaire, you will receive an email letting you know we have your information. You may also receive a phone call if it looks like you may be eligible for a study.

Current Studies

We are currently seeking participants for a clinical trial of modified stem cell therapy for TBI called STEMTRA (STEM cell therapy for TRAumatic brain injury)

Have Questions?

Visit us at TBIStemCellStudy.ucsf.edu

Participant Recruitment Registry for TBI Research
at the University of California,
San Francisco (UCSF)

TBIStemCellStudy.ucsf.edu
Email: tbistemcellstudy@ucsf.edu
Phone: 1-800-574-0906

UCSF Weill Institute for Neurosciences

State Affiliate NEWS

GEORGIA

The Brain Injury Association of Georgia (BIAG) held its annual Camp BIAG 2016 in partnership with Camp Twin Lakes. More than 100 campers, volunteers, and caregivers attended the Olympic-themed camps. Participants were encouraged by volunteers from the Pi Kappa Phi fraternity as they began their Olympic march. BIAG board members and advisors toured the camp and socialized with the campers in conjunction with their meetings.

BIAG's director, Jane Jackson, CBIS, conducted a training session on brain injury with Stuart Hanzman, LCSW, for the staff at Annandale Village. Annandale Village is a community offering residential services that recently began admitting individuals with brain injuries. Recognizing the unique challenges associated with brain injury care, the staff embraced tools for managing behaviors, performing intervention techniques, and helping with language skills.

BIAG also hosted Chow Down for Camp, an opportunity to honor some of its key volunteers. The "Camp Champion Awards" for 2016 went to Mike McCord (McCord Rehabilitation) and Leanne Dennis (Shepherd Pathways). Mike and Leanne are both kind, caring, and generous individuals who have dedicated their careers to brain injury rehabilitation.

Jane Jackson, CBIS, speaks with Annandale Village staff.

A delighted camper, flanked by volunteers from Pi Kappa Phi fraternity, takes part in the Olympic March.

Mike McCord holds a photo of Leanne Dennis while he accepts their awards at Chow Down for Camp.

MAINE

In late August, BIAA-ME joined the Brain Injury Association of New Hampshire (BIANH) to offer a summer camp experience for adults living with brain injury. The camp was held at Pine Tree Camp in the Belgrade Lakes region of Maine. Campers participated in activities like swimming, boating, archery, arts and crafts, fishing, and even human foosball! BIAA-ME was also able to secure scholarship funds for seven of the 13 campers!

On Oct. 25, 2016, BIAA-ME held the Seventh Annual Conference on Defining Moments in Brain Injury at the University of Southern Maine in Portland. Ray Ciancaglini, a former professional boxer and award-winning concussion awareness activist, delivered the keynote address, and Jeff Sebell, a local brain injury survivor, gave the Beverley Bryant Memorial Lecture. The annual conference offers five tracks and is open to professionals, survivors, family members/caregivers, students, and anyone interested in learning more about living with brain injury in Maine.

BIAA-ME's second Bowling for Brain Injury^{SM} event will take place Dec. 4, 2016, at Spare Time Portland.

A camper, Steven Nataupsky, about to enjoy a paddle on beautiful North Pond at Pine Tree Camp.

MICHIGAN

The Brain Injury Association of Michigan (BIAMI) was fortunate to have Dr. Bennet Omalu as one of the keynote speakers at its Annual Fall Conference. Dr. Omalu is best known for his discovery of chronic traumatic encephalopathy (CTE), which he identified as a major factor in the deaths of professional athletes. During his keynote speech, Dr. Omalu discussed some of the trials in his life that lead to his discovery of CTE and called for the removal of contact elements from football for players under the age of 14.

This year's Annual Fall Conference also held significance for BIAMI as it marked the last conference before BIAMI President Mike Dabbs retires. There were 1,482 attendees and 157 exhibitors, making it the second largest in attendance and the most exhibited BIAMI conference yet. The purpose of BIAMI's Annual Fall Conference is to provide state-of-the art information about brain injury treatment and therapies. It is designed to benefit not only professionals, but people recovering from brain injuries and their caregivers as well.

Retiring BIAMI President Mike Dabbs (center) is flanked by Keynote Speaker Dr. Bennet Omalu (left) and incoming BIAMI President Tom Constand (right).

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MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted "Unmasking Brain Injury" events Sept. 13 and 20. During these events, survivors decorated masks expressing their feelings and sharing how their lives have changed since brain injury. The masks will be part of BIA-MO's educational and advocacy efforts, helping to increase understanding of brain injury among elected officials and the general public.

Unmasking Brain Injury Masks displayed at Boeing Employee Appreciations event in September.

In October, more than 150 professionals attended the BIA-MO 12th Annual Statewide Professional Conference in St. Charles. National and local experts addressed issues such as aging with brain injury, pediatric brain injuries, substance abuse, changes to health care, and vocational techniques. The Survivor and Family Seminar, held after the conference, provided practical suggestions for life with brain injury. In addition, BIA-MO volunteers were recognized at the annual awards luncheon and meeting to celebrate the courage and dedication of survivors, family members, and professionals.

Professionals who are interested in increasing or refreshing their awareness of resources for survivors of brain injury have the opportunity to do so at the quarterly BIA-MO Networking Coffees held in Springfield and St. Louis. For more information, visit www.biamo.org.

NEW HAMPSHIRE

The 33rd Annual BIANH Golf Tournament was held in August at The Oaks in Somersworth. The tournament was presented by Northeast Rehabilitation Hospital Network and hosted by BIANH and Robin Hill Farm. Over 100 golfers came to support BIANH and its service to the brain injury community. John Prochilo, CEO of Northeast Rehab, commented, "We are proud to be a part of this important fundraising event for BIANH and thank them for the valuable services they provide to brain injury survivors seeking ways to re-enter the community where they can live enriching lives after a life-changing event."

For the third year, BIANH hosted a summer camp for adults with brain injuries. Nearly 40 campers enjoyed a three-day experience at Camp Allen in Bedford. Through the generosity of an anonymous donor and her family, several caregivers and friends were able to enjoy a respite in cabins surrounded by woods, water, and mountains at Camp Wulamat on beautiful Newfound Lake in Bristol. Later this year, BIANH will host its annual Walk-By-the-Sea & Picnic as well as the 10th Annual Caregiver's Conference.

Campers enjoy the weather at Camp Allen in Bedford, N.H.

NEW YORK

Participants gather together at the BIANYS March On for Brain Injury event.

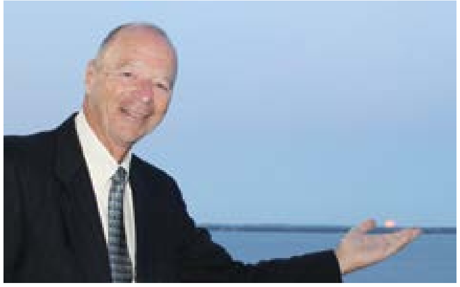
After months of planning and the work of many dedicated volunteers, people from all over the state gathered at three locations in New York to participate in "March On for Brain Injury." An annual event to raise funds and create awareness of brain injury, the Brain Injury Association of New York State's (BIANYS) first walk was held three years ago in Hudson Valley. The success of the Hudson Valley walk led to the creation of walk events in both Rochester and New York City. This year, two of the three sites honored individuals who have made significant contributions to increasing awareness of the needs of persons with brain injury and the people who support them.

"March On for Brain Injury grows each year, both in terms of who we reach with our message and the funds we raise, which allow us to continue our support, education, and advocacy work," said BIANYS Executive Director Eileen Reardon, who noted that nearly $80,000 was raised through the March On for Brain Injury walks. "It is truly an amazing site to see so many people across the state dedicated to supporting the mission of our organization."

RHODE ISLAND

One of the best kept secrets in our state is us – the Brain Injury Association of Rhode Island (BIARI)! That is why our second formal fundraiser is called the Hidden Treasure Gala. This year, we let the cat out of the bag with a high profile get-together that went off without a hitch. We increased attendance, added some new sponsors, and met our fundraising goal. Our celebrity host was the health reporter for our local NBC affiliate, and she used her talents to boost bidding on pledges to fund our mission. The Mayor of Warwick showed up and bid on a couple of silent auction items. The Senate President saluted our honorees – a state senator and her business partner. Additionally, our congressman, Jim Langevin, added to the luster of the evening and captivated guests as he punctuated the critical need for our work in his home state. Held on Sept. 16 at the Aldrich Mansion, with a million-dollar-view of Narragansett Bay, the gala dovetailed with a glorious full moon, adding extra brightness and richness to the night.

Rhode Island's Board Chairman Michael Baker introduces Jim Langevin at Warwick's sprawling Aldrich Mansion.



Stanley Bickmann of North Dartmouth, Massachusetts, has the moon in his hand at the start of the Brain Injury Association's Hidden Treasure Gala.

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SOUTH CAROLINA

Brain Injury Association of South Carolina (BIASC) mourns the loss of a great supporter and friend, Linda Veldheer, Ph.D., Director of the Head and Spinal Cord Injury Division of the SC Department of Disabilities and Special Needs, who passed away in May. Dr. Veldheer was an active member of the BIASC and provided leadership and expertise in areas such as the statewide conference, outreach, prevention, information, and referral. She was a member of the executive committee of the SC Brain Injury Leadership Council (SCBILC) and was instrumental in securing over $1 million in federal funds to improve brain injury service and training needs in the state. Two days before her passing, Dr. Veldheer was honored with a South Carolina Senate Resolution for her distinguished career and contributions to persons with TBI throughout the state.

More than 300 people attended the BIASC and SCBILC Statewide conference in July. The conference offered a memorial scholarship fund in Dr. Veldheer's name, which was given by Roger C. Peace Rehabilitation Hospital for brain injury survivors and caregivers to attend. She was truly missed at this year's conference. Her contributions to the brain injury community in South Carolina will never be forgotten.

VERMONT

The Brain Injury Association of Vermont (BIAVT) held its 28th Annual Brain Injury Conference Oct. 5 at University of Vermont Davis Center. More than 275 participants listened as keynote speaker Hannah Deane Wood delivered an inspirational speech entitled "Survive and Thrive." Governor's Awards were given to Lisa Bernardin for Survivor of the Year, Gary Wade for Professional of the Year, Chelsy Thompson for Caregiver of the Year, and Fairbanks Scales for Employer of the Year. Lorraine Wargo, emcee for the awards, noted that all attending deserved awards for surviving and thriving and helping each other to do so.

Attendees listen to the keynote speech at BIAVT's 28th Annual Brain Injury Conference.

News & NOTES

ACBIS 20th Anniversary Update

The Academy of Certified Brain Injury Specialists (ACBIS) has seen a 45 percent increase in the number of ACBIS test takers this year! Approximately 25 percent of the tests were taken during the last two weeks of August as applicants raced to earn their Certified Brain Injury Specialist (CBIS) credential before the transition to the new exam.

Earlier this year, BIAA launched the fifth edition of the Essential Brain Injury Guide – a hard cover, 25-chapter, 500-page textbook that provides a wealth of vital information about brain injury, its treatment, and rehabilitation. The Essential Brain Injury Guide serves as the newest training manual for the CBIS certification exam and is used as the primary brain injury reference by thousands of professionals and para-professionals in the field of brain injury.

BIAA staff members Jessica Lucas and Tiffany Epley display the ACBIS test schedule for August 22-28.

New Hampshire Teenager Brooke Mills Supports Concussion Awareness

New Hampshire student Brooke Mills founded National Concussion Awareness Day, which took place on Sept. 16, 2016. BIAA extends a special thank you to Brooke and her mother, Stephanie, for their tireless efforts to raise awareness about the prevalence of concussions in the United States. If you would like to make a donation to support Brooke's goal and help improve the quality of life for all people affected by brain injury, please visit http://biausa.donorpages.com/NCAD2016/BrookeMills.

Brooke Mills helps to raise awareness about concussions during a radio interview.

Celebrate your #BrainInjuryHero with BIAA

BIAA is inviting brain injury advocates across the country to join us in recognizing #GivingTuesday, a global day of giving that harnesses the collective power of individuals, communities, and organizations in order to encourage philanthropy and celebrate generosity worldwide. The event takes place Nov. 29, 2016.

To help raise awareness of brain injury from now until #GivingTuesday, BIAA is asking people to share photos of their brain injury heroes – people who are living with the effects of brain injury, family caregivers, advocates, or medical professionals – and post those pictures on Facebook, Twitter, and Instagram with the hashtag #BrainInjuryHero.

We're also partnering with QCard, founded by TBI survivor Sergio Di Giovanni, to increase awareness of this initiatiative. Qcard will be matching all donations in support of #GivingTuesday. To learn more, visit www.biausa.org/givingtuesday.

Upcoming WEBINARS

BRAIN INJURY ASSOCIATION OF AMERICA
CAROLYN ROCCHIO
CAREGIVERS WEBINAR

BRAIN INJURY ASSOCIATION OF AMERICA
ROBERT SBORDONE
CONCUSSION/mTBI WEBINAR

BRAIN INJURY ASSOCIATION OF AMERICA
BUSINESS WEBINARS

Carolyn Rocchio Caregivers Webinar – Discharge Planning: What Families Need to Know to be Advocates
Nov. 16, 2016, 3 p.m. eastern/12 p.m. pacific
Prissi Cohen, RN, BSN, ProPatientAdvocacy

Robert Sbordone Memorial mTBI/Concussion Lecture – Recovery After mTBI
Nov. 30, 2016, 3 p.m. eastern/12 p.m. pacific
Lori Terryberry Spohr, Ph.D., ABPP, Madonna Rehabilitation Hospital

Robert Sbordone Memorial mTBI/Concussion Lecture – When Patients Don't Get Better: What are we missing?
Dec. 6, 2016, 3 p.m. eastern/12 p.m. pacific
Jonathan Silver, M.D., NYU School of Medicine

Carolyn Rocchio Caregivers Webinar – Pooled Special Needs Trust Planning: What Families Need to Know
Dec. 14, 2016, 3 p.m. eastern/12 p.m. pacific
Joanne Marcus, MSW, Commonwealth Community Trust

Business of Brain Injury Webinar – The Need for a Mental Reboot: Work-Related Stress in Brain Injury Rehabilitation
Jan. 12, 2017, 3 p.m. eastern/12 p.m. pacific
Gillian Murray, DSW, LSW, CBIS, MossRehab

Business of Brain Injury Webinar – TBI and the Criminal Justice System: A Review for Forensic and Legal Professionals
April 11, 2017, 3 p.m. eastern/12 p.m. pacific
Jerrod Brown, M.A., M.S., M.S., M.S., Pathways Counseling Center, Inc.

To register, please visit shop.biausa.org/products/livewebinars

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The Lighthouse Neurological Rehabilitation Center	www.lighthouserehab.com	21
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University of California, San Francisco (UCSF)	www.tbistemcellstudy.ucsf.edu	27

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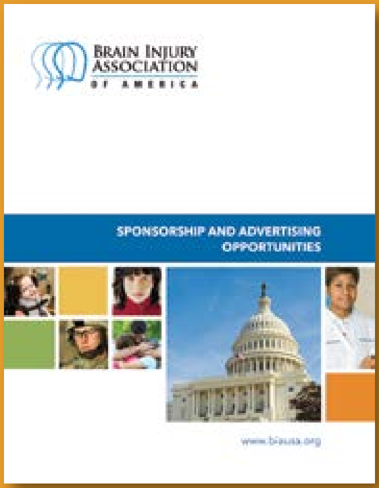

BRAIN INJURY ASSOCIATION OF AMERICA

SPONSORSHIP AND ADVERTISING OPPORTUNITIES

www.biausa.org

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 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.

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