

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 9, Issue 1

THE CHALLENGE!



Maintaining intimacy
and relationships

AFTER BRAIN INJURY

WINTER 2015

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
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From My Desk



During Brain Injury Awareness Month, I encourage you to get involved and show others that we are not alone in brain injury.

As readers of *THE Challenge!* know, March is a big month for the Brain Injury Association of America (BIAA).

BIAA leads the nation in observing Brain Injury Awareness Month by conducting an awareness campaign in March each year. The theme for the 2015 to 2017 campaign is: Not Alone.

The Not Alone campaign provides a platform for educating the public about the incidence of brain injury and the needs of people with brain injuries and their families. The campaign also lends itself to outreach within the brain injury community, empowering those who live with brain injuries to promote the many types of support that are available.

And that brings me to why March is such a big month for me personally. In March 1995, I started a new job at what was then the National Head Injury Foundation, now called the Brain Injury Association of America. Over the last 20 years, I've had the privilege of meeting and working with many individuals who not only survived their injuries but thrived.

They taught me that people living with brain injuries want the same things we all want: a good job, someone to love, a nice home, and fun in their lives. With that in mind, this issue of *THE Challenge!* focuses on the impact on relationships after brain injury. Love and intimacy are important to everyone, and in this issue you will read about couples whose lives were changed in an instant. Theirs are stories of how relationships survived, changed, and even grew stronger after brain injury.

Visit the Brain Injury Awareness Month page of BIAA's website for information on what you can do to help spread the word.

Your efforts help increase awareness across the country and improve the lives of people with brain injuries and their families. Your involvement helps to remind all of us that we are #NotAloneinBrainInjury.

A handwritten signature in black ink that reads "Susan H. Connors".

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

Like a **VIRGIN**

By Sonya Lea



In the 23rd year of your marriage, your husband goes into surgery for a rare cancer and comes out without any memory of your life. A surgeon nicks an artery and internal bleeding causes an anoxic insult: a traumatic brain injury (TBI). You won't know for months that your husband has lost his short-term and his long-term memory, that he hasn't just lost his capacity to remember new material. Not just his capacity to remember new material, but his connection to his entire identity — his childhood, his wedding day, his children's births — is lost. Both the RAM and the hard drive are shot.

In the time leading up to the surgery, you think you can prepare yourselves for what eventually happens. You cannot. It's impossible to imagine. In the months after he comes home he feels fragile, barely able to speak more than a few words. As you wait for him to return, you are rewriting the narrative of your lives. He is not a child. He is silent, dark, and handsome. If you think of him in this way, then his muscles, manliness, and might will return.

One day you stand undressed before him and his body responds. You join him as you have done thousands of times before. His eyes are never for a second removed from your eyes. He doesn't turn away from your face and you do not turn away from him. You do not close your eyes. You watch and watch and watch, which means you must really see him. You see a face completely unaware of its expression of pleasure. It is the simple stare of a man who senses all and relates to nothing. When he comes to orgasm, it surprises you both — the fast, sharp impulse, the release that he doesn't seem to recognize.

You watch him closely then, both of you silent, his face remarkably unlike the man you have known, guardedness replaced with the purity of an open gaze. You lean against the pillow, watching his expression. Across his face, none of his former expressions. He hadn't known what you were going to do, what your touch was going to be like. That orgasm came as directly and forcefully as a teenage boy's.

"Honey," you say, "I have to ask you. Whatever your answer is, it's OK."

He nods, eyes sleepy, still taking in every inflection of your demeanor.



"Do you remember sex?" you ask, your voice a whisper.

"I don't think so," he says, and then he watches your eyes for reaction.

He says this without shame, without guilt, without remembering. You look at his face for a few moments, and then you look away, toward the crimson-painted wall where there is a dark column of ants weaving in an unbroken line toward the ceiling. With your finger you smash the ants. The ants reform the line as if you were never there, destroying their lives.

His hand reaches out, enfolds your hip. It is the first time he has moved toward you since the surgery. You do not cry, though you wish you could. In your mind,

(continued on page 6)

Like a **VIRGIN**

(continued from page 5)

you add sex to the list of things forgotten. You think about the ways you have made yourself a “we” — who we are, what we like and don’t like, what we do and what we will never do — and you watch those things vanish too. After a while, you watch him sleep. The man who taught you to explore has become a virgin.

Sex was once a creative commons, a place for libre learning, freewheeling, edupunk, DIY, no rights reserved action. In the years that follow the injury, you will teach your husband everything he once taught you when you were teenagers. The brain changes have made his desire immense and you cannot ignore him. You want a complex, intimate partner again. You show him how to kiss, flirt, and the mechanics of moving the body. You demonstrate affection: compliments, rapport, embraces, calls, catcalls. The French kiss. Every action, forgotten. He must be reminded thousands of times. You have to

learn to respond with compassion rather than anger, something that will take you years to learn. So whose brain is injured?

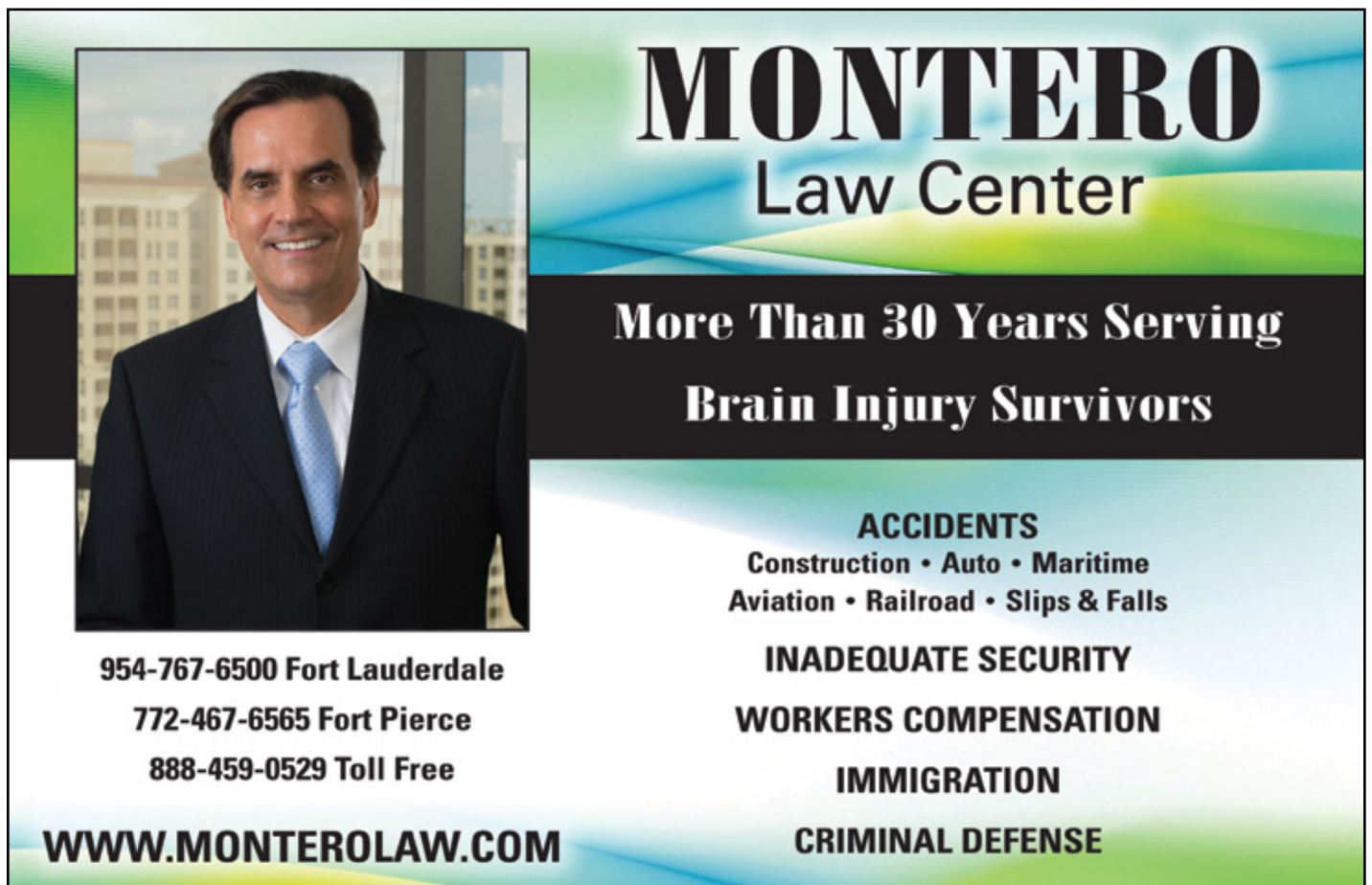
You have what many women would enjoy — a new man, a fresh man, an unencumbered man.

“What are your erotic desires?” you ask him on one of many dates you begin to enjoy again.

“That you accept me as I am,” he says. “Sex allows me to express myself nonverbally with passion in a way that I would like to be able to express verbally, but can’t.”

“Amen, my man,” you answer, because you love him not for what he offers you, or reflects onto you, or leaves with you, but for the essence of him.

Sonya Lea's memoir Wondering Who You Are (Tin House, July 2015) is about her husband losing the memory of their life. To learn more, visit www.sonyalea.net.



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The Ride of a LIFETIME

By Rob Traister, Director of Communications, Brain Injury Association of America

“I love you, have a great day!”

Those were the last words Daniel Mollino’s wife, Amber, would hear from her husband for more than three weeks. A few hours later, Daniel and Amber’s lives were changed in an instant.

On August 11, 2010, Daniel was working for a cable company in Teaneck, N.J. He was making repairs to some overhead lines when he fell approximately 20 feet from the top of a telephone pole to the street below. Paramedics who responded to the 911 call from a passing motorist found Daniel with a severe traumatic brain injury (TBI) and other serious injuries. They feared he might not survive the trip to the hospital in nearby Hackensack.

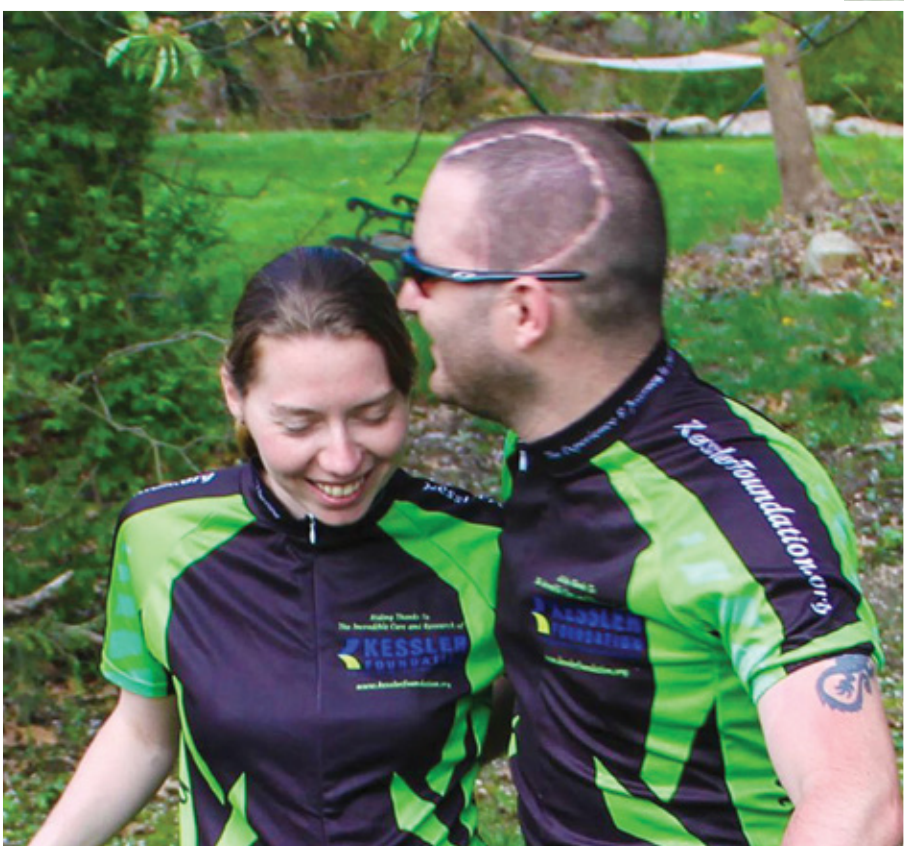
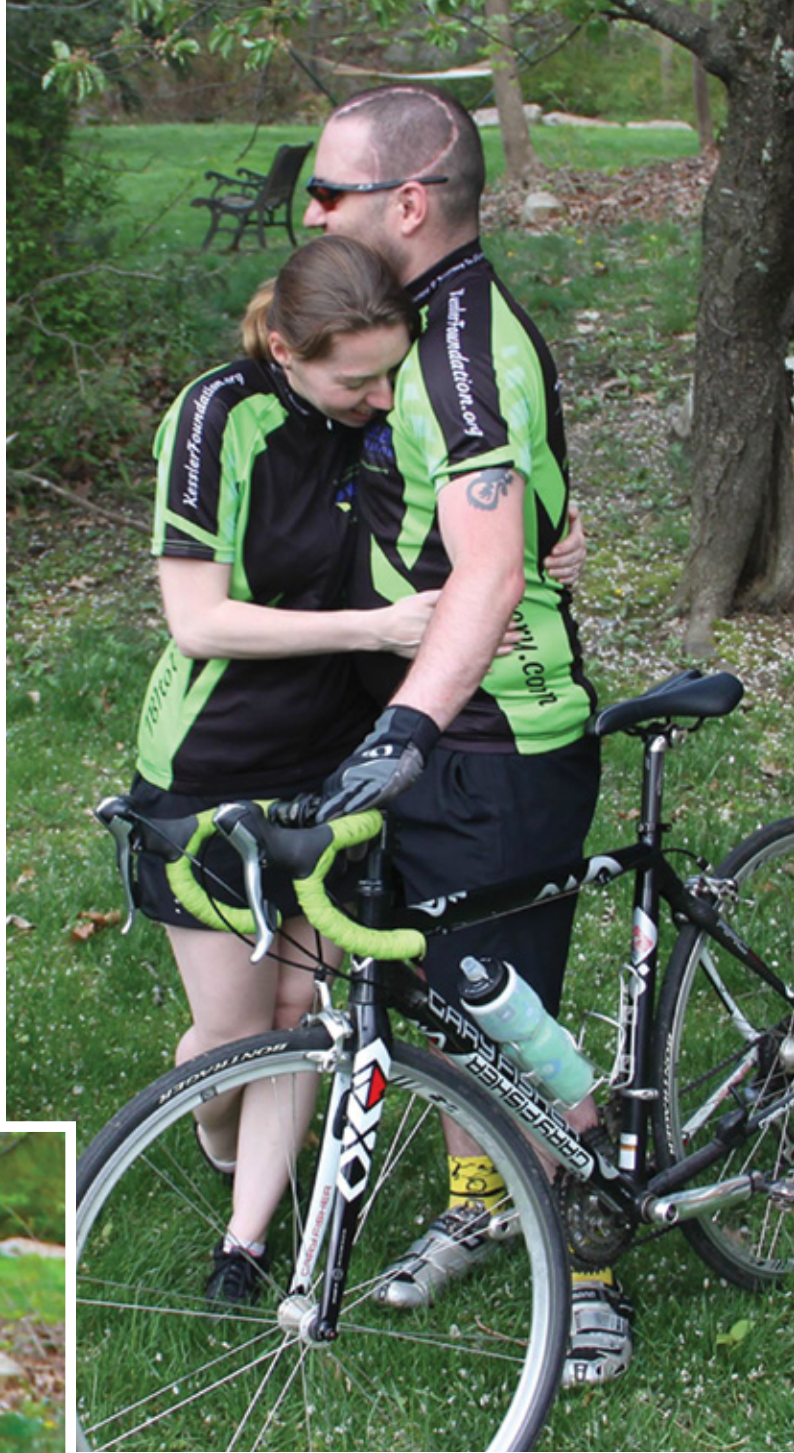
Amazingly, Daniel made it to the emergency room where doctors removed a portion of his skull to alleviate pressure and save his life. They also placed Daniel in a drug-induced coma to keep him calm and allow his brain and body to heal. Doctors warned his family that he would be probably left with severe brain damage, but the extent would not be known until they brought him out of the coma.

Approximately two weeks after the accident, Daniel was out of the coma and steadily making improvement. He knew his name and recognized his family, but he still had lapses in memory and suffered from confusion.

After two months in the hospital, Daniel transferred to Kessler Rehabilitation Center in West Orange, N.J., where the next two months of intense therapy were critical to his recovery. He relearned basic skills, such as walking and talking, and he also learned how to manage pain. Then he began more than 18 months of intensive therapy to rebuild his cognitive function.

Amber was with Daniel through every phase of his recovery. "As the wife of someone who survived a TBI, I never would have expected my life to change in the way that it did," Amber says in an essay she wrote on Daniel's website, TBItoVictory.com. "Most married couples have day-to-day marriage struggles. When you live with someone who has to deal with personal struggles everyday, you realize the small stuff doesn't matter. In the same capacity, you grow to appreciate them more as a friend, caretaker, and partner."

Part of Daniel's rehabilitation was learning his new limits. Despite the balance issues he experienced as a result of his injury, he decided to get back on his beloved bicycle. He persisted and was eventually able to overcome his balance issues and ride again, which inspired him to take up the challenge of riding his bike across the country.



"This is not just a personal goal but also a way to thank the doctors, nurses, and therapists who helped me and for the tremendous work they do on a daily basis for their patients," Daniel said. "I want to be a role model for those who have suffered brain injuries or other debilitating injuries to show that people can overcome or live with their disabilities and persevere." Daniel will start his ride across the country at the end of March, which he says is fitting since March is Brain Injury Awareness Month. ●

A Sudden Action with a Powerful Effect

By Kathy Waters

The word *stroke* has two dictionary definitions: "a sudden action with a powerful effect," and "to pass the hand over gently." It takes a combination of both meanings to adequately describe the two years since my husband's stroke Oct. 1, 2012.

Because he never felt any pain, my husband Terry was incredulous when I called 911 to report that he was having a stroke. Even in the emergency room just a mile away, it was hard to take in the fact that our lives had been permanently altered in just a few minutes.

We had been married for 17 years. Terry, a prominent family law attorney in Ventura for almost 40 years, was semi-retired and enjoying the opportunity to work on his stamp collection, visit his grandchildren, and help me a little more around the house since I am still working full time as a high school teacher.

We loved to travel, play Scrabble, dance, and exercise together. Since we had cycled our usual 10-mile route the day before Terry's stroke, it took us totally unaware.

When the initial stroke was then followed by an extensive bleed in Terry's brain, it was devastating.

Terry's left side was paralyzed; the peripheral vision in his left eye was gone; his facial muscles and ability to swallow were compromised. He could no longer read, do a crossword, put in his contacts, roll over, control his bladder or bowels, or sit upright without falling over. What he could do, however, was learn the names of each of the people who cared for him and thank them every day; bask in the love of his longtime friends who arranged to play their monthly poker game in the hospital rec room; maintain his sense of humor and positive outlook on life; and remind me every day how much he loved me.

As is true for most stroke victims, this was not an event that happened only to an individual: it happened to a couple; a family; a group of peers;

a set of colleagues; a community of beloved friends and acquaintances; and a variety of caregivers, therapists, doctors, nurses, and medical personnel. Each of these "passed a hand over gently" to encourage, support, instruct, train, heal, and guide Terry toward recovery.

My husband is the bravest and most patient man I know. He has persevered with humor, hard work, and appreciation for every single person who has helped him. Two months after his stroke, we came home to a hospital bed, a leg brace, a wheelchair, a portable commode, visiting therapists, and a caregiver. Now, a little more than two years later, Terry is able to dress himself, help make dinner, plan an evening out, walk 4 miles with a cane, travel on an airplane, board a sailboat, and put his arms around me and give me a hug.

Of course, this journey has been — and continues to be — difficult. Each of us was in mourning, both for the life we enjoyed so much and the people we had each been before the stroke. This was a large part of the "powerful effect" on our lives: trying to adjust to what is while still yearning for what was. It is a battle that continues even today. Although painful, the process of adjusting to Terry's new pace and limitations as well as his struggle to regain executive functioning; of assuming new roles, duties and



I believe that it takes a team to work toward recovery, as well as patience, sacrifice, and a willingness to adapt, both to circumstances and to each other, but it is worth it.

expectations; of coping with elderly parents and other family members; of sustaining old friendships and creating new ones has also provided the opportunity to uncover and value strengths that might not have been obvious to us or appreciated before now.

Terry says he sees me as his "biggest support and his lifelong love," and believes that I am "beautiful, both inside and out, and that I have driven us toward a life together that is far beyond what anyone expected." Because of this, we try to seek out opportunities to encourage others who have been so affected and want them to know that there is always hope and always the chance for things to get better. I believe that it takes a team to work toward recovery, as well as patience, sacrifice, and a willingness to adapt, both to

circumstances and to each other, but it is worth it. Terry is my best friend and a daily inspiration for me. We are lucky; we have each other. ●



We are not Islands in the Stream: **INTIMACY AFTER TBI**

By Elisabeth Sherwin, Ph.D., Professor of Psychology, University of Arkansas at Little Rock

Whether you recognize the title as part of a poem by John Donne or from a song, the statement is equally true. People are not islands; we need intimate relationships to sustain us. However, the way each of us defines intimacy in a relationship is subjective because there are many types of intimacy that may be expressed in different ways and appear within the context of different types of relationships.

In “Broken hearts and mending bodies: the impact of trauma on intimacy,” Mills and Turnbull (2004) suggested that one way to think about intimacy is as a combination of *intrapyschic* and *interpersonal* elements. Intrapyschic intimacy includes self-knowledge, awareness of strengths and limitations, self-acceptance, and an “ability to experience a wide range of feelings deeply and spontaneously and foster willingness to share these thoughts and feelings with others.” This description sounds similar to what Erik Erikson (1963) says is a very important issue for adolescents. He claims that part of being a teenager is figuring who you are, what you are, what you need, and what you can give. Most specifically, Erikson says that a person must know himself or herself before they can build healthy, close, intimate relationships with others. If a person’s intrapyschic intimacy is not mature, then relationships can be very clingy, needy, and dependent. The person uses their relationship to define who and what he or she is. They have little identity outside of the relationship.

TBI does not kill intimacy, but it is a major challenge for relationships. If the couple wants to keep intimacy alive both may need to fight for their relationship – and the odds for succeeding are in favor of the relationship!

On the other hand, interpersonal intimacy sounds a lot more like what we traditionally consider as related to intimacy:

- Psychological (respect, trust, loyalty);
- Emotional (sharing of emotional needs);
- Physical (sexual and non-sexual); and
- Operational (sharing of responsibilities, making decisions, role expectations).

When we think about these two elements and how central they are to who and what we are, it is not surprising that a traumatic brain injury (TBI) strikes at the very heart of intimacy. Regardless of the severity of the injury, the likelihood of the injury influencing intrapyschic and interpersonal intimacy, even if only temporarily, is significant.

A TBI may influence the intimacy of the relationship in multiple ways:

- Physical disability;
- Communication problems (the person cannot speak and or will not share);
- Changes in roles: from breadwinner or mom to dependent;
- Alternating from caregiver to lover and back;
- Financial strain; and
- Physical and psychological exhaustion.

The way these factors influence a relationship is not as straightforward as you might suspect. In their paper “Predictors of marital stability two years following traumatic brain injury,” Arango-Lasprilla, Ketchum, Defuzlian et al., (2008) interviewed married couples

in which one person had sustained a TBI. They found that 85 percent of those who were married at the time of injury were still married two years later. However, younger couples in which the husband was the one who sustained an injury under violent circumstances were less likely to make it. Women are seen as the caregiver and caretaker in relationships. So it is very surprising that the research found that women (especially younger women) were not likely to stay in the marriage.

An article called “Marital adjustment and stability following traumatic brain injury: A pilot qualitative analysis of spouse perspectives” by Hammond, Davis, Whiteside et al., (2011) identified a gender-based difference that seems to explain why this is so. Women were more likely to mourn the changes in their spouse and to hope he would eventually recover and be

who he was before the injury. Women also found the burden of care more debilitating. In contrast, men tended to accept the situation, focus on the here and now, and see their role as a caregiver as the natural outcome of the commitment they made to their wives.

Gill, Sander, Robins et al., (2011) wanted to find out to what couples (where one of the partners had a TBI) attributed the survival of their relationships. In their article “Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners” they published the results of their

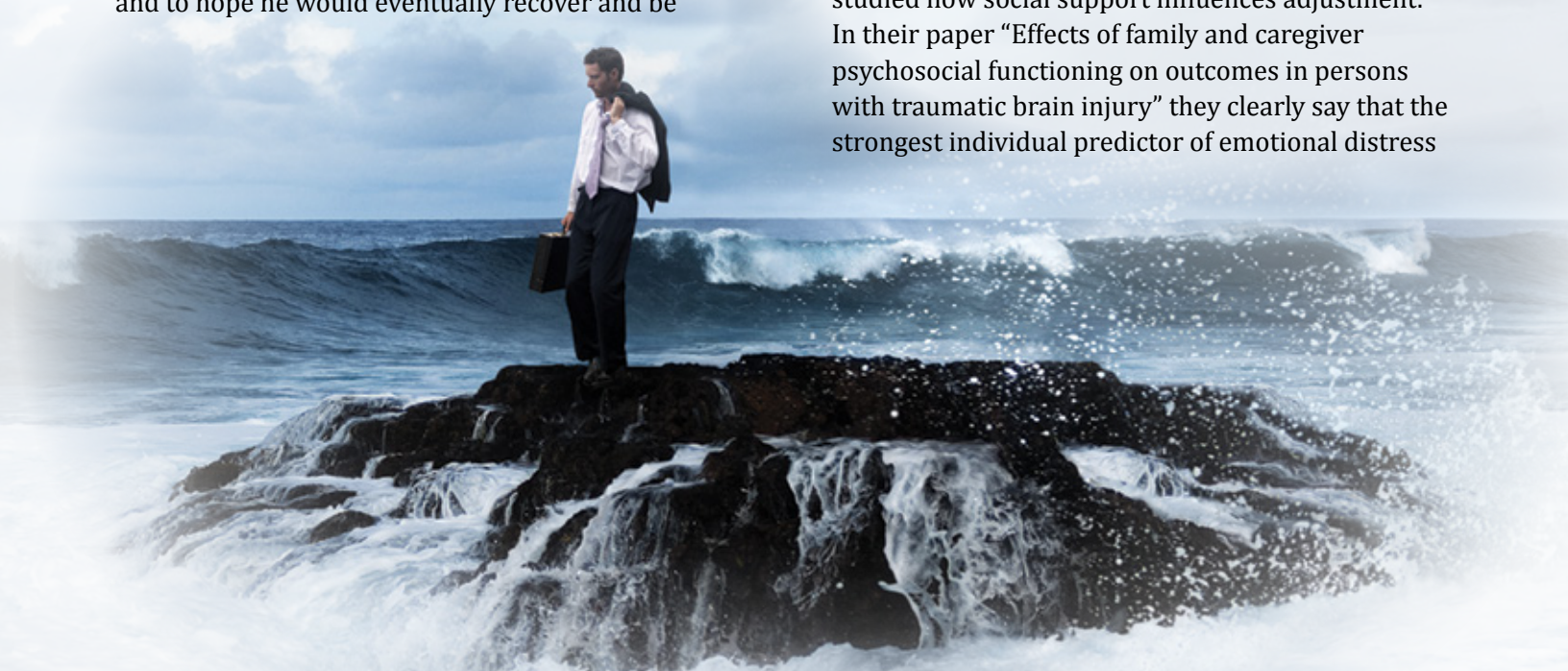
interviews with both partners. The couples identified the following as factors that helped them cope and survive:

- A strong pre-injury commitment;
- Previous experience in overcoming hardship;
- Bonding through surviving the challenges of the injury;
- Family bonds;
- Unconditional commitment;
- Open communication;
- Spirituality; and
- Social support.

The role of social support cannot be stressed enough. Social support, for both partners, appears over and over as critical to coping, adjustment, and survival of both partners. Vangel, Rapport, and Hanks (2011) studied how social support influences adjustment. In their paper “Effects of family and caregiver psychosocial functioning on outcomes in persons with traumatic brain injury” they clearly say that the strongest individual predictor of emotional distress

for persons with TBI was the life satisfaction of the caregiver. It is interesting that in order for the person coping with a brain injury to feel well, it is critical that their caregiver feel well too. What is even more fascinating is that how much social support is actually available is not very important. What is important is how much support the caregiver feels that he or she has! This suggests that a big part of social support is to meet the needs of the individual caregiver. The actual availability or presence of support is not important if the caregiver feels there is not enough.

(continued on page 30)



What Does Research Tell Us About Intimacy and Sexuality After Brain Injury?



By Susan L. Vaughn,
S.L. Vaughn & Associates, L.L.C.
and Public Policy Consultant,
Brain Injury Association of America

Over the past 20 years numerous articles have been published on the impact of traumatic brain injury (TBI) on sexuality and intimacy as well as the effects on marriage, partners, and important relationships. These articles generally feature studies and research with regard to contributing factors, such as depression, fatigue, cognitive and emotional changes, and adjustment, and interventions to address these problems. Some of the articles also addressed the role of professionals in assessing and treating intimacy issues and use of appropriate assessment tools. This article provides a thumbnail sketch of recent studies conducted by TBI

Model Systems, a group of 17 research centers that are funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

A collaborative effort among TBI Model Systems at TIRR Memorial Hermann, the Mayo Clinic, Craig Hospital, Carolinas Rehabilitation Institute, Wayne State University/Rehabilitation Institute of Michigan, and the Rehabilitation Institute of Chicago, resulted in a project to determine the frequency, type, and severity of changes in sexual functioning associated with TBI. The studies associated with the project were published in scientific papers and contributed

to the development of a fact sheet on TBI and sexual function, which can be downloaded from the Model Systems Knowledge Translation Center (MSKTC) website at <http://www.msktc.org/tbi/factsheets/Sexuality-After-Traumatic-Brain-Injury>.

In the September/October 2014 issue of the *Journal of Head Trauma Rehabilitation*, researchers at the JFK Johnson Rehabilitation Institute and the Department of Rehabilitation Medicine at the Icahn School of Medicine at Mount Sinai reported that fatigue plays a different role in the subjective experience of sexual activity for men and women with TBI than for those without brain injuries. Furthermore, fatigue and sex should be taken into account in future research and interventions focused on sexual function after TBI.

A current research project at the Virginia Commonwealth University (VCU) TBI Model System is focused on survivors and couples, although not specifically on sexuality and intimacy. The project study is examining a structured, curriculum-based approach to improve survivors' resilience and adjustment to everyday life. Meanwhile, a second study is examining the benefits of an intervention for couples.

In a 2011 article written by researchers at the VCU Model System, the authors concluded that there was insufficient research evaluating marriage after brain injury due to methodology and study design limitations. The purpose of the study was to determine the predictors of continuous marital stability over two years post-injury and examine the moderating effects of ethnicity. Prior to 2011, researchers at Carolinas Rehabilitation, Carolinas Healthcare System, VCU, and Craig Hospital Model Systems sought to identify themes of marital adjustment and stability and how a spouse who has experienced TBI affects the marital relationship. The study was one of the first to look at this issue.

The Department of Veterans Affairs is not currently conducting any studies with regard to sexuality and intimacy among veterans, service members, and families. Similar to the civilian sector, articles have been published noting an array of problems, including issues with trust and intimacy.



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(continued from page 17)

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Advocacy UPDATE

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

Welcome to the 114th Congress! The first session convened on Jan. 6, 2015, with Republicans in control of both chambers. Rep. John Boehner (R-Ohio) kept his position as Speaker and Sen. Mitch McConnell (R-Ky.) became Senate Majority Leader. On Jan. 20, 2015, President Barack Obama delivered his State of the Union Address, outlining a series of proposals to strengthen middle-class families. While policymakers could strike a deal on tax reform, they remain far apart on other major issues. Amid the continuing partisan divide in Washington, the Brain Injury Association of America will pursue an ambitious policy agenda. Our goals are to:

- Strengthen federal and state TBI Programs;
- Increase access to medically-necessary care, including rehabilitation;
- Keep individuals with brain injury financially solvent and family caregivers strong;
- Advance and accelerate brain injury research; and
- Expand the Congressional Brain Injury Task Force.

Grassroots advocacy will be critical to achieving these goals. Please visit the Advocacy and Government Affairs section of BIAA's website to download our 2015 legislative issue briefs. You can sign up for our free *Policy Corner* e-newsletter, and plan now to attend Awareness Day on Capitol Hill on March 18. For more information see our ad on page 21.

Strengthen TBI Programs

Following last year's victory to secure the TBI Reauthorization Act, BIAA and its partners, the National Association of State Head Injury Administrators (NASHIA) and the National Disability Rights Network (NDRN), are eager to see the Federal TBI State Grant Program and the



Protection and Advocacy Grant Program moved to the Administration for Community Living (ACL).

BIAA, NASHIA, and NDRN sent a joint letter to U.S. Department of Health and Human Services (HHS) Secretary Sylvia Burwell urging her to place the TBI Programs in the ACL. Starting in July 2015, ACL will administer the TBI Model Systems, the Research and Training Center on TBI Community Reintegration, the Independent Living Center program, and the Assistive Technology program. The joint letter also called on Secretary Burwell to begin work on the plan to coordinate and maximize federal agencies and resources that may impact TBI as directed by the TBI Reauthorization Act.

Increase Access to Care

Congress included rehabilitative and habilitative services and devices as one of 10 essential health benefit categories under the Patient Protection and Affordable Care Act but did not adopt a uniform definition or set minimum standards for coverage. Last fall, the Centers for Medicare and Medicaid

Services (CMS) invited public comment on these issues. Through its memberships in the Coalition to Preserve Rehabilitation (CPR) and the Habilitation Benefits Coalition (HAB), BIAA joined with other health and disability advocates to recommend CMS adopt the National Association of Insurance Commissioners' definitions and require coverage of durable medical equipment, orthotics and prosthetics, low vision aids, augmentative and alternative communication devices, hearing aids, and assistive listening devices.

Advocates also urged CMS to require that rehabilitation and habilitation benefits be available without arbitrary restrictions that would limit a person's ability to achieve his or her therapeutic goals. We recommended a prohibition on states and health plans imposing additional copayments or coinsurance beyond the plan's standard provisions, and that issuers be prevented from denying coverage based on age, disability, or life expectancy. We suggested the use of an exceptions process for persons whose rehabilitation or habilitation needs

exceed typical limits based on having complex, chronic, or catastrophic conditions, such as TBI and stroke. CMS will consider all of the input it received and issue regulations that would become effective beginning in 2016.

The Protecting Access to Medicare Act of 2014 (also known as the "Sustainable Growth Rate (SGR) patch") was a nice win for BIAA and other advocates last April. The law delayed – for one year – the 24 percent cut in payments to physicians who accept Medicare and extended the exceptions process for Medicare therapy caps. But as the term "patch" suggests, last year's action was only a temporary fix.

Rep. Charles Boustany (R-La.), along with Reps. Xavier Becerra (D-Calif.), Marsha Blackburn (R-Tenn.), and Lois Capps (D-Calif.), introduced the Medicare Access to Rehabilitation Services Act Feb. 5, 2015. If enacted, this legislation would permanently repeal the \$1,940 therapy cap imposed on physical therapy and speech-language pathology combined and

(continued on page 22)



ATTEND BRAIN INJURY AWARENESS DAY

ON CAPITOL HILL • Wednesday, March 18, 2015

10 a.m. to 1 p.m. – **Awareness Fair, Rayburn House Office Building Foyer**

1:30 p.m. to 3 p.m. – **Briefing on "Living with Brain Injury," 121 Cannon House Office Building**

5 p.m. to 7 p.m. – **Evening Reception, B-339 Rayburn House Office Building**

Follow the link on www.biausa.org for instructions how to schedule visits with your Members of Congress and to study the top issues for 2015.



#NotAloneinBrainInjury

Advocacy UPDATE

(continued from page 21)

the separate \$1,940 cap on occupational therapy services. In the 113th Congress, a similar bill enjoyed bipartisan support in the House and Senate. Enacting this legislation before the March 31, 2015 deadline would end the pattern of yearly extensions that puts access to medically-necessary therapy for 1 million Medicare beneficiaries at risk.

On Jan. 14, 2015, Rep. Sean Maloney (D-N.Y.) introduced H.R. 356. The bill directs the Secretary of Veterans Affairs to develop and publish an action plan for improving vocational rehabilitation services provided by the Department of Veterans Affairs. BIAA will monitor the bill to see if it moves.

Keep Individuals with Brain Injury Solvent and Family Caregivers Strong

As a result of Congress' approval of the fiscal year 2015 budget, Social Security will expand its hours nationwide. Offices will be open to the public for an additional hour on Mondays, Tuesdays, Thursdays, and Fridays beginning March 16, 2015. Offices will continue to close to the public at noon every Wednesday to give employees time to complete current work and reduce backlogs. For more information about Social Security's decision to expand field office hours, see <http://www.socialsecurity.gov/news/#!/post/1-2015-1>.

Before leaving for the winter break, the House and Senate passed and President Obama signed into law the Achieving a Better Life Experience (ABLE) Act of 2013 (S. 313/H.R.647). This law amends Section 529 of the Internal Revenue Service Code of 1986 to allow individuals who became disabled before age 26 to create tax-free savings accounts. The account funds are for disability-related expenses such as transportation, housing, education, and employment training. ABLE accounts will supplement — not replace — benefits provided through private insurance, the Medicaid program, the supplemental security income program, beneficiaries' employment, and other sources. Before establishment of this law, money saved outside a trust account disqualified those with disabilities from Medicaid-based benefits and Social Security. The legislation was championed

by Sens. Robert Casey, Jr., (D-Pa.) and Richard Burr (R-N.C.) and Reps. Ander Crenshaw (R-Fla.), Chris Van Hollen (D-Md.), Cathy McMorris Rodgers (R-Wash.), and Pete Sessions (R-Texas). For a summary of the ABLE Act, see: <https://www.congress.gov/bill/113th-congress/house-bill/647>.

Medicaid expansion under the Patient Protection and Affordable Care Act (ACA) increased access to care for up to 2.5 million low-income people in 28 states. However, the ACA prohibits individuals who are eligible for Medicare from continuing their coverage under Medicaid expansion. As a result, when adults transition from Medicaid to Medicare, they face higher cost-sharing requirements. A new report from the American Association for Retired Persons (AARP), "Transitioning from Medicaid Expansion Programs to Medicare: Making Sure Low-Income Medicare Beneficiaries Get Financial Help," describes programs and policy options that could help low-income persons when they reach age 65. To access the report, visit: <http://www.aarp.org/content/dam/aarp/ppi/2015/transitioning-from-medicaid-expansion-programs-AARP-ppi-health.pdf>.

Rep. Barbara Lee (D-Calif.) introduced H.R. 263 on Jan. 9, 2015, directing the Assistant Secretary for Aging within the Administration for Community Living (ACL) to survey day programs that provide care and support to young adults living with neurological diseases or conditions and to develop guidance on best practices. Thereafter, ACL would establish a competitive grant program to encourage the development of new young adult day programs serving people with neurological conditions. Such programs would seek to maintain or improve participant function, prevent the onset of complications, promote alternatives to nursing home placement, and reduce strain on family caregivers. The program would be funded at \$1 million the first year to cover five grants and grow to \$10 million in the fifth year to cover 15 grants.

On Jan. 20, 2015, Senate Health, Education, Labor and Pensions (HELP) Committee Chairman Lamar Alexander (R-Tenn.), Ranking Member Patty Murray (D-Wash.), and Sens. Bernie Sanders (I-Vt.) and Richard Burr (R-N.C.), introduced S. 192 to reauthorize the Older Americans Act. This law provides for the National Family Caregivers Support

Program, Aging and Disability Resource Centers, and home care. The proposed bill expands and clarifies that older adults caring for adult children with disabilities and older adults raising children under the age of 18 are eligible for assistance provided by the National Family Caregivers Support Program. The bill also promotes the delivery of evidence-based programs, such as falls prevention and chronic disease self-management programs.

Advance and Accelerate Brain Injury Research

For the past year, House Energy and Commerce Committee Health Subcommittee Chairman Fred Upton (R-Mich.) and Rep. Diana DeGette (D-Co.) have led a discussion about the discovery, development, and delivery cycle of new cures and treatments in the United States. Through four white papers, eight hearings, and several roundtable discussions, 21st Century Cures has engaged advocacy organizations and federal agency leaders in its discussions, including HHS Secretary Sylvia Burwell, Food and Drug Administration Commissioner Dr. Margaret Hamburg, and National Institutes of Health Director Dr. Francis Collins.

“21st Century Cures is about hope. We seek to provide hope to patients and families all across the country who are desperate for new cures and treatments. We also seek to provide hope to those who have seen Washington as a partisan city incapable of getting things done. As we look toward this new year and new Congress, I am encouraged by the bipartisan achievements we have already made throughout the 21st Century Cures initiative and grateful for the support of top administration officials,” said Upton.

BRAIN INJURY AWARENESS DAY ON CAPITOL HILL

Wednesday, March 18, 2015

Follow the instructions on the side bar on how to contact your Members of Congress.

For more information visit www.biausa.org
#NotAloneBrain Injury

GET PREPARED TO ACT IN 2015

Now is a good time to get ready for action alerts that may come later in the year. Simply follow these steps:

For communicating with senators:

- 1 > Go to www.senate.gov.
- 2 > Click on the drop-down menu to find your state and press “Go.”
- 3 > Click on the “Contact” link for the first senator listed on the page.
- 4 > Bookmark the opening page to send emails in the future.
- 5 > Use the site’s navigation bars to find phone numbers and office addresses and save the information for future use.
- 6 > Make note of any advice offered about scheduling visits.
- 7 > Repeat Steps 1 to 6 for the second senator listed on the page.

For communicating with representatives:

- 1 > Go to www.house.gov
- 2 > Enter your ZIP code and press “Go.”
- 3 > Click on the email icon for your representative.
- 4 > Bookmark the opening page to send emails in the future.
- 5 > Enter your ZIP code again to verify you are a constituent. (You may need to know your Zip+4 number, find it by visiting https://tools.usps.com/go/ZipLookupAction_input.)
- 6 > Use the site’s navigation bars to find phone numbers and office addresses and save the information for future use.
- 7 > Make note of any advice offered about scheduling visits.

State Affiliate **NEWS**

DELAWARE

The Brain Injury Association of Delaware 24th Annual Brain Injury Conference is slated for March 12, 2015 from 9 a.m. to 3 p.m. . The conference will be held at the Dover Downs Conference Center and the theme is “Joined Voices, Shared Journeys; The Brain Injury Experience.” The conference will bring together survivors, veterans, and health-care providers.

Dr. Maulik P. Purohit, director of research for neuro-rehabilitation and traumatic brain injury (TBI) at the Defense and Veterans Brain Injury Center at Fort Belvoir in Virginia is the keynote

speaker for the conference. Dr. Purohit will discuss the roles of sleep, activity, and nutrition’s in recovering from brain injuries.

Following the keynote there will be a panel discussion, moderated by Dr. Michael Alexander followed by specialized breakout sessions on brain injuries in veterans, children, young to middle-aged adults, and the elderly.

The conference will conclude with remarks from Gov. Jack Markell and Rita Landgraf, Secretary of Health and Human Services.

FLORIDA

The Brain Injury Association of Florida (BIAF) is headed into our 30th year with big plans and hopeful hearts for the 214,000 Floridians living with TBI and the 146,000 Floridians who sustain TBI each year.

Nearly 250 survivors and family members from across Florida attended BIAF’s Camp TBI — “The Best Imagined!” — where they participated in a variety of workshops and activities designed by



volunteers and experts in the field of brain injury. The Art of Masks project created more than 100 beautiful, poignant masks designed by survivors and caregivers to help tell their stories and raise awareness during March. To see their work and view our educational videos visit www.campptbi.org.

It is hard to surprise Carolyn Rocchio, BIAF's founder, but at Camp TBI we succeeded! Carolyn was the recipient of BIAF's prestigious 2014 Valiant Heart Award with heartfelt thanks from all of us!



Carolyn Rocchio, Gary Clarke, Board Chairman, and Valerie Breen, CEO

BIAF is pleased to announce a new way to access resources in Florida. Through our partnership with the Florida Department of Health, www.floridatbihelp.com provides easy access to Florida providers, useful publications, videos, and support groups. Data collected will be used to identify gaps in needs and services while providing a "one stop" place for access to brain injury information, resources, and help.

GEORGIA

With the Georgia Concussion Coalition now working under the Brain Injury Association of Georgia's umbrella, exciting new initiatives are being developed. BIA-GA is working with a local Minor League Baseball team, the Gwinnett Braves, to pilot a grassroots concussion awareness and prevention program that will engage a spectrum of community partners. BIA-GA is cultivating a partnership with the Atlanta Science Festival and College Football Hall of Fame to host a community education event focused

on the science of sports safety and concussion. A grant awarded by the Rotary Club of Gwinnett County is enabling a new concussion education webinar series for multiple audiences. BIA-GA served on a panel for the Atlanta Community Huddle on Concussion presented by the National Council on Youth Sports Safety. As well, BIA-GA has been invited to join in partnership with Georgia Partnership for TeleHealth, Georgia Department of Public Health and healthcare providers to pilot a telemedicine project focused on concussion diagnosis and management. A new concussion support group is also being launched to serve youth athletes with long-term concussion symptoms and their families. BIA-GA is excited to be working with a wealth of community stakeholders to expand outreach and impact related to concussion awareness and prevention.

MASSACHUSETTS

The Brain Injury Association of Massachusetts (BIA-MA) has developed, in collaboration with experts in the field of brain injury, an Acquired Brain Injury (ABI) Clinical Continuing Education Program. Included under this program is an ABI Clinical Continuing Education Basic Certificate as well as five advanced topics (Overview of Diagnostic Procedures, Aphasia and Cognitive-Communicative Disorders, Review of Neuropharmacology, Substance Abuse and ABI, and Problematic Sexual Behavior.)



Nicole Godaire, Executive Director, Brain Injury Association of Massachusetts

(continued on page 26)

State Affiliate NEWS

(continued from page 25)

In 2007, the Brain Injury Association of Massachusetts (BIA-MA) and the Center for Public Representation filed a landmark, federal class action lawsuit on behalf of persons living with ABI (Hutchinson v. Patrick). The settlement agreement reached with the Commonwealth of Massachusetts provides for the transition of persons with ABI from institutionalized settings, as well as the expansion and development of a continuum of community-based services, via implementation of several Medicaid waivers.

Service providers and staff working in community mental health settings, day health, residential, and other programs serving this population have identified the need for specialized training with respect to ABI. In response to these educational needs, it is BIA-MA's goal and hope that the ABI Clinical Continuing Education Program will serve to inform programs and services that will, in turn, serve to enhance quality of life for persons who have survived an acquired brain injury.

MICHIGAN

During the last part of 2014 the Brain Injury Association of Michigan (BIAMI) said goodbye to two of our valued team members, Vice President of Operations and Programs Cheryl Burda and Veterans Program Manager Rick Briggs.

After 13 years serving as BIAMI's Vice President of Operation and Programs, Cheryl left BIAMI to become the Clinical Evaluator at NeuroRestorative Michigan. During Cheryl's tenure, she managed the Association's Capitol Day program and our Annual Meeting, and she grew the BIAMI Fall Conference into the nation's largest brain injury conference. Cheryl also assisted with the development and organization of the National ACBIS program, and created and oversaw

training programs for those certified in Michigan. Her expertise and depth of experience will be greatly missed at the Association.

Retired U.S. Air Force Major Rick Briggs served as BIAMI's Veterans Program Manager for nine years. Unfortunately, Rick's position ended with the loss of grant funding. Rick continues to help military families adjust to community re-entry as he develops Camp Liberty, a therapeutic recreation facility in Brooklyn, Mich. Rick was well respected at the Association for his knowledge of PTSD and TBI, and for the amazing services he provided veterans.

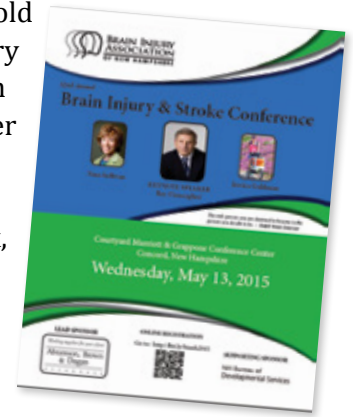
With deep gratitude for their contributions, we wish both Cheryl and Rick well in their new endeavors.



NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) has received a HRSA grant for TBI Implementation. Our program, Concussion Chalk Talk (CCT), is a collaborative effort with the New Hampshire Bureau of Developmental Services and the Geisel School of Medicine. CCT is a program that assists schools with their concussion management policies and procedures, especially with return to learn. The program includes the formation of a concussion management team (CMT), consisting of key personnel both inside and outside the school. A highlight of the program is the presence of a neuropsychologist on the CMT, who will visit the school to consult on challenging cases and to answer questions. The focus is a data-driven individualized approach to concussion management.

In May 2015, BIANH will hold its 32nd Annual Brain Injury & Stroke Conference, which will feature keynote speaker Ray Ciancaglini, founder of The Second Impact. A native of Geneva, New York, Mr. Ciancaglini is a former professional boxer and award winning concussion awareness activist.



Additional speakers at the conference include: Jessica Goldman, who recently completed a 3,400 mile run across the United States in order to raise awareness for the Brain Injury Association of America; and Tina Sullivan, mother, caregiver, and author of *Nourish Your Noggin*.

PENNSYLVANIA

The Brain Injury Association of Pennsylvania (BIAPA) has recently implemented the program NeuroResource Facilitation for Youth with Brain Injury in Juvenile Detention. The project is aimed at creating and implementing protocols for the early identification of juvenile detainees with brain injuries so that youth identified with brain injury can be offered strategies and support that will allow them to become successful and make positive contributions to their communities. The project will educate professionals working with juvenile detainees at various trigger points in the juvenile justice system about brain injury, how to identify it, and about what interventions are available. A NeuroResource Facilitator with expertise in brain injury will work in the Detention Centers to implement protocols and made connections to resources.

Goals of the project include:

- Providing brain injury education and training within the Juvenile Justice system;

- Developing and implementing a screening protocol to identify youth with a history of brain injury;
- Assessing for cognitive impairment in youth who screen positive for a history of brain injury;
- Utilizing information from screenings and neurocognitive evaluations to plan and guide the delivery of interventions;
- Making connections to appropriate resources for youth with brain injury;
- Building the capacity of BrainSTEPS School Re-entry Program;
- Providing consultation and training within the Juvenile Justice system to build capacity to screen for brain injury; and
- Providing consultation within the Juvenile Justice system to build capacity to administer neurocognitive testing.

This project is implemented through a contract with the Pennsylvania Department of Health with HRSA funding.

News & Notes

Nutcase Partners with BIAA to Raise Brain Injury Awareness

Nutcase, the Portland-based maker of bike, skate, snow, and water helmets has signed a partnership agreement with the Brain Injury Association of America (BIAA). The partnership kicks off with monetary donations from helmet sales throughout Brain Injury Awareness Month.

During the month of March, Nutcase will donate \$2.00 to BIAA for each helmet sold through www.nutcasehelmets.com. Nutcase has also provided custom video content from Nutcase pro trials rider Ryan Leech for use on the BIAA website (www.biausa.org) to engage and attract young riders to the site. The company has also created a donation page at <http://bit.ly/biadonations> with proceeds going directly to BIAA.

“We all love our brains,” said Susan H. Connors, President and CEO of BIAA. “A Nutcase helmet is not only a way to express that, but it’s also a way to express individual personality.”

“Nutcase is all about fun and self expression,” says Michael Morrow, founder and president, Nutcase Helmets. “But there’s a reason we put the slogan I Love My Brain on the back of every helmet we make. It’s a reminder to us – and every Nutcase out there having fun – to keep safety top of mind. We’re looking forward to working with the BIAA team and finding ways we can spread our joint message throughout the year.”



Update on TBI Guidelines Project

In July of last year the Brain Injury Association of America (BIAA) awarded a grant to the Brain Injury Research Center at the Icahn School of Medicine at Mount Sinai. The grant funds a three-year investigation to develop Guidelines for the Rehabilitation and Disease Management of Adults with Moderate to Severe Traumatic Brain Injury (TBI).

The project was conceived as part of BIAA’s mission to advance research and appropriate treatment for people with brain injuries. At present, there are no universal guidelines regarding how much rehabilitation adult patients with moderate to severe TBI should receive, in what setting, and at what time. Individuals who sustain TBIs rarely have access to rehabilitation of sufficient timing, scope, duration, and intensity that would allow them to recover to the maximum extent possible.

Fifty of the nation’s top researchers and clinicians, as well as family members of people with brain injuries,

were selected to review and assess evidence in functional, medical, cognitive, behavioral, and social domains.

The first phase of creating these Guidelines is development of questions on what is known about appropriate, effective, and properly delivered rehabilitation and life-long management services. The panel chairs and panel members have developed questions that will be used to find existing research evidence on what type of services need to be offered, in what setting, for which groups of adults with moderate-severe TBI, at what point after onset of their disorder, and with how much intensity. Analysts will build evidence tables that synthesize the literature around each of the questions. The evidence will be used by the panels to make recommendations.

Members of the five panels have developed and prioritized their initial research questions. The evidence identified and synthesized in response will

help answer the following overarching questions:

- How much rehabilitation should adults with moderate to severe traumatic brain injury (TBI) receive?
- In what setting?
- At what time?

BIAA encourages you to participate in this process by reviewing and commenting on these questions. Please visit www.biausa.org/tbiguidelines and select "Panel Questions" to learn more and provide your feedback.

Free BIAA Webinars for People with Brain Injuries

The Butch Alterman Memorial Webinars are a series of free webinars that are focused on and primarily for people who are living with brain injury.

The series is made possible through the Butch Alterman Memorial Fund, which was established by Maureen Alterman in memory of her husband and supports BIAA's education efforts. Maureen established the fund to keep alive those things that meant the most to her husband, whose life centered around family, faith, serving his community via various charitable endeavors, educating his students, and serving his country through his military service in the United States Navy.

Butch was an elementary educator for 35 years; his classroom motto was "let me teach so I can quench your thirst for learning." He believed that education was the key to shaping his young students. The fund is the perfect way to educate those who have a thirst for knowledge about brain injury.

Webinars already presented include:

- Realistic Hope After Brain Injury;
- Getting Back to Work;
- Understanding Social Security Disability; and
- Strategies for Coping with "Brain Injured Moments"

Recordings of these webinars can be viewed on the BIAA website at www.biausa.org/alterman. ●



Mardi Gras Masquerade Raises Money for BIAA

David and Cindy Whitehouse of Lexington, Kentucky, hosted a Mardi Gras Masquerade on February 13, 2015 and raised more than \$4,000 on behalf of the Brain Injury Association of America (BIAA). Distinguished guests included members of state and city government, representatives from leading state associations, business executives and entrepreneurs, and Susan H. Connors, President and CEO of BIAA.



David Whitehouse has been a leader in government relations for more twenty years and owns The Bluegrass Group, a government relations and marketing consulting firm. Cindy Whitehouse has more than twenty years of experience in case management, worker's compensation, and managed care. She founded Ascential Care Partners, LLC in 2011 with the goal to redesign managed care.

Upcoming WEBINARS

AWARENESS, DEPRESSION AND CATASTROPHIC REACTION AFTER BRAIN INJURY

BIAA Caregiver Webinar

Thursday, April 16, 2015

3:00 p.m. eastern/12:00 (noon) pacific

Ron Sasso, Director Brain Injury Rehabilitation Center

MEASURING OUTCOMES IN POST-HOSPITAL BRAIN INJURY REHABILITATION

BIAA Business of Brain Injury Webinar

Thursday, April 23, 2015

3:00 p.m. eastern/12:00 (noon) pacific

Franks Lewis, Ph.D., CBIST and Gary Seale, Ph.D.

AGING AND BRAIN INJURY

BIAA Caregiver Webinar

Thursday, June 24, 2015

3:00 p.m. eastern/12:00 (noon) pacific

Deb McMorrow, CEO of Learning Services

COLLEGE AFTER BRAIN INJURY

BIAA Caregiver Webinar

Wednesday, September 23, 2015

3:00 p.m. eastern/12:00 (noon) pacific

Dr. Mary Kennedy, Chapman University College of Educational Studies

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We are not Islands in the Stream: **INTIMACY AFTER TBI**

(continued from page 13)

Furthermore, it doesn't matter what kind of an intimate relationship is being studied. Robins (2013) interviewed different types of couples and published her results in her dissertation "Exploring intimacy after traumatic brain injury (TBI) for TBI survivors and their partners." She made an effort to include couples who were unmarried, individuals from various racial, cultural, and ethnic backgrounds, as well as couples with relationships established after TBI. Her findings are the same to those of Vangel's. Support is very important for intimate relationships after a TBI.

The statistics are on the side of intimacy. Intimate relationships can survive if one commits to fighting for them. Of course, a lot depends on the relationship the couple had before, and their ability to make a new relationship with the person they are married to now. Mills and Turnbull suggest both partners should work hard to "Listen, Observe, Verify, Empathize, and Reassure [LOVER]." Sometimes that may not be enough. It is also important to know that it is OK to reach out and get help. Help can be counseling for the couple or one of the partners.

TBI does not kill intimacy, but it is a major challenge for relationships. If the couple wants to keep intimacy alive both may need to fight for their relationship – and the odds for succeeding are in favor of the relationship!

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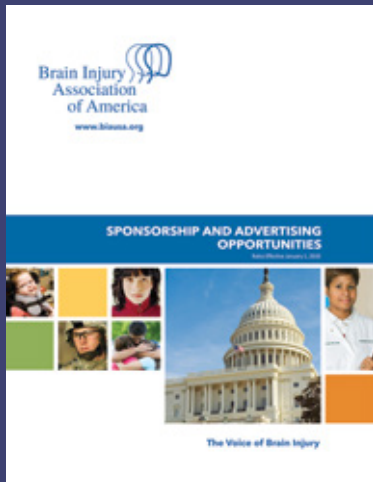




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For more information on how to become part of Brain Injury Association of America Corporate Sponsors Program, please visit the sponsorship and advertising page at www.biausa.org or contact Susan H. Connors at 703-761-0750 or shconnors@biausa.org.

