BRAIN INJURY IN THE COMMUNITY

THE CHALLENGE!

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 11, Issue 1
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March is Brain Injury Awareness Month!

As always, the Brain Injury Association of America (BIAA) has many reasons to celebrate. For the eighth time, the Traumatic Brain Injury Litigation Group of the American Association for Justice is generously supporting our national campaign, #NotAloneInBrainInjury. You’ll find a fact sheet, flyers, posters, and pre-recorded public service announcements available for download free from our website at www.biausa.org/brain-injury-awareness-month.htm.

New this year: Craig Hospital, based in Englewood, Colorado, is our social media sponsor. BIAA will use Twitter (https://twitter.com/biaamerica), Facebook (www.facebook.com/BrainInjuryAssociationofAmerica), and Instagram (www.instagram.com/bia_usa/) to provide weekly content focusing on various issues related to brain injury. We invite all of BIAA’s friends and followers to participate. The weekly themes are:

**Week of Feb. 26–March 4:**
*Advocating for Your Loved One*

**Week of March 5–11:**
*Living with Brain Injury*

**Week of March 12–18:**
*Caregiver Coping*

**Week of March 19–25:**
*BIAA and Brain Injury History*

Again this year, the Congressional Brain Injury Task Force will host Brain Injury Awareness Day on Capitol Hill, Wednesday, March 22. BIAA supports this annual event by assisting with planning, exhibiting, and sponsoring the reception in collaboration with the National Association of State Head Injury Administrators, the National Disability Rights Network, and other stakeholders.

If you have sustained a brain injury, care for someone who has been injured, conduct research, or provide rehabilitation or other services, we hope you will meet with your congressional lawmakers in Washington, D.C., or when they are in their district offices during the month of March. BIAA has composed a series of legislative issue briefs to use in educating your representative and senators about issues affecting the brain injury community. The issue briefs, which are made possible through generous grants from the Centre for Neuro Skills and Avanir Pharmaceuticals, will be available at the BIAA exhibit booth during the Awareness Fair, or they can be downloaded free from www.biausa.org/biaa-advocacy.htm.

Please check with your state brain injury association to coordinate a visit to Capitol Hill and learn about awareness activities in your community. Contact information for BIAA’s chartered state affiliates is available at www.biausa.org/state-affiliates.htm.

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

*I wish you well in your advocacy and awareness efforts.*
I have been supporting people with brain injuries and helping them to live in their own communities for the past 30 years. At the end of a day, I often ask myself what I need to know about brain injury. I have learned I need to know a lot more about how to connect with people, what community resources are available, and how to build a keen sense of problem solving to help people connect the dots in a given situation. I need to know how to help people make their way, learn about their own injuries, and decide for themselves how to accommodate for disability.

Moving from a place where you are surrounded by brain injury experts to a community setting is a huge transition. Here are the top ten things to know about living in the community with a brain injury:

1. Nothing for me without me.

Those living with brain injury need to be in charge of their lives. That means that they must be involved in every conversation that relates to them. If they want someone to know about their brain injury, they need to be the one driving that process. That could mean that they explain it themselves or that they choose to have someone else explain it for them. There are no meetings about the person without the person.
If you want to be an equal participant in the community, you must not seek special treatment because of your brain injury or your disability. You can, however, express your civil rights by asking for accommodations, whether that is having a ramp installed in your building, asking others to repeat what they are saying so you can write things down, or any other accommodation that increases your participation in the community.

3. Remember we are all more alike than different.
Look for common elements rather than differences when figuring out how you can be part of the community or when helping someone else figure this out.

4. Learn to adjust.
While a person may be considered a hero for having survived the brain injury, the adjustment to life with a brain injury goes on forever. Once the “hero status” ends, people need to be there to help that person adjust to everyday life.

5. Relationships matter.
Often friends who knew the person before his or her brain injury will go away or have their roles change. Those who remain can be cherished as they help the person make new friends and connections based on mutual dreams and desires.

6. Intentionally connect.
There are many intentional ways to learn to be connected to the community. Increasing social capital (friends and social networks) starts with expressing what you want to do and with whom you want to do it. Once you have those basics down, start joining groups, classes, or communities who share those common interests. Do you want to bowl? Join a bowling league, figure out how to get to the bowling alley, and be a part of the team.

7. Find a gatekeeper.
When you join a new club, church, or other activity group, look for the person who seems to know everyone. Let him or her help you make your way.

(continued on page 26)
Politics is everywhere these days – on every T.V. channel, social media feed, radio station, newspaper, and t-shirt. In January, a New York Times poll found more than eight in 10 Americans expressed “significant disgust” with the state of American politics.

Luckily for us, there is a distinct difference between politics and advocacy. Politics are the activities undertaken to influence the way a country is governed, whereas advocacy is the process of supporting a particular principle, policy, or plan of action to address specific needs.

Advocacy is essential to creating effective policies at the local, state, and federal levels. The Brain Injury Association of America (BIAA) and its affiliates rely on advocates to advance policies that improve awareness, prevention, research, healthcare, and civil rights for individuals with brain injury. For example, it was through the efforts of grassroots advocates that the Traumatic Brain Injury Act of 1996 was enacted more than 20 years ago. With changes or perhaps even repeal of the Patient Protection and Affordable Care Act (ACA) looming, it is especially important for advocates to educate and inform policymakers at every level of government.
What Can Advocates Do?

1 GET INVOLVED.

No matter the state you call home, there are opportunities to improve or advance some aspect of care, support, and services related to brain injury. Subscribe to BIAA’s Policy Corner e-newsletter, reach out to your state affiliate, or speak with health and disability advocates in your community to discover opportunities for change. If your state has a brain injury advisory council, reach out to its members and ask if there are ways you can be involved.

2 FIND OUT WHO REPRESENTS YOU.

Elected officials represent you and make important decisions on your behalf every day. You can find your lawmakers by visiting www.usa.gov/elected-officials.

3 SPEAK TO POLICYMAKERS.

Take the time to reach out and communicate with those representing you at the local, state, and federal levels. Let them know about your connection to brain injury and describe your own experience with treatment and access to care, availability of resources and supports, and effectiveness of long-term services that are available to you. BIAA provides legislative issue briefs for advocating at the federal level. Visit www.biausa.org/advocacy.

4 SEEK OPPORTUNITIES TO INCREASE AWARENESS.

During Brain Injury Awareness Month (in March) and throughout the year, look for ways to raise awareness of brain injury. For example, request your favorite radio station share a public service announcement (PSA) or engage with BIAA on social media using the hashtag #NotAloneInBrainInjury. Awareness materials are available free from www.biausa.org/NotAlone.

5 SHARE YOUR STORY.

As a person with a brain injury or someone who has experience with brain injury, sharing your personal story is the best way to provide a meaningful impact when expressing your position. You can share your story on BIAA’s website at www.biausa.org/_blog/Personal_Stories and by commenting when media outlets publish stories about brain injury.

6 STAY ENGAGED.

Advocacy is a marathon, not a sprint. Individuals who live with brain injury are effective advocates, but family members and care providers are also knowledgeable and can attest to the consequences of brain injuries and the needs of individuals who sustain them. Together, the community can bring about positive change for coverage of brain injury and related services.

7 ALWAYS REMEMBER…

There is strength in numbers, and every person has something to offer.

JOIN US FOR
BRAIN INJURY AWARENESS DAY ON CAPITOL HILL
MARCH 22, 2017

We are #NotAloneInBrainInjury
For more information, visit www.biausa.org/awareness2017

WWW.BIAUSA.ORG 7
A Special Needs Trust (SNT) is a trust created specifically for individuals with disabilities. The person managing the trust is called the “trustee,” while the person who will benefit from the trust is called the “beneficiary.” The trust lasts as long as it is needed, which usually means the trust will exist until the beneficiary’s death or until the funds are exhausted. For many, knowing that the funds are well-managed and will enrich the quality of life of the beneficiary provides peace of mind and is the reason that SNTs are so popular. Having a SNT is important for an individual with special needs when he or she receives a sum of money or when a family member wants to provide financial support in the future.

If an individual has more than $2,000 in assets, Supplemental Security Income (SSI) and Medicaid benefits could be jeopardized. Establishing a SNT preserves funds that can be used for the individual’s benefit while protecting their eligibility for SSI and Medicaid, as a SNT is not counted as income or assets.

Nonprofit organizations, like Commonwealth Community Trust (CCT), specialize in the administration of Pooled Special Needs Trusts (PSNT). Beneficiaries’ funds are collectively pooled together for investment purposes while an accounting of each beneficiary’s sub-account is maintained. Pooling funds can provide for greater investment opportunities and lower trust administration fees. Earnings based on the beneficiary’s share of the principal are added to each sub-account, meaning that funds can be spent on beneficiaries in proportion to their share of the pooled investment.

Professional trust administration services include making financial decisions on behalf of the beneficiary by evaluating disbursement requests, tracking expenses, and ensuring funds are spent prudently without jeopardizing SSI and Medicaid benefits.

Types of Pooled Special Needs Trusts

- A Third-Party Pooled Special Needs Trust is established and funded by a grantor, typically a parent or grandparent, and can be coordinated with an estate plan or life insurance policy. The trust holds funds that the grantor leaves for the beneficiary and is available for a beneficiary of any age.

- A First-Party Pooled Special Needs Trust is funded by the person with a disability with assets of his or her own, such as a personal injury settlement, an inheritance left directly to the beneficiary, excess Social Security back payment,
Example of Paid Expenses Using a PSNT

Trust funds can be used to pay an array of goods and services for the benefit of a beneficiary. Examples include, but are not limited to:

- Internet services
- Assistive technology
- Clothing
- Vocational training
- Eye glasses
- Medication, services, and devices not paid for by Medicaid or other insurance
- Educational expenses
- Transportation
- Household items

- Recreational expenses
- Furniture
- Home purchase / Renovation / Repair
- Cable services
- Mobile phone plans
- Dental services
- Hearing aids
- Prosthetic devices
- Caregiver expenses

About the Author: Joanne Marcus, MSW, is the executive director of Commonwealth Community Trust (CCT), a national nonprofit organization that provides administration of pooled special needs trusts since 1990. CCT trust services are available nationwide. For enrollment documents, fee schedules, and more information, email info@trustCCT.org, call 804-740-6930, toll-free 1-888-241-6039, or visit http://www.trustCCT.org.
A Lasting Legacy: Dr. Robert Sbordone

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

The world of brain injury lost an authority and leader in research and education when Dr. Robert Sbordone passed away in 2015. Dr. Sbordone’s lifelong interest in brain injury was ignited when he served as an expert witness in a case regarding a young man’s car accident. He received his doctorate in psychology followed by a postdoctoral fellowship in neuropsychology with a specialization in patients with Alzheimer’s disease and other brain disorders. He became the chief of the neuropsychology unit at the University of California, Irvine. He treated patients with traumatic brain injury (TBI), cerebrovascular disorders, and disabling neurological conditions. In addition to clinical care, Dr. Sbordone was very committed to education and taught at UCLA, California State University at Los Angeles, Long Beach VA Hospital, and the Fielding Institute.

Dr. Sbordone made major contributions to brain injury research. He wrote six textbooks, 30 book chapters, and more than 100 articles in peer-reviewed medical and scientific journals. He also developed and published a standardized memory assessment called the Sbordone-Hall Memory Battery. He was one of only a few neuropsychologists certified by both the American Board of Clinical Neuropsychology and the American Board of Professional Neuropsychology. In recognition of his years of work, Dr. Sbordone was nominated for the Lifetime Achievement Award by the National Academy of Neuropsychology.

According to longtime friend Kristen Long, Dr. Sbordone was also very adventurous and athletic. Growing up in East Boston, he spent his free time training as a body builder. He won a body building competition and was an alternate member of the 1960 Olympic team in javelin. As an adult, he loved roller coasters, science fiction, interior decorating, cars, and trips to Hawaii. Those who knew him said he was a very caring, generous person who was always a kid at heart. “He wanted to leave the world a better place by giving a chance to the underdog,” Ms. Long explained. Dr. Sbordone continues to help others through his generous bequest to the Brain Injury Association of America (BIAA).

The bequest provides an unprecedented opportunity for BIAA to invest in strategic revenue growth and long-term stability. In honor of Dr. Sbordone’s generosity, BIAA created the Robert Sbordone Memorial Lecture series on mild traumatic brain injury (mTBI) and concussion. These online lectures are led by licensed social workers, medical doctors, and other professionals in the field of brain injury. Recent topics include recovery after mTBI, gender and sex differences in concussion, and challenges in diagnosis. Susan Connors, BIAA president and chief executive officer, said, “We are deeply grateful for Dr. Sbordone’s gift and pleased to honor him through this webinar series.” To view the Robert Sbordone Memorial Lecture series, visit https://shop.biausa.org/products/sbordonelectures.

“He wanted to leave the world a better place by giving a chance to the underdog.”
This March, as part of Brain Injury Awareness Month, we’re honoring patients, families, caregivers, and those who work with people living with brain injury.

Find out how Craig patients and staff are #empoweringlives and sharing the message #notaloneinbraininjury.

Share your story using these hashtags!

Follow us to learn more! @craighospital

craighospital.org
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October 1, 2016 – December 31, 2016

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Thank You!
Save the Date!
Brain Injury Awareness Day
on Capitol Hill, March 22, 2017

The Brain Injury Association of America (BIAA) thanks the Congressional Brain Injury Task Force, co-chaired by Reps. Bill Pascrell, Jr. and Thomas J. Rooney, for hosting Brain Injury Awareness Day on Capitol Hill, March 22, 2017. As in previous years, the day will begin with an awareness fair in the Rayburn House Office Building, First Floor Foyer. This is an exciting opportunity to network with members of Congress and congressional staff while visiting with multiple exhibitors representing the brain injury community. A briefing, “Faces of Brain Injury: The Invisible Disability Affecting Children and Adults” will be held in the Gold Room (Rm. 2168) of the Rayburn House Office Building. The day will end with a reception in the Gold Room to honor the Congressional Brain Injury Task Force and to celebrate brain injury awareness month, which takes place every March. BIAA looks forward to seeing you on Capitol Hill!

115th Congress Convenes

On January 3, the 115th Congress convened with 63 new members in the House of Representatives and 34 new members in the Senate. Republicans hold majorities in both chambers.

Congress Begins Steps to Repeal ACA

Senate Budget Chairman Michael Enzi (R-Wyo.) introduced S. Con Res. 3, a budget resolution bill to lay the groundwork for repeal of the Patient Protection and Affordable Care Act (ACA). Through a budget resolution, the majority party in Congress can use a set of rules called “reconciliation” to advance...
policies by a simple majority vote. Only provisions that are budget-related are permitted to be included in a reconciliation bill. The ACA was enacted in 2010 through the same process.

Democrats offered a number of amendments to S. Con Res. 3, including a proposal by Sens. Mazie K. Hirono (D-Hawaii) and Joe Donnelly (D-Ind.) to prevent changes to the Medicare and Medicaid programs without a supermajority in the Senate (60 votes). The amendment failed 49-47 with two Republicans voting for the amendment – Sens. Susan Collins (R-Maine) and Dean Heller (R-Nev.). Despite BIAA’s urging to vote “no,” S. Con. Res. 3 was approved, stripping fees, taxes, and subsidies relating to the ACA. Sen. Rand Paul (R-KY) was the lone Republican opponent of voting on a repeal bill before coming up with a replacement package.

The reconciliation budget for 2017 sets levels of new budget authority, revenues, outlays, and deficits and projects Social Security funding over ten years. The bill directs certain Senate and House committees to find at least $1 billion in cost-cutting over ten years and estimates the deficit to be over $1 trillion in that time. The bill largely retains parliamentary procedures such as dynamic scoring, a process under which the Congressional Budget Office (CBO) calculates the long-term economic impact of federal legislation. The bill also shows Social Security in the black over the next ten years. The House is poised to take up similar legislation.

**BIAA Opposes Medicaid Block Granting**

During the 114th Congress, BIAA joined with other health and disability organizations in sending a letter to House and Senate lawmakers expressing strong opposition to any block granting, setting of per capita caps, or significant cuts to the Medicaid program, which is a joint State-Federal health care program. Advocates are working to prevent these changes, which are favored by some Congressional leaders.

Medicaid provides health care services and long-term services and supports that maintain the health, function, independence, and well-being of 10 million enrollees living with disabilities. Block grants or per capita caps would further reduce an already lean program and force states to make service and eligibility cuts that put the health and wellbeing of people with disabilities at significant risk.

**Lawmakers to Introduce Bills to Repeal Therapy Caps**

Lawmakers in both chambers have introduced legislation to repeal the Medicare therapy caps. Under the Balanced Budget Act (BBA) of 1997, Congress placed an annual cap on rehabilitation services under Medicare. Since enacting the BBA, Congress has acted several times to prevent implementation of a hard cap. Reps. Erik Paulsen (R-Minn.) and Ron Kind (D-Wis.) introduced legislation in the House, and Sens. Ben Cardin (D-Md.), Susan Collins (R-Maine), Bob Casey (D-Pa.), and Dean Heller (R-Nev.) introduced the Senate version.

**Day Program Legislation**

Rep. Barbara Lee (D-Calif.) introduced H.R. 325 to expand and enhance existing adult day programs for younger people with neurological diseases or conditions, including traumatic brain injury, in order to support and improve access to respite services for family caregivers who are taking care of individuals with these conditions. BIAA supports this legislation.

**21st Century Cures Act**

On December 13, 2016, President Obama signed the 21st Century Cures Act into law. Section 2040 of the law includes a provision to enhance and better coordinate medical rehabilitation research at the National Institutes of Health (NIH). BIAA strongly advocated for inclusion of this provision.

BIAA championed the provision during a congressional briefing moderated by Justin Moore, PT, DPT, chief executive officer of the American Physical Therapy Association, that featured remarks by researchers and patients. Alison Cernich, Ph.D., director of the National Center for Medical Rehabilitation Research (NCMRR), part of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) at the NIH, shared her Center’s newly revised 2016 NIH Research Plan on Rehabilitation aimed at advancing and energizing the field of rehabilitation research over the next five years. Brain injury advocate Josh Rouch shared his experience and explained how proper rehabilitation enabled him to return to work.

●
KANSAS

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS) is able to expand its reach to promote brain injury awareness thanks to the efforts of post concussive syndrome survivor and volunteer Cari Anne Cashon of Augusta. Using the BIAA media tool kit and the public speaking skills she worked hard to regain after her TBI, Ms. Cashon has been meeting with local municipalities, including Wichita and surrounding areas, and asking their mayors to designate March as Brain Injury Awareness Month. She also is contacting Kansas Governor Sam Brownback’s office to advocate for a Governor’s proclamation (the Governor last signed a proclamation in 2012).

BIAKS will present its annual “Beyond Rehab: Succeeding at Life” Professional Conference March 30-31, 2017. The conference will offer two full days of programming and will also celebrate BIAKS’ 35th Anniversary with the theme: Past, Present, and Future of Brain Injury Treatment and Rehabilitation.

The keynote presenter is Richard Payne, M.D., of Duke University School of Medicine/School of Divinity. Dr. Payne is a medical ethicist whose presentation topic is “Ethical Considerations with Concussion – Do we allow our Children to Play?” Other presentations will cover topics such as community reintegration, brain imaging technology, and encephalopathy. New graduate Amanda Thompson will also share her story about how and why she became a speech language pathologist after experiencing a TBI.

The professional conference is held at University of Kansas Edwards Campus in Overland Park and usually draws 160 or more participants from Kansas and the Kansas City area.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its second Bowling for Brain Injury℠ event Dec. 4, 2016, at Spare Time Portland. The event was a great success with 16 teams and 67 bowlers raising more than $11,000. Later in December, the first edition of the Maine Brain Injury and Stroke Resource Directory was published in both print and online formats. The directory will be distributed across the state.

BIAA-ME will hold its second annual Maine Brain Injury Resource Fair March 30, 2017, in Augusta. The event will have exhibitors from across the state representing services, resources, and opportunities for Maine brain injury survivors, family members/caregivers, and professionals. To register, visit https://shop.biausa.org.
The Brain Injury Association of Massachusetts (BIA-MA) is pleased to announce the appointment of David P. Dwork, Esq. as president of the board of directors. For more than 30 years, Mr. Dwork has dedicated his career to traumatic brain injury (TBI) litigation and helped guide brain injury survivors through the complicated legal processes of trials and out-of-court settlements. He is a magna cum laude graduate from Boston University Law School and a former assistant district attorney for Middlesex County.

“I’ve been fortunate to have had a front row seat to one of the most important events of the past generation: the change in our understanding of the human brain,” Mr. Dwork said. “Through the development of our board, collaboration with public and private agencies and business leaders, our support groups and members, and the use of technology, we’re expanding our organization’s reach.”

Dwork was preceded by Teresa Hayes, who served as president of the board for four years. “Like many who serve, I did not seek out this prestigious position nor was it on my list of goals in life; yet, four of my five years on the board have been as the role of President,” explained Ms. Hayes. In early November, the Brain Injury Association of America (BIAA) awarded Ms. Hayes an Award of Excellence for Affiliate Association Leadership.

The Brain Injury Association of Michigan (BIAMI), along with fellow members of the Coalition Protecting Auto No-fault (CPAN), achieved an impressive victory during the final week of the lame duck session of the Michigan State Legislature. A bill, supported by the auto insurance industry and the Michigan Health and Hospital Association (MHA), was proposed at the last minute. This legislation would have capped benefits for uninsured children, seniors, bicyclists, and pedestrians; cut family-provided attendant care for catastrophically injured accident victims; and created an unbalanced fraud authority funded by the auto insurance industry.
Despite the last minute introduction of this bill, the strong push from the Senate Majority Leader and two insurance coalitions, and the shocking support by MHA, a CPAN member at the time, BIAMI and the remainder of CPAN succeeded in mobilizing their advocates so effectively that it rendered the whip count too low. Supporters of this bill determined it would be a mistake to force a vote and asked the Speaker to remove it from the final priority list. This incident highlights the importance and power of ongoing advocacy in protecting the rights of brain injury survivors and the well-being of the community as a whole.

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual “Sports Concussions: Facts, Fallacies, and New Frontiers” seminars Jan. 26–March 2, 2017. Sports and school personnel attended the seminars and learned about topics such as concussion signs and symptoms, developing protocols to manage concussion, current research in brain injury, and management of concussion for Return to Play and Return to Learn.

The annual Survivor and Family Seminars will be held in Springfield and Independence this spring. During these sessions, survivors and family members will discuss differences before and after their brain injuries as well as suggestions on how to adjust to living with a brain injury. Seminar attendees can participate in yoga, music therapy, and Unmasking Brain Injury activities. The “Meet Your Elected Officials” session is included for state representatives and senators. These seminars will also be offered in St. Louis in the fall.

The BIA-MO Donald Danforth Jr. Wilderness Camp will be held June 18–23. Survivors of brain injury will enjoy a week of fun, independence, and adventure while their family members have a week of respite at home to rejuvenate emotionally and physically. For more information, visit www.biamo.org.

NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) will host its 34th Annual Brain Injury & Stroke Conference this May at the Grappone Conference Center in Concord. The keynote speaker is Nicole Bingaman, author and mother of a son with TBI. Nicole has been sharing her family’s journey with TBI over the last four years and has recently published her first book, “Falling Away From You.”

Participants huddle together for warmth at the 30th annual Walk by the Sea and Picnic 2016.

New Date and Season for the Annual Walk by the Sea! BIANH has moved its annual Walk by the Sea to June 4, 2017, hoping for much warmer weather than in all the previous years. Last year’s fundraiser brought in over $27,000. Looking ahead, BIANH will be holding its 34th Annual Golf Tournament in August 2017 at The Oaks in Somersworth. This tournament, co-hosted by BIANH and Robin Hill Farm, will be sponsored by Northeast Rehabilitation Hospital Network. The fourth annual summer camp for adult survivors will be held at Camp Bedford at the end of August.
The Brain Injury Association of Rhode Island (BIARI) continues to enjoy its 34th year by providing bigger, better, and bolder programs and services. Most recently, BIARI worked to grow its annual conference. Experts presented the latest research focusing on understanding how our brains create new pathways through healing. The conference ended with big smiles from a session of laugh yoga. Again this year, the CVS Health Charity Classic was extremely generous. BIARI is grateful to the Charity Classic for donating the conference and to BIARI’s Vets Golf Strong, a golf program for veterans who are survivors of a mild, acute, or chronic brain injury.

BIARI’s half-year challenge to increase membership is well on its way to ramping up. The new year kicked off with a comedy-show fundraiser called “Laugh Your Head Off,” which was a hilarious success. Top comedians from Rhode Island played to a packed house filled with an audience of supporters who bought plenty of raffle tickets. BIARI looks forward to a successful 2017.
Anne Forrest is an original member of the Brain Injury Association of America (BIAA) Brain Injury Advisory Council (BIAC), which was established by BIAA President and CEO Susan Connors in 2008 to provide input and feedback on a broad range of activities, especially those involving brain injury awareness and advocacy.

Anne sustained a traumatic brain injury (TBI) in 1997 when she was rear-ended while driving in Washington, D.C. She woke up early the following Monday morning with the worst headache of her life, yet she continued into work. At work, the lawyers she worked with suggested that she should see a doctor. She refers to this as her first clue that she had a brain injury, as it hadn’t even occurred to her to see a doctor until that point.

She recalls the doctor telling her she had whiplash and that she should take it easy. After a week at work, Anne was politely told to go home and rest when she couldn’t add up the hours on her timesheet.

A few weeks later, over the fourth of July weekend, she noticed that she had trouble tracking the fireworks display with her eyes and realized she needed to seek help. She eventually saw a neurologist, who told her she had had a mild traumatic brain injury (mTBI). Anne was treated for headaches and the doctor ordered a range of tests, but he did not refer her to cognitive rehabilitation therapy.

She would eventually come to find a neuro-optometrist who helped her to understand she was having trouble reading because she was over-doing things and needed to reduce activity until her eye-brain connection improved. The doctor gave her some basic eye tracking exercises and she began vision therapy class. She continued to work with him as well as with her other doctors to find therapies to help her continue to get better.

In 1999, Anne followed her then boyfriend (now husband) to Austin, Texas, where she found a neurologist who was willing to take her on as a patient. He referred her to St. David’s Rehabilitation Hospital even though it had been more than two years since her brain injury. She had previously been told that the brain can’t recover beyond that point. She began getting rehab and started volunteering at the University of Texas. Anne and her boyfriend were married in October 2001, and they considered the wedding to be a rehabilitation exercise as it took a lot of project-management skills!

In March 2002, Anne and her husband moved back to Washington, D.C., where she eventually attended a Brain Injury Association conference and found Northern Virginia Brain Injury Services (BIS). Anne was assigned a mentor through BIS in whom she confided that she had hoped she had left her brain injury back in Texas. BIS asked her to join the
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 and travels the country with her Yorkie, Pixxie, to help raise awareness of brain injury.

At one event, Anne recalls attendees assuming she was one of the organizers because she didn't exhibit outward signs of a brain injury. At this time, few members of the public understood that a concussion is a brain injury. Anne was able to help shed light on the subject through her speaking engagements.

Anne also volunteered at the BIAA office. In March 2007, she was profiled in a Washingtonian magazine story, “I Wanted My Brain Back,” which is available for download from the Mild TBI page in the Living with Brain Injury section of BIAA’s website. She worked with BIAA staff and long-time advocate Robert DeMichelis on several policy issues but especially the Annual Brain Injury Awareness Day on Capitol Hill. Anne was invited to speak on the briefing panel, “The Value of Rehabilitation,” in March 2011.

Shortly afterward, Anne and her husband moved back to Austin, where they reside today with their 8-year-old son, Daniel. Anne continues to serve on BIAA’s Brain Injury Advisory Council and leads the group as chairperson.

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

“I feel so blessed to be a part of this group. So many members are doing exciting things and have modeled for me where I want to go with my life and advocacy work. My first goal is to keep getting better and better and watch other brain injury survivors solve problems and see their strengths. It has been amazing for me, so inspiring. I feel like we’re thriving as a group. It’s a lonely journey, especially if you don’t get the proper care right away. It’s been a blessing to have so many brothers and sisters taking this journey with me and pointing out different ways of doing things. It’s so meaningful, and the inspiration I get from the other members is tremendous. We have an understanding of each other and each other’s backs.”

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 and travels the country with her Yorkie, Pixxie, to help raise awareness of brain injury.
Like many Americans, Joanie and Larry Kerpelman were enjoying their retirement. Each day, the couple walked the three mile round trip to their favorite coffee shop. One beautiful morning, as Joanie jogged ahead toward home, she fell on the road and hit her head. What initially seemed like a minor injury was found to be a traumatic brain injury (TBI) with a subdural hematoma.

Joanie faced an uphill battle in her recovery, including two hospitalizations, a brain surgery, and memory loss. In “Pieces Missing: A Family’s Journey of Recovery from Traumatic Brain Injury,” Larry Kerpelman invites readers alongside in the couple’s journey to get Joanie back home.

After her TBI, an otherwise motivated Joanie struggled with headaches, word finding, memory loss, and depression. She had always been healthy and active, and it was difficult for her to come to terms with the fact that a fall on the side of the road could cause such a serious medical problem.

Pieces Missing provides a detailed example of what happens to patients and their families when a brain injury occurs, including how they cope, adjust to new roles, and support one another. Readers will find themselves balancing their support of Joanie’s quest to get well quickly against her family’s concern she may be attempting too much too soon. Throughout this emotional and touching story, readers will come to grasp the enormity of a brain injury and its rippling effect on all involved.

To purchase your copy of Pieces Missing, visit BIAA’s Online Marketplace at https://shop.biausa.org.
In a unique collaboration of three national providers of brain injury rehabilitation, the artwork of patients was featured at a reception held in New Orleans November 30 during the 25th Annual National Workers’ Compensation and Disability Conference and Expo. The Centre for Neuro Skills (CNS), ReMed, and NeuroInternational were the three sponsoring organizations.

The reception, “The Art of Brain Injury Rehabilitation,” showcased paintings and drawings created by patients of the three companies and was a touching reminder of the beauty that can be achieved through rehabilitation. The event was also a powerful example of collaboration between providers. “Joining forces helped conference attendees understand what our industry does,” said Paul Greenspan, CNS National Director of Payor Relations. “We care for those who’ve endured catastrophic injuries, and the reception gave us a chance to discuss patient care with workers’ compensation professionals.”

Blink Once for Yes

Produced by John Fecile, Steven Jackson, and Lizzie Schiffman Tufano, “Blink Once For Yes” is an audio documentary recounting the story of a family’s experience with traumatic brain injury (TBI), and the four years of challenges they face in the aftermath. Michael Fecile, John’s younger brother, sustained a TBI during a four-story fall and passed away four years later, in 2015. The documentary first aired on the Love + Radio podcast.

In sharing their story, the Fecile family wanted others facing the same challenges to know that they weren’t alone. They also wanted to raise money for a partner organization dedicated to helping those with TBI and their families. Michael’s injury was a terrifying ordeal, with no roadmap. The Brain Injury Association of America aims to provide such a roadmap. Donations made in Michael’s name will help fund the National Brain Injury Information Center, a hotline that connects people affected by brain injury with resources and a network of support. For more information, visit https://biausa.donorpages.com/BlinkOnceforYes/.

Upcoming WEBINARS

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

Robert Sbordone Memorial mTBI/Concussion Lecture – Return to Work After “Mild” Brain Injury
April 19, 2017, 3 p.m. EST/12 p.m. PST
Melanie Whetzel, M.A., CBIS, Job Accommodation Network

Robert Sbordone Memorial mTBI/Concussion Lecture – Athlete Brain Health: Injury and Long Term Consequences
May 2, 2017, 3 p.m. EST/12 p.m. PST
Jeffrey Kutcher, MD, CORE Institute

David Strauss Memorial Clinical Lecture – Cognitive Rehabilitation: Deficits of Initiation/Action
May 24, 2017, 3 p.m. EST/12 p.m. PST
Deirdre Dawson, Ph.D., Rotman Research Institute at Baycrest

Carolyn Rocchio Caregivers Webinar – Using Technology to Help with Problem Solving After Brain Injury
June 8, 2017, 3 p.m. EST/12 p.m. PST
Michelle Wild, M.A., Coastline Community College, and Laurie Ehnhardt Powell, Ph.D., University of Oregon, Center for Brain Injury Research and Training

To register, please visit http://www.biausa.org/upcomingwebinars
Community Education: A Paradigm Shift
(continued from page 5)

This person will know not to introduce you as someone who has a disability, but rather as a valued member of the group.

8. Sideline the professionals.

Once you transition to the community, brain injury professionals should become your coaches and advisors. They should not be out front telling others about your brain injury or speaking for you. There are no experts in community, only members who want to make a contribution. A great contribution that can be made by those who know something about brain injury is to assist the individuals with brain injury in identifying and securing the accommodations they need and want.


Individuals who have experienced brain injuries should be encouraged to tell their own stories in the community. Sure, a professional can go to the Rotary Club and tell people what they know about brain injury, but it is far more effective for individuals with brain injury to do so.

10. Decide for yourself.

Opinions differ over the value of wearing a medical alert bracelet or carrying a brain injury identification card. For some people, these items are tools that help individuals explain their brain injuries. For others, cards and tags are labels that are used to stigmatize individuals with disabilities. That’s why each person must decide for himself or herself whether or not to use them. It is your choice.

There is a vital role for everyone in supporting people with brain injuries as they adjust to life in the community. Making the paradigm shift – moving from the traditional view of families and professionals being in charge to truly supporting persons with brain injury as they take control of their own lives – is difficult but not impossible. It takes time, empathy, and patience. When we honor the idea that individuals with brain injury must be in charge of every decision and involved in every conversation, independent community living becomes sustainable. Professionals and families can be out front clearing the way for someone to follow, or you they stand next individuals as they make their own way. For true inclusion and participation, individuals with brain injury must lead while community members provide whatever support is needed.

Janet M. Williams, MSW, Ph.D., is founder and president of communityworks, inc and Minds Matter, LLC. She can be reached by telephone at 1-866-429-6757 x101 or via email at janetw@mindsmatterllc.com.

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

For more information on how to become part of 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.