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THE CHALLENGE!

Non-Traumatic Brain Injury

BRAIN INJURY ASSOCIATION OF AMERICA

WINTER 2018

THE Challenge! is published by the Brain Injury Association of America. We welcome manuscripts on issues that are important to the brain injury community. Please send submissions in a standard Microsoft Word® document to publications@biausa.org.

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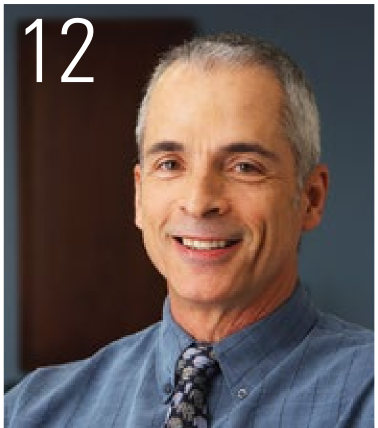


From my **DESK**

CHANGE YOUR MIND ABOUT BRAIN INJURY

My thanks to everyone who participates in the campaign.

Good luck!

Correction: University of Texas (UT) Southwestern, a TBI Model Systems grant recipient, was inadvertently omitted from "NIDILRR Awards TBI Model Systems for FY2017 – FY2021" in our most recent issue of *THE Challenge!* (Volume 11, Issue 4, page 22). We sincerely regret the error.

In 1999, the members of the National Head Injury Foundation voted to change the name of our organization to the Brain Injury Association to more accurately describe our purpose and the constituency we serve. The term "traumatic" was not used as part of our name because the members wanted our organization to welcome people with all types of brain injury. A few years later, a study funded by the U.S. Department of Health and Human Services' Federal Traumatic Brain Injury Program and conducted by the National Association of State Head Injury Administrators showed that 13 states used the broader, more encompassing definition of acquired brain injury (ABI) to describe their service population. The study also showed that six states use both ABI and TBI definitions in their public service plans.

Since 2004, the Brain Injury Association of America (BIAA) has operated the National Brain Injury Information Center (NBIIC) in collaboration with our chartered state affiliates. Roughly 25 percent of the NBIIC inquiries/requests for help we receive relate to ABI. Elected leaders at the state level include individuals who have survived brain tumors and local chapters operate support groups for people who have sustained strokes. Recognizing the makeup of our community, we changed the name of this newsmagazine from TBI Challenge! to *THE Challenge!* in spring 2007.

Over the years, *THE Challenge!* has included many stories of people with ABI. For this issue, we decided to focus on toxic brain injury, mostly resulting from substance misuse. We've also included information about our totally redesigned and completely fabulous new website and news from our affiliates. Last, but definitely not least, we are rolling out a new Brain Injury Awareness Month theme.

As *Challenge* readers know, BIAA leads the nation in observing Brain Injury Awareness Month. The theme for the 2018 to 2020 campaign is Change Your Mind. Posters, flyers, fact sheets, and other tools for advocates are available on BIAA's website at biausa.org/ChangeYourMind. Everyone is encouraged to use the campaign hashtag, #ChangeYourMind, and download the Facebook photo frame, featuring the campaign stamp, at biausa.org/frame.

Susan H Connors

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

THE SOLUTION TO OPIOIDS IS TREATMENT

Over the past several years, the misuse of opioids – ranging from prescription painkillers to black tar heroin – has reached epidemic proportions. In 2015, the Media Research Center reported that drug overdoses had surpassed motor vehicle accident fatalities nationwide for the first time. Since 1999, nearly 200,000 Americans have died from a prescription drug overdose. Heroin use increased in response to advocate and lawmaker efforts to restrict overprescribing, doctor shopping, and opioid sales via online pharmacies. As prescription drug overdoses fell from 2010 to 2015, the number of heroin overdoses tripled.

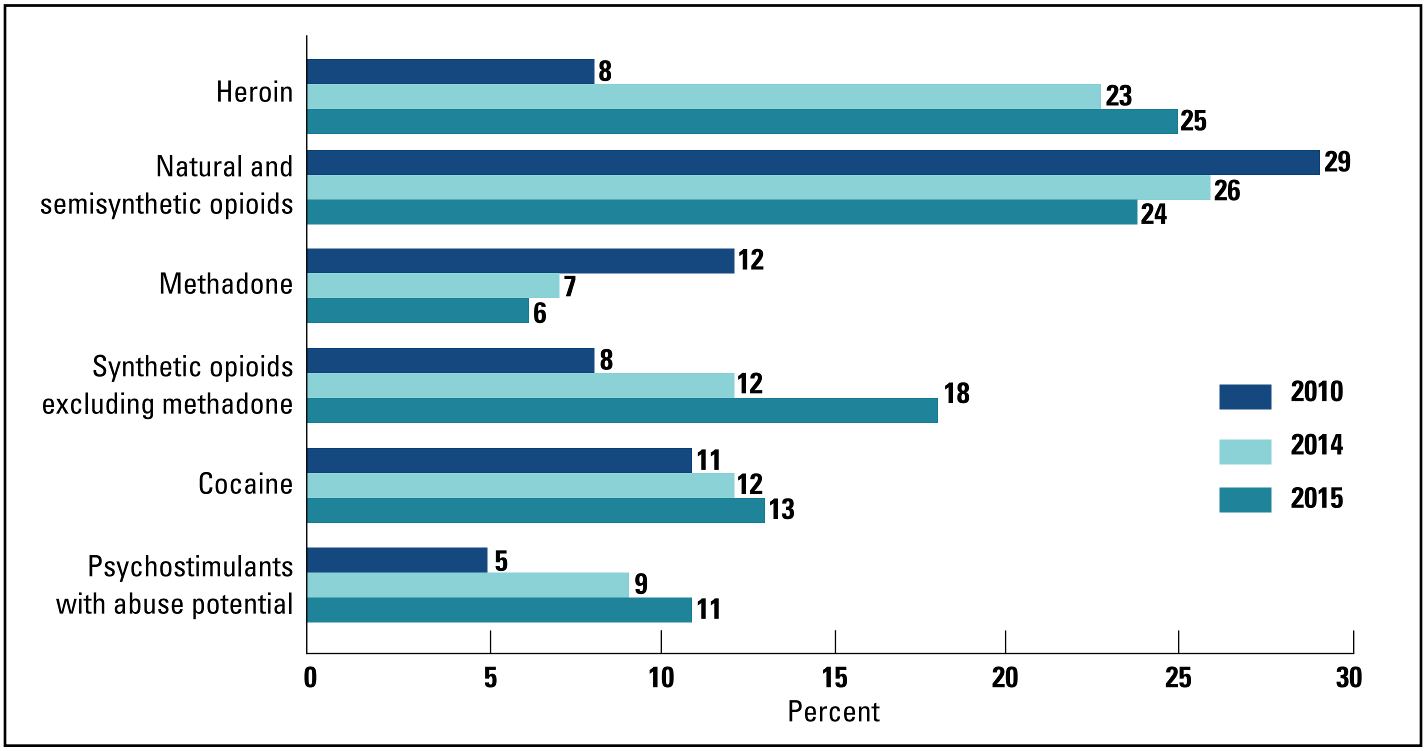
By Tiffany Epley, Will Dane, and Dianna Fahel, Brain Injury Association of America

Opioids are synthetic or semisynthetic substances originating from the poppy plant. Examples include heroin, Fentanyl, and prescription opioid painkillers, all of which operate in the same fashion, albeit with varying degrees of strength. Synthetic opioids are among the most dangerous and addictive. The synthetic opioid Fentanyl, for example, is 25 to 50 times more potent than heroin, which is a semi-synthetic substance.

The National Institute on Drug Abuse explains, "[Opioids] act by attaching to specific proteins called opioid receptors, which are found on nerve cells in the brain, spinal cord, gastrointestinal tract, and other organs in the body." When substances attach to these receptors, they change how the brain perceives pain and instead produce feelings of euphoria. They also slow essential body functions, such as heart rate and breathing.

Opioids are depressants, or "downers," meaning that they inhibit the central nervous system (CNS). During an overdose, the body experiences CNS depression, which can result in decreased rate of breathing, decreased heart rate, and loss of consciousness, possibly leading to coma or death. In other words, an overdose causes the body to forget to breathe on its own. As such, the most significant risk of an overdose is the lack of oxygen.

Figure 5. Percentage of drug overdose deaths involving drug categories: United States, 2010, 2014, and 2015



Source: National Center for Health Statistics, National Vital Statistics System Mortality, NCHS Data Brief No. 273, February 2017.

Oxygen is essential to the human brain, and a lack of oxygen to the brain causes damage. So, what about those who are overdosing but not dying? The opioid epidemic has led to the creation of a new term: Toxic Brain Injury. This type of brain injury occurs from prolonged substance misuse and nonfatal overdose. This encompasses two forms of brain injury resulting from a lack of oxygen – hypoxic and anoxic brain injury. Hypoxic brain injury occurs when the brain does not receive enough oxygen, while anoxic brain injury occurs when the brain does not receive any oxygen. In these situations, the amount of time the brain is without adequate oxygen dictates the severity of injury.

Toxic Brain Injury has multiple effects on the brain. Brain damage caused by use of drugs could include disruption of nutrients needed by brain tissue; direct damage, injury, and death of brain cells, including neurotransmitter receptors; alterations to brain chemical concentrations, including neurotransmitters and hormones; and deprivation of oxygen to brain tissue. The effects on the brain will differ depending on the type of substance, the amount used, and the duration of use.

Substance Misuse and Brain Injury

There is a strong correlation between substance misuse and brain injury. Approximately one quarter of those entering brain injury rehabilitation are there as a result of drugs or alcohol, while nearly 50 percent of people receiving treatment for substance misuse have a history of at least one brain injury.

Research on the risk of substance misuse following a brain injury is scarce, as are facilities equipped to provide parallel treatment for both brain injury and substance misuse disorders. Oftentimes, substance misuse is ignored in the treatment of brain injury because the symptoms of intoxication and brain injury can appear to be similar. When a person comes into the hospital with a brain injury, the focus is on life-saving measures to treat the injury. The person may then be referred to a brain injury treatment facility, where his or her substance misuse disorder is often overlooked.

Adversely, epidemiological surveys have shown that substance misuse substantially increases the risk of brain injury, and recovery from brain injury

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> Toxic Brain Injury may not strike someone you love, but will affect someone you know.

is prolonged when substance misuse is present. Together, substance misuse and brain injury increase the negative effects each condition has on brain function and structure. Failure to treat both means that an individual is more likely to return to his or her drug or drink of choice following discharge from brain injury rehabilitation, often leading to a worsened outcome. Individuals are at an increased risk of falls, seizures, decreased cognitive ability, depression, subsequent brain injury, and potential death.

Although there is evidence of reduced drug use within the first year post injury, those with a prior history of substance misuse before their brain injury are 10 times more likely to resume past behavior. Further, studies have indicated that between 10 and 20 percent of people with traumatic brain injury develop a substance misuse problem for the first time after their injury. This could be from stimulants and painkillers that are often prescribed to treat cognitive disruption and pain from their injury, which have their own potential for abuse. The cycle of risky behavior causing negative physical and mental outcomes will continue unless both conditions are treated concurrently.

Parallel Treatment is Essential

The opioid epidemic is not slowing in the United States. Awareness and education may be useful in combating its growth, but the solution is treatment. No matter the state, city, county, village, or neighborhood, communities throughout the nation are suffering from a lack of available treatment options for substance misuse. For every fatal overdose, there may be five nonfatal overdoses, many of which go unreported. Increasing the number of facilities equipped to treat substance misuse disorders and brain injury – together – is essential.

Physical and mental recovery from brain injury takes time, as does recovery from addiction. In situations where both are present, parallel treatment is the gold standard of care.

"Toxic Brain Injury may not strike someone you love, but will affect someone you know," said Susan Connors, BIAA's president and chief executive officer. Establishing long-term, multi-coordinated therapy, rehabilitation, and support is vital to the treatment and recovery process. The Brain Injury Association of America is dedicated to changing minds about brain injury and opioid abuse and will work diligently to seek new opportunities to bridge the treatment gap between these two deadly diseases.

Additional reading is available online at www.biausa.org/opioids. ●

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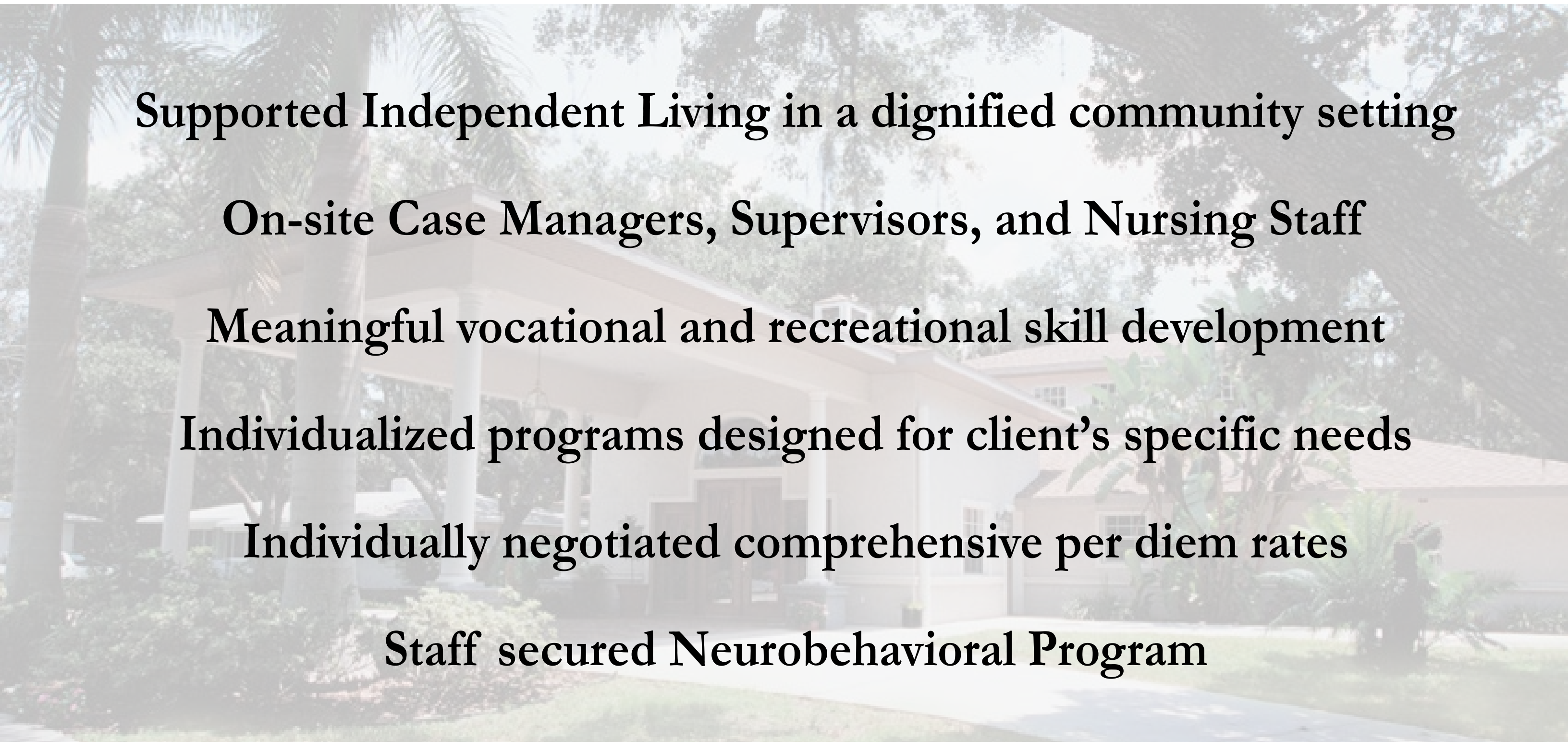

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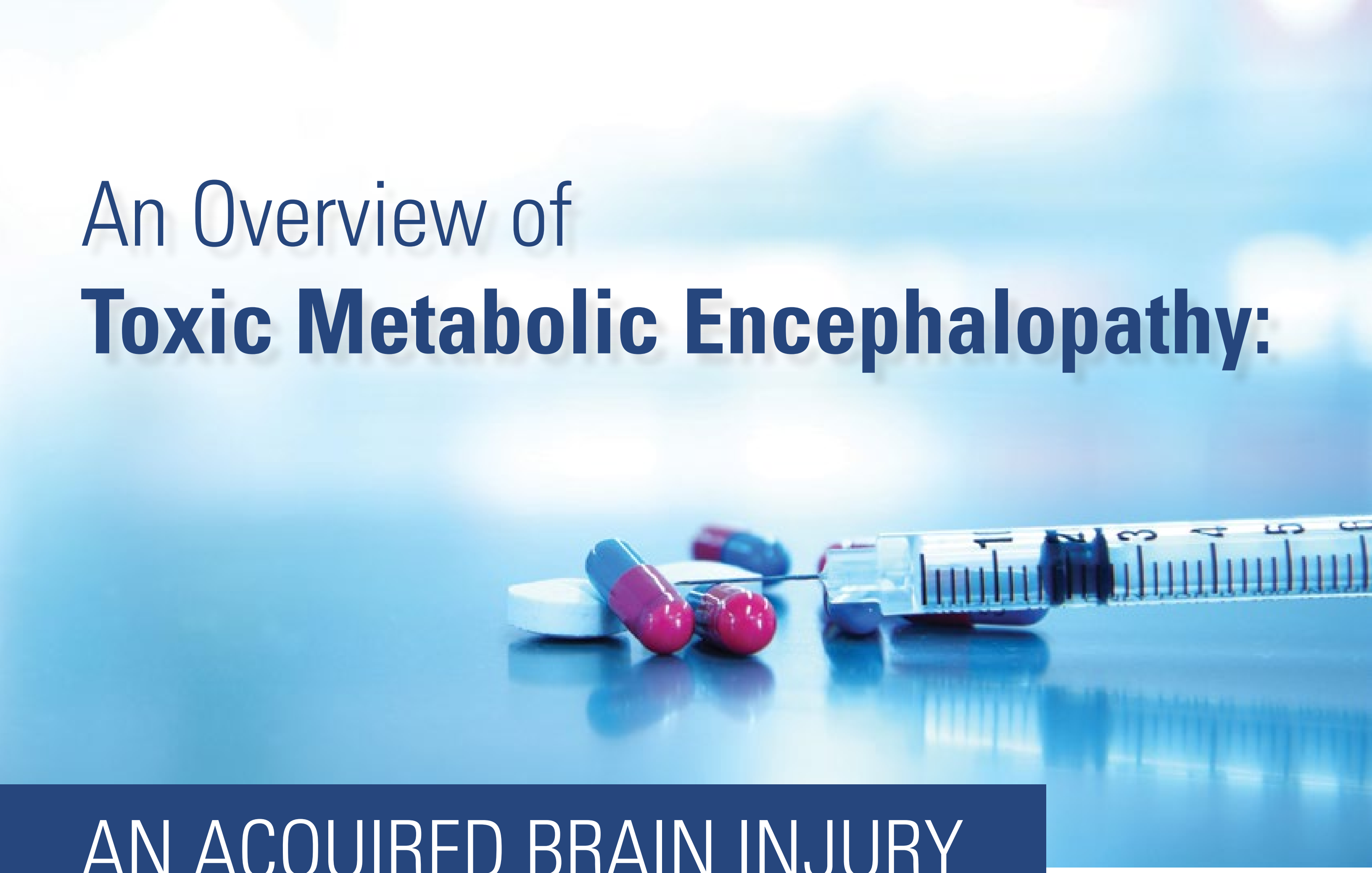
An Overview of **Toxic Metabolic Encephalopathy:**



AN ACQUIRED BRAIN INJURY

By Kristen Schreier, M.A., CCC-SLP, CBIST, HealthSouth Rehabilitation Hospital of Toms River

Have you known someone who experienced a change in his or her physical functioning or thinking skills after an infection or anesthesia? This change is often diagnosed as encephalopathy. Symptoms can develop suddenly and disappear within a few hours. However, for some, encephalopathy can be more serious, especially if you have a history of dementia or previous brain injury. One type of encephalopathy with an increased potential for lasting effects is toxic metabolic encephalopathy (TME).

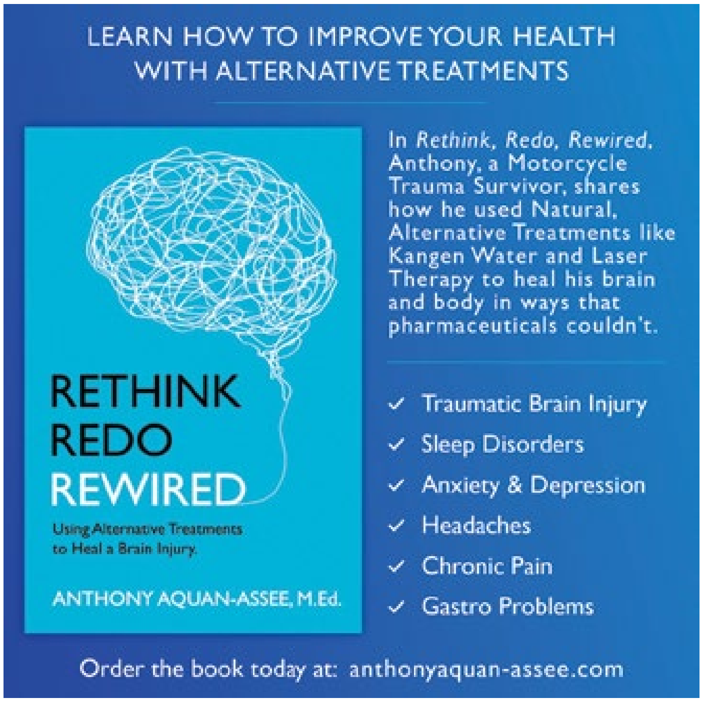
Toxic is defined as something composed of or containing poisonous material capable of causing serious debilitation. Your body's **metabolism** comprises the processes essential for life by which the complex substances in the body's cells are built up or broken down. **Encephalopathy** is a general term that describes brain disease, damage, or malfunction usually related to inflammation within the body (Merriam-Webster, 2018). If we combine all these terms, a TME diagnosis would follow when toxic cells in the body do not allow the healthy breakdown of substances leading to inflammation of the brain cells. This can cause an altered mental status, changes with walking, and overall weakness and deconditioning. Delirium is another term you may hear for TME.

Is TME a brain injury?

Yes; it is a non-traumatic, acquired brain injury, or something that happens to the brain after birth. TME is debilitating for some, especially as we age, and may cause changes in physical and cognitive functioning. The causes of TME are numerous and varied. Some causes are infections, dehydration, malnutrition, alcohol toxicity, liver/kidney disease, metabolic imbalances, or reduced oxygen to the brain. If you have a pre-existing medical condition or if you're not as active as you once were, you are more susceptible to developing TME. Researchers consider encephalopathy to be a symptom of an underlying condition, such as chronic urinary tract infections or uncontrolled diabetes. Therefore, if an encephalopathy is diagnosed, a pre-existing condition must also be addressed.

It is difficult to diagnosis TME because other issues have to be ruled out first. Rather than specific diagnostic testing, a combination of results from standard lab work and tests must be evaluated. Tests assess for infection, abnormal blood glucose levels, elevated ammonia levels, or changes with liver or kidney enzymes. A CT scan or MRI of the brain is used to rule out underlying neurological conditions or changes in your brain function. The results of these tests assist your physician in determining an accurate diagnosis.

Certain conditions lead to increased toxicity levels, increasing your risk of developing TME. Current or previous drug or alcohol abuse could lead to an imbalance in your metabolism, which can lead to an altered mental status. Additional causes of this type of imbalance are dehydration and malnutrition. When you drink water and consume nutrients, your body takes in a balanced amount of electrolytes, keeping the body's cells nourished and functioning. When you are not drinking enough water, cells have a higher level of sodium, resulting in the metabolic imbalance. This leads to functional decline, an acute state of confusion, seizures, or death (Panther, 2016). "A diet rich in vitamins and minerals such as Folic Acid and Omega-3 fats prevents a cognitive decline as we age and decreases serious health risks" (Torres, et. al, 2012). Dehydration and malnutrition can lead to emergency care needs and hospitalization. With knowledge and recognition of symptoms, both are avoidable.



"Some medications can cause or exacerbate cognitive deficits and thus complicate rather than facilitate restoration of health. Use of anti-epileptic drugs to reduce seizures or cancer treatment drugs have been reported to cause delirium, reduced cognitive processing, or deficits with short term memory" (Youse, 2008). Medications that help the kidneys reduce sodium or water levels in the body can change the body's chemical make-up and lead to dizziness and confusion. This is because the body is not breaking down the medications thoroughly, and that build-up of medications leads to toxicity. "The chances of a medication build-up increases especially in the elderly and with other medication interactions" (Abou-Khalil, 2015). It is important to review your current medications with your primary physician and pharmacist. Certain medications may have side effects or have interactions with other medications that cause symptoms of TME.

While there is no specific cure for TME, there are treatments for the underlying causes that may lead to an improvement in symptoms. For example, if your TME occurs because of an infection, you may notice your altered mental status improves and you have more energy to complete daily activities once you complete the course of antibiotics. If your sodium levels are too high because of dehydration, you will notice overall functional improvements

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Exercise promotes a healthy lifestyle and keeps the body going, including getting oxygen and blood to all parts of the body – especially the brain!

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once adequately hydrated. Underlying pre-existing conditions may prolong recovery time, and some changes and deficits may become permanent, especially as we age. Recovery might have to include adjusting how you complete routine activities.

If you are diagnosed with TME, your doctor may recommend a length of stay at a rehabilitation hospital to improve your physical or cognitive functioning. Physically, you may present with weakness and fatigue and changes with walking. This impacts your ability to complete everyday tasks such as getting in and out of bed, and increases your risk for falls. Physical and occupational therapies focus on improving strength, endurance, and balance. Therapists will educate you about compensatory strategies and will recommend necessary equipment to complete your daily activities safely. According to Gion (2013), those diagnosed with TME have a higher percentage of falls. Nearly all patients who have fallen in a hospital setting have had evidence of TME and are six times more likely to fall after they are discharged. Fall prevention and safety training through skilled therapy are key in minimizing a fall risk for yourself or a loved one.

Diagnosis of TME can impact cognition, or the everyday thinking skills that control areas such as memory, judgment and problem solving. Deficits in cognition can impact your ability to continue to live independently. For example, you may have difficulty following recipes for daily meals or organizing a daily pill schedule for medication management. Cognitive therapy at a rehabilitation center may be performed by neuropsychologists, speech-language pathologists, and occupational therapists. The focus is to improve mental skills and train compensatory strategies to improve functional daily activities.

Encephalopathy might not be fully preventable, but there are some general wellness tips that are recommended. Keep your mind active by completing your daily responsibilities and enrichment activities, such as word searches or jigsaw puzzles. As the saying goes, "If you don't use it, you lose it." You should also think about your nutrition. Eat the foods recommended to you by your doctor or dietician for a well-balanced diet, and make sure you're well-hydrated to keep the cells of your body nourished. If you don't like plain water, add some sliced fruit to give it flavor. Lastly, make sure you exercise within your means. If you can go for a walk, take it! If you can do chair yoga, do it! Exercise promotes a healthy lifestyle and keeps the body going, including getting oxygen and blood to all parts of the body – especially the brain!

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If you or your loved one would like additional information on acute rehabilitation hospitals, like those with Encompass Health, formerly HealthSouth, or the HealthSouth Rehabilitation Hospital of Toms River specifically, visit www.encompasshealth.com or www.rehabnj.com.

Contributors: *Jessica Heimall, DPT, CBIS; Jared Burch, DPT*

Pushing for Policy Change

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

For more than 30 years, John Whyte, M.D., Ph.D., has been committed to brain injury research and advocacy, both professionally at the Moss Rehabilitation Research Institute and personally as a self-described policy advocate. He is an extraordinary researcher, clinician, advocate, and leader who gives very generously to the Brain Injury Association of America and the field. His impact on the brain injury community is regularly demonstrated by his dedicated efforts to improve the quality of life for all those affected by brain injury.

Dr. Whyte was one of the first clinicians to take a special interest in persons with severe disorders of consciousness due to brain injury. After only one year of working with individuals who sustained a traumatic brain injury (TBI) patients during his medical fellowship, he was hooked. "Once I started to work with patients with TBI clinically, I became interested far more deeply than just as a population I could study," Dr. Whyte explains. "I became fascinated with the complicated combination of biological, psychological, and sociological factors that are relevant to TBI." His current research focuses primarily on the cognitive effects of severe TBI, with particular emphasis on attention, executive function, and consciousness.

A clinical scientist with dual training in physiatry and experimental psychology, Dr. Whyte has received many awards in recognition of his achievements in brain injury research and clinical care. He was honored with BIAA's 2002 William Fields Caveness Award and the 2005 Pioneer Award by the Brain Injury Association of Pennsylvania. He has also been active in academic pursuits related to rehabilitation, including serving as president of the Association of Academic Physiatrists and being an active member of the American Congress of Rehabilitation Medicine, where his contributions have been recognized with the Distinguished Academician and Fellow awards, respectively.

His advocacy efforts on behalf of persons with brain injury began early in his career. He became involved with the Brain Injury Association of America (BIAA) more than 20 years ago, when it was known as the National Head Injury Foundation. In those days, he says, brain injury was “truly the silent epidemic,” and he felt compelled to help raise awareness of the condition. He implemented what he calls a “tithing budget” and used his funds to support the causes and organizations that mattered most to him. While some of his passions have changed over time, his commitment to brain injury – and BIAA – have remained consistent.

Due to his interest in effecting policy change, Dr. Whyte has served on peer review and scientific planning committees for the National Institutes of Health, the National Institute on Disability, Independent Living, and Rehabilitation Research, and the Veterans Administration. He is impressed with BIAA’s work as the “information clearing house” for individuals affected by brain injury. “Few people are well-informed about brain injury before they or a family member experience it,” he explains, “But then suddenly they are in desperate need of information. BIAA helps to make sure that information is readily available to everyone.”

As a clinician, Dr. Whyte knows the importance of access to proper rehabilitative care after brain injury and is grateful for BIAA’s advocacy efforts over the last two decades.

“In addressing policy and payment issues, which is incredibly important during these times of rapid policy change and fiscal constraint, BIAA helps the brain injury community as a whole. One thing I’ve learned as both a researcher and a policy advocate is that evidence only goes so far in influencing policy. Organized groups of people with common policy interests need to PUSH for policy change even when the evidence exists to support it. BIAA is the most important and effective entity in representing the needs of people with brain injuries.”

To join Dr. Whyte in helping BIAA continue this important work, visit www.biausa.org/support and make your donation today.

INTRODUCING BIAA'S NEW WEBSITE

The Brain Injury Association of America is proud to announce the all-new, completely redesigned www.biausa.org!

Mobile Friendly

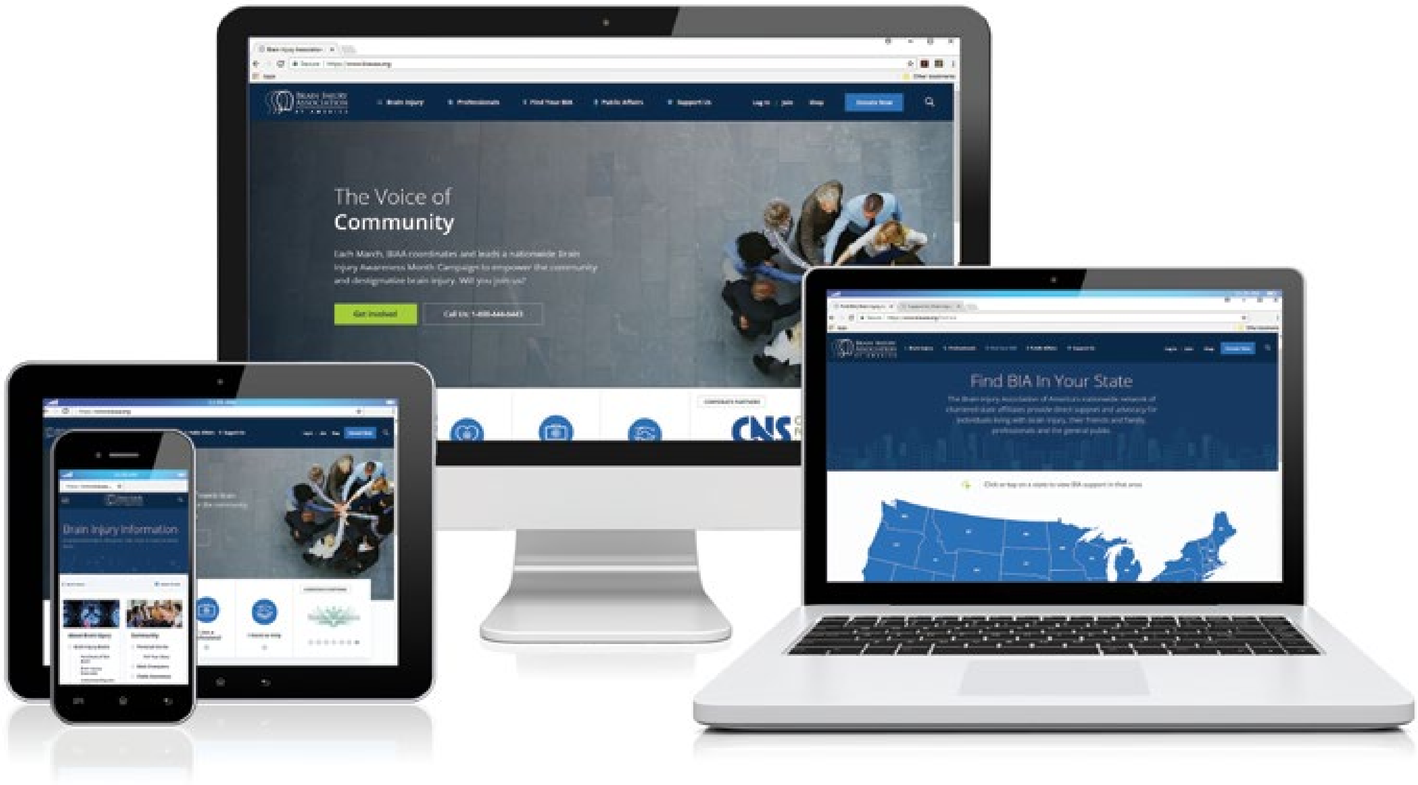
More than half of the 1.5 million annual visitors access www.biausa.org from their smart phones or tablets, and the new design provides accessible information regardless of device.

Innovative Design and Enhanced Performance

Website visitors are easily able to sort through information about brain injury diagnosis, treatment, care, prevention, education, awareness, and advocacy.

Fresh Content

Whether you are a person with a brain injury, a family member or caregiver, a medical professional, or you're simply curious to know more, www.biausa.org has the information you need.



Homepage

Read the latest news, find upcoming events, and discover content BIAA has created specifically for you.

Brain Injury Information

Brain injury is unpredictable in its consequences and can change everything about us in a matter of seconds. Whether it's you or your loved one who has sustained a brain injury, you will find the information you're seeking on our website.

Preferred Attorneys

Selecting the right legal representation is critical. The BIAA's Preferred Attorneys have demonstrated their knowledge of the physical, cognitive, emotional, and financial tolls a brain injury can inflict. Search online for a local legal expert specializing in brain injury.

Research

BIAA advocates for increased funding from public and private sectors, promotes participation in research studies, and disseminates research findings to the brain injury community.

Find Your BIA

BIAA's nationwide network of chartered state affiliates provide direct support and advocacy for individuals living with brain injury, their friends and family, professionals in the field, and the general public.

Enhanced Personal Stories

A long-time favorite on BIAA's website, the revamped Personal Stories section offers website visitors an opportunity to tell their story and engage with others

Building a Community

BIAA serves every member of the brain injury community at every point in his or her journey. By joining the website, visitors will receive news and information with their individual interests in mind.

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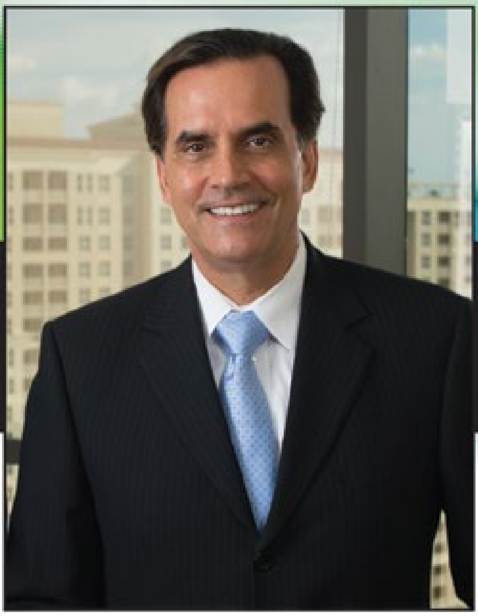

Advocacy UPDATE

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

The second session of the 115th Congress has gotten off to a rocky start, with two government shutdowns and two six-week Continuing Resolutions to fund the federal government. There were, however, victories for the brain injury community during this uncertain time of the congressional process. Congress approved an increase in spending for domestic programs, repealed the arbitrary Medicare therapy caps – a huge win for the brain injury community – and extended the Children's Health Insurance Program (CHIP) for ten years.

BIAA Legislative Agenda Announced for 2018

The Brain Injury Association of America (BIAA) will focus on critical legislative initiatives in 2018. BIAA's top priorities include protecting access to health insurance for individuals with brain injury and protecting federal resources for the brain injury community. Over the last year, Congress and the Administration aggressively attempted to dismantle the Patient Protection and Affordable Care Act and block grant Medicaid, which would have resulted in individuals with brain injury losing access to health care. BIAA will continue to advocate for increased funding for the traumatic brain injury (TBI) state grant program, the TBI programs at the Centers for Disease Control and Prevention (CDC), the TBI Model Systems of Care, and TBI programs at the Department of Defense. Other priorities have been detailed in BIAA's 2018 legislative issue briefs:

- Coordinate Federal Resources
- Increase Access to Care for Individuals with Brain Injury
- Bolster Research for TBI
- Grow the Congressional Brain Injury Task Force
- Keep Individuals with Brain Injury Financially Solvent and Caregivers Strong
- Improve Awareness and Understanding of Brain Injury

To download the issue briefs, visit www.biausa.org.

BIAA Supported Legislation Included in the Funding Bill

President Trump signed a bill Feb. 9 to reopen the federal government, which briefly shut down, and provide funding for most of the government through March 23. The legislation lifts statutory budget caps, allowing increased spending for defense and non-defense federal programs. The bill raises the debt ceiling through March 2019; extends CHIP for another four years; provides funding to address the opioid crisis, research, and disaster relief; and repeals the Medicare Therapy Caps imposed on outpatient physical, occupational, and speech-language therapies.

Repealing the Medicare Therapy Caps has been a long-term goal for BIAA and it represents a huge win for the brain injury community! BIAA has been a longstanding member of the Medicare Therapy Cap Coalition, which has been working to repeal the arbitrary caps. Over the years, BIAA has circulated action alerts to our grassroots community, funded ads in Hill publications, met with lawmakers and staff, and engaged in social media campaigns – all to try to repeal these caps. BIAA Board members also flexed their political muscle to get this done.

The Feb. 9 legislation includes a two-year reauthorization of community health centers, funding for which had expired Sept. 30. It also ensures that ambulances can continue to serve rural areas and closes the Medicare Part D coverage gap for drugs by 2019. The bill includes $2 billion for National Institutes of Health (NIH) research and provides for five years of funding for early childhood home visiting programs. BIAA supported several health care bills in the House, including the repeal of the Medicare Therapy Caps, the Steve Gleason Enduring Voices Act of 2017 (H.R. 2465), the Medicare Independence At Home Medical Practice Demonstration program (H.R. 3263), and the Furthering Access to Stroke Telemedicine Act of 2017 (H.R. 1148).

Both the House and Senate Appropriations Committees plan to move forward with the full-year appropriations bills before the March 23 deadline in order to fund government through Sept. 30.

CBITF Hosts Brain Injury Awareness Day on Capitol Hill

Brain Injury Awareness Day on Capitol Hill, hosted by the Congressional Brain Injury Task Force (CBITF), chaired by Reps. Bill Pascrell, Jr. (D-N.J.) and Tom Rooney (R-Fla.), will be held March 20. If you are unable to attend Brain Injury Awareness Day on Capitol Hill in person, be sure to take action at home! Here are some things you can do to raise awareness:

- **Set up meetings in your elected officials' district offices to share the needs of individuals with brain injury in your state.**
- **Call your elected officials in Washington, D.C., and invite them to attend events you are hosting in your state throughout the month.**
- **Get active on social media: like your elected officials on Facebook, follow them on Twitter, and share BIAA's online resources with them.**

BIAA and Chartered State Affiliates Request CDC to Collect TBI State Data

BIAA and its network of state affiliates have partnered on an important letter-writing campaign to the director of CDC, requesting that the agency collect state-by-state data on the impact of TBI. In a response letter from CDC, leadership stated that CDC is currently using existing datasets to better understand the prevalence of TBI:

"We are collaborating with agency colleagues to publish reports describing TBI-related indicators by using emergency department data collected within a number of CDC-funded states. We also continue to explore ways to analyze and report on TBI-related emergency department visits and hospitalizations using Healthcare Cost Utility Project data. In addition, CDC is analyzing sports-related concussion data from High School RIOTM: Reporting Information Online and the 2017 Youth Risk Behavior Survey."

(continued on page 30)

State Affiliate NEWS

FLORIDA

The Brain Injury Association of Florida (BIAF) greeted 2018 with a flurry of activity. Djenaba A. Burns, who previously served BIAF as the director of operations/chief financial officer, was appointed president and CEO. Additionally, BIAF welcomed Katina Williams as the director of communications and development. Williams joins the BIAF team with extensive corporate and fundraising/nonprofit experience.

Last November, BIAF presented its first one-day, regional Camp TBi in Winter Park. Camp TBi is dedicated to providing an experience like no other by connecting families to a lifetime of hope and opportunity. Its premier line-up of activities included caregiver sessions by world-renowned experts, art expressions, gentle yoga, SLAM poetry, seated volleyball, and much more. In partnership with Orlando Health, BIAF hosted nearly 100 participants!

March launches WalkAbout Brain Injury season for the BIAF. Last year, walks were held in Tallahassee, Sunrise, and Navarre; BIAF welcomed more than 1,500 participants and raised more than $60,000 for the brain injury community! Thank you to BIAF long-term Platinum Partner, HealthSouth Sunrise, for its commitment and service to BIAF and the brain injury community. The final dates and locations for the 2018 WalkAbout Brain Injury season and the Camp TBi schedule are available at www.biaf.org.

▲ Campers having a great time at Camp TBi.

KANSAS

Like many other BIA affiliates, the Brain Injury Association of Kansas and Greater Kansas City (BIAKS) has a volunteer program that makes a tremendous impact on the efficiency and output of its office. Volunteers are survivors, family members, health professionals, students studying to be health professionals, and individuals who have a passion for helping others.

Each volunteer comes to us via a different path. Barb, who began volunteering two years after her brain injury, says she volunteers for many reasons: "I can relate to some of the struggles of those with brain injury and can act as a support system. I have had so many people help me the past four years and by volunteering, I can give back. Volunteering helps me to have a purpose and helps me not to isolate myself. It helps me to stay active in the community."

▲ BIAKS volunteer Barb is hard at work.

As part of the BIAKS volunteer program, we try to match tasks and roles to every person's skills and aspirations. For example, we asked a speech-language pathology student volunteer interested in research to help us expand our foundation database. Another very important feature of our volunteer program is that we, as staff, learn from our volunteers. These individuals help us gain a better understanding of how they cope, the skills and assets they carry over from "before," and the new skills they develop through their volunteer experiences. Our wonderful volunteers help us be more responsive and professional and allow us to carry out our mission of improving the quality of life for those affected by brain injury.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its third Bowling for Brain Injury^{SM} event Dec. 3, 2017, at Spare Time Portland. The event was a great success, with 81 bowlers raising nearly $10,000. Later in December, BIAA-ME published the second edition of the Maine Brain Injury and Stroke Resource Directory, in both print and online formats. Staff are currently in the process of distributing the directory across the state.

BIAA-ME was selected to be part of the Hannaford Bag Cause Program. Throughout February, $1 from the sale of each "Blue Bag with the Good Karma Message" at the Augusta Cony Street Hannaford supported BIAA-ME.

The Third Annual Maine Brain Injury Resource Fair will take place March 29 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.

Goodwill of Northern New England"s team, the BaySide Believers, were this year's top fundraisers. *Photo credit: Sarah Gaffney*

BIAA-ME Program Coordinator Sarah Gaffney"s daughters were ready to bowl! *Photo credit: Sarah Gaffney*

MICHIGAN

Through much of 2017, the Brain Injury Association of Michigan (BIAMI) and its legislative allies advocated rigorously against a bill that would have eliminated many of the state's Auto No-Fault benefits. Had the bill succeeded, the repercussions for brain injury survivors and caregivers would have been disastrous.

Thanks to assistance from the Coalition Protecting Auto No-Fault and our community of survivors, caregivers, and professionals, our opposition to this bill was expressed to legislators via letters, phone calls, social media posts, op-eds, and extensive personal lobbying. Our presence at insurance committee hearings, town hall meetings, and at the Michigan State Capitol in Lansing in the days leading up to the vote further made the case and rallied support.

The bill in question was defeated in a dramatic late night vote on the Michigan House floor Nov. 2, despite enormous financial and political pressure from Detroit's mayor and insurance company forces. While much work remains, the bill's defeat is a significant victory for those relying on Auto No-Fault benefits.

Advocates rally to protect Auto No-Fault benefits.

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MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual seminars, "Sports Concussions: Facts, Fallacies and New Frontiers," Jan. 29-Feb. 12. Sports and school personnel attended to learn from concussion experts across the state about topics such as concussion signs and symptoms, research, and changing the concussion culture in youth sports.

In March, the annual Survivor and Family Seminars were held in Springfield and Kansas City. Survivors and family members shared their stories and discussed adjusting to life with a brain injury. Attendees also participated in sessions about stress management, behavior, nutrition, exercise, and options related to post-injury health care and guardianship. The seminars will be offered in St. Louis later this year.

Survivors of brain injury can enjoy a week of fun, independence, and adventure at the BIA-MO Donald Danforth, Jr. Wilderness Camp May 27–June 1. For more information, visit www.biamo.org.

◀ Sports and school personnel learn about concussion at BIA-MO's annual seminar.

NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) was recently awarded a $25,000 grant from the New Hampshire Charitable Foundation to develop a Veterans' Brain Injury Clinic. The purpose of the clinic is to provide veterans living with TBI/PTSD and their family caregivers with brain injury resources in the community as well as military services. It will be held monthly, and referrals will come directly from the VA.

The 11th Annual Statewide Caregivers Conference, hosted by the Coalition of Caring Planning Committee for New Hampshire, was held in November. Keynote Speaker Kathleen Rusnak gave an inspiring, honest presentation, "The Spiritual Journey of the Caregiver." The 35th Annual Brain Injury & Stroke Conference will be held May 16 at the Grappone Conference Center in Concord. Carole Starr, leader of Brain Injury Voices of Maine, will be the keynote speaker.

This year's Walk by the Sea & Picnic will be held June 3. Last year, this fundraiser generated more than $32,000. For the fifth year in a row, team Moving Ahead raised the most money for the event!

▲ Attendees gather at last year's Walk by the Sea & Picnic event.

VIRGINIA

The Brain Injury Association of Virginia's (BIAV) 13th Annual Charity Golf Classic, held Oct. 9, was a great success. More than 70 golfers participated and helped BIAV raise more than $37,000.

BIAV collaborated with the Department for Aging and Rehabilitative Services to host the Seventh Annual Caregiver Forum November 4. Caregivers enjoyed a day of networking followed by a resource panel and sessions on mindfulness, caregiver resiliency, and Social Security benefits.

▲ Golfers gather at the 13th Annual Charity Golf Classic.

BIAV will host the 35th Annual Camp Bruce McCoy, a two-week summer camp for persons with a brain injury, at the Triple R Ranch May 20 to June 2. Camper activities include archery, riflery, horseback riding, fishing, arts and crafts, swimming, canoeing, and cooking, to name a few. To learn more about BIAV's 2018 events, visit www.biav.net.

▲ Campers enjoy activities at BIAV's 34th Annual Camp Bruce McCoy.

VERMONT

The Brain Injury Association of Vermont (BIAVT) is excited to host its first-ever Brain Injury Caregiver Retreat on June 3. The retreat will address topics including compassion fatigue, advocacy skill building, stress relief, and navigating benefits.

A new intern from St. Michaels College, Leah Seften, recently joined the BIAVT team. Leah will assist with several projects, including organizing a Youth Concussion Task Force and distributing Concussion Toolkit clipboards. The clipboards will be given to volunteer coaches of town recreation programs and to adults facilitating other non-school activities, such as martial arts classes, where concussions are likely to happen.

After 15 years of service, Montpelier-area support group facilitators Kathy Grange and Marsha Bancroft are stepping down. BIAVT thanks them for creating a safe and welcoming environment for the brain injury community. ●

Brain Injury ADVISORY COUNCIL CORNER

Member Spotlight: CAROLE STARR

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

Carole Starr is a published author, keynote speaker and the leader of the award-winning survivor group Brain Injury Voices. However, 18 years ago, she was a teacher early in her career and an amateur musician who loved performing. On July 6, 1999, her car was broadsided in an accident – and she was completely unprepared for the way her life and self would change.

In the emergency department, she was told she had whiplash. When she tried to go back to her regular activities a few weeks later, however, it became apparent that more was wrong than just whiplash. It was only then that doctors told Carole she had suffered a traumatic brain injury (TBI).

Carole could not understand her extreme mental fatigue, heightened sensitivity to light and sound, and difficulty managing everyday tasks. She had to quit playing music because she could no longer tolerate the sound, and would have to rest for days after struggling to teach for only two hours. She was frustrated that she couldn't just push through it.

As she began rehab, she started to understand more about TBI and why everything was so challenging for her. At the time, she believed she would make a full recovery.

Carole tried repeatedly to return to teaching and music, but each time she failed. It took her about eight years to accept her injury and to acknowledge that she was not going to get her old life back. She mourned the loss of her old life and her old self. Eventually, she began to embrace the "new Carole" and to focus on building a new life. Finding meaning in her experience and paying it forward were very important to her.

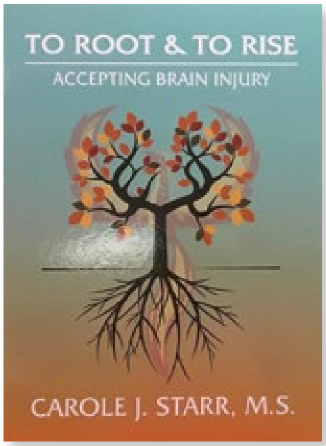
"I didn't think I could ever come to terms with this new Carole, but eventually I did," Carole says. "I want to help others on this journey because it is so hard. I want to give others hope to know that it is possible to have a happy, meaningful, productive life, even when coping with a disability. You have to let go of what was in order to live what is."

In 2010, Carole teamed up with her mentor, Bev Bryant, to found Brain Injury Voices, a survivor volunteer group in her home state of Maine. Their mission is simple: Educate, Advocate, Support. Their motto is all about paying it forward for others on the brain injury path.

In the past seven years, members of Brain Injury Voices have volunteered more than 15,000 hours, given more than 150 presentations, and mentored more than 1,500 peers. This year, they were able to

raise enough money to help some of their members, including Carole, attend Brain Injury Awareness Day on Capitol Hill in Washington, D.C., March 20, 2018.

Only in the last few years, and with support from friends and family, has Carole been able to resume traveling. She now gives inspirational keynotes at brain injury conferences. “My goal is to travel the country as a brain injury speaker and to share what I’ve learned from my eighteen-year journey to help others,” she says.



Carole’s latest way to pay it forward is through her book, “To Root & To Rise: Accepting Brain Injury,” which was published in 2017. “To Root & To Rise” is a workbook intertwined with Carole’s memoir. Each chapter discusses a different aspect of the grieving and the acceptance process. The book is designed in such a way that readers can choose which chapters to read, and they don’t have to read them in order. Carole’s teaching roots come out in this book. Each chapter includes questions and space for self-reflection, so readers can apply Carole’s strategies to their own experience. To purchase the book and support BIAA in the process, visit shop.biausa.org.

Through her book, keynotes, and leadership of Brain Injury Voices, Carole is paying it forward and making a difference in the brain injury community.

Carole joined the Brain Injury Advisory Council shortly after attending her first Brain Injury Awareness Day in March 2016. When asked how the BIAA has changed her life, Carole replied, “I didn’t have a passion for a cause before my injury, and now I do. For that, I am very grateful. BIAA helps me to focus on that passion. I like knowing that there is a larger organization out there working for survivors – that we are not alone. I have the opportunity to become more involved and be a voice nationally. Doing that alongside BIAA means a lot to me.” ●

(continued from page 23)

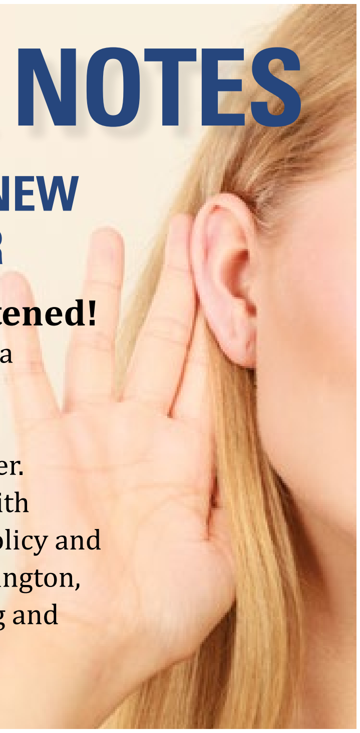
Advocacy **UPDATE**

CDC also referenced its pilot initiative, the National Concussion Surveillance System. Additional funds are needed to take this important work to the national level. BIAA has been advocating to Congress for an increase for CDC to complete this needed work.

New Director Announced at NIDILRR

Robert Jaeger, Ph.D., has been named the new director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), home to the TBI Model Systems of Care. Dr. Jaeger's research experience spans more than four decades. Much of his work has been focused on disability and rehabilitation research. He came to the Administration for Community Living in December 2017, following 10 years with the Office of Research and Development at the Department of Veteran Affairs (VA), where he first served as scientific program manager for prosthetics and rehabilitation engineering, and then as director of post-deployment health research. Prior to his time with the VA, Dr. Jaeger was the program director for the Research to Aid Persons with Disabilities Program at the National Science Foundation. He also served as a special volunteer with the Rehabilitation Medicine Department at NIH's Clinical Center. ●

News & **NOTES**



BIAA UNVEILS NEW POLICY CORNER

You asked – we listened!

March saw the release of a new, mobile-friendly template for our weekly e-newsletter, Policy Corner. If you'd like to keep up with important brain injury policy and news directly from Washington, D.C., visit www.biausa.org and sign up for Policy Corner.

Upcoming **WEBINARS**

Robert Sbordone Memorial mTBI/Concussion Lecture – Diagnosis and Treatment of Complex mTBI

March 29, 2018, 3 p.m. ET/12 p.m. PT

Christina Weyer Jamora, Ph.D., UCSF School of Medicine

Carolyn Rocchio Caregivers Webinar – Cognitive Tools and Strategies to Promote Independence After Brain Injury

April 11, 2018, 3 p.m. ET/12 p.m. PT

Tom Thompson, CCC-SLP, Loyola University

Business of Brain Injury Webinar – TBI and Domestic Violence

April 17, 2018, 3 p.m. ET/12 p.m. PT

Jerrod Brown, M.A., M.S., M.S., M.S., Pathways Counseling Center, Inc.

To register, please visit

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

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

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