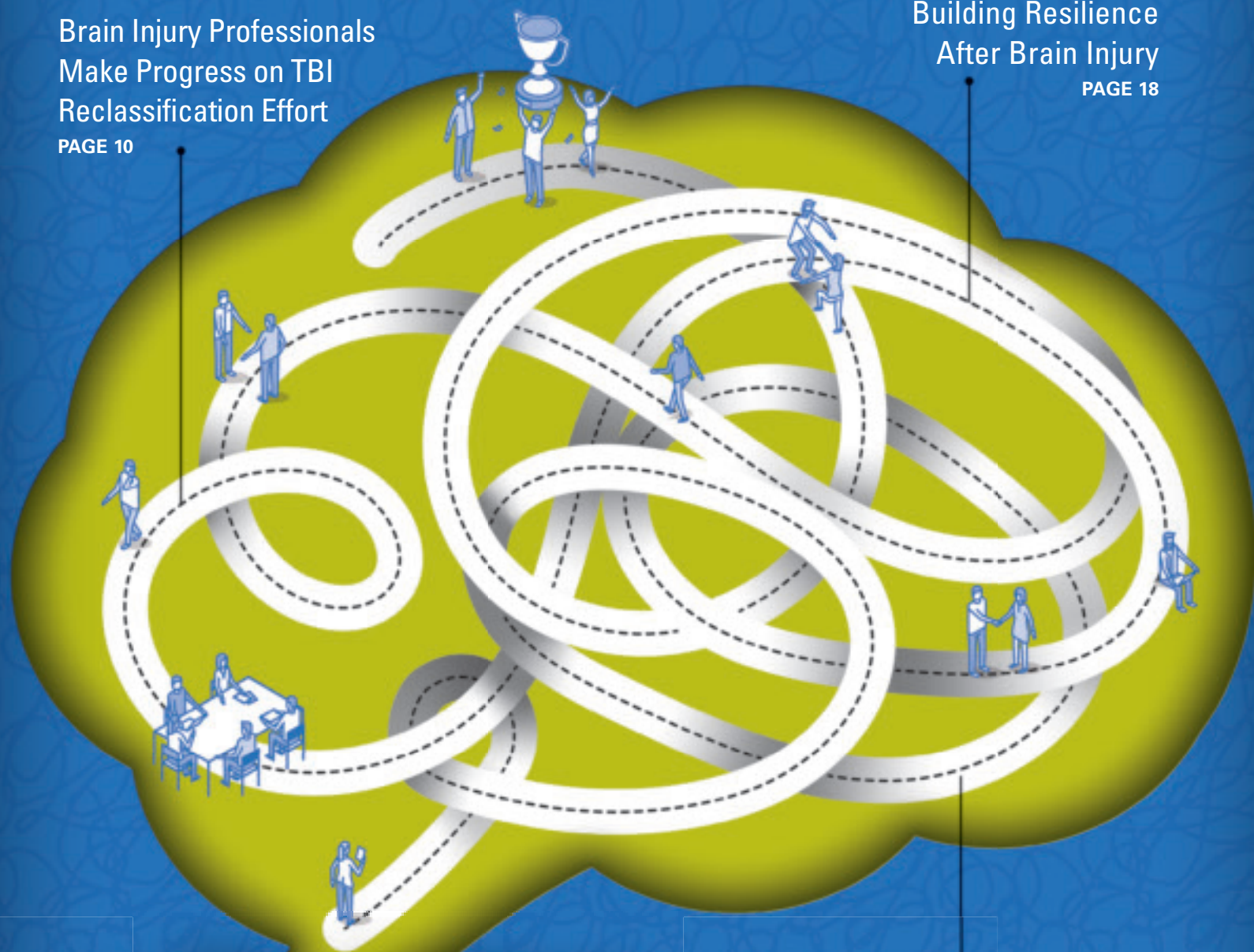


BRAIN INJURY ASSOCIATION OF AMERICA | Volume 18, Issue 1

THE CHALLENGE!

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Building Resilience
After Brain Injury
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The Lifelong *Journey* of Brain Injury

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MARCH 2024

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THE CHALLENGE!

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FROM MY DESK

Greetings,

Those affected by brain injury – survivors, their families and loved ones, and the people who treat them – all have their own stories to tell about how brain injury has changed their lives. The parts that have stayed the same, and the parts that have forever shifted. Who they were before brain injury became a part of their lives, and who they are after.

This Brain Injury Awareness Month, BIAA is proud to launch its new awareness campaign: My Brain Injury Journey. Through this campaign, we will bring attention to the changing nature of brain injury over an individual's lifetime and shine a light on its long-term effects and complexity.

This awareness campaign is closely tied to our advocacy work. As our community gathers for Brain Injury Awareness Day on Capitol Hill in Washington, D.C., we're making the case that long-term support for people with brain injury should be improved through the reauthorization of the Traumatic Brain Injury Act.

We are calling for the Centers for Disease Control and Prevention and the Centers for Medicare and Medicaid Services to designate brain injury as a chronic health condition, similar to heart disease or diabetes, and we believe that brain injury should be recognized, treated, and covered as such.

There are more than 5.3 million people in America estimated to be living with a permanent brain injury-related disability – that's 5.3 million stories, each one as unique as the person sharing it. This Brain Injury Awareness Month, we hope you'll share yours.

You can learn more about how you can get involved with our campaign, share your story, and support the reauthorization of the TBI Act at biausa.org/MyBrainInjuryJourney.



I also want to take the time to acknowledge a new partner, the Toyota Way Forward Fund, and thank them for their generous support of our Brain Injury Awareness Day activities in Washington, D.C. The Way Forward Fund is a multi-year initiative aimed at strengthening access to care and injury recovery support for individuals and their families, with an initial focus on children with TBI.

Sincerely,

A handwritten signature in black ink that reads "Rick Willis".

Rick Willis
President and CEO
Brain Injury Association of America



Be part of our awareness campaign and share your story. Visit biausa.org/mybraininjuryjourney or scan the QR code.





BRAIN INJURY: A LIFELONG JOURNEY

Survivors, Caregivers, Healthcare Professionals Share Why Brain Injury Should be Designated as a Chronic Condition

By Lauren Moore, Marketing and Communications Manager, BIAA

Every year, at least 2.8 million Americans sustain a traumatic brain injury. While many of them are fairly mild and can cause temporary neurological impairment, there are currently more than 5 million people living with a permanent brain injury-related disability – that’s one in 60 Americans.

The chronic, long-term effects of brain injury are wide-ranging, and can include fatigue, sensitivity to noise and light, memory loss, mobility problems, chronic migraines, trouble with focus and executive functioning, depression, anxiety, and susceptibility to conditions such as Alzheimer’s disease, stroke, Parkinson’s disease, and CTE.

Brain injury is currently viewed by the American healthcare system as well as the general public as a one-time event, rather than the beginning of a process of recurring or persistent effects. Unfortunately, the idea that brain injury can permanently change a person – their capabilities, their personality, their ability to work and socialize as they once did – is not something most people can wrap their heads around. There is a lack of understanding amongst the general public as well as within much of the medical field about the long-term effects and chronic nature of brain injury, particularly amongst those survivors living with invisible disabilities. But designating brain injury as a chronic condition that can require lifelong management of symptoms would go a long way toward correcting misconceptions about a condition that impacts millions of Americans.

”

The pieces of me are still in there, but I use them differently. I had to go through the mourning process for a long time, and to realize that this different Carole is not a cracked version of who I used to be. She is a worthy person in her own light.

Carole Starr



This Brain Injury Awareness Month, the Brain Injury Association of America is calling for the Centers for Disease Control and Prevention and the Centers for Medicare and Medicaid Services to designate brain injury as a chronic condition, and that brain injury should be recognized, treated, and covered as such. This designation would not only go a long way toward correcting misconceptions about a condition that impacts millions of Americans, it would impact funding for brain injury research, allow for additional public health resources to be focused on lifelong effects of TBI, and would incentivize health insurance providers, particularly Medicare and Medicaid, to provide additional benefits and other supports as they do for other chronic health conditions.



Look for BIAA’s full position paper on this topic at biausa.org

Living with Chronic Brain Injury

Survivors Share Their Experiences

Cazoshay Marie was walking back to her car after an event at the Downtown Phoenix Science Center in May 2017 when she was struck by a car driving 48 miles per hour. The accident left her with numerous injuries, many of which were obvious at the time, such as broken bones and a dislocated jaw. Others were not – including the traumatic brain injury that she said has completely changed the trajectory of her life.

“Prior to my brain injury, I was a wellness professional. I had my own business and held classes,” Cazoshay shared.



Cazoshay Marie

Nearly seven years later, Cazoshay still lives with lingering side effects from her TBI, including chronic migraines, difficulty with short term memory and concentration, and vestibular issues

impacting her vision, which have affected her ability to do everyday activities like driving and cooking.

“There was a lot that I felt like I lost in a sense of my old self, but I also gained a newfound strength and determination to move forward, and to advocate for other people who are in my same position,” she said, adding that it led her to become a speaker and disability advocate. “Although it changed my life’s direction completely, it was not necessarily all negative.”

Her story – one of long-lasting symptoms, journeys of acceptance, and a need to reevaluate one’s life path – is not uncommon among brain injury survivors.

“There’s not much that’s familiar about my life since my injury,” said Stacia Bissell, who sustained a brain injury after a bicycling accident in 2011.

At the time of her injury, Stacia was at a pivotal point in her teaching career, having taken on a new role in administration as the next step in her aspirations to run her own school. She was married with three children on the cusp of adulthood, had a robust social life, and was recovering well from back surgery two years prior. Her brain injury, and the lingering effects of it, changed everything.

Many TBI survivors who live with the chronic effects of brain injury speak about their lives in two stages – the person they were before their injury, and the person they are post-injury.

“My life totally changed,” shared Angela Leigh Tucker, who sustained a TBI following a crash with an 18-wheeler in 2008. “There was an acceptance journey that happened, once I was able to accept that Angela One died on July 31, 2008, and Angela Two was born on that same night.”

”

In my experience, I have not met many people who know someone living with a brain injury, as prevalent as it is. Most folks that I know, I am the one that they know who has a brain injury. It’s a lack of education, and a lack of awareness, that these misconceptions are so prevalent.

Angela Leigh Tucker



That acceptance journey is not one that is quick, nor is it easy.

“I was 32 when it happened,” shared Carole Starr, who sustained a TBI in a car crash in 1999. She was building a career as an educator, was an amateur violinist and singer, and figured she would be a wife and a mother one day. But her brain injury put her on a different path. “I had to mourn that for a long time,” she said.

And unfortunately, the idea that brain injury can permanently change a person – their capabilities, their personality, their ability to work and socialize as they once did – is not something most people who don’t have experience in life with brain injury can wrap their heads around.

It’s especially common for those survivors whose lingering effects are invisible.

“She looks fine. She looks like an average, 25-year-old woman,” Kelly Lang said of her daughter Olivia, who sustained a traumatic brain injury in a car crash at the age of 3.



Olivia Lang and Kelly Lang

“People think she’s much more capable, and then when she doesn’t succeed, they’re like, ‘Well I don’t understand what the problem is.’”

Olivia continues to live with several chronic effects of that TBI, including fatigue, processing issues, migraines,

peripheral vision loss, and mental health struggles. Kelly, who was diagnosed with a brain injury from that same car crash as well, also lives with chronic effects including sleep disorders, difficulty multitasking, and fatigue.

Kelly and her daughter have faced this backlash and lack of understanding about the chronic and invisible effects of brain injury at school, at work, and even among some health care professionals. “I have had to explain, ‘Look, she has a processing delay due to a brain injury. You yelling at her in a waiting room full of people is not going to help.’ People have invisible disabilities you can’t see, and you need to have more compassion.”

For some survivors, even attempting to explain the reasons for those changes – the chronic fatigue, the difficulties with memory and processing, the migraines – can exacerbate the misunderstanding.

“Language fails us. When I say, ‘I get really tired,’ or ‘I have trouble remembering things,’ people say, ‘Well, me too,’” Carole explained. “And it’s very isolating, when you can’t describe to people why you’re not the same anymore.”

Stacia commented that over the years she has developed strategies to help her cope with the lingering effects of her TBI, which include migraines, memory issues, fatigue, sensitivity to noise and light, tinnitus, speech problems, word retrieval issues, distractibility, difficulty sequencing, and anxiety.

“People don’t know that I’m using strategies for just about everything so I can keep up with conversations and my responsibilities, so I’m not overwhelmed by lights or crowds or noises,” she explained. “People don’t realize that my overplanning – I have to have a Plan A and a Plan B, and it’s tiring to make two plans for everything, but it’s necessary.”

There are dozens of misunderstandings and misconceptions about what brain injury is, and what it isn’t. But designating brain injury as a chronic condition would go a long way toward correcting those misconceptions about a condition that affects millions of Americans.

”

I think it's just a common misconception that people have, that we're functioning without actually working at functioning.

Stacia Bissell



“It would do huge favors for anyone living with brain injury,” Stacia said. “Designating brain injury as a chronic condition would help people understand what brain injury is and what it isn’t. It would remove some stigma.”

Cazoshay agreed. “I think it would have a huge impact, because I think that it would be taken more seriously as a medical condition that affects people more than just in the short term. I think that it would provide people the opportunity to access more resources and education regarding what brain injury is, not just for people who have sustained brain injury, but also for individuals in the community at large.”

It would also help the public understand the importance of prevention, or what to do if a person or their loved one sustains an injury.

“People take their brains for granted, I think, and they do not know that protecting their brains should be as important as eating right to protect their heart or overall health,” Stacia said. “If there was extra effort being made about the value of protecting brains because of what could happen, just like what will happen if you don’t eat right because of your heart health, that would go a long way.”

Designation and the Impact on Public Health and Health Insurance

The misconception that brain injury is a solitary event poses problems for patients who live with chronic symptoms and are seeking treatment for those symptoms.

"It leads to a prejudice against patients that have continued symptoms, which leads to a misinterpretation of those symptoms to being either malingering, fabricated, some sort of psychiatric disorder, or some sort of secondary process that is completely unrelated to the primary traumatic brain injury at large," said Gregory O'Shanick, MD, the Brain Injury Association of America's national medical director-emeritus. "That leads to misdiagnosis, mistreatment, and increased morbidity, mortality, and excess medical cost. And in some situations, leads to suicide, because patients despair and give up."

There are a significant number of people who survive their brain injury, only to develop problems later on, explained Brent Masel, MD, BIAA's national medical director.

Formal recognition by the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) would provide several advantages for brain injury survivors, including the allocation of additional public health resources to focus on the lifelong effects of TBI as well as health insurance plans, primarily Medicare and Medicaid, providing additional benefits and other supports as they do for other chronic health conditions.

The CDC spends a good deal of resources on public as well as provider education, noted John D. Corrigan, PhD, the Brain Injury Association of America's national research director and professor in the department of physical medicine and rehabilitation at The Ohio State University, explaining that designating brain injury as a chronic health condition would provide the opportunity to educate health professionals not immersed in the world of brain injury about the importance of a history of brain injury as a factor in a person's health, similar to how a primary care provider would consider whether a patient was prone to high cholesterol. In that instance, Dr. Corrigan explained, "You would give them advice and tell them what they could be doing to minimize that chronic condition and optimize their overall health."

Flora Hammond, MD, Nila Covalt Professor and Chair of Physical Medicine and Rehabilitation, Indiana University School of Medicine, and Chief of Medical Affairs at the Rehabilitation Hospital of Indiana, believes the designation would provide infrastructure

and resources for providers as well as the community to be more proactive and intentional in how people are helped after brain injury, with the potential for improved outcomes as well as a more appropriate alignment of resources for people living with brain injury.

"It would provide focus that goes beyond the short term," Dr. Hammond said. "Presently, there is such a focus on how someone is doing in the first weeks to months after injury, over time people forget about the potential effects of injury to recover and prevent worsening. Thinking of it as a chronic condition would have more focus on the long-term."

Dr. Hammond pointed out that most people living with brain injury do not have a brain injury specialist treating them – and if they do, it generally is not happening over the long term. "Many people are left with no follow-up after acute care," she explained.

The CDC also provides attention and resources for surveillance when a health condition is considered a chronic condition. While CDC spends uses a lot of resources for surveillance of chronic health conditions, none of that is being spent on brain injury, Dr. Corrigan noted. As a result, estimates of brain injury prevalence in the U.S. are outdated. "CDC's prevalence estimate was done more than 25 years and is based on the flawed assumption that only those who have immediate and persistent disability at one year post-injury should be considered a prevalent case," he said. "Everybody else is considered as not being affected by their brain injury." Overall prevalence of brain injury and its chronic effects is likely closer to 11 to 12 percent.

Dr. Corrigan added that, in addition to the public health resources allocated to the study and surveillance of chronic health conditions, there are benefits related to health insurance and benefits that come with the designation of a chronic health condition. "There are insurance benefits that provide access to additional services," he explained, citing the Medicare Advantage Plan as an example. These plans, he said, can create what are called C-SNPs, that provide additional services tailored to a chronic condition.

On the Medicaid side, Dr. Corrigan said, the benefits are potentially enormous. An overwhelming majority of Medicaid patients are on managed care plans, which are regulated by the states via contractual obligations. "People with chronic health conditions always receive additional attention in those contracts. Managed care providers have to make commitments to give people with chronic conditions more service," he said. Often, that service is case management, but can also include other services that help to keep someone living in the community and not in a nursing facility.

Chronic Conditions Recognized by CDC

- ▶ Arthritis
- ▶ Cancer
- ▶ Diabetes/Prediabetes
- ▶ Epilepsy
- ▶ Heart Disease
- ▶ Stroke
- ▶ Lupus

Chronic Conditions Recognized by CMS

- ▶ Alcohol Abuse
- ▶ Alzheimer's Disease and Related Dementia
- ▶ Arthritis
- ▶ Atrial Fibrillation
- ▶ Autism Spectrum Disorders
- ▶ Cancer (Breast, Colorectal, Lung, Prostate)
- ▶ Chronic Kidney Disease
- ▶ Chronic Obstructive Pulmonary Disease
- ▶ Depression
- ▶ Diabetes
- ▶ Drug Abuse/ Substance Abuse
- ▶ Heart Failure
- ▶ Hepatitis (Chronic Viral B&C)
- ▶ HIV/AIDS
- ▶ Hyperlipidemia (High Cholesterol)
- ▶ Hypertension
- ▶ Ischemic Heart Disease
- ▶ Osteoporosis
- ▶ Schizophrenia and Other Psychotic Disorders
- ▶ Stroke

Bolstering Brain Injury Research

One of the myriad benefits of designating brain injury as a chronic condition is the potential for more funding for efforts to study brain injury and its chronic and dynamic nature. While there are a few projects that are dedicated to studying brain injury outcomes, such as the TBI Model Systems and TRACK-TBI, this research is tremendously underfunded.

"I don't know of any funding programs by the National Institutes of Health or the Centers for Disease Control and Prevention that are dedicated solely to TBI," pointed out John Corrigan, PhD, national research director for the Brain Injury Association of America. "If you look at cancer, at Alzheimer's disease, and many chronic diseases, they have large portfolios."

But the incidence of traumatic brain injury is much higher than Alzheimer's, and is higher than cancer, yet traumatic brain injury research gets a fraction of the resources and attention, Dr. Corrigan noted. "I think the prospect that, when healthcare realizes that this indeed is a chronic condition and they want to know why, what's behind the dynamic-ness, what's behind the higher levels of excess mortality, we would start getting funding programs looking for the answers. But until the problem is recognized, the questions won't be asked."

Flora Hammond, MD, pointed out that while both the Veterans Administration (VA) and National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) have been looking at brain injury and its long-term effects, the topic of brain injury as

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I would like to see more of a focus on social determinants of health. Besides the injury itself, there are so many more influencers that affect it, like education, healthcare quality, and a social or community context. I would like to see more funding toward those other components and influencers that are really going to affect recovery.

Dr. Kelli Talley

a chronic condition is vastly underfunded and underrecognized by funding agencies.

Greater funding would allow for more elaborate longitudinal studies, Dr. Corrigan pointed out. And while there are longitudinal data sets out there – such as the TBI Model Systems – they tend to be loss leaders for the funded programs. "There are so many people we follow over time but the funding stays the same," Dr. Corrigan said. "We are constantly talking about ways we have to cut the data we are collecting." As a result, they do not have data about treatment received, medications taken, or the genetics of the people studied. "Just think about what that one program could do if it was fully funded."



STUDY UNCOVERS HIGH INCIDENCE OF CHRONIC PAIN AFTER TBI

A recent study published in the Journal of Head Trauma Rehabilitation (JHTR) found that chronic pain affects approximately 60 percent of traumatic brain injury (TBI) survivors, with some respondents reporting chronic pain up to 30 years post-injury. The research surveyed patients who were being followed in 18 TBI Model System centers, a research program that includes 16 civilian and five veteran rehabilitation centers in the U.S.

"We have known for some time that chronic pain frequently co-occurs with chronic brain injury," said John D. Corrigan, PhD, national research director of the Brain Injury Association of America and editor-in-chief of JHTR. "Clinically, it can both limit independence and diminish well-being. This series of studies has demonstrated empirically that indeed it is both frequent and disruptive."

All 3,804 respondents had been hospitalized with moderate to severe TBI. Time since injury ranged from one to 30 years, with the average time since injury being five years.

Cynthia Harrison-Felix, PhD, FACRM, co-project director of the TBI Model System at Craig Hospital in Englewood, Colo., said this is the first study that examines the experience of chronic pain in a large TBI sample this far post-injury. "Pain status did not differ significantly across follow-up years," she added. "While our data are not longitudinal, it suggests that chronic pain occurs at varying points after injury, and may interfere with initial recovery and long-term, necessitating proactive pain assessment and treatment."

The survey informed participants that chronic pain can be defined as "persistent or recurring pain that lasts longer than three months. It includes headaches or pain anywhere in the body, which occurs more than half of the days over a three-month period." When study participants were asked for specifics about their own pain, key results included:

- 46 percent reported current chronic pain
- 14 percent reported past chronic pain (after TBI)
- 40 percent reported no chronic pain
- 32.5 percent of participants with current chronic pain reported constant pain
- Compared with participants who reported no chronic pain after TBI or only past chronic pain, those with current chronic pain had significantly worse results on all three outcome measures included in the survey: the Functional Independence Measure motor and cognitive subscores, the Disability Rating Scale, and the Glasgow Outcome Scale-Extended

Medications, physical therapy, and home exercise programs were the pain treatments most commonly reported amongst respondents. Medications were used by 91 percent of participants with current chronic pain and had been used by 90 percent of those with past chronic pain. The least frequently reported treatment was comprehensive chronic pain rehabilitation.

The researchers concluded that chronic pain should be assessed and treated along with other neurocognitive and neurobehavioral disorders such as memory deficits and depression, and that while the directionality of the relationship between pain and outcomes cannot be assessed, the findings indicate that the presence of chronic pain after TBI is "far from benign."

PROFESSIONALS WHO ARE INTERESTED IN LEARNING MORE ABOUT THE CORRELATION BETWEEN CHRONIC PAIN AND TBI ARE ENCOURAGED TO DOWNLOAD BIAA'S WEBINAR, "CHRONIC PAIN AND TBI."



Scan the QR code or visit our online store at shop.biausa.org/products/recordedwebinars

The Next Big Step

Brain Injury Professionals Make Progress on TBI Reclassification Effort

By Lauren Moore, Marketing and Communications Manager, BIAA



The medical community took the next step towards implementing an updated classification system for traumatic brain injury (TBI) last month, as professionals from around the world gathered at the National Institutes of Health in Bethesda, Md., for a two-day TBI classification and nomenclature workshop.

The current TBI classification system, which categorizes patients as having sustained “mild,” “moderate,” or “severe” TBI, has been criticized as outdated, inaccurate, and ineffective for serving patients, clinicians, or payers. Calling this system “unsatisfactory from the vantage point of all constituents,” Dr. Michael McCrea, director of the Center for Neurotrauma Research at the Medical College of Wisconsin, pointed out that no other disease uses such reductionistic language as “mild, moderate, or severe,” and especially not to categorize conditions as complex and heterogeneous as TBI.

Under the guidance of a Steering Committee made up of doctors and researchers in the brain injury field, six working groups featuring clinical experts and stakeholders in the TBI field were developed, with each group focusing on one of six key areas: clinical/symptoms (including Glasgow Coma Scale, or GCS scores); imaging (including CT and MRI); blood-based biomarkers; psychosocial and environmental modifiers; knowledge to practice; and retrospective classification.

Dr. Andrew Maas, steering committee member and emeritus professor of neurosurgery at Antwerp University Hospital in Belgium, said the aspect of the knowledge to practice working group was a unique one. “We can come up with recommendations, we can write a publication about it, we can talk about it at meetings – but that doesn’t mean that the medical community takes it up and implements it,” he explained. Including experts in knowledge transfer and implementation science throughout the process has added value to the entire initiative, he added.

Members from each of these groups converged at the two-day workshop to share their findings and collaborate while seeking public input and feedback from the TBI community and stakeholders, with the goal of informing the development of a more precise and evidence-based classification system. The new

system, the steering committee stressed, must be both pragmatic for clinical use while also being adaptable for research applications.

Participants came to a general consensus about developing a classification according to a concept referred to as CBI-M – Clinical, Biomarkers, Imaging, and Modifiers. These pillars for the proposed new system are intended to help health care professionals consider multiple factors not only at the time of the injury, but at different points in the recovery process, while also considering pre-injury, psychosocial, and environmental modifiers that can impact a patient’s trajectory.

“We’ve focused primarily on the core objective of severity classification, with the expanded ability to reach a richer and deeper characterization in our patients with traumatic brain injury,” Dr. McCrea said.

Clinical Assessment

The Clinical Assessment building block speaks to the role of clinical assessment on Days 1 through 14. This group recommends that core clinical information be collected and recorded for all patients who present to a hospital with TBI. A research priority here would be to optimize the accuracy and utility of the Glasgow Coma Scale, as well as addressing its ceiling and floor effects.

“We’ve known forever that clinical severity is a critical element in classifying the grade of TBI, but also has enormous prognostic utility,” Dr. McCrea said. “There’s no coincidence that the cornerstone of any classification system is clinical indicators.”

The clinically actionable recommendations must go beyond the conventional GCS classification into three categories, Dr. McCrea explained, to the full spectrum of GCS, specifying the component scores of motor, verbal, and eyes, while noting confounds that could impact the score. He also noted the importance of understanding the dynamic nature of clinical status.

Blood-Based Biomarkers

The Blood-Based Biomarkers pillar focuses on select biomarkers for specific use cases in certain settings at specified time points. In certain cases, including among TBI patients who do not receive a CT scan, certain blood-based biomarkers may suggest clinically important brain injury that may not show positive finding on a CT. There is also the possibility that they can help predict the onset or harbinger of neuroworsening.

Compared to the other pillars outlined, biomarkers are a bit of a “newcomer,” Dr. McCrea said. One of the benefits of using biomarkers to classify or categorize patients is the added sensitivity they offer, particularly among the “mildest of the mild” injuries, such as in patients with a GCS between 13-15 and negative MRI and CT.

Imaging

The Imaging pillar addresses the importance of the role of scans such as CT and MRI in diagnosing and categorizing brain injury. The working group focusing on imaging noted the need to strike a balance between the pragmatic usefulness of CT scans with the increased sensitivity of an MRI.

Dr. McCrea noted the difficulty medical professionals might face when treating patients on the lower limit of detection – those whose CT and MRI scans are negative for TBI.

Modifiers

The final pillar in the proposed new classification framework is focused on a biopsychosocial model – preinjury characteristics of the patient that could affect recovery, such as age or history of prior injuries, psychological factors such as the response to trauma or rehabilitation, and social and environmental factors such as the patient’s social support system, geography, and access to care.

“Recovery after TBI is about damage evident on imaging, but it’s also about who comes to injury. Those premorbid factors or host variables. And ultimately the response to injury and the environment in which it takes place,” Dr. McCrea said.

The steering committee provided an example of how this framework could be applied in a real-world setting, by presenting two hypothetical patients with TBI. Under the current model, Patient A, a 29-year-old female, presents with a mild TBI, while Patient B, a 79-year-old male, presents with severe TBI. Within

the new framework using the CBI-M pillars, the presentation would include the patient’s GCS score, detailed information about the patient’s scan results, biomarker levels, and relevant medical history, such as a history of depression or prior brain injury.

Dr. Maas added that although the focus going into the conference was on initial injury classification, one important message that came out of the conference was the need for repeated assessment over time. “Which is completely appropriate – a patient can improve, while some patients might deteriorate,” he explained. “They might have a transition, where an injury that was formerly called mild, transforms to a severe TBI.”

Dr. John Corrigan, professor in the department of physical medicine and rehabilitation at The Ohio State University and national research director for the Brain Injury Association of America, led a working group focused on retrospective identification. “We will always need to identify and characterize injuries that occurred in a person’s past. Self-report and medical record abstraction are invaluable tools for clinical, epidemiological and research applications,” he said.

The steering committee noted that this is an ongoing process, with more work to be done as the community works toward a better classification system. “This is a living initiative,” Dr. McCrea told attendees. “This is not something we put to bed two weeks after this workshop and come back and revisit it again in seven years.”

The next steps toward cementing a better TBI classification system includes refining the CBI-M pillars and finalizing its framework, preparing a consensus document, conducting a pilot test in existing data sets, and developing and executing an implementation plan in partnership with stakeholders.

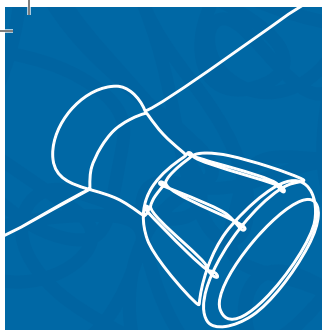
**Recordings of the two-day workshop
are available on the NIH website:**



Day One Recording



Day Two Recording



SURVIVORS IN THE SPOTLIGHT

TBI Classification Workshop Features Testimonials from Patients with Lived Experience

By Lauren Moore, Marketing and Communications Manager, BIAA

As part of the TBI Classification and Nomenclature Workshop held last month at the National Institute of Health, several individuals who have lived experience with traumatic brain injury (TBI) were invited to participate in a panel discussion to offer their personal perspectives on the current TBI classification system. Although each panelist had a unique story and experience with brain injury, with the severity of the initial injury varying greatly from person to person, a common thread amongst every participant was that the current classification system did not accurately reflect their own brain injury journey.

‘Mild’ Diagnosis Works Against Patients

Lindsay Simpson shared that she was diagnosed with a mild TBI – her eighth brain injury – by an EMT after a 40-pound beam fell on her head while on the job as a sports reporter in 2018. “Because it was ‘mild’ the initial response to my injury was treated with the same amount of urgency. I never went to the ER, was never properly evaluated for bleeding or swelling, and it was days before I followed up with a doctor,” she shared. “But over the past nearly six years, it is clear that my brain injury was anything but mild.”

Over the weeks and months that followed the initial injury, more symptoms began to present themselves – many of which have yet to resolve.

“Being diagnosed with a mild concussion has created substantial challenges in my recovery,” Simpson said. “I have constantly had to fight to be taken seriously by friends, and family, and doctors, and this misnamed mild categorization was weaponized against me as I had to fight it during contentious worker’s comp and litigation processes. It was used to try to malign my character, to prove that I was faking or malingering, and caused a mountain of stress that inhibited my ability to simply focus on recovery.”

The diagnosis, she added, did not take into account her seven prior brain injuries, nor the severity of the most recent injury’s impact. And because her injury was categorized as mild, it was never recommended that she receive inpatient treatment – although several of her doctors have concluded, in hindsight, that she should have been in an acute care facility.

“An appropriate diagnosis should have taken into consideration the type of impact that I suffered, my substantial history of traumatic brain injuries, and the continued decline I showed in the months following the accident. A proper classification would cause the responding providers to make sure I was under immediate medical observation, and given me applicable short and long-term treatment plans by the medical care team,” she said.

Nearly six years after her most recent brain injury, Simpson been unable to return to work, and lives with cognitive deficiencies; eye convergence issues; chronic dizziness, headaches, fatigue, and nausea; loss of sensation in her hands, right leg, and right foot; hearing loss and auditory processing challenges; and a stutter.



When you’re having to fight to be believed at every turn, the emotional toll that it takes absolutely hinders your ability to heal.

Lindsay Simpson,
TBI Survivor

'Severe' Patients Subvert Expectations

On the other end of the spectrum was Scott Hamilton, who was brought to the hospital in a coma after a Vespa accident in San Francisco.

"Most of the doctors and nurses who diagnosed my severe TBI 18 years ago could not imagine that I would be alive, let alone walking and talking on this stage today," he said. His wife was told by two doctors that he would not survive the night – he had a GCS

score of 3, right frontal contusion, subdural hematoma, and nick in his brain stem – and that given the severity of his injury, that was better than his surviving.

"According to the stats, I had about a one in 10 chance of coming out of my coma, and about a one in 20 chance of being able to talk, live independently, and not become a drug addict or alcoholic if I did live," he said.

He came out of his coma 12 days later, only to face a battle with his insurance to cover his acute rehab. Although he won that battle, he did not receive any post-acute care after leaving rehab: no check-ins, no assessments, no updates on how he would be classified or characterized. It was only due to the good fortune of having a neurosurgeon who gave him his cell phone number – Dr. Geoffrey

Manley, a member of the Steering Committee leading the charge to reclassify TBI – that Hamilton was able to receive guidance and help when things got bad.

"GCS oversimplified, and 'severe' reinforced the pessimism and resignation that would have led to life support being pulled, or bed confinement instead of rehab," Hamilton said. "In my case, my wife and Geoff Manley were the only two people in the hospital who

thought that I was worth fussing over, that there was anything worth doing."

The current classification system of "mild, moderate, and severe" promotes the idea that brain injuries are a hierarchy, Simpson said, adding that it boxes patients into linear, compartmentalized categories that, ultimately, are the antithesis of what a brain injury is. "We need to move away from something that resembles a ranking system, and something that categorizes people in more appropriate, applicable terms," she explained.

John Del Cecato, who was diagnosed with a severe TBI in 2021 following a scooter accident, said health care professionals would ask him questions about how he was feeling based on his scans, rather than how he was feeling that day, or that week. If the providers he was seeing had put more emphasis on his current state, they might have been able to examine the depression or the anosmia he later developed.

"I am not an expert in any way, but in my amateur view, if we change the way we label TBI, moving away from the severity of the injury when you enter the ICU and towards a metric like the health of the survivor at discharge, or the speed of the survivor's recovery ... that kind of a shift, in my view, would avoid putting medical professionals and patients in a position where they're so focused on the life and death stuff, that they miss the quality of life stuff."

Testimonials 'Remind Us Why We're Here'

Steering committee member Dr. Andrew Maas, emeritus professor of neurosurgery at Antwerp University Hospital in Belgium, said the testimonials that the people with lived experience shared "reminded all of us why we are here, and what the reasons are that we want to work towards a new approach to classification of TBI." He added, "It set the paces for the whole meeting, and got everyone inspired to do their best."

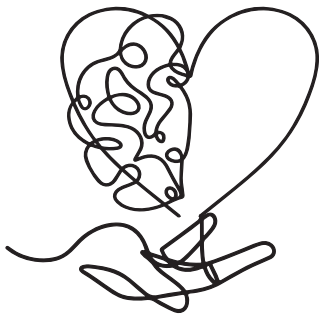
Dr. Michael McCrea, steering committee member and director of the Brain Injury Research Program at the Medical College of Wisconsin, commented on the "palpable bias" invoked by the "mild, moderate, severe" labeling. "We saw the impact on access to care, eligibility for benefits, communication," he said. "These individuals, our patients, have to not only overcome the effects of their traumatic brain injury on their life function, they have to overcome the core systems we have in place to take care of them. And we saw on display, the human will it sometimes takes to come out better on the other side. ... We must do better, and we will do better, with the valued input of our patients and our persons with lived experience."

”

'Severe TBI' is a term that reinforces resignation and the ignorance of the long-term acceptable and possible outcomes that are possible. 'Mild TBI' is a term that promotes denial about the symptoms that the majority endure for severely long periods, with big challenges and bad consequences.

Scott Hamilton,
TBI Survivor





COMMITTED TO DRIVING POSITIVE CHANGE

By Stephanie Cohen, Development Manager, BIAA

John Del Cecato, a seasoned political professional with a career spanning nearly 30 years, embarked on his journey in the political landscape by answering phones and making coffee for Dick Gephardt, the House Democratic Leader. He went on to work on local, state, and national campaigns, helping to craft media and communications strategies for politicians including Barack Obama, Pete Buttigieg, Bill de Blasio, Deval Patrick, and others. He eventually settled in New York City and formed a close partnership with mentor David Axelrod. During that time, John witnessed firsthand the transformative power of nonprofits in creating real change, when David and his wife Susan started a nonprofit dedicated to epilepsy research.

However, the fall of 2021 brought an unexpected turn when an electric scooter ride in Ohio resulted in a severe traumatic brain injury. With no memory of the incident, John woke up in the ICU facing a challenging recovery journey. Neurologists, ENTs, and audiologists played crucial roles in his recovery, conducting a slew of x-rays, MRIs, and CT scans.



Miraculously, John made a complete recovery, prompting a reevaluation of his priorities. The experience led him to research brain injury groups, ultimately discovering the Brain Injury Association of America (BIAA). Impressed by BIAA's mission clarity and efficient use of donations, John made his first donation.

During his post-injury journey, John experienced bouts of depression and a loss of taste and smell, both linked to his TBI. These experiences demonstrated the complex and dynamic nature of brain injury, motivating him to champion continued research and advocacy in the field. Inspired by the care he received and the recognition of his fortunate circumstances, John became an advocate for those who might face unexpected challenges like he did. For individuals undergoing similar experiences, John advises against letting the initial diagnosis define their path forward.

John retired from his busy political career in 2023, embracing a year of global travel, volunteer work, and helping his parents move from Virginia to the New York suburbs. His mission for the current year involves slowing down the world tour, adding a furry companion to his life, and helping BIAA with the reauthorization of the TBI Act, a piece of legislation that can unite members from both sides of the aisle for a common cause. Through fundraising and support, John is determined to propel BIAA's mission forward, recognizing the crucial role it plays in driving positive change. This commitment inspired his increased involvement with BIAA and a personal commitment to match donations made during the 2023 year-end fundraising push.

John's remarkable journey, from the world of politics to his incredible recovery from his accident, showcases his resilience, advocacy, and enduring spirit. BIAA is privileged to have such a passionate advocate in our corner, and we look forward to continuing this journey together, making a meaningful impact on the lives of those affected by brain injury.



LEAVE A LASTING LEGACY

A bequest is a gift from your estate – a transfer of cash, securities, or other property made through your estate plans. You can make a bequest to the Brain Injury Association of America by including language in your will or living trust to leave a portion of your estate to the Association or by designating BIAA as a beneficiary of your retirement account or life insurance policy.

Remembering the Brain Injury Association of America with a bequest from your estate will help sustain and strengthen the Association in years to come. Some of the advantages of creating a bequest include:

- Retaining control and use of your assets during your lifetime
- The ability to modify your bequest if your circumstances change
- Tax exemptions as gifts to BIAA from your estate are exempt from federal estate taxes

Let Us Thank You: Futures Fund Legacy Society

If you have included the Brain Injury Association of America in your estate plans, please let us know. We would like to thank you for your generosity, make sure the purpose of your gift is understood by the Association, and recognize you as a member of the Futures Fund Legacy Society.

Futures Fund Spotlight: Dr. Robert Sbordone

The world of brain injury lost an authority and leader in research and education when Dr. Robert Sbordone passed away in 2015. 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.



Learn more by contacting the development department at development@biausa.org or 703-761-0750 ext. 645 or visiting biausa.org/futuresfund.



BIAA AMPLIFIERS

Thank you to our recurring donors. Their support helps form a predictable source of income we can count on to fund services for people living with brain injury and their caregivers.

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THE FUTURES FUND LEGACY SOCIETY

The Futures Fund Legacy Society recognizes donors who have made a provision for BIAA through a planned gift or in their will or estate plan. Legacy gifts make it possible for BIAA to invest in new lines of research and meet the ever-evolving needs of the brain injury community.

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BUILDING RESILIENCE AFTER BRAIN INJURY

By BIAA Brain Injury Advisory Council members Stacia Bissell, Paul Bosworth, Darcy Keith, Kelly Lang, Cazoshay Marie, Kellie Pokrifka, Carole Starr, Angela Leigh Tucker

Brain injury can leave us feeling lost, like every part of our lives has been drastically affected. Many of us are overwhelmed by the questions of what our lives will look like now, and how we should take our next steps.

Building resilience is a key part of moving forward after brain injury. As members of BIAA's Brain Injury Advisory Council, we live these challenges every day.

Here is what we've learned about being resilient:

Accept & Celebrate the New You: Many people struggle to come to terms with their "new self" after brain injury. It is a lengthy process to grieve the many losses of brain injury, learn to accept yourself and get to know who you are now. Focus on what you can do rather than what you cannot do. This can help you move forward with your life.

Find Support: Living with brain injury is a team effort. You may need assistance, so remember that it's OK to reach out for support and help, no matter where you are in your journey.

Focus on Small Steps: It can be overwhelming to try and figure everything out all at once. By taking small steps, celebrating victories, and allowing yourself grace when things do not go according to plan, the big picture will gradually come together.

Find Gratitude/ Silver Linings: When each day is filled with so many challenges, like cognitive symptoms, emotional/physical pain, and more, life can feel unbearable. Learning to persevere and find beauty and happiness in your days – even when you feel they are significantly more difficult than your "before" days – can help reignite that light in your life. Keep track of specific things you're grateful for each day. Consider recording them in a gratitude journal or a gratitude jar and reflect back on those things on challenging brain days.

Find a New Sense of Purpose: A life changed does not have to mean a life ruined. After a brain injury, you may need to revise your dreams and discover a different path. Experiment with new activities and hobbies. Learn who you are now and find what resonates with your new self.



To view the full Resiliency Series, scan the QR Code or visit youtube.com/@bia_usa.



LUMINARY OF THE YEAR — 2024 —

The Brain Injury Association of America's Luminary of the Year campaign gives a platform to people who have been affected by brain injury and the people who support them to tell their story and raise awareness for this misunderstood and misdiagnosed health condition.

Nominees for the award participate in a philanthropic competition to support BIAA and our mission to improve the quality of life of people affected by brain injury. You can help us create a world where everyone who sustains a brain injury is recognized, treated, and accepted.

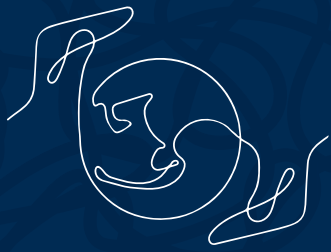
SHARE YOUR STORY AND SUPPORT OUR CAUSE

Nominees commit to sharing their story and working towards a fundraising goal. Top fundraisers are awarded the title of Brain Injury Association Luminary of the Year at a campaign celebration event in the fall of 2024 in Washington, DC, amongst their colleagues and peers.

Help us launch this important initiative for brain injury survivors and position yourself as a leader in our community by being a member of the inaugural class of the Brain Injury Association of America's Luminary of the Year.

To nominate yourself, someone else or more information contact: Paula Eichholz at peichholz@biausa.org or 703.761.0750 x648





STATE AFFILIATE NEWS

Delaware

The Brain Injury Association of Delaware (BIADE) ended 2023 strong and is looking forward to 2024. BIADE was honored to be Delaware Statewide Independent Living Council's (SILC) first organizational SPOTLIGHT. The SPOTLIGHT focuses on disability organizations in Delaware and highlights the services and support they offer.

BIADE said thank you to the outgoing Corporate Board President, Dr. Terry Harrison-Goldman. Her dedication, expertise, and contributions have left an indelible mark on the organization. Her legacy will undoubtedly serve as a foundation for our continued growth and success in the years ahead. The organization is pleased to welcome incoming President Stefanie Lancaster. She will be an amazing leader who understands intimately what survivors and caregivers need, as she is a TBI survivor herself. Lancaster has the pulse on what is happening in Delaware as she works at the DE Developmental Disabilities Council. BIADE looks forward to the leadership she and the other Corporate Board and Advisory Board members will bring to the organization.

BIADE feels it is important to educate those who work with its population. The organization partnered



BIADE Corporate Advisory Board members Stefanie Lancaster, Kellie Rychwalski, and Mark Kidwell were on hand to accept a gift from the Del-One Foundations Board.

with Nemours Children's Health to provide Continuing Education Units to nurses, PTs, OTs, and SLPs. The four educational training courses, presented by local professionals, covered a range of topics, and the Educate Delaware webinar series will continue with quarterly offerings.

BIADE's second annual Survivor and Caregiver Celebration and Community Awards Luncheon is scheduled for March 14. This wonderful event is a time to bring the community together to spend time in fellowship while celebrating and honoring everyone affected by brain injuries.



Indiana

The Brain Injury Association of Indiana (BIAI) had a beautiful and active ending to 2023. BIAI held our second annual Wiffleball Tournament at the end of October, with eight teams made up of individuals

with lived experience, their family members and supports, and various professionals. It was a fun-filled, fantastic day that also included costume contests, face painting, vendors, yummy food and treats, and a wonderful silent auction. Be sure to be on the lookout for the third annual Wiffleball Tournament – the save the date will be out soon.

BIAI also held two virtual information and discussion sessions during the months of September and December. The September session focused on the importance of voting and knowing your rights in any election that is held, while the December session focused on Love Your Brain Yoga and the benefits of getting involved in this incredible program. To gain access to either of these recorded sessions, or to learn more, please contact BIAI.

BIAI is excited to go to Washington, D.C. in March and participate in Brain Injury Awareness Month. Be on the lookout for more information and this and various other events taking place. Wishing a very happy and healthy new year to all!

Kansas

This fall, the Brain Injury Association of Kansas and Greater Kansas City (BIAKS) was privileged to present two Family and Survivor seminars and Hays and Overland Park. These two events, attended by more than 100 participants, offered opportunities for individuals affected by brain injury and family members to learn about new strategies and therapies that could make their lives easier. Breakout sessions provided time for individuals to share questions and concerns with others facing the same issues. The Hays event, held at Ft. Hays State University, also had a track for professionals working in the brain injury field and CEUs were available. Plans call for adding a third family and survivor event in 2024.

Additionally, BIAKS hosted its second professional conference in November in Wichita. The conference planning committee worked to ensure that the topics were timely and relevant for attendees from south central Kansas. Over the course of a day and a half, attendees heard speakers discuss TBI cognitive changes, overcoming challenges for kids returning to school, and veteran suicide prevention, as well as a survivor's experience facing the challenges presented by his injury.



Upcoming events on the BIAKS calendar include a March 14 Advocacy Day in Topeka; a March open house for volunteers, supporters, and friends; a professional conference in Overland Park; and the 37th Memorial Day Run for Brain Injury.

Maine

In early 2024, the Brain Injury Association of Maine (BIA-ME) published the eighth edition of its Maine Brain Injury and Stroke Resource Directory in both print and digital formats and is in the process of distributing the directory across the state.

During Brain Injury Awareness Month, BIAA-ME will hold the 2024 BIAA-ME Brain Injury Resource Fair in Augusta on March 21. The fair is designed for Maine brain injury survivors, family members/caregivers, and professionals to have the opportunity to explore a wide variety of resources, services, and supports.

Working with the State of Maine to complete deliverables under the Administration for Community

Living's Traumatic Brain Injury Partnership Grant, BIAA-ME also continues to collaborate with community behavioral health agencies on co-occurring ABI/Mental Health/Substance Use Disorder training, identification through the Online Brain Injury Screening and Support System (OBISSS) tool, and access to service linkages for ABI through NeuroResource Facilitation.

BIAA-ME provides extensive I&R and NeuroResource Facilitation services, support to Maine's 22 brain injury support groups, and several ongoing webinar series for the Maine brain injury community.

Massachusetts

As part of commemorating Brain Injury Awareness Month, the Brain Injury Association of Massachusetts (BIAMA) will hold its 42nd Annual Brain Injury Conference on Wednesday, March 27 and Thursday, March 28.

At the two-day in-person conference, brain injury survivors, caregivers, families, and professionals will learn about the latest research, therapies, support, and services. Last year over 600 individuals attended. Exhibitors will enable participants to identify health care solutions and professionals can obtain continuing education credits (CEs).

The keynote speakers will be Marina Ganetsky, a 13-year-old who survived a massive stroke, and her mother, Sasha Yampolsky, an impassioned speech language pathologist, co-authors of "Or So They Thought: A True Story." Together, the story they share will reveal the incredible impact of person-centered service-delivery rehabilitation. To learn more about BIA-MA's Annual Conference biama.org/annualconference.



Michigan

For over 40 years, Michigan's Auto No-Fault system provided world class healthcare for all drivers injured in an automobile accident. There were no limits to access to reasonably necessary products, services, and accommodations related to the recovery, rehabilitation and care of injuries caused by an accident. Everything changed in 2019. The so-called "auto no-fault reform" law implemented sweeping changes to this system. As a result, no longer is everyone guaranteed equal access to care as consumers are now able to choose policies with monetary caps on the amount of rehabilitation and care needed after an accident. To make matters worse, those choosing to continue to pay for lifetime care have limits to the care they can access because of the reimbursement system implemented by the 2019 law.

Medical providers have seen their reimbursement for essential long-term care services cut by nearly 50% from what they charged in 2019. This fee cap system has reduced reimbursement to levels lower than cost of providing care for services such as in-home healthcare, residential and supported living programs. As a result, people with catastrophic injuries such as traumatic brain or spinal cord injuries do not have access to the specialized care needed for positive

outcomes and a healthy quality of life.

While a recent Michigan Supreme Court ruling (ANDARY v USAA CASUALTY INSURANCE COMPANY) has provided some relief to those who have been catastrophically injured prior to the 2019 reform, there is still a tremendous amount of changes to be made.

For over four years, the Brain Injury Association of Michigan, crash survivors, families, care providers, and disability rights groups, have called on the Michigan Legislature to make modifications to the law to rectify this injustice.

Senate bills 530, 531 and 575 make the necessary changes that will restore the continuum of care these advocates have urged. The proposed legislation implements a reasonable and sustainable fee schedule that brings consistency and predictability to the system and most importantly ensures crash survivors have access to care they have paid for through their insurance policies.

To date, these bills currently sit in the House of Representatives Insurance and Financial Services Committee.

Mississippi

The Brain Injury Association of Mississippi (BIAMS) saw a change in leadership at the end of 2023 as Lee Moss stepped down as executive director after 16 years of service. Moss was honored at the annual “NogginFeast: A Celebration of the Brain” not only by the Board of Directors and staff of BIAMS but also by the Mississippi National Guard which bestowed the Distinguished Civilian Service Award on her, along with three honorary coins from officers in various units of the Guard. The BIAMS family welcomed Catherine Bishop as the new executive director in January.

In November, BIAMS launched its “Building a Bridge” project, aimed at bringing support groups and resources to survivors in all eight of Mississippi’s geographic regions. With one new group beginning in south central Mississippi in February, the project is already well underway. The next two target areas are the coastal region and northeast region.

Two events ended 2023 with a bang. NogginFeast, a food tasting and live music event, had record attendance as we once again honored the National Guard. This year’s recognition went to the 122th Military Police Battalion. The night was a fun-filled evening and ended with a \$5,000 drawdown. The



Lee Moss, outgoing executive director of BIA-MS, right, receives the Distinguished Civilian Service Award.

last event for 2023 was the Support Group Holiday Party, which was a blast with gift exchange, food, and fellowship. The “Most Festive Award” went to MS brain injury survivor Will Parker.

On March 20 the BIAMS will host Brain Injury Awareness Day at the Capitol Building in Jackson. All are invited to join in support of Brain Injury Awareness in the rotunda at 7:30 a.m. For more information about this and other upcoming BIAMS events, including our annual conference, visit msbraininjury.org.

The philosophy of Beechwood NeuroRehab is to maximize each individual’s ability to participate in meaningful roles within their community. We accomplish this by providing specialized, brain injury rehabilitation for people who have sustained any kind of acquired brain injury. Beechwood NeuroRehab uses a person-centered, transdisciplinary approach, utilizing innovative treatment concepts, applied technology, and evidence-based research to help each individual to achieve a fulfilling life.



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Neuropsychological Evaluations
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Speech & Language Therapy
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Missouri

The Brain Injury Association of Missouri (BIA-MO) Sports Concussions: Facts, Fallacies and New Frontiers Seminars were held across Missouri between Feb. 26 and March 1, 2024. There were three in-person seminars and one live stream seminar. Recordings of the sessions are also available on-demand until May 30. These seminars provide free education for youth sports and school personnel to reduce the risks of concussions for students.

The seminar focus for 2024 was the updated Concussion Consensus Statement, mental health and concussions, return to learn, and current concussion-related research. Statewide keynote speakers were internationally known concussion experts, Ruben Echemendia, PhD, and Jared Bruce, PhD. Additional international, national, and regional experts shared their knowledge across Missouri as presenters for Regional Seminars 2024.

The BIA-MO Survivor and Family Seminars 2024 provided practical suggestions for life with brain injury for Missourians in Springfield (March 23) and Kansas City (April 20). The topics for this year include Brain Injury 101, Pushing Through Recovery, Getting Social Security, Managing Anger, Anxiety and Depression Following Brain Injury, and more. We also had Fun with Cognitive Tasks and shared through the Let's Talk breakout sessions for persons with brain injury and a separate group for family and friends. Attendees also had the opportunity to learn about resources from vendors. Life with brain injury is not easy, but the BIA-MO Survivor and Family Seminar helps individuals know they are not alone on their journey to a quality life with brain injury.

New Hampshire

The Brain Injury Association of New Hampshire is pleased to announce a new training specifically for families and caregivers: "Behavioral Changes after Brain Injury." Behavior changes following moderate and severe TBI are common and can cause significant stress for individuals and their families. These presentations will create an opportunity for discussion around why changes in behavior occur and how to decrease the likelihood of challenging behaviors during the recovery process. Specifically, participants will learn how to identify factors that make challenging behaviors more likely and how to use this information to promote positive behavior change over time. This training is presented by Toni M. Curry, PhD, NCSP. Curry is a second-year postdoctoral fellow in pediatric neuropsychology at Dartmouth-Hitchcock Medical Center in Lebanon, N.H. She is a licensed clinical psychologist in the state of New York and a nationally certified school psychologist. Curry has maintained a strong interest in studying brain-behavior relationships, with the ultimate goal of using her knowledge to improve the lives of patients and families from underserved backgrounds. These trainings will be offered quarterly.



ENHANCE CENTER
enhance Enhancing Neurocognitive Health, Abilities, Networks, & Community Engagement

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Approved for use 20-Apr-2021

PARTICIPANTS NEEDED

Are you 60 years or older?

Have you had a traumatic brain injury that has affected your cognition (e.g., thinking, memory, or concentration)?

Do you have a family member or friend who supports your cognitive needs?

Both you and your family member/friend may qualify to participate in a research study!

If you are interested in participating, please contact us at:
(646) 962-7141 or AgingBehavioralRsrch@med.cornell.edu

Participants will be compensated.

The research study is conducted by Weill Cornell Medicine. ENHANCE is a Rehabilitation Engineering Research Center (NERC) funded by the [National Institute on Disability, Independent Living, and Rehabilitation Research](#) (NIDILRR; grant number #90AR00062-01-00).

New York

The Brain Injury Association of New York State (BIANYS) is excited to announce a couple events and initiatives to raise funds and awareness in recognition of Brain Injury Awareness Month.

All month, individuals are encouraged to Go Blue! For Brain Injury by starting a fundraiser that benefits brain injury survivors and by sharing information and resources on social media.

In partnership with Rusk Rehabilitation at NYU Langone Health, BIANYS is hosting a Brain Injury Symposium on March 9, and invites professionals and specialists in the fields of brain injury medicine and rehabilitation to attend and learn about advances in treatment, network with other professionals and gain access to cutting-edge research and information.

Lastly, all members of the brain injury community are invited to Advocacy Day on March 26 at the Capitol in Albany to ask for additional funding for the Continuum of Care for Neuro-Resource Facilitation Program. The Continuum of Care program provides the information



brain injury survivors and their families need to be connected to supports, rehabilitation services and other community-based services, which will assist them in their time of need.

Pennsylvania

The Brain Injury Association of Pennsylvania (BIAPA) is currently immersed in preparations for its annual conference in June. The BIAPA conference committee is diligently reviewing speaker and session presentation outlines, making every effort to provide a diverse and informative program. A noteworthy highlight this year is the inclusion of sessions specifically tailored for pediatric caregivers, which is reflective of BIAPA's commitment to address the needs of families that have children and adolescents with brain injury! The upcoming conference promises to be an enriching experience for all attendees.

The Brain Injury Association of Pennsylvania's mission includes education to both survivors and professionals. In addition to its annual conference, BIAPA offers online Clinical Forums several times a year. The purpose of the Clinical Forum is to bring current information on topics of interest, presented by recognized leaders in the field, to professionals working in the field. Clinical Forums are attended



by professionals from a variety of disciplines from across the country and have no cost associated with them. In April, Dr. Amelia Hicks of the Icahn School of Medicine at Mount Sinai will present "Suicidality and Self Harm in Individuals with Traumatic Brain Injury: Characterization, Assessment and Management." To learn more, visit biapa.org/clinical_forum

South Carolina

The Brain Injury Association of South Carolina (BIASC) started the new year off with the addition of three accomplished Board Members. Katie Davis is an optometrist and owner of Vision Therapy Institute in Columbia. Dr. Jeff Holloway is a pediatrician who specializes in sports medicine and is the Director of the Pediatric Concussion Clinic of Prisma Health Hospital in Columbia. Both board members are part of BIASC Brain Injury Safety Net Task Force which educates adults in a young person's life who has experience a concussion or other type of brain injury. Amanda Winburn is a physical therapist who is Supervisor of Rehabilitation Optimization at Prisma Health's Peace Outpatient Brain Injury and Young Stroke program in Greenville.

BIASC's first quarter of 2024 includes teaching A Matter of Balance Class for senior fall prevention in January, a virtual art class in February, as well as providing TBI Overview and Employment-Readiness Strategies training for the South Carolina Vocational Rehab Department. For Brain Injury Awareness Month, BIASC is teaming up with the South Carolina Department of Disabilities and Special Needs for a Community Art Project entitled "Metamorphosis: Striving and Thriving After Brain Injury." Brain injury survivors and caregivers will decorate butterfly cutouts which will become part of a larger piece of artwork. BIASC will also hold its annual statewide Walk, Run and Roll for BI awareness March 17-23.

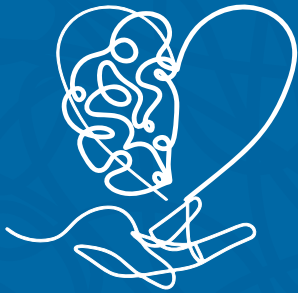


Virginia

The Brain Injury Association of Virginia (BIAV) kicked off 2024 ready to connect the community with the monthly webinar series "Mindful Matters." These free webinars include activities that help engage the mind and body and share other opportunities

for these activities in the community. As part of its Screen and Intervene project, BIAV is partnering with the Virginia Department of Health to explore the intersection between traumatic brain injury and domestic violence. BIAV provides education, training, and technical assistance and facilitates the collaboration between brain injury and domestic violence programs. Domestic violence programs are learning to screen for brain injury, and brain injury programs are learning more about the domestic violence service system and their role in service provision to serve better those who may have suffered a brain injury.

Overall, the project aims to increase the domestic violence program's understanding of the challenges and strategies for working with persons with brain injury, as well as improve the overall effectiveness of the program's interventions with persons who have sustained a brain injury as a result of domestic violence. The data analysis will inform recommendations on intervention strategies, resource development, screening and referral processes, replicating the model in other regions, and training needs.



OUR ALLIES IN CAREGIVING

By Page Melton Ivie, Chairwoman of the Board, BIAA



I walked past Tommy dozens of times before I really saw him. He was a slight man, who sat out of the way in the Starbucks at our local Target store, and I'm sure for many months that I didn't give him a second thought. In retrospect, I can see myself hurrying past, anxious to get errands done, to get back to my work. In that Target, I'm usually with, and very focused on, Robert, who in 2003 lost most of his memory from an anoxic brain injury. It was the often-overlooked Tommy who gave me a valuable lesson about caregiving.

Robert stopped me one day as I hustled past Tommy and said, "There's my friend," whose name he couldn't remember. We got tea and coffee and sat down so I could meet Tommy, who spent most mornings at the Starbucks nursing a cup of coffee, waving at children, talking with their harried parents, joking with staffers. Robert knew Tommy because the facility where Robert lives takes a group to Target at least once a week. Tommy told me that he'd look out for Robert on those visits when I wasn't there, keep him company, and make sure he got back on the bus with his group. "He can't remember very much," Tommy said, "so I've got my eye on him. He's a gift."

After that, our store visits included coffee for me, tea for Robert, and a visit with Tommy. He always had a compliment, and would wink and point to Robert, saying, "We have to look out for this young man, keep him out of trouble." Tommy had introduced Robert to employees who often stopped to chat. His empathy for Robert was a beautiful thing to see and I felt like I had an ally in caregiving, knowing this unlikely friend was in it with us.

One January a few years later, we showed up to shop and found flowers at the seat where Tommy usually sat. He had died earlier that week, just shy of his 75th birthday that we had been planning to celebrate with him. The folks at Target had added the flowers, then a framed photo of Tommy, and shoppers and employees left cards and more pictures. I met Tommy's sister a few days later and we hugged; she had come by to thank everyone for the outpouring of sympathy. I learned then that she had been providing caregiving for Tommy, and her husband had been driving Tommy to Target once he wasn't able to get there on his own. Quietly, with little fanfare, they were providing care for someone who meant a lot to so many.

It's been about four years since Tommy passed and there's still a photo of him in the window of the Starbucks at our Target. We always stop and acknowledge him when we visit the store and today just about every employee knows Robert – and now they, like Tommy did, look out for him when he's shopping.

Tommy's life reminded me that in the sometimes-hard work of caring for someone with a brain injury — or any challenging condition — there can be moments of humor, compassion, and great joy. His life reminded me that we need to stop sometimes, have patience, revel in the unexpected, and appreciate the sense of community in caregiving that even strangers with some empathy can understand and embrace

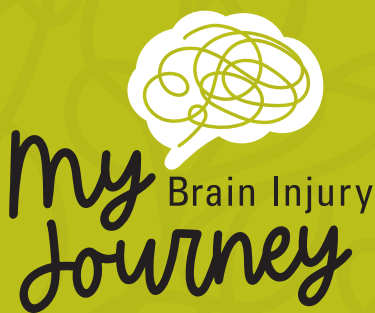
TRAUMATIC BRAIN INJURY (TBI) ACT



Nearly 3 Million Americans sustain TBIs in the United States every year.

MORE THAN 5 million PEOPLE IN THE UNITED STATES LIVE WITH A BRAIN INJURY-RELATED DISABILITY, THAT'S ONE IN EVERY 60 PEOPLE.

The TBI Act provides much-needed support for persons with brain injury. The TBI Act was passed in 1996. At the time, it was the only federal legislation that specifically addressed TBI prevention, research, and service delivery. The law provided funding for research and grants to states to create systems of care for persons with brain injury. **It's up for reauthorization in 2024.**



ACCOMPLISHMENTS OF THE TBI ACT

- ▶ Created and expanded TBI Surveillance program to collect information on the incidence of TBI in the United States
- ▶ Called for and funded civilian and military/veterans' TBI research
- ▶ Created State Partnership Grant program to build systems of care for those with brain injury
- ▶ Authorized the CDC to collect and analyze data regarding the national prevalence and incidence of concussions
- ▶ Commissioned cognitive and neurobehavioral research; Authorized Protection and Advocacy grant funding

Why is it Important to Reauthorize the TBI Act?

- ▶ **IT FUNDS RESEARCH** at the National Institutes of Health and the Centers for Disease Control and Prevention.
- ▶ **IT PROVIDES GRANTS** to states to build better systems of care for persons with brain injury.
- ▶ **IT SUPPORTS** state protection and advocacy agencies, who are the legal watchdog for people with disabilities.
- ▶ A National Concussion Surveillance System **PILOT STUDY FOUND** significant underreporting of concussion among adults and children as compared to national datasets.
- ▶ **EVIDENCE COMPREHENSIVELY DEMONSTRATES** that TBI is a chronic health condition, characterized by enduring functional impairment, cognitive deficits, comorbid health conditions, and psychosocial challenges across the lifespan as a person ages with a TBI.



GRANT ADMINISTRATION

The TBI Act grants are administered by the Administration on Community Living within the U.S. Department of Health and Human Services. States leverage modest federal investment with their “match” money and use this catalyst to develop local brain injury programs.

Who's Involved with Reauthorization

- ▶ **Senate Sponsors:**
Senator Robert Casey (D-PA)
Republican sponsor TBD
- ▶ **House Sponsors:**
Rep Bill Pascrell (D-NJ) and
Rep Don Bacon (R-Nebraska)

ORGANIZATIONAL SUPPORT

- ▶ Brain Injury Association of America
- ▶ National Association of Head Injury Administrators
- ▶ United States Brain Injury Alliance
- ▶ Other stakeholders are expected to support the bill.

Have you or a loved one had a brain injury?



We know how overwhelming and confusing it can be when you or a loved one is adjusting to life with a brain injury. It's not uncommon to have questions about treatment and rehabilitation options, coping with changes in personality or physical capabilities, access to counseling or legal assistance, and so much more.

Our brain injury specialists are here to help, and can provide you with individualized, confidential resources and support, Monday through Friday, from 9 a.m. to 5 p.m.

**Call the National Brain Injury
Information Center
1-800-444-6443**

Let's Stay in Touch



Get brain injury updates in your email inbox. Sign up for one of our mailing lists!

- **ADVOCACY** – Action alerts and our weekly Policy Corner newsletter
- **EDUCATION** – Information about upcoming webinars, conferences, and other learning opportunities
- **GENERAL** – Brain injury resources, BIAA updates, and even digital copies of *The Challenge*!
- **RESEARCH** – The latest information about brain injury research, including our own grant program



biausa.org/connect

EVENTS AND WEBINARS

March 18, 2024, 3:00 p.m. ET

Health Literacy and TBI – Angelle Sandler, PhD
and Monique Pappadis, M.Ed, PhD

March 21, 2024, 3:00 p.m. ET

Disparities in Care Transitions for Individuals
with TBI – Amol M. Karmarkar, PhD

April 25, 2024, 3:00 p.m. ET

Acquired Brain Injury in Teenagers and
the Transition into Adulthood –
Sharon Grandinette, M.S., Ed., CBIST

**To register, scan the QR code or
visit shop.biausa.org/products/livewebinars**



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Contact Peter Knockstead, *Director of Corporate Partnerships*
pknockstead@biausa.org | **703-761-0750, ext. 640**



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The Corporate Partners 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 Partners 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 the Brain Injury Association of America Corporate Partners Program, please visit biausa.org/corporate or contact Peter Knockstead at (703) 761-0750, ext. 640, or email pknockstead@biausa.org.

