

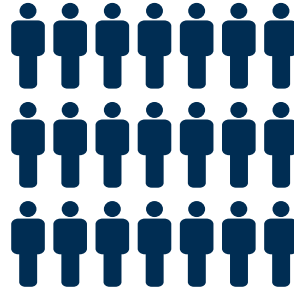
THE CHALLENGE!

Over \$300,000

Amount of money
BIAA has invested
in its Research
Fund since 2019



21 participants



Since 2020, BIAA has
awarded 21 recipients
of seed grants and
dissertation grants

5 years of Progress

WITH THE
Brain Injury Research Fund

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Study Suggests
Waiting Longer Before
Withdrawing Life
Support for Severe
TBI Patients

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Why Self-Compassion
Matters after Brain
Injury: Research
and Practice

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Studying TBI
in Veteran
Populations

JULY 2024

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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THE  CHALLENGE!

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FROM MY DESK

Greetings,

In 2019, BIAA established its Research Grants program, with an overall theme and goal of finding cures for chronic brain injury. We know that brain injury is not a one-time event, but a sometimes-lifelong condition, especially for the 5.3 million living with a permanent brain injury-related disability. It's why we're advocating for brain injury to be recognized as a chronic health condition. Brain injury must be identified and proactively managed as a lifelong condition to improve health, independent function, and participation in society.

For five years, BIAA has had the privilege of seeing firsthand how the brain injury community is dedicated to finding effective treatment and potential cures for the chronic effects of brain injury, awarding more than \$300,000 in grant money to date. Since the program's inception, BIAA has funded 21 projects, with recipients studying pediatric TBI, social determinants of health, chronic health condition management, progressive degenerative processes, aging and TBI, chronic pain, and more.

In this issue of THE Challenge, you'll have a chance to read about this year's funded projects, as well as updates from past grant recipients. This issue also features articles about research around TBI in veteran populations, the benefits of exercising self-compassion while living with the chronic effects of brain injury, and the importance of helmet safety in preventing TBI. Beyond the updates on the research front, this issue also features a recap of our Brain Injury Awareness Day event on Capitol Hill, as well as stories our community has submitted as part of our new My Brain Injury Journey awareness campaign.



I hope you enjoy this year's annual Research issue. If you found yourself moved by any of the ongoing research endeavors in the field of brain injury, please consider donating to BIAA's Research Grants Program. You can learn more about the program by scanning the QR Code below.

Sincerely,

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

Rick Willis
President and CEO
Brain Injury Association of America



**Interested in learning more about BIAA's Brain Injury Research Fund?
Scan the QR code or visit biausa.org/supportresearch**

5 years of Progress WITH THE Brain Injury Research Fund

In 2019, the Brain Injury Association of America established its Brain Injury Research Fund, setting a goal of finding cures for chronic brain injury. The program is grounded in the understanding that for some people, brain injury evolves into a chronic health condition that can cause or accelerate multiple diseases. To date, BIAA has awarded more than \$300,000 to 21 recipients through the program.

BIAA identified five research priorities for the 2024 competition, each of which relates to the chronic phase of brain injury:

1. Progressive Degenerative Processes
2. Late Consequences of Childhood TBI
3. Excess Mortality
4. Chronic Health Condition Management
5. Social Determinants of Health

Earlier this year, BIAA awarded five grants totaling nearly \$85,000 that will go towards brain injury research. This year's recipients include two Brain Injury Scholar Seed Grants, one Young Investigator Seed Grant, and two Dissertation Grants.



Support the Brain Injury Research Fund

The Brain Injury Research Fund is the pinnacle of BIAA's long-standing mission of supporting the people, programs, and institutions that have advanced brain injury science and medicine. By supporting the Brain Injury Research Fund, you can support BIAA's commitment to the best and most promising research projects. Learn more about how you can support the Brain Injury Research Fund by scanning the QR code or visiting <https://www.biausa.org/support/support-research>.

2024 Brain Injury Scholar Seed Grants

PROJECT: Repetitive Mild Traumatic Brain Injury and Signs of Accelerated Neurocognitive Aging in Young Adults

JACLYN STEPHENS, PHD *Colorado State University*

People with repetitive mild traumatic brain injury (mTBI) have an increased risk for developing diseases, like dementia, as they age. There is a need to better understand disease development and to devise interventions that can prevent it. Stephens' proposed project works toward both. There is some evidence

AMOUNT: \$24,805

that young adults with repetitive mTBI have signs of premature aging which may contribute to disease development. Thus, Stephens plans to further evaluate young adults with repetitive mTBI to test for other signs of premature aging and find brain-behavior features to target in future intervention work.

PROJECT: Pre-injury Sleep Quality as a Risk Factor for Increased Alcohol Consumption Following TBI

RACHEL ROWE, PHD *University of Colorado Boulder*

While research has investigated the effects of TBI on alcohol use, no study has considered pre-injury sleep quality as a risk factor for increased alcohol consumption post-TBI. Rowe's project will investigate if sleep fragmentation pre-TBI alters chronic alcohol consumption and worsens acute and chronic functional outcome

AMOUNT: \$25,000

post-TBI. This project will also examine neuroinflammation as a mechanism that modulates alcohol consumption. An understanding of how pre-injury sleep quality contributes to chronic alcohol consumption following TBI will improve prognostication efforts and early intervention for TBI survivors.

2024 Young Investigator Seed Grant

PROJECT: Physical Activity and BDNF in Neurobehavioral Recovery from Pediatric TBI

BAILEY PETERSEN, PHD *University of Pittsburgh School of Medicine*

MENTOR: AMEREY TREBLE-BARNA, PHD

There is a critical need for therapies to promote neurobehavior in children with moderate-to-severe traumatic brain injury (msTBI). In adults, physical activity (PA) improves neurobehavior, in part by increasing expression of a biomarker of TBI recovery, brain-derived neurotrophic factor (BDNF).

AMOUNT: \$25,000

Using wearable sensors to measure PA, Petersen's project aims to (1) characterize PA in the first six months after TBI and (2) identify aspects of PA associated with neurobehavior. This study will advance the field of pediatric TBI by providing a clear understanding of the therapeutic potential of PA after TBI.

2024 Brain Injury Dissertation Grants

PROJECT: A Social Ecological View of Participation for Persons of Color Living with Traumatic Brain Injury

JUDITH WILSON, New York University

MENTOR: GERALD VOELBEL, PHD

Wilson's study explores how persons of color living with a traumatic brain injury (TBI) experience participation in relation to the immediate support, community, and societal systems. The persistence of racial disparities in the outcomes for persons with TBI needs to be addressed to improve health

AMOUNT: \$5,000

outcomes, by detailing the social environments that support or hinder participation. Data from interviews and behavioral observations will be collected to investigate people of color's experiences of participation after TBI, and those experiences' relationships with their social environments.

PROJECT: Acute Neuropsychological Profiles of Pediatric Traumatic Brain Injury

MARY SIMONS, Marquette University

MENTOR: JAMES B. HOELZLE, PHD

Simons' research will identify acute profiles of pediatric traumatic brain injury (TBI) during inpatient hospitalization. Variables that are predictive of chronic cognitive and psychological outcomes (e.g., pre-injury adaptive functioning; post-injury cognitive functioning) will be used to establish

AMOUNT: \$5,000

profiles. Differences in long-term cognitive and psychological outcomes, and health care utilization, will be investigated among the identified profiles. Identifying homogenous groups of acute pediatric TBI profiles that are predictive of outcomes will facilitate personalized treatment.

Recently, BIAA had the opportunity to check in with past grant recipients and receive updates on their projects.

Past Grant Recipients



Michael Williams, PhD

PROJECT: Using Mobile Technologies for Research Engaging Persons with Traumatic Brain Injury and Chronic Pain

2022 Seed Grant Recipient

MICHAEL WILLIAMS, PHD *University of Pittsburgh School of Medicine*

Chronic pain is common among people with TBI, and typical clinic-based evaluations of pain may not fully capture the patient's day-to-day experience. Williams used

BIAA's seed grant to implement a pilot study that utilized mobile technology (a smartwatch and an app) to track study participants' pain symptoms as well as their mood (including anxiety and depression), sleep quality, and activity levels over a four-week period. Participants would also complete a traditional survey at the clinic at the beginning and end of that four-week period.

"That gave us objective measures of movement and activity, objective data that would inform the subjective ratings that people provided to us," Williams explained. "The day-to-day assessments allow us the opportunity to consider what might be relevant. For example, we can look at their sleep patterns

the night before and consider how that relates to any pain the next day, or we can look at whether mood and pain relate over time, or the emotional influence on pain."

Giving participants the ability to log their symptoms in real-time, rather than requiring them to recall and relay their moods and pain symptoms retroactively, also helps to sidestep the memory or attention difficulties that often affect people with TBI.

BIAA's grant enabled Williams to purchase the smartwatches and subscription for the mobile survey app he and his team used to conduct their research. "Technology makes life easier, but it's not free," he commented. It also allowed Williams to pay the study participants, which he believes is good practice.



Khalil Mallah, PhD

PROJECT: Complement Mediated Cognitive Decline and Neuroinflammation Chronically Post Repetitive Brain Injury

2022 Seed Grant Recipient

KHALIL MALLAH, PHD *Medical University of South Carolina*

A history of TBI, even years after the initial injury, can result in cognitive deficits similar to those seen in patients with Alzheimer's disease. Mallah proposed that the complement system – a

major part of the neuroimmune response after injury – is a major contributor to this phenomenon, and hypothesized that inhibiting this system would prevent such deficits seen years after TBI.

The seed grant Mallah received from BIAA allowed him to perform experiments as well as behavioral analysis using a therapeutic approach. "In the lab, we used an inhibitor

of one of the most important parts of immune system, the inhibitor that inhibits C3 convertase. The complement inhibitor showed that if we treat mice with it, and then look at their behavior one year later, it stopped them from developing cognitive deficits and their behavioral performance was comparable to their counterpart mice," he explained. "I hope to use the results we got from this grant to pursue research in the future." He added that he will hear back in August if he received an additional grant that would allow him to continue to pursue his TBI research. "The results from the study made possible by the BIAA grant would be opening a very big door for me to pursue in my future research career."

Past Grant Recipients



Amy Kemp

PROJECT: Examining the Use of Self-Regulation in Behavior Change in Older Adults: A Mixed Method Study **2023 Dissertation Grant Recipient**

AMY KEMP, *University of Georgia*

Although older adults have the highest rates of TBI incidence, mostly from falls, little research has examined rehabilitative management in older adults. Health-behavior changes are key to maintaining health and

safety. Kemp's mixed-method study collects pilot data from a sample of older adults with TBI. Participants use a self-regulation strategy to increase the adoption and execution of fall prevention recommendations. These findings will identify factors specific to participation and inform efforts to improve safety and self-management.

"I was looking at, if there are any cognitive or psychosocial predictors involved in self-management among older adults with brain injury," Kemp explained. "I was looking to collect a meaningful enough sample in order to deduce if there was a difference in people with and without brain injury, in aging, and trying to address the issue of what it looks like to age with brain injury, what are the chronic effects, and how that

might impact self-management." Prior to receiving the grant, Kemp had collected data on adults without TBI. The grant she received from BIAA allowed her to broaden her population base and include people with TBI, as well as include people from a nationwide pool.

"What the BIAA dissertation grant allowed me to do was, it provided me the funds to complete the study, and to make it computerized, offer a validated neurocognitive test administered virtually, and it allowed me to pay my participants for their time and effort. It made a big difference," she explained. "People wanted to know their cognition, and have a 'status report' on what it's like to age with brain injury." She added that this tends to be a population with lower opportunities for monetary support, that is also looking to be involved in something impactful. "Being able to support them was meaningful for me," she added. "I am really grateful for BIAA. It was a wonderful experience and something that really launched my own learning and career."

Kemp is currently in the revision stage of her dissertation.



Joel Blanchard, PhD

PROJECT: Establishing the Mechanisms of TBI-mediated Susceptibility to Alzheimer's Disease **2023 Seed Grant Recipient**

JOEL BLANCHARD, PHD *Icahn School of Medicine at Mount Sinai*

Although we know that TBI alters how the human brain ages, increasing the susceptibility to Alzheimer's disease and dementia later in life, the mechanisms underlying this association are largely

unknown. Because of this, there are limited diagnostics and therapeutics for intervention. Blanchard proposed investigating Alzheimer's disease using highly tractable human brain tissue engineered from patient stem cells. When applying for this grant, Blanchard's models had already discovered two FDA-approved drugs that improve memory in mice with Alzheimer's disease; he proposed applying these models to dissect the mechanistic connections between TBI, genetic risk factors, and Alzheimer's disease.

The lab where Blanchard conducts his research primarily studies Alzheimer's disease, developing human brain tissue which allows them to replay the events of Alzheimer's disease in a controlled setting and ask questions about what's going wrong.

"The seed grant from BIAA allowed us to take the models we've been using for Alzheimer's disease and develop ways to apply the proxies of TBI to them," Blanchard explained. "There have been pretty exciting results, when we applied a contusion of force to the mini brain models, we can see the cells starting to move and respond to the injury. This support lays the foundation for more broad studies that could look at these mechanisms and try to develop therapies around them."



STUDY SUGGESTS WAITING LONGER BEFORE WITHDRAWING LIFE SUPPORT FOR SEVERE TBI PATIENTS

By Lauren Moore, Marketing and Communications Manager, BIAA

When a person is hospitalized for sustaining a severe traumatic brain injury (TBI), their family and loved ones may be faced with the difficult decision to withdraw life support. Families of patients with severe TBI, which by current definition includes a period of unconsciousness, are often asked to make decisions about withdrawal of life-sustaining treatment within days of injury. But a recent study in the *Journal of Neurotrauma* found that both doctors and patients' families are likely to make better decisions if they wait even a few days longer than they normally would.

“

Traumatic brain injury is a chronic condition that requires long-term follow-ups to understand patient outcomes. Delaying decisions regarding life support may be warranted to better identify patients whose condition may improve.

— YELENA BODIEN, PHD
MASS GENERAL RESEARCH INSTITUTE



While some doctors would say that patients with severe TBI do not have a strong prognosis, the Journal of Neurotrauma study, which used a national database including 1,392 TBI patients, points out that there is high prognostic uncertainty but growing evidence that recovery of independence is possible.

The study investigated the potential for not only survival, but recovery of independence after acute TBI in patients who died after withdrawal of life-sustaining treatment (WLST) using Transforming Research and Clinical Knowledge in TBI (TRACK-TBI) data. The study compared patients with WLST (WLST+) to those with a similar probability of WLST, but whose life-sustaining treatment was not withdrawn (WLST-).

Although 55 percent of the patients whose life-sustaining treatment was continued died in the hospital – typically within about six days – 42 percent who continued life support recovered to the point of having some degree of independence within the following 12 months. Some even resumed their lives prior to their injury.

“Our findings support a more cautious approach to making early decisions on withdrawal of life support,” corresponding author Yelena Bodien of the Department of Neurology’s Center for Neurotechnology and Neurorecovery at Massachusetts General Hospital and of the Spaulding-Harvard Traumatic Brain Injury Model Systems told The Harvard Gazette. “Traumatic brain injury is a chronic condition that requires

long-term follow-ups to understand patient outcomes. Delaying decisions regarding life support may be warranted to better identify patients whose condition may improve.”

These results, the study says, suggest a substantial proportion of patients with TBI and WLST may have survived and achieved at least partial independence had life-sustaining treatment not been withdrawn. However, the fact remains that death or severe disability is a common outcome when the probability of WLST is high. Although the study concludes that further research is needed, its findings do support a more cautious clinical approach to WLST and more complete reporting on WLST in TBI studies.

Brent Masel, MD, National Medical Director of the Brain Injury Association of America, said this has always been his approach when talking to family members of patients with severe TBI. “The way I explain this is in terms of a bell-shaped curve,” he explained. While doctors can’t say with any certainty which side of the curve a particular patient will fall on, they can explain what will happen based on where the patient does fall. “I think presenting things in that way to the patients’ families and saying, ‘You know, there are studies that show that if we wait a while longer, they may be, relatively speaking, OK. But there is no way to know.’ I think what families are going to take from this, is perhaps we shouldn’t jump the gun to withdraw life support. Not so quickly.”

SELF COMPASSION AND BRAIN INJURY

By Kyla Pearce, CBIS, RYT-200, MPH, PhD
Senior Director of Programs and Research,
LoveYourBrain Foundation



Imagine you're experiencing intense pain from chronic headaches. If you're practicing self-compassion, you're able to notice your pain and say something to yourself like, "I understand there's a lot of pain right now. You're not alone. I know you're doing the best you can. I'm here for you." But without self-compassion, your narrative would be something more like, "I can't believe I'm in so much pain. Why won't this pain go away? No one understands. I can't do anything right."

How does it feel for you to read these different approaches? The truth is, we all intuitively know that meeting difficulty with warmth and care matters, but most of us have never learned how to approach our own pain in this way.

Brain injury comes with wide ranging psychological, physical, behavioral, and cognitive impacts, often leading to isolation and difficulty adjusting to the person they are now. And, while the risk of developing depression and anxiety increases substantially, access to evidence-based therapy is limited (Sharma et al., 2015).

In the past few decades, a growing body of research has shown that self-compassion interventions can improve a variety of health outcomes common among brain injury survivors, including anxiety, depression, rumination, self-criticism, and stress. Neuroscience shows us that compassion increases activity in the areas of the brain involved in dopamine and oxytocin release, and thus enhances positive emotions in response to adverse situations.

Self-compassion means to treat oneself with warmth and understanding in difficult times and recognize that making mistakes is part of being human. According to Kristin Neff, PhD, a leading researcher on this topic, there are three main pillars of self-compassion:

- ▶ **Mindfulness** – To pay attention to our present experience non-judgmentally. When we're being self-compassionate, we must first turn towards our own difficulties instead of avoiding them. We bring our attention inwards to acknowledge our feelings, thoughts, and sensations with open-heartedness and curiosity. This is in contrast to how we often approach our difficulties, where we so easily fall into patterns of blame, self-pity, and judgment, or run away from them altogether.
- ▶ **Self-Kindness** – This refers to your inner voice, which might sound more like an inner critic. When you're practicing self-compassion, you treat yourself the way you treat someone you respect and appreciate – with gentleness, kindness, and care. Instead of criticizing yourself each time you mess up or feel inadequate, you acknowledge, "I'm human and make mistakes. What can I learn from this?"
- ▶ **Common Humanity** – Common humanity reminds us that we're not the only ones struggling. This contrasts what typically happens, where our difficulties leave us feeling further isolated and that no one understands what we're going through. Yet, we all have something in common – we're all struggling in some way, and we all wish to find peace. Ultimately, our suffering connects each of us even more deeply to what it means to be human.

Several studies specifically within brain injury have begun to explore the benefits of self-compassion for improving psychological health and self-coping. For example, a study of 12 people with ABI participated in group Compassionate Focused Therapy (CFT) as part of their neurorehabilitation. Compassionate Focused Therapy is a type of psychotherapy that aims to help people develop kinder thinking habits. In this study, self-reported pre-post data and qualitative interviews revealed improvements in anxiety, depression, and ability to self-soothe. Participants perceived that CFT gave them tools to effectively manage continued psychological difficulties, like shame and self-criticism, which have been found to undermine adjusting to life after brain injury.

Acceptance and Commitment Therapy is another evidence-based intervention that integrates self-compassion as a key strategy for psychological health after trauma. It's rooted in the "four A's" framework: Acknowledge, Allow, Accommodate, and Appreciate, and has been successfully adapted to address common cognitive impacts of TBI using visual materials, experiential activities, and repetition. In this randomized controlled trial, 93 individuals with mild-moderate TBI participated in either an eight-week ACT program or an active control group. The results showed participants in the ACT intervention experienced significantly greater reduction in psychological distress on the Brief Symptom Inventory and improvements in psychological flexibility.

In summary, self-compassion can support people with brain injury to:

- ▶ **Better self-regulate** by acknowledging what's happening in the moment without over-identifying with it. This skill is critical for emotional regulation and managing depression and anxiety, since it offers more perspective to work with thoughts, feelings, and behaviors that can undermine mental health.

TIP: Try acknowledging, "I understand there's a lot of pain right now," instead of being overwhelmed by "I can't believe I'm in so much pain."

- ▶ **Improve psychological adjustment** by using kinder self-talk to interrupt self-criticism, self-compassion doesn't mean that we get rid of negative thoughts (as much as we may want to!), instead we notice them and then gently shift our attention to more helpful thoughts as best we can.

TIP: Try encouraging yourself like, "I know you're doing the best you can. I'm here for you," instead of being self-critical, "I can't do anything right."



- ▶ Counteract isolation by remembering that they're part of a larger community of people who also struggle. This is important because isolation is one of the primary predictors of depression and suicide among the brain injury community.

TIP: Try reminding yourself, "You're not alone," instead of, "No one understands."

Moreover, research also suggests self-compassion reduces symptoms of posttraumatic stress disorder (PTSD), which occurs more often after TBI. PTSD encompasses three symptom categories (arousal, avoidance, intrusions), which closely correspond to the stress response (fight-flight-freeze) and to our reactions to internal stress (self-criticism, self-isolation, and self-absorption). Self-kindness can have a calming effect on autonomic nervous system hyperarousal, common humanity is an antidote to shame, and mindfulness allows us to disentangle from intrusive memories and feelings (Germer and Kneff).

Ultimately, more research is needed to continue to understand the effectiveness and optimal design timing of self-compassion interventions following brain injury. In the meantime, accessing resources specific to the brain injury community is a helpful starting point:

- ▶ Practice meditation that emphasizes mindfulness and kindness. "Loving kindness meditation" has been shown to increase positive emotions, feelings of purpose in life and social support, and to decrease illness symptoms (Fredrickson et al. 2008) and stress-linked immune responses (Pace et al. 2009).
- ▶ Explore a range of self-compassion meditation and self-inquiry practices, including a Self-Compassion Break.
- ▶ Sign up for free programs for the brain injury community that offer guidance in self-compassion.

STUDYING TBI IN VETERAN POPULATIONS

By Carrie Esopenko, Andrea Kalvesmaki,
Tristan Wimmer, Jess Collazo, Amanda
Watsula, and Kristen Dams-O'Connor



More than 20 percent of adults in the United States have experienced at least one traumatic brain injury (TBI) in their lifetime. Among the military population, that percentage more than triples, with approximately 67 percent of veterans having experienced at least one TBI. And while history of TBI is associated with an increased risk of Alzheimer's disease and other dementias, as well as a greater risk for suicide compared with the general population, evidence suggests that military veterans are also more likely to experience mental health challenges such as post-traumatic stress disorder (PTSD) and suicidal ideation following TBI, which may further jeopardize their long-term health and well-being.

Currently, medical researchers cannot predict recovery after TBI, but we know that the initial severity of a TBI does not accurately predict long-term outcomes over time. It is not known exactly how TBI contributes to neurological decline. Right now, there are no objective clinical assessments, blood tests, or imaging tests that can predict or track cognitive decline or mental health challenges such as suicide risk. This has made it difficult to develop treatments to optimize long-term brain health in both veteran and civilian populations.

Our team has taken on the task of addressing these gaps in knowledge regarding the long-term effects of TBI and mental health concerns. Through the "Leveraging Nationwide Research Infrastructure to Enrich (ENRICH) Brain Health Study" we are seeking to understand and improve long-term health

after TBI. Across five distinct studies, we leverage existing research infrastructure including large-scale datasets, cohort studies, and brain autopsy archives to accelerate scientific discovery, improve early diagnosis, and help develop personalized treatments. Ultimately, we hope that this work will lead to measurable improvements in TBI care and identify new opportunities to optimize brain health and reduce the risk of suicide after TBI.

Lived Experience Guides Our Work

What sets this research apart is that our team has partnered with people who have lived experience with TBI, representatives from community-based organizations, and national TBI advocacy groups to refine and implement our research projects. The ENRICH study is grounded in community-based participatory research, a type of research

that involves persons with lived experience, and members of the community who are affected by or concerned with a specific condition. This approach allows us to conduct scientifically rigorous research that addresses the key challenges that matter most to people with TBI, their loved ones, and those who serve them.

The Community Advisory Group for Enriched Brain Health allows the ENRICH project to have direct, real-time impacts on the health of civilians and veterans with TBI and their families. The Advisory Group is composed of 18 individuals with a variety of lived experiences with TBI. Our members include active-duty military service members and veterans, TBI advocates, members of TBI and veteran service organizations, people living with TBIs, caregivers, and experts in TBI, PTSD, and suicide.

Several members of the Advisory Group have personal experiences of living through TBI or supporting someone else with TBI. One group leader, Tristan Wimmer, a Marine veteran, has used his own family experience with the grief and raw pain following the loss of a brother to suicide. Tristan's brother Kiernan sustained a massive TBI while serving in Al Anbar, Iraq, in 2006. Kiernan's slow-motion deterioration and subsequent suicide in 2015 devastated his family. Tristan channeled that grief into action. As a military veteran, he has strengthened the Advisory Group through his personal and professional connections with the military community and provides guidance on how researchers can best interact with and serve veterans.

Including the lived experience perspective is not only part of the Advisory Group, but is also a key component of the four studies investigating the long-term effects of TBI and suicide risk in veterans.

Veteran and Military Brain Research

Our study has a unique interest in finding answers for veterans who are living with TBI. One project, The Late Effects of TBI in Military Service Members (LETBI-MIL) is focused on identifying the clinical features and postmortem signatures of post-TBI neurological change in veterans to inform new treatments and therapies.

TBI is considered the "signature wound of war" for veterans who have served since 2011 (post-9/11 veterans), and although veterans and service members make up a large majority of individuals with TBI, they remain an understudied population. Post-9/11 veterans are more likely to sustain injuries like TBI that require long-term care, are at elevated risk for homelessness and suicide, and are less likely than veterans of previous eras to use VA health services for their care. There is a great urgency to study this population as veterans from our most recent conflicts may be at higher risk of dementia if they have sustained a TBI.

The LETBI-MIL study was designed in direct response to veterans who asked our team, "Why isn't anyone studying our brains?" Our team realized then that existing studies of TBI in military service members and veterans recruit exclusively from Veteran and Department of Defense care centers for TBI, which serve only a small fraction of those who sustain a TBI. Many veterans have TBIs that were never diagnosed or treated. A unique feature of LETBI-MIL is that we are partnering with veterans to recruit directly from the community to ensure our research is generalizable to most veterans living with TBI. The veterans on our research team expressed their desire to conserve the fighting force by supporting research that will help active-duty military members and veterans now and into the future.



GET INVOLVED

The ENRICH Brain Health Study is actively enrolling veterans in the LETBI-MIL study. Veterans serve in its Advisory Group and on each of the LETBI Clinical Teams in both New York and Seattle. Scan the QR code to learn more about these ongoing efforts.

LIEUTENANT COMMANDER USES HER EXPERIENCE TO SUPPORT TBI SURVIVORS

By Stephanie Cohen, Development Manager, BIAA

Lieutenant Commander (LCDR) Jeanne Van Gilder, a native of Webberville, Mich., always knew she wanted to pursue a career in the Navy, particularly as a submarine officer. Inspired by her father's service as a Naval Officer, her determination never wavered, even when submarines were not open to women. Her persistence paid off when, during her time at the University of Michigan, submarines were finally opened to women.



Female Submarine Officers of USS MINNESOTA: Lieutenant Commander Jeanne Van Gilder and her fellow female submarine officers of the USS Minnesota attend the Submarine Birthday Ball.



LCDR Van Gilder has served aboard multiple submarines including USS FLORIDA (SSGN 728)(GOLD) and USS MINNESOTA (SSN 783), demonstrating her leadership and dedication to duty. Notably, she played a significant role in the conversion of USS FLORIDA to support enlisted women on submarines. She holds a Master of Engineering (MEng) in Systems Engineering and Design from the University of Michigan and has completed the Submarine Officer Advanced Course and Joint Professional Military Education (Phase 1) certification from the Naval War College. Her naval career has been marked by numerous accolades, including the Navy Commendation Medal (gold star in lieu of fourth award) and the Navy and Marine Achievement Medal.

Throughout her service, LCDR Van Gilder witnessed firsthand the dangers inherent in submarine operations, including traumatic brain injuries (TBIs) sustained by two of her shipmates. They both will battle with the effects of their injuries for the rest of their lives.

For most people, the knowledge of submarine life is based on movies and therefore they do not recognize how dangerous submarines can be. In addition to injuries sustained at work, LCDR Van Gilder has also learned about TBIs through her role as a certified Sexual Assault Victim Advocate. Her goal as a Victim Advocate is to make people feel safe and to protect and help her shipmates.

LCDR Van Gilder's commitment to supporting those affected by traumatic brain injuries extends beyond her work in the Navy. Recognizing the personal and often invisible nature of these injuries, she actively supports organizations like the Brain Injury Association of America. By supporting the BIAA, she aims to facilitate access to vital resources and programs that empower servicemembers and sexual assault survivors to lead fulfilling and meaningful lives.

**Laughing at a funeral?
Crying uncontrollably for no reason?
It could be Pseudobulbar affect.**

If you or someone you love has been diagnosed with Pseudobulbar affect (PBA), BIAA wants to connect with you.

Drop us a line at PBA@biausa.org to connect, share, and learn more about living with PBA.



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.

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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To see the list of our donors,
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LUMINARY OF THE YEAR — 2024 —

The Brain Injury Association of America will hold its inaugural Luminary of the Year campaign celebration on November 15, 2024 at the National Press Club in Washington, D.C.

Nominations are now open for fundraising champions!

Nominate yourself or someone you know at biausa.org/fundraising-champions

KEEP YOUR BRAIN SAFE WHILE BIKING

Research backs the importance of helmet safety when cycling

By Tracie Bearden, MS, CCC-SLP, CBIST

Biking has become one of the most eco-friendly and popular methods of recreation and commuting in America. In 2022, the number of Americans who rode a bike reached 54.7 million, up from 51.4 million the year before. Biking is an excellent way to stay active, but it's important to be safe, as biking is a common cause of brain injury.



Imagine this scenario: You ride your bike to work every day. One day, you wake up 20 minutes late, scramble to get ready, and realize that you forgot your helmet. You may think to yourself, "I've been riding a bike for 20 years, I'll be fine this one time," but the reality is, all it takes is one time to have a bike-related accident without a helmet to sustain a severe traumatic brain injury (TBI).

A TBI can result from a forceful impact, strike, or jolt to the head or body, or from an object that penetrates the skull and enters the brain. However, not every impact or jolt to the head leads to a TBI. Certain types of TBI can cause temporary or short-term issues with typical brain functions, affecting a person's thought processes, comprehension, movement, communication, and behavior. More severe TBI can cause significant and lasting disability and can even be fatal.

I have personally worked with the brain injury population for 14 years and have seen the ramifications of someone not wearing a helmet even one time on their bike. A severe traumatic brain injury can look like someone in a coma, a vegetative state, or minimally conscious. The individual may not be able to eat, move, breathe on their own, or be able to recognize familiar faces or objects. An individual with a moderate-severe TBI may experience short or

long-term memory loss, visual impairments, physical impairments, and seizures.

Motor vehicle accidents, including those associated with bikes, are the third most common cause of TBI. This makes helmet usage more important than anything when riding any type of bike. Helmets reduce the likelihood of brain injuries by 65 percent to 88 percent, and they lower the risk of facial injuries to the upper and mid-face by 65 percent. They reduce the risk of severe brain injury by 75 percent. With the research showing these consistent statistics, it's not hard to see the benefits of wearing a helmet while riding a bicycle.

Bicycling leads to the highest number of sport and recreation-related emergency department (ED) visits for traumatic brain injuries (TBIs) in the United States. The use of bicycle helmets was found to reduce head injury by 48 percent, serious head injury by 60 percent, traumatic brain injury by 53 percent, face injury by 23 percent, and the total number of killed or seriously injured cyclists by 34 percent.

Not only has the popularity of pedal biking risen, but the rise in usage of e-bikes and e-scooters – also known as MMPs – has significantly soared since the COVID-19 pandemic. A 2023 report released by the U.S. Consumer Product Safety Commission (CPSC), showed that injuries associated with all MMP devices



increased by nearly 21 percent in 2022 from 2021. MMP-related injuries have trended upward since 2017, increasing by an estimated average 23 percent annually.

A JAMA Surgery study released in 2024 revealed that only 44 percent of hospitalized e-bike riders were wearing helmets. This same study showed that riders without a helmet were almost twice as likely to suffer head injuries than ones wearing a helmet. E-bikes can travel at speeds up to 20 miles per hour, making them more hazardous than traditional pedal bicycles. This speed makes e-bikes harder to control and more difficult to stop in the event of an accident. Additionally, some e-bikes can even reach speeds of up to 30 miles per hour, which is why it's essential to wear a helmet when riding them.

Wearing a helmet on a pedal bicycle or an e-bike is essential to preventing a severe traumatic brain injury. Helmets are the best defense for preventing serious head injuries, lifelong disabilities, and even death when riding a bike of any kind. While you might be an experienced rider, the people and cars around you aren't necessarily paying attention, adding an extra layer of danger when you're on two wheels. A helmet is hard on the outside to absorb the impact of the crash and soft on the inside to protect your head.

And it's not just about the helmet, it's about a properly fitting helmet: your helmet should sit level on your head and low on your forehead—one or two finger-widths above your eyebrow. The helmet's side straps should both form a V-shape under, and slightly in front of, the ears. Tighten the chin strap after snapping it together to ensure a snug fit that you can fit only two fingers between your chin and the strap.

I recommend going to a qualified and trusted helmet store to have your helmet properly fitted before hitting the road.

There is no federal law for the use of helmets while riding a bicycle. Currently, 22 states – less than 50 percent of the country – have statewide helmet laws. Many of these statewide laws only apply to riders under the age of 16-18 years old, or e-bike riders. Not having proper safety protocols in place for high-risk activities and transportation puts riders at a high risk on the road.

Wearing a helmet decreases the risk of severe traumatic brain injuries, facial fractures, and skull fractures. The more we advocate for safety protocols including bike lanes, regulation of motorized bicycles and scooters, and universal helmet laws, the safer and less likely riders are to sustain severe traumatic brain injuries and facial fractures. This allows riders to enjoy these eco-friendly transportation methods and recreational activities without the added risks and dangers.

Tracie is a Denver-based Speech Language Pathologist and Certified Brain Injury Specialist Trainer. She has over 14 years of experience working with patients who have survived brain injuries in an acute care or intensive rehabilitation setting. She is the owner of TBI MedSLP, a non-profit organization that provides accessible and affordable brain injury education to speech pathologists and healthcare providers to improve patient outcomes and patient experiences.



PROMOTING HELMET SAFETY THROUGH GIRL SCOUTS

By Mailelani Lessenberry

My family and I moved to Northwest Arkansas nearly three years ago. Bentonville, Arkansas is often called the “Mountain Bike Capital of the World,” and you can’t go anywhere in the area without seeing someone riding a bike. Because of all the two-wheeling activity around here – whether it’s mountain biking, BMXing, road biking, or gravel riding – I decided to do my Girl Scout Gold Award project on traumatic brain injury (TBI) awareness and the importance of helmet safety. It’s an occurrence that affects many people on bikes. In fact, the number one cause of hospital visits among children is due to bicycle accidents, and the leading cause of death and disability is from head injuries.

Similar to a Boy Scouts Eagle Project, a Gold Award Project is the final and highest award a Girl Scout can achieve. For most of my life, I’ve been riding bikes and skateboarding, and although I have only experienced small accidents and sustained minor scrapes, bruises, and concussions, I felt compelled to spread awareness about TBI and just how often it happens.

With this project, I started a social media campaign called Our Grey Matters Facts, which can be found on Instagram. I am hoping to partner with many organizations just like BIAA to create online content that will spread the word about brain injuries and how wearing helmets can help prevent them.



I know many kids, and even some adults, who choose not to wear helmets while riding a bicycle, skateboard, or scooter, because they think they’re inconvenient or uncool to wear. Some even think that since they’ve been going without a helmet for so long and nothing bad has happened to them yet that nothing bad will happen to them. Experiencing a traumatic brain injury, however, is far from cool. Helmets are quite affordable and immensely cheaper than hospital treatment from an injury. Wearing a helmet will reduce the hazard of structural head injuries, skull fractures, and fatality, and they are designed to scatter the force and energy sustained upon impact, which decreases the damage to the skull and brain. A concussion may still occur, but wearing a helmet is likely to lessen the impact and overall injury.

Traumatic brain injuries are very dangerous and pose a major risk to everyone, especially our youth. We can help protect our future by taking care of the brains of the younger generations. By using our heads and choosing to wear a helmet, and by telling others about the potential hazards, we can prevent TBI and reduce the number of accidents, hospital trips, and fatalities.

After a personal experience with traumatic brain injury and doing the research on this topic, I discovered a lot about TBI that has encouraged me to be much more careful about protecting my head. I hope that you, too, will remember to put safety first when it comes to protecting the most important organ in our bodies, especially in young growing children. Our futures depend on it!

STATE AFFILIATE NEWS

Delaware

During Brain Injury Awareness Month, the Brain Injury Association of Delaware (BIADE) proudly unveiled the Brain Injury Network (BIN), a beacon of hope set to make a profound impact. In January, the BIADE board's visionary investment paved the way for the creation of BIN, born from careful consideration of other affiliates, an exploration of current BIAA priorities, and a commitment to incorporating national material and training on a local level. As we build out case management disciplines and a more user-friendly resource library, we're also initiating community training leveraging BIAA's programs, including Brain Injury Fundamentals and Certified Brain Injury Specialist training for professionals in the field.

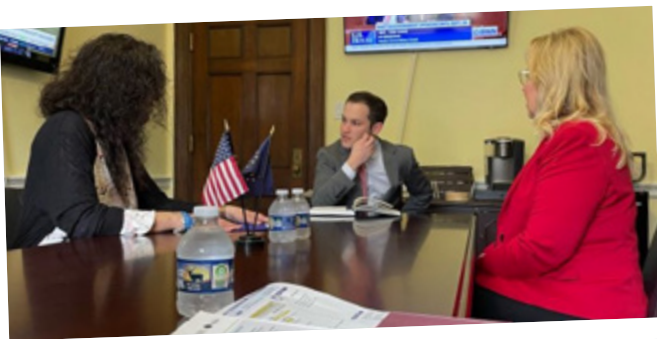
At its core, BIN is more than a network; it's a lifeline, a community-driven initiative designed to provide solace, resources, and navigation support to those affected by brain injury. Whether it's survivors seeking guidance or caregivers needing assistance, BIN offers a warm embrace, connecting individuals to the tools they need to overcome the challenges they face.

Embedded within BIN's mission is a powerful Theory of Change: if brain injury survivors and caregivers have timely access to education, resources, and



navigation support, they can persevere and achieve the best quality of life possible. This principle guides every aspect of BIN's approach, ensuring that help is available precisely when it's needed most.

BIN's immediate goals include increasing awareness of support resources; facilitating relevant referrals efficiently; reducing the time to access critical services; and cultivating a sustained sense of solidarity and community. Beyond the immediate, BIN aspires to secure increased financial support as needed; empower individuals with a sense of agency and control over their circumstances; and assist in achieving and sustaining a "new normal" post-injury. Ultimately, BIN's vision extends far into the future: to improve the quality of life for all those impacted by brain injury. Through dedication, collaboration, and unwavering support, BIN seeks to create a world where hope shines brightly for every survivor, caregiver, and provider.



Indiana

The Brain Injury Association of Indiana (BIAI) had a wonderful start to 2024! BIAI was extremely busy during the first months 2024 preparing for Brain Injury Awareness Month in March. We planned out our "My Brain Injury Journey" campaign in Indiana and shared materials and a brain injury awareness toolkit across our state to help us push forward with our awareness messaging. In the actual month of March, BIAI went

to Washington, and met with our legislators to advocate for increased brain injury funding. BIAI along with the BIAA and other state affiliates attended a reception with Rep. Bill Pascrell (N.J.) who chairs the Brain Injury Congressional Task Force. Incredible discussion and much fun was had by all while promoting awareness of chronic brain injury!

In April, BIAI put together a short video consisting of pictures of individuals impacted by brain injury in Indiana sharing about their own personal brain injury journey. Visit BIAI's website to view the video.

BIAI also held our popular and yummy popcorn three-day pop-up sale in March to acknowledge Brain Injury Awareness. BIAI is busy planning for our third annual Wiffleball Tournament, taking place on Oct. 26. Be on the lookout for more details to come, and a happy summer to all!

Louisiana

During Brain Injury Awareness Month, the Brain Injury Association of Louisiana (BIALA) presented its 15th annual conference, "Together in Harmony & Hope." Throughout the two-day event, more than 250 allied health professionals, caregivers, and individuals living with brain and spinal cord injuries gathered and had the opportunity to advance their knowledge and to learn together. A high level of energy and excitement ran through the exhibit hall where 40 sponsors and exhibitors were thrilled to share new information on products, services, and available resources. A survivor and caregiver track was offered with presentations that included neurologic music therapy, cognitive strategies for daily use, and setting up support systems for success. The highlight of the survivor track was the afternoon where everyone was actively engaging in a variety of recreational activities facilitated by three dedicated and passionate recreational therapists.

Louisiana's Unmasking Brain Injury art exhibit was on display with many new masks to show. Individuals



who painted masks were excited to see their creation as part of the display and posed for many pictures. Caregivers connected and left the conference with increased feelings of hope, support, and community. Many are coming together for Caregiver Coffees and support groups that have emerged over the past year as well as a monthly virtual support group.

Maine

During Brain Injury Awareness Month, the Brain Injury Association of Maine (BIAA-ME) held the 2024 BIAA-ME Brain Injury Resource Fair in Augusta on March 21, with nearly 60 exhibitors. 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.

On Sept. 30, BIAA-ME will hold its 15th annual conference on Defining Moments in Brain Injury at the DoubleTree by Hilton in Portland. Maine brain injury survivor and advocate Carole Starr will deliver the keynote, and the agenda will be packed with 16 breakout sessions.

BIAA-ME continues to work with the State of Maine to complete deliverables under the Administration for Community Living's Traumatic Brain Injury Partnership Grant and is collaborating with the University of Maine to address pediatric brain injury needs in Maine.





Mississippi

On April 5, the Brain Injury Association of Mississippi (BIAMS) hosted the 2024 NeuroTrauma Symposium. With a focus on “Empowering Resilience: Innovative Solutions to Neurotrauma Care,” this year’s annual conference drew a record number of attendees. Survivors, caregivers, healthcare workers, researchers, and industry innovators joined together for a day of looking at the brain injury journey holistically. Dr. Mark Shapiro of the University of Texas Medical Center San Antonio shared the exciting advancements his research team is making with medical treatment to reduce the impact of traumatic brain injury. Addie Grace Keyes, Miss Vicksburg’s Teen and survivor of a pediatric traumatic brain injury, participated as part of her passion for brain injury advocacy. Dwight Owens, who survived a car accident that left him paralyzed, ended the day with a powerful message of turning pain into purpose.

BIAMS’s project, “Building a Bridge,” continues to flourish. Adding to the list of in-person support groups will be a monthly meeting on the coast. Beginning July 20, survivors, their families, and their caregivers will be meeting on the third Thursday of each month at the YMCA in Ocean Springs.

Missouri

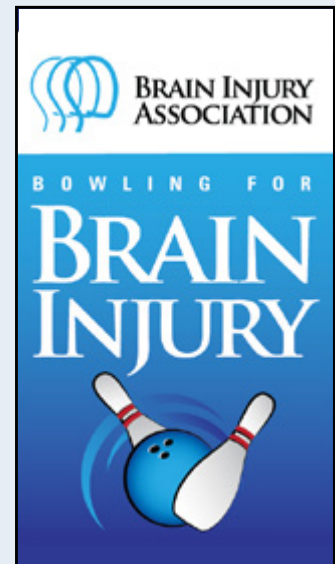
The Brain Injury Association of Missouri (BIA-MO) held our Bowling for Brain Injury events in June 2024. Teams in Kansas City, Springfield, and St. Louis enjoyed two hours of bowling, friendly competition, and pizza. Spectators joined the fun to cheer on their favorite Bowling for Brain Injury teams. The “Spare the Alley, Join the Rally” Teams participated with fundraising and no bowling.

More than \$30,000 has been raised so far. Sponsors, teams, bowlers, and donors joined in this great event to make a difference for a great cause. Event proceeds raise awareness about brain injury and provide services for persons with brain injury and their families.

The BIA-MO Survivor and Family Seminars 2024 were held in Springfield (March) and Kanas City (April). Topics included Fun with Cognitive Tasks, Coping with Changes and Adapting to New Roles, and Managing Anger, Anxiety and Depression. Survivor

and family members learned from others during the Pushing Through Recovery and Let’s Talk sessions. The same sessions will be presented in St. Louis on Nov. 9.

The BIA-MO Annual Statewide Professional Development Conference will be held Nov. 7-8 in St. Louis. This is a great opportunity for professionals who provide services on a full-time, part-time, or periodic basis to increase, expand, and maintain their knowledge about serving persons with brain injury.



New York

In partnership with Rusk Rehabilitation at NYU Langone Health, the Brain Injury Association of New York State (BIANYS) held the 2024 Brain Injury Symposium on March 9 at NYU Langone.

Sessions for the day focused on current TBI research and practical applications. Professionals and specialists in the fields of brain injury medicine and rehabilitation attended to learn about advancements in treatment, network with other professionals, and gain access to cutting-edge research and information.

A few notable sessions include Return to High-Level Mobility: From Mild to Severe TBI Recovery, Rusk Rehab BI Wellness Program: Engagement, Socialization, Connection, The Burke Rehabilitation Intensive Comprehensive Aphasia Program (ICAP), and The Art of Recovery: Nurturing Eye-Hand Coordination after a Stroke, just to name a few.

Accomplished and well-respected professionals presented throughout the day including Christopher Stavisky, PhD, OTR/L, clinical assistant professor at University of Buffalo; Ekaterina Dobryakova, Ph.D., the assistant director at the Neuroscience Research Center for TBI Research, Kessler Foundation; Gwenn Fried, the

Program Manager at NYU Langone Medical Center; Susan Wortmann Jutt, MS, CCC-SLP, a speech language pathologist at Burke Rehabilitation; Mahya Beheshti, a physician scientist at NYU Langone; and many more.

BIANYS is thankful to our partner, Rusk Rehabilitation, and all the presenters and attendees that made the Brain Injury Symposium a success.



Ohio

The Spring season has been blooming with successful events for the Brain Injury Association of Ohio (BIAOH)! On March 14, more than 100 brain injury survivors, caregivers, board members, and community advocates gathered at the Ohio Statehouse and met with 40 legislators to share their stories and increase awareness about the need for continued support of brain injury resources. Kevin Miller, Director of

Opportunities for Ohioans with Disabilities, received the Impact Leadership Award in honor of his dedication to brain injury services. During his acceptance speech, he shared with the guests how one of his family members is a brain injury survivor and that he witnessed firsthand some of the challenges that survivors and caregivers face. It was a heartfelt and inspiring speech that resonated with all of the guests in attendance at the luncheon.

Just a week later on March 22, BIAOH hosted a brand new event, "Resilient Minds: Artistry After Injury," which highlighted the powerful connection between art and healing and celebrated the talent of local brain injury survivors. One of the lead committee members, Brian Murphy, is a ballet dancer with the Ohio Ballet who experienced a brain injury after a bike accident. He credits ballet and artistry as a key factor in his ability to recover. The full day event featured an art gallery, afternoon workshops (featuring painting, dance and other interactive art activities) followed by an evening with cocktails, appetizers, and amazing performances by survivors. It was an unforgettable event for everyone in attendance.

Pennsylvania

The Brain Injury Association of Pennsylvania (BIAPA) was thrilled to welcome back the Brain Safety Fair this spring! Following the resounding success of our recent fair in Western Pennsylvania in March, we are pleased to resume these events as they contribute to our mission of brain injury prevention. Brain Safety Fairs provide important information and education about the brain and how it works, while offering fun-filled activities for attendees of all ages. Central to our efforts is the custom fitting and distribution of free bicycle helmets, underscoring our commitment to ensuring the safety of individuals within our communities. We look forward to hosting more of these family-friendly events and spreading awareness about the importance of safeguarding our brains!

The BIAPA Conference Committee is very busy planning for our annual conference. This two-day event, which took place on June 24- 25 at the Lancaster Marriott at Penn Square in Lancaster, Pa., was a valuable learning and networking experience. This year's annual conference theme is "Creating Roadmaps for Brain Injury Rehabilitation: The Journey from Initial Treatment to Community Inclusion." Designed for professionals, survivors, family members, caregivers,



and volunteers, some conference highlights include: up to 11 CEU and CE opportunities; exhibits and poster presentations; networking and social opportunities; coffee house and open mic for attendees to share their poetry, music or stories; a caregiver support group; yoga and tai chi sessions; and a sensory room. An exciting addition to this year's conference are a group sessions designed for pediatric professionals and caregivers, including an opportunity for pediatric caregivers to meet one another and develop a support network. A full listing of conference sessions, plus keynote and plenary speaker information, can be found at biapa.org/2024conference/.



Rhode Island

Following on from our highly successful 40th anniversary golf tournament in 2023, the Brain Injury Association of Rhode Island (BIARI) Classic returns for a second year on June 24 at Alpine Country Club in Cranston. Alpine CC is a private club and is considered one of the state's premier venues for golfers around the region. A couple of highlights at this year's tournament include two (2) Hole in One competitions and a Cash Putting Contest. Hole in One # 1 features a \$50,000 SUV for the lucky winner should (s)he hole out in one. Hole in One # 2 offers a six-day, five-night stay for two at the Home of Golf – St. Andrew's Scotland, including roundtrip air from Boston or New York, as well as tee times at St. Andrew's and Gleneagles, homes to both the British and Scottish Open Championships. And, if that isn't enough, we're also hosting a \$5,000 cash putting competition for one potential winner. So, as they say, "Beam me up Scottie" and "May the Fores Be with You" (apologies to all you Star Trek and Star Wars fans out there!).

South Carolina

The Brain Injury Association of South Carolina (BIA-SC) and its members participated in multiple awareness events during Brain Injury Awareness Month, including a Community Art Project entitled *Metamorphosis: Striving and Thriving After Brain Injury*. BIASC collaborated with the South Carolina Department of Disabilities and Special Needs on the project. Butterfly cutouts were decorated by brain injury survivors and caregivers from brain injury support groups, day programs, schools, rehabilitation hospitals and outpatient centers. The butterfly was also the theme of BIASC's online art class in February. The decorated cutouts were collected and pasted on a large canvas and displayed at the SCDDSN state office in Columbia. The canvas will also be on display at the upcoming Life with Brain Injury Conference.

Eric Washington, from Kansas City, Missouri, will be the keynote speaker at the annual Life with Brain Injury Conference on Friday, July 26, in Columbia. Eric is a powerful advocate for those living with a traumatic brain injury. He contributes valuable expertise from his own life experiences for The

National Center on Advancing Person-Centered Practices and Systems (NCAPPS). Last year there were 204 in attendance with 28 exhibitors. We hope this year will be even bigger and better. We are also continuing the butterfly theme into our conference marketing materials!



Virginia

The Brain Injury Association of Virginia (BIAV) collaborated with fellow brain injury providers and community advocates for Brain Injury Awareness Day 2024 in January. This year, BIAV appealed to the Virginia Legislature to invest in the brain injury community, emphasizing the importance of investing in both people and services to expand support to underserved and unserved areas across Virginia. Our efforts resulted in the General Assembly passing two budget amendments totaling \$2.5 million. To support additional advocacy efforts, in March, BIAV, alongside BIAA and other advocates, participated in Brain Injury Awareness Day in Washington, DC.

We also successfully organized our annual Making Headway Conference, featuring informative sessions tailored for professionals, individuals with brain

injuries, family members, and caregivers. Following the conference, we celebrated our annual Legacy Award event, where we expressed gratitude and admiration for the advocates and pioneers who are making a significant impact. Among our honorees was Christina Baggini, our Resource Manager, who dedicated 24 years of service to BIAV. As she embarks on retirement, she passes on her invaluable role as the liaison between BIAV and those needing our assistance and resources. We extend our heartfelt appreciation to her for her dedication and service.

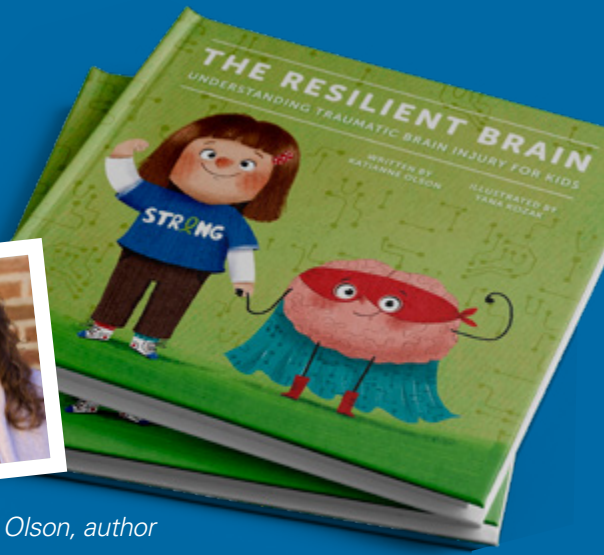
For further details about our programs and mission work, please visit biav.net.

BRINGING BRAIN INJURY AWARENESS TO CHILDREN

By Lauren Moore, Marketing & Communications Manager, BIAA



Katianne Olson, author



When Katianne Olson's husband sustained a traumatic brain injury in May 2020, she needed to figure out how to explain what had happened to their two young children. As a teacher, the first place she turned was children's literature – but she soon realized that there weren't any books that explained brain injuries to this young demographic. So, she set out to write her own book. As a result of her personal experience and extensive research, she penned *The Resilient Brain*, an illustrated children's book that explains what traumatic brain injury is, how brain injuries can happen, and how brain injuries affect people, in a way that young children can understand. Read on to learn more about what she learned and how she applied those learnings to her new book:

What sort of research did you have to do in preparation for writing *The Resilient Brain*?

I felt it was really important to collaborate with other families who also navigated a loved one sustaining a traumatic brain injury. Everyone's story surrounding a traumatic brain injury is unique and individualized and I wanted to be sure that I wasn't writing *The Resilient Brain* only in the perspective of our family's journey. A lot of research went into *The Resilient Brain* to be sure that the medical aspects and functions of the brain and the explanations of the roles of therapists were accurately explained (especially in kid-friendly language!) We had an incredible medical team that I was able to collaborate with that included brain injury doctors, therapists, and more! I feel beyond fortunate to have experienced such a collaborative process with incredible medical professionals, families, and educators to create this much needed resource for the brain injury community!

What new or surprising information did you learn about brain injury?

I experienced through watching my husband's rehabilitation journey, the incredible power our brains have. Being able to see it firsthand though, especially

with someone you love really drove me to learn more about neuroplasticity. It was really interesting to learn about the new therapies and research that is out about a variety of therapies post injury, specifically yoga. It took a couple years after navigating my husband's brain injury to connect with organizations like Love Your Brain and read up on the research on the power of meditation, yoga, and how powerful our brain is to rewire itself (even from my viewpoint as a caregiver!). I think often times we focus so much on the physical healing of a brain injury in those critical early moments of an accident, but addressing the emotional healing post-TBI for those who sustained a TBI and their loved ones is just equally, if not just as important as the physical healing.

What do you wish that people knew about brain injury?

It's a lifelong journey that is going to have many ebbs and flows. The big message we often hear surrounding brain injury is that it's an invisible injury — and it's so true. It's so hard to know the fight and battles that one with a brain injury and their families are going through on the outside every single day — everyone's brain injury is unique to them.

What are your hopes for *The Resilient Brain*?

My hope is that *The Resilient Brain* can be utilized as resource that takes a very complex and confusing injury, into a very easy to understand story that helps families navigating a TBI, and also build awareness in our world on this common, invisible injury.

Most importantly, my deepest desire is that it gives those navigating this complex injury, hope. I think there can be so much darkness in those early (and really all!) moments surrounding a brain injury diagnosis... but I hope my book allows those to see the light that the brain is resilient and you are resilient as a person too.



BRAIN INJURY AWARENESS DAY ON CAPITOL HILL

On March 5-6, hundreds of brain injury advocates came together on Capitol Hill for Brain Injury Awareness Day. More than 300 attendees from 38 states held more than 215 meetings with their Senators, Congressional representatives, and their staff to advocate for more services, more research, and more funding for brain injury, particularly through reauthorization of the Traumatic Brain Injury Act. In addition to facilitating congressional appointments, the event included an orientation and training session, a survivors' meet and greet, and a Brain Injury Awareness Fair.



300+
attendees



38
States represented



215+
Meetings with State
Representatives
& Senators

SHARING THEIR STORIES

Since launching My Brain Injury Journey, our new awareness campaign, earlier this year, dozens of survivors and caregivers have shared their stories about how their brain injury has had an impact on the trajectory of their life:

“‘Hope’ is the operative word in my life. Never give up hope for recovery... baby steps, sometimes few are far between! I’m not even supposed to be here, realistically. Any gain is a gift.” – Howard

“I have days where I think I can do this and days when I feel I just can’t stand the constant pain. The most upsetting thing is people don’t understand unless they have gone through it themselves. Traumatic brain injury is an invisible condition, and the struggle is daily.” – Diane

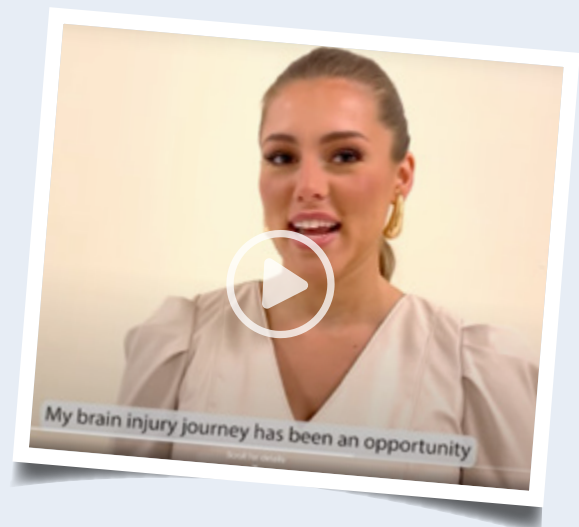
“It’s not been easy. My brain doesn’t work like it used to. I could never be an executive again, even if I wanted to do so. I mix up words and numbers. I need a long nap each day. I get killer headaches. I can’t remember details. I cannot multitask AT ALL. Don’t ask me a question while I’m trying to divide a salad or write down a number. It won’t happen. I can’t do two things at once. But what I’ve found is I have great peace.” – Mary Kay

“If I had to think of one word to describe my journey, from the very start to present day, it would be perseverance. Whether it was my parents, my siblings, my rehab therapist, or my friends, I always had encouragement to keep pushing forward and advance in my healing journey.” – Elijah

“With the newness of brain injury also came the reality no one knew we needed support and friendship when we got home. It was so very lonely adjusting.” – Donia

“My Brain Injury Journey is the most difficult challenge I have ever experienced, but also a blessing. While I have not been able to recall the night that changed my life, I focus on the journey moving forward.” – Erik

Read more stories of perseverance, resilience, frustration, and hope here: <https://www.biausa.org/brain-injury/community/personal-stories>



My Brain Injury Journey Campaign Goes Live in DC

During the events for Brain Injury Awareness Day on Capitol Hill, brain injury survivors, caregivers, and advocates described their brain injury journeys to us, sharing what they have learned about themselves and what they wish others knew about brain injury. Scan the QR code to watch the video and hear their stories, and share your own story at biausa.org/mybraininjuryjourney



Get Involved with Brain Injury Advocacy

There are many opportunities for the brain injury community to advocate for brain injury causes. The BIAA has advocacy materials available for download at biausa.org/get-involved. We are also still advocating for the reauthorization of the Traumatic Brain Injury Act, which is up for renewal this year. To send a letter to your congressional representative and/or senators asking them to support reauthorizing the TBI Act, scan the QR code.

EVENTS AND WEBINARS

August 6, 2024, 3 p.m. ET

Persistent Visual Dizziness Post-Concussion: Is It the Ears, the Eyes, or the Neck

DR. JACQUELINE THEIS, O.D., FAO, FNAP

Patients with persistent post-concussion oculomotor dysfunction often complain of dizziness with visual tasks including scrolling on a computer or phone, reading, grocery shopping, visual motion, or being in a car. This webinar will cover the differential diagnosis of post-traumatic visual dizziness and how to clinically decipher if the etiology is truly visual (eyes), vestibular (ears), cervical (neck), or something else entirely. Register at shop.biausa.org/products/livewebinars

August 20, 2024, 4 p.m. ET

Attention and Information Processing Speed Following Brain Injury – An Interdisciplinary Approach

In this David Strauss Clinical webinar, Amanda Heys, MHS, OTR/L, Tori Stramara, DPT, CBIS, and Tracy Graham, MSP, CCC-SLP, CBIS we will explore attention and processing speed deficits following brain injury and the importance of an interdisciplinary approach to achieve functional outcomes. Register at shop.biausa.org/products/livewebinars

August 29, 2024, 3 p.m. ET

Navigating the Educational Needs of Students Who Do Not Bounce Back After Mild Traumatic Brain Injury

BRENDA EAGAN-JOHNSON, EDD, CBIST-AP

In this Robert Sbordone Memorial mTBI/Concussion webinar, Brenda Eagan-Johnson, Ed.D., CBIST-AP, will focus on the challenges faced by a subset of students who experience ongoing learning issues after sustaining a mild traumatic brain injury (mTBI). Unresolved symptoms of mTBI can impact academic performance, school activities, and post-high school plans. Register at shop.biausa.org/products/livewebinars

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Contact Peter Knockstead,
Director of Corporate Partnerships

pknockstead@biausa.org | 703-761-0750, ext. 640

September 5, 2024, 3 p.m. ET

Concussion Management: Putting Research into Practice

CRISTIN BEAZLEY, PT, DPT

Concussion is a complicated injury that can result in multi-system impairments and can often be challenging to identify. The recommendations in this population are continuously evolving based on ever-changing evidence and therefore can be difficult to keep up with. In this Robert Sbordone Memorial mTBI/Concussion webinar, Cristin Beazley, PT, DPT will discuss the latest evidence-based recommendations for management of concussion and concussion-related injuries across populations and rehab settings. Register at shop.biausa.org/products/livewebinars

November 7, 2024, 3 p.m. ET

A New Clinical Approach to Anger After Brain Injury

DAWN NEUMANN, PHD

In this David Strauss Clinical webinar, Dawn Neumann, Ph.D., FACRM will describe newly identified factors, known as negative attributions, that significantly contribute to anger and aggression after brain injury. Dr. Neumann will demonstrate two assessments that can be used to clinically evaluate a patient's tendency toward negative attributions and describe a new clinical approach for treating anger and aggression associated with negative attributions called Intervention to Change Attributions that are Negative (ICAN). Register at shop.biausa.org/products/livewebinars

November 15, 2024

Luminary of the Year

NATIONAL PRESS CLUB, WASHINGTON, D.C.

BIAA will celebrate its first-ever Luminary of the Year gala, where attendees and honorees will have the opportunity to hear stories of resolve, determination, and compassion from the brain injury community. This event includes a cocktail reception, dinner, auction, and Fund the Mission Moment. Learn more at biausa.org/luminary-of-the-year.



To register for one of our webinars, scan the QR code or visit shop.biausa.org/products/livewebinars

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**



3057 Nutley Street, #805
Fairfax, VA 22031-1931



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.

