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PRESEARCH



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FROM MY **DESK**

The Brain Injury Association of America (BIAA) is pleased to join with disability organizations across the nation in celebrating the Americans with Disabilities Act (ADA). President George H. W. Bush signed the ADA on July 26, 1990. The law prohibits discrimination against people living with disabilities in employment, government services, public accommodations, and telecommunications.

Right after the ADA became law, the City of Boston held the first Disability Pride Day event. Since then, communities across the country have commemorated the ADA's passage by celebrating Disability Pride Month in July. The observance honors all people who live with a disability and recognizes the vast diversity in disabilities. Regrettably, Disability Pride Month is not officially recognized by the federal government. BIAA and other organizations are encouraging Congress to change this.

Despite the tremendous progress in reducing discrimination in the last 32 years, there is still much work to be done to create a more equitable and inclusive country for all people living with a disability. In the U.S. and around the world, we need to provide opportunities for participation and education and spread awareness of disability justice. We need to fight for inclusion, intersectionality, and accessibility and advocate for the rights of children and adults who have disabilities. We need to confront ableism head on.





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

Margaret Mead said, "Never underestimate the power of a small group of committed people to change the world. In fact, it is the only thing that ever has." Although the U.S. disability community is no longer small – 61 million according to the Centers for Disease Control and Prevention – your voice can help. Speak up. Speak out. Make your community more accessible to all.

In the meantime, please enjoy the research-related articles found in this issue of *THE Challenge!*, the news from our State Affiliates, and please thank our individual and corporate contributors that help keep our doors open.

Ensur H anno

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

Calling on Congress to Increase Understanding of Long COVID



S ince 2020, our knowledge of post-acute sequelae of SARS-CoV-2 infection (PASC), also known as Long COVID, has significantly grown. Currently there are more than 87 million survivors of COVID in the United States. It is estimated that 33% have PASC.

According to one study, one-third of patients diagnosed with COVID-19 developed psychiatric or neurological disorders within six months. The disorders included depression, anxiety, stroke, and dementia. In that same study, among patients admitted to an intensive care unit (ICU), the incidence of psychiatric or neurological disorder rose to an unprecedented 46%.

The Effects of Long COVID

Researchers have identified post-COVID health problems in many different organ systems, including the heart, lungs, and kidneys. Other issues identified have involved blood circulation, the musculoskeletal system, and the endocrine system. Gastrointestinal conditions, neurological problems, and psychiatric symptoms were also present.

A study examining more than 353,000 patients diagnosed with COVID-19 at the start of the pandemic found that they had twice the risk of uninfected people of developing respiratory symptoms and lung problems, including pulmonary embolism, and post-COVID patients aged 65 and older were at greater risk of developing kidney failure, neurological conditions, and most mental health conditions.

Another study found that after the first 30 days of infection, individuals with COVID-19 are at increased risk of cardiovascular diseases, including cerebrovascular disorders, dysrhythmias, ischemic and non-ischemic heart disease, pericarditis, myocarditis, heart failure, and thromboembolic disease.

Prioritizing Patient Health

Given the number of COVID-19 cases across the U.S., the impact of post-COVID symptoms is likely enormous, and without proper information sharing, patients could suffer devastating consequences and misdiagnoses. Additionally, understanding the core causes of PASC will make it easier for

providers to identify patients who are more at risk of developing its chronic symptoms, and potentially providing early interventions.

There is considerable work to do to build knowledge around PASC, including:

- 1. Clarifying definitions and the language used to describe PASC symptoms;
- 2. Enhancing research, data collection, and surveillance;
- 3. Focusing on patient diversity in research and mitigating disparities in care;
- 4. Defining outcomes;
- 5. Educating medical professionals and patients about PASC; and
- 6. Developing clinical treatment guidelines and care coordination across primary care and several specialty providers.



Taking Action

Several bills have been introduced in Congress to focus on these
broad themes that could serve as a potential starting point for assessing this rapidly developing issue. Similarly, the Biden

Administration directed federal agencies to develop the first-ever interagency national research action plan on PASC. The initiative is expected to advance progress in prevention, diagnosis, treatment, and provision of services, supports, and interventions for individuals experiencing PASC.

In the meantime, the National Institutes of Health (NIH) created the RECOVER Initiative to learn about the longterm effects of COVID. The RECOVER Initiative brings together patients, caregivers, clinicians, community leaders, and scientists from across the nation to understand, prevent, and treat PASC, including Long COVID. To learn more, visit recovercovid.org.

The nation's health system must follow the science as it relates to researching and caring for people affected by PASC, relying on leading experts to lead the dialogue to ensure continued progress on key priorities and additional federal investment is made. The American Academy of Neurology has joined with other professional societies and consumer organizations, including the Brain Injury Association of America, to urge members of Congress to consider PASC a priority and ensure that individuals suffering from PASC can receive the timely care coordination they need.

This article was adapted from a letter to Congress, signed by BIAA and 40 other organizations. For references, please visit the online version of this article at biausa.org.

The Voice of **Brain Injury**

The Brain Injury Association of America is the country's oldest and largest nationwide brain injury advocacy organization. Our mission is to advance awareness, research, treatment, and education and to improve the quality of life for all people affected by brain injury. We are dedicated to increasing access to quality health care and raising awareness and understanding of brain injury.



Learn more at biausa.org

Transforming Traumatic Brain Injury Assessment: The Role of Brain-Specific Biomarkers in Blood



Can you tell me your name?

Follow this light with your eyes.

Lift your left arm and make a fist.

By Dr. Beth McQuiston, neuroscientist, registered dietitian, and medical director for Abbott's diagnostics business

hen assessing a traumatic brain injury (TBI), professionals use a variety of techniques, including the Glasgow Coma Scale (GCS), physical exams, subjective questions, and potentially an MRI or CT scan.

First published in 1974, the GCS gave doctors a scale to assess a patient's injuries based on their responsiveness, including eye-opening, motor, and verbal responses. A patient's GCS score helps healthcare professionals determine how severe the injury might be and what next steps should look like, including potential imaging, and whether a patient can safely be discharged. Unfortunately, a 2015 study found that GCS scoring accuracy across more than 200 emergency providers was only 33%. Additionally, another study found that an estimated 82% of patients with suspected TBI were given CT scans but more than 90% were negative and showed no evidence of traumatic abnormality.

Biomarkers Change the Game for TBI Assessment

It has been nearly 50 years since the GCS was published, and there is clearly room to innovate and build upon the process of assessing TBI. One way to do this is by providing quick, objective measurements for a potential TBI. That's where brain injury-specific biomarkers come into play. The biomarkers glial fibrillary acidic protein (GFAP) and ubiquitin carboxyl-terminal hydrolase L1 (UCH-L1) appear in the blood after a TBI occurs. Looking for GFAP and UCH-L1 can transform our ability to evaluate TBI. Healthcare professionals have had blood tests for the heart, liver, and kidneys for some time, but they haven't been able to run blood tests for the brain – until now.

One biomarker, GFAP, reliably indicates whether a patient has a recent mild traumatic brain injury (mTBI). It is a specific marker of glial injury to the brain that can be elevated when brain injury occurs. The levels of this protein are notably unaffected by extracranial trauma or exercise as well, unlike other biomarkers that have been previously studied.

UCH-L1 is a degradation enzyme that is highly specific for neurons. Blood levels can help distinguish between patients who do and do not have a mTBI.

Brain Injury Biomarkers Can Be Detected by FDA-cleared Test

First cleared by the FDA in 2021, and later registered in Europe and other countries, healthcare professionals now have access to a test called the i-STAT TBI Plasma test that can tell them if these two biomarkers' levels are "Elevated" or "Not Elevated" in a patient presenting with a possible mTBI. This helps them evaluate whether further testing is needed.

This rapid, biomarkers blood test can help healthcare professionals quickly evaluate mild traumatic brain injury, such as concussion – even in cases when a CT scan may be normal. It has a negative predictive value of 99.3% and clinical sensitivity of 95.8%.

What's Ahead

At least 69 million people are estimated to sustain a TBI each year. Streamlining the TBI assessment process with these biomarkers can potentially decrease unnecessary exposure to radiation while decreasing costs for both healthcare systems and patients — all by answering the broader need to avoid excessive use of CT scans. Patients can also get results quicker when this test is compared to the wait time and the procedure for obtaining a head CT scan. Test results are available on the i-STAT TBI Plasma test in approximately 15 minutes after plasma is placed in the test cartridge.

GFAP and UCH-L1 help

rule out the need for a

that can revolutionize

professionals assess TBI.

In the future, we could

portable blood test for

concussion is available

and ambulances, on the

even on the playground at

school - wherever it's

sidelines of a game, or

in urgent care clinics

see a world where a rapid,

the way healthcare

head CT scan and together form an invaluable tool



The Abbott i-STAT TBI Plasma test

needed most – to give quick assessments that will lead to the best possible outcomes and care. Pairing an objective diagnostic test that is powered by biomarkers with the assessments used today gives physicians and their patients a clearer picture about what is happening to the brain at a time when it is needed most.

For references, please visit the online version of this article at biausa.org.



Preserving access to lifesaving flights

FACTS

Since 2010, more than 130 rural hospitals have closed, putting more distance between veterans and the nearest trauma center.

Air ambulances fill this critical gap in rural America by transporting patients quickly and safely.

The SOAR Campaign

is committed to preserving access to emergency air medical services for 85 million Americans who live more than an hour away from trauma centers best suited for treating brain injuries. This includes many of our nation's veterans.

Unfortunately, the Department of Veterans Affairs is proposing to cut the reimbursement rate for air medical providers, putting this lifesaving service at risk.

The SOAR Campaign is working hard to protect access to health care for those who bravely served our country.

Visit **soarcampaign.com** today to learn more.

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Deep Brain Stimulation and Traumatic Brain Injury

By Dr. Clausyl J. Plummer II

Traumatic brain injury (TBI) is the disruption of brain function as a result of external forces, which can include closed head injuries (blunt force trauma to the head by or against an object) or penetrating head injuries. According to the Centers for Disease Control and Prevention (CDC), approximately 1.5 million individuals in the United States survive a traumatic brain injury annually, and many develop both short-term and long-term disabilities related to wakefulness, cognition, behavior, and movement.

Managing Care

Healthcare professionals have traditionally recommended medication to manage negative outcomes, but the efficacy has been limited. This is especially evident in post-traumatic neuro-psychiatric derangement and post-traumatic movement disorders. When pharmacologic interventions are not an adequate treatment, healthcare professionals may consider options in the form of neuromodulation.

Neuromodulation is the process of inhibition, stimulation, or modification of electrical and chemical activity in the nervous system. It can involve both the central and peripheral nervous system and is further classified as non-invasive and invasive modalities.

- *Non-invasive neuromodulation* examples include transcranial stimulation and transcranial direct current stimulation. These methods are currently being studied for efficacy in the brain injury population.
- *Invasive neuromodulation* examples include deep brain stimulation (DBS), which is being studied for use in a variety of ailments.

Of note, there have been multiple studies that have demonstrated efficacy in the treatment of depression, PTSD, and anxiety with trans-cranial stimulation and direct current stimulation, but far fewer studies assessing deep brain stimulation in the TBI population.

Deep Brain Stimulation (DBS)

DBS is a surgical treatment option that involves the use of constant or intermittent electrical stimulation through the placement of electrodes into specific areas of the brain that assist with movement and cognitive behavioral function. These areas are also referred to as subcortical regions of the brain and include structures like the thalamus and the globus pallidus in the basal ganglia.

DBS was first approved by the United States Food and Drug Administration (FDA) for treatment of essential tremors in 1997 and was later approved for the treatment of Parkinson's disease in 2002. Since then, there have been multiple studies demonstrating its efficacy in these patient populations and as a result, indications for deep brain stimulation have been expanded to include refractory depression, post-traumatic stress disorder (PTSD), obsessive compulsive disorder (OCD), and are also being investigated in the TBI population.

Studying the Effects of DBS Among TBI Survivors

There are an increasing number of studies being done to evaluate DBS among TBI survivors.

Minimally Conscious States (MCS)

One study looked to investigate the potential therapeutic use of DBS of patients in a minimally conscious state or vegetative state caused by traumatic brain injury or hypoxic encephalopathy. Fourteen out of 49 patients met inclusion criteria for the study, and they underwent surgical placement of electrodes into the thalamic centromedian/parafascicular (CM-Pf) complex for deep brain stimulation.

Four of the selected patients showed functional improvement within 38 to 60 months after implantation with three of those previously being at a minimally conscious level and one at a vegetative state level. Two of the patients in a MCS regained consciousness and progressed to functional improvement in ability to ambulate, speak fluently, and live independently. One of the patients in a MCS also regained consciousness and was still utilizing a wheelchair at the time of the study's publishing.

This small study was able to demonstrate possible benefits to the utilization of DBS for patients who are suffering from disorders of consciousness.

Behavioral Challenges

Another study done by Rezai et al. (2016) investigated the safety and effectiveness of DBS for individuals with chronic TBI coupled with behavioral challenges, including impulsivity issues and reduced initiation. This study included four patients who had sustained severe TBIs from motor vehicle collisions and were six to 21 years post-injury. These patients underwent DBS bilaterally into the nucleus accumbens in addition to the anterior limb of the internal capsules and were tracked with serial assessments for two years. After two years of serial assessments, three of the four patients demonstrated functional improvement as measured by the Mayo-Portland Adaptability Inventory-4 assessment and demonstrated improvement in impulsivity, initiation, and ability to perform activities of daily living. Several of the patients involved also tolerated weaning various atypical antipsychotics and benzodiazepines that were previously being used for behavioral problems prior to DBS implantation.

Though this study had several limitations, it provides additional insight into potential areas in which DBS can be considered in the chronic TBI population.

Post-Traumatic Dystonia

A more recent case series done by Li et al. (2019) looked to highlight the efficacy of DBS for post-traumatic dystonia (PTD) in five patients that demonstrated improvement in function. These patients were considered to have disabling PTD and underwent DBS implantation in the globus pallidus internus, the subthalamic nucleus, or the ventral intermediate nucleus. They were assessed using the Burke-Fahn-Marsden dystonia rating scale (BFMDRS) at baseline and then again at the last follow-up appointment over 12 months after implantation.

All five of the patients demonstrated improvement ranging from 65.9% on the BFMDRS movement assessment and by 68.6% on the disability score. This functional improvement also resulted in all five patients demonstrating improvement in quality of life as illustrated on the Short Form health survey (SF-36). This small case series provides another example of the potential for DBS to help facilitate functional recovery for PTD after a TBI.

In all, there have been studies that demonstrate some potential for efficacy with DBS in the TBI population, but larger randomized trials are needed to better demonstrate effectiveness in treatment of behavioral disturbances and movement disorders in this population. It remains a more invasive form of treatment and there must be continued attention to the mitigation of surgical complications. Not all studies on DBS and TBI have demonstrated efficacy and there needs to be more robust research to further explore those differences in results. 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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For general information about brain injury, visit biausa.org

Study Shows Increased Risk of Neurological Disorders Following COVID-19 Infection

study recently published in The Lancet, a psychiatry journal, found that previous infections of COVID-19 are associated with an increased risk of neurological disorders. The authors compared the health data of over 1.2 million patients with a recorded COVID-19 diagnosis and an equal number of patients with a non-COVID respiratory infection. Analysis showed a substantial difference in risk trajectories of in the cohort with a prior COVID-19 infection.

"Risks of the common psychiatric disorders returned to baseline after 1–2 months (mood disorders at 43 days, anxiety disorders at 58 days) and subsequently reached an equal overall incidence to the matched comparison group (mood disorders at 457 days, anxiety disorders at 417 days)," the study reports. "By contrast, risks of cognitive deficit (known as brain fog), dementia, psychotic disorders, and epilepsy or seizures were still increased at the end of the 2-year follow-up period."

> The study found the increased risk for neurological disorder was the same for different COVID-19 variants, including both the delta and most recent omicron variants.

"The fact that neurological and psychiatric outcomes were similar during the delta and omicron waves indicates that the burden on the healthcare system might continue even with variants that are less severe in other respects," the report concludes.

The study is available on The Lancet's website: doi.org/10.1016/S2215-0366(22)00260-7.

International Brain Bee World Championship

Congratulations to the winners of the 2022 International Brain Bee (IBB)!

F ifteen-year-old Canadian high school student Helene Li is the 2022 International Brain Bee World Champion. Second place went to 17-year-old Anmol Bhatia from the USA, and third place to 17-year-old Ugne Birstonaite from Lithuania. The winners were announced at the Federation of European Neuroscience Societies (FENS) Forum 2022 in Paris. The 11 finalists joined the conference stage by Zoom and were introduced by special guest and last year's World Champion Viktoriia Vydhzak from Ukraine.

2022

The Brain Bee is the world's premier neuroscience competition for teenagers. The World Championship brings together students from across the world for an important educational and cultural experience. A total of 31 national Brain Bee champions from across the globe took part in the virtual 2022 event held in July, hosted by FENS, and organized in collaboration with the Paris Brain Institute. Each competitor had previously won their national or regional Brain Bee to qualify for the international championship.

Finding Cures for Chronic Brain Injury Through Research

An Update on the BIAA Research Grants Program



njury to the brain can evolve over time into a lifelong health condition called chronic brain injury (CBI), which may impair the brain and other organ systems and persist or progress over an individual's life span. Little is known about how or why this happens.

In 2019, the Brain Injury Association of America (BIAA) established its research grant program with the goal of "Finding Cures for Chronic Brain Injury" thanks to a generous bequest from the estate of Dr. Linda Redmann coupled with funds from BIAA's reserves. Each year, researchers from across the country can apply for dissertation grants of up to \$5,000 and seed grants of up to \$25,000 to fund scholarly work that seeks to answer questions and further our understanding of CBI. Since 2019, donors have generously contributed to the Brain Injury Research Fund, which has made it possible for BIAA to support more than \$170,000 in research projects to date.

Below, we checked in with three of the 2021 BIAA Research Grant Award recipients to see how their careers in brain injury research were impacted by the grants we awarded and what new lines of inquiry they are pursuing now.

DANA LENGEL

Childhood TBI and Psychosocial Disorders

Dana Lengel, Ph.D., Drexel University was awarded a dissertation grant of \$5,000 for her project "The Role of FK506binding Protein 51 (FKBP5) in Longterm Psychosocial Outcomes of Pediatric TBI." Her project



examined how to mitigate the risk of psychosocial disorders that can emerge in adolescence and adulthood among children who survive traumatic brain injury. Dr. Lengel's dissertation grant was supported by a generous gift from Dr. Lance and Mrs. Laura Trexler.

Receiving the dissertation award from BIAA was an extremely important accomplishment during my graduate

training. The support from this award helped to fund important preclinical research on novel treatments for cognitive and stress-related impairments following pediatric traumatic brain injury.

The results from these studies have led to two original manuscripts, one of which was recently published in Journal of Neurotrauma and another which was recently submitted for publication. These results are also being followed up on in the laboratory in the form of an NIH Research Project Grant Program (R01) submission. Since receiving the dissertation award, I have defended my dissertation and graduated from the Ph.D. program at Drexel University, and completed a postdoctoral fellowship at the Icahn School of Medicine at Mount Sinai. The BIAA grant has overall had an immeasurable impact on my research, and was instrumental in allowing me to execute my graduate research project and continue into a successful career in science.

KATHRYN LENZ

Sex-Specific Immune Responses to Childhood TBI



Kathryn Lenz, Ph.D., The Ohio State University Institute for Behavioral Medicine Research, was awarded a seed grant of \$25,000 for her project "Pediatric TBI effects on longterm myelination: sex specificity and

neuroimmune modulation." Her project is examining sex-specific inflammatory functions and immune responeses of the brain, which could help discover new strategies to treat or prevent long-term outcomes of childhood TBI.

Our studies on pediatric brain injury have been progressing rapidly. We have exciting new data showing unique sex differences in the brain's immune response to pediatric brain injury in a rodent model that are totally different from those seen in adult TBI.

The BIAA seed funding has been instrumental to catalyzing our initial project development, begin

related collaborative and ancillary projects, and allowed our team to apply for other funding, including major grants from NIH. We have begun an exciting new project based on our BIAA seed project to study the combined effects of early life adversity and pediatric TBI on brain development.

We have recently received a Department of Defense Traumatic Brain Injury and Psychological Health grant to study the effects of early life adversity on risk for TBI-induced psychiatric complications.

COLEEN ATKINS

Early Life Stress and Mild Traumatic Brain Injury



Coleen Atkins, Ph.D., University of Miami Miller School of Medicine was awarded a seed grant of \$25,000 for her project "The Effects of Early Life Stress on Outcome after Mild Traumatic Brain Injury." Her project

examined how early life stress can limit recovery from a mTBI and tested an anti-inflammatory drug to see if it improved recovery after mTBI and stress.

The major objective of this project was to determine if chronic stress limits recovery after a mild TBI. The BIAA grant provided us with support to investigate how immune cells in the brain, microglia, are altered with chronic early life stress.

We found that chronic early life stress primes microglia. A subsequent mTBI after chronic early life stress activates inflammatory signaling in the microglia, which worsens pathology in the brain and causes persistent cognitive deficits. Treatment with an anti-inflammatory treatment after mild TBI reduced the microglia activation and improved cognition.

Thanks to support by the BIAA grant, we used the data from this project to successfully apply for and received a five year grant from the Veterans Administration Rehabilitation R&D Service.

(continued on page 14)

(continued from page 13)

BIAA has been able to offer these grants to promising researchers due to the generous support of our donors, and we are currently seeking funds to support grants awarded in future years.

Dissertation Grants

recognize outstanding doctoral dissertations that contribute to our understanding of chronic brain injury. These grants provide researchers up to \$5,000 for up to two years.

Seed Grants

support the research of both new and experienced investigators. These grants provide up to \$25,000 in funding.

• Young Investigator Seed Grants support the work of new researchers who are working under an experienced mentor. These grants help new investigators prepare for larger funding from other public or private sources.

• **Brain Injury Scholar Seed Grants** support the work of experienced researchers who need supplemental funding in order to expand the scope of an existing project by testing new

hypotheses or conducting secondary analysis.

For more information about how you can support the Brain Injury Research Fund, contact Robbie Baker at (703) 761-0750, ext. 648 or rbaker@biausa.org. For information on the research grants program contact research@biausa.org.

Surviving Marriage with Brain Injury



Cynthia Lim is the author of *Wherever You Are: A Memoir of Love, Marriage and Brain Injury,* Coffeetown Press, 2018.



"Caregiving filled me with exasperation and hopelessness at times, but it was my ultimate expression of love."

By Cynthia Lim

"Marriage is memory, marriage is time," wrote Joan Didion in The Year of Magical Thinking. But what happens to a marriage when one partner loses those accumulated memories? In 2003, my husband suffered an anoxic brain injury due to cardiac arrest that deprived him of oxygen. At age 47, he lost the ability to initiate speech and had short-term memory loss. He needed help with all daily activities and could not be left alone.

My husband and I were college sweethearts and had been together for 28 years. After his brain injury, he wasn't the same person and was never able to resume his career as an attorney. His thoughts were jumbled and at times incoherent. He couldn't remember what happened to him that day or the week before. But his long-term memories remained. He never forgot his love for me or our two sons. His eyes lit up at the sight of me, as if he was seeing me anew each time.

Along with his capacity for love, this is what sustained me through the years of disability: I acknowledged that caregiving was stressful and that it was normal to feel angry at times. I wasn't a saint and didn't have to act like everything was under control. I reached out to others for help when I felt overwhelmed. I took breaks and carved out time for myself.

Caregiving filled me with exasperation and hopelessness at times, but it was my ultimate expression of love.



5 FACTS ABOUT PBA

Despite years of research, there is still confusion and misinformation surrounding PseudoBulbar Affect (PBA). If you suspect that you or a loved one may be affected, the first step towards treatment is an accurate diagnosis, so be sure to talk to your doctor.

1

Typically, PBA occurs secondary to a neurological disorder or brain injury. PBA is commonly found in patients with a stroke, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), traumatic brain injury (TBI), Alzheimer's disease or Parkinson's disease.



Studies have found that nearly 7.1 million Americans have symptoms typically associated with PBA.

- **PBA is often confused with depression.** However, PBA is a neurological disorder, meaning that it is caused by damage to the nervous system. It is different from psychological disorders like depression and bipolar disorder that are related to a person's emotional and mental state. Because sudden emotional outbursts can be a symptom of several conditions, it is important to visit a doctor receive a proper diagnosis.
- 4

PBA episodes - including uncontrollable laughter and involuntary crying - are unpredictable. They can occur at any time and last several seconds or minutes. Many times, these episodes can happen at inappropriate times and can cause the person and/or their caregivers to feel embarrassed and confused.

5 There are ways to manage PBA. If you talk with your doctor, they can help determine which treatments may work best for you. Prior to meeting with your doctor, keep a diary to track your episodes. Remember to include if something triggered the episode, if the episode was consistent with your actual feelings at the time, and how long the episode lasted.



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THANK YOU!

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. Thank you to the following individuals who have made this commitment.

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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. A special thank you to the following individuals who have made such thoughtful commitment.

Dr. Guillermo Arbona Mark Lane Brandt Dr. John Corrigan Mr. Mark W. Davis Dr. Christina Dillahunt-Aspillaga Mr. & Mrs. John and Alice Dillon Mr. Bud Elkind Ms. Luann Good-deCurnou E.P. Halstead Ms. Heather Hamilton Mr. Thomas Hardman Ms. Margaret "Peggy" Harris Ms. Page Melton Ivie Mrs. Sharon Keith Mrs. Stephanie Rivard Lane Dr. Shelly Levy Dr. Brent Masel Mr. Douglas Minturn Ms. Rhonda Oetzel Mr. Reynaldo T. Palacio Mr. Daniel Pando Mrs. Jill Pando Mr. Harold Pritchard Dr. Linda Redmann Mr. John Rivard Albert and Nadene Robertson Dr. Robert Sbordone LCDR Jeanne Van Gilder Mr. Larry Volchok

For more information about how you can recognized as a member of the Futures Fund Legacy Society, contact Robbie Baker, Vice President & Chief Development Officer at (703) 761-0750, ext. 648 or rbaker@biausa.org

ADVOCACY UPDATE

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

The 2nd Session of the 117th Congress of the United States has been quite active for brain injury advocates.



Appropriations

On June 30, 2022, the U.S. House of Representatives' Committee on Appropriations approved the fiscal year 2023 Labor, Health and Human Services, Education, and Related Agencies bill on a vote of 32 to 24. The Appropriations Committee released an accompanying report for Fiscal Year (FY) 2023 explaining its intentions for the appropriated funding.

For the National Center for Injury Prevention and Control (NCICP) at the Centers for Disease Control and Prevention (CDC), the Committee voted for a total appropriation of \$897,779,000. This is an increase of almost \$183 million over last year but \$385 million less than the Biden Administration requested. Of interest is the \$11,250,000 allocated to NCICP's Traumatic Brain Injury (TBI) Program, which includes \$4 million for the Center's Concussion Surveillance system. The Brain Injury Association of America (BIAA) strongly supported the concussion funding as well as these other NCICP program initiatives:

| Elderly Falls | \$ | 4,050,000 |
|---|-------|------------|
| Domestic Violence Community Projects | \$ | 9,500,000 |
| Drowning Prevention | \$ | 2,000,000 |
| Opioid Overdose Prevention | \$ 52 | 15,579,000 |
| Firearm Injury and Mortality Prevention Research | \$ 3 | 35,000,000 |

The Administration for Community Living (ACL) operates a number of Aging and Disability Services Programs to increase access to community supports. This is includes the TBI Program, which provides grants to States to develop comprehensive, coordinated family and person-centered service systems. The House Appropriations Committee allocated \$13,118,000 to the TBI Program. This is an increase of \$1,297,000 above FY 2022 and equal to President Biden's budget request. Other ACL programs of interest to our community include:

| Home and Community-Based Supportive Services\$4 | 50,000,000 |
|--|------------------|
| National Caregiver Support Program\$ 2 | 230,000,000 |
| Care Corps\$ | 5,500,000 |
| Direct Care Workforce Demonstration\$ | 3,000,000 |
| Respite Care for Family Caregivers \$ | 14,220,000 |
| Falls Prevention\$ | 10,000,000 |
| Aging and Disability Resource Centers\$ | 9,110,000 |
| Voting Access for Individuals With Disabilities\$ | 12,414,000 |
| Independent Living Centers Program \$ 1 | 40,000,000 |
| (com | inueu on paye zo |

(continued from page 19)

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is the federal government's primary disability research organization. NIDILRR administers the TBI Model Systems (TBIMS) grant program. Currently 16 hospitals/ research institutions receive funding to improve care and contribute knowledge to the nation's oldest and largest non-proprietary database to allow researchers to identify ways to improve health outcomes. The Appropriations Committee recommends \$117,470,000 for NIDILRR, which is \$1,000,000 above the FY 2022 enacted level.

For the National Institutes of Health (NIH), the bill provides a total of \$47.5 billion, an increase of \$2.5 billion above the FY 2022 enacted level. This includes an increase of \$100 million for research related to opioids, stimulants, and pain/pain management and an increase of \$100 million for health disparities research.

President Signs Law to Curb Gun Violence

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On June 25, 2022, President Joe Biden signed the bipartisan Safer Communities Act to help curb gun violence. The Act authorizes funding to implement red flag laws, improves background checks, closes the "boyfriend loophole," and more. The bill also includes significant investments for mental health services for children and family. Red flag laws generally permit police to petition a state court to order the temporary removal of firearms from a person who they believe may present a danger to others or themselves.

ABLE Age Adjustment Act Advances

The ABLE Age Adjustment Act would extend eligibility for tax-advantaged savings accounts to individuals whose disability occurred after the age of 26 but before age 46. ABLE accounts allow individuals with disabilities to accumulate savings without risk of losing federal benefits. Prior to the passage of the ABLE Act in 2014, individuals could not accumulate more than \$2,000 in assets. Under this bill, individuals could save up to \$16,000 a year for a total of \$100,000, without jeopardizing benefits. The ABLE Age Adjustment Act is included in the Encouraging American Retirement Now (EARN) Act and will now head to the full Senate for consideration.

Warrior Brain Health Act Introduced

Rep. Don Bacon (R-Neb.), who is also co-chair of the Congressional Brain Injury Task Force (CBITF), introduced H.R. 8141, the Warrior Brain Health Act of 2022, on June 17. The legislation directs the Secretary of Defense to establish an initiative to unify efforts and programs across the Department of Defense to improve the cognitive performance and brain health of members of the Armed Forces. Through education, training, prevention, protection, monitoring, detection, diagnosis, treatment, and rehabilitation, the bill proposes to enhance, maintain, and restore the cognitive performance of members of the Armed Forces.

Senate Committee Bans Electrical Stimulation Behavior Management

On June 14, the Senate Health, Education, Labor and Pensions (HELP) Committee advanced S. 4348, the Food and Drug Administration (FDA) Safety and Landmark Advancements Act of 2022. The bill would prohibit the use of electrical stimulation devices used to limit a person's aggressive or self-injurious behavior. The FDA has determined that these devices present an unreasonable and substantial risk of illness or injury that cannot be corrected or eliminated by labeling.

TBI & PTSD Law Enforcement Training Bill Introduced in Senate

Sens. Jon Ossoff (D-Ga.), Chuck Grassley (R-Iowa), and John Kennedy (R-La.) introduced S. 4286, the TBI and PTSD Law Enforcement Training Act, to implement several measures to better train law enforcement and first responders for interactions with individuals living with traumatic brain injury (TBI) or post-traumatic stress disorder (PTSD). Similar to H.R. 2992 that passed the House on May 18, the Senate bill would authorize funding through the U.S. Department of Justice to train responders to be better prepared to de-escalate any inappropriate behaviors or other issues and be equipped to refer individuals with brain injury to the appropriate professional help.

Call for GAO Study on Disability Access to Health Care

Several senators recently sent a letter to the Government Accountability Office (GAO) asking for a study on the barriers facing Americans with disabilities when they seek access to medical treatment, services, equipment, and care. The letter stated, "Even though discrimination based on disability is prohibited by law, people with disabilities continue to face issues with accessibility when it comes to getting the healthcare they need, when they need it. The lack of accessible healthcare contributes to and exacerbates health disparities experienced by people with disabilities." The letter was sent by Sens. Tammy Duckworth (D-III.), Patty Murray (D-Wash.), Bob Casey, Jr. (D-Pa.), Kirsten Gillibrand (D-N.Y.), Elizabeth Warren (D-Mass.), and Sherrod Brown (D-Ohio).

Senators Announce Bill to Update the Asset Limits for SSI

The Savings Penalty Elimination Act was introduced in the Senate on May 3 to update the asset limits for Supplemental Security Income (SSI) beneficiaries. If enacted, the legislation would enable beneficiaries to have more savings in case of an emergency without affecting their benefits. The senators' bill, the first significant bipartisan SSI legislation in decades, would bring the SSI program into the 21st Century and ensure individuals living with brain injury and on SSI, as well as those with other disabilities and who are elderly, are able to live with dignity.

Lawmakers Introduce the Protecting Health Care for All Patients Act

On April 28, 2022, House members introduced the Protecting Health Care for All Patients Act to expand access to treatment and prevent discrimination against people with disabilities by prohibiting the use of "quality adjusted life years" (QALYs) in all federal programs. Currently, only Medicare is prohibited from using QALYs. QALYs are a metric used to determine the cost-effectiveness of medications and treatment in healthcare. The metric is a subjective quality of life standard that anticipates a person's lifespan. The use of QALYs can lead to denying medications and treatment to people with disabilities. BIAA is vehemently opposed to the use of QALYs for any purpose.





My Father, My Hero

By Stephanie Barish

"Daddy had a stroke."

Those four words—delivered stoically by my sister over the phone—forever changed our lives.

I got her call on a stormy afternoon in Missoula, Montana in 2010. I remember watching the snowflakes fall as a chill set in.

I had just moved 2000 miles from my family in Long Island, New York, after accepting a new job. My father, Joel, had helped me settle in. He was in good spirits and apparently good health. He made sure I had everything I needed—an apartment, furniture, even a washer and dryer.

My father was the type of guy who fought hard for those he cared about and loved even harder—especially when it came to my mom, my sister, and me. He was our "Mr. Fix It" and the best person to ask for advice. When a friend was diagnosed with cancer, he bought her groceries. He advocated for my grandmother while she received end-of-life care and stood by my mom's side when she was diagnosed with and beat cancer. So when my sister called, I was in disbelief.

"He'll be OK," she said. "But you should probably come home immediately."

It was eerily quiet when I arrived. My sister was sitting in the living room and my mom was sitting opposite her on the loveseat, where my dad usually sat. I could tell this was worse than I expected.

My dad was in intensive care. The doctors had removed part of his skull due to severe brain swelling. They didn't know if he would live. Tears swelled in my eyes as I grappled with the news.

Nothing could've prepared me for what I saw next. My dad was unconscious on a ventilator and the right side of his head was partially caved in. "This isn't the man who drove me to 'Big Sky Country' last week," I thought. He had suffered an ischemic stroke. His carotid artery, a blood vessel that carries blood from the heart to the brain, was blocked. The entire right side of his brain was dark; the left side of his body was paralyzed.

He emerged from coma after several months. Upon waking, his speech was slurred, his left eye permanently shut, and he was angry and confused. Doctors referred him to a rehabilitation center for people with severe traumatic brain injuries where he received occupational and physical therapy. I watched, teary-eyed, as he relearned simple tasks—combing his hair, brushing his teeth, dressing. Since he couldn't move his left side, his progress was slow and he got frustrated easily.

The stroke also triggered his left leg to contract, so when they placed a brace on his leg he would cry in pain as he slowly walked, often with the help of multiple aides. It hurt my heart, and I knew that he would probably use a wheelchair for the rest of his life.

My father, an army veteran, was transferred to the Long Island State Veterans Home in Stony Brook. The swelling had reduced, so the doctor could reattach the part of his skull that had been removed. He settled into his new life, but was clearly unhappy. The only thing that made him



One of my last visits with my dad in May 2021.

truly happy was seeing family, and luckily, we were eventually able to bring him home.

We cleared the dining room to make way for his hospital bed. We had the help of nurses' aides, but my mom, my sister, and I picked up the brunt of the work. We fed, changed, and bathed him. The man known for his independence was dependent on others, but somehow, he stayed strong.

I wanted him to remain that way, so I took time to keep his memory sharp. We read many books and I would test to make sure

he was retaining information. We also practiced writing with his right hand, played memory games, and listened to his favorite music—mostly The Duprees "You Belong To Me" and Dion and the Belmonts, "Teenager in Love."

One afternoon, he asked me if he would be this way forever—never able to walk again, or drive, or complete daily tasks. I froze, afraid to be truthful.

"Dad," I said. "You're perfect the way you are, but keep on fighting and you'll get there. I promise." I still feel bad for making that broken promise.

He became weaker over the years. Eventually, he asked to return to the Veteran's Home so he wouldn't be a burden. He wasn't, but we obliged. We visited him daily, and he would always perk up and say, "I love my girls." We loved him, too.

When COVID-19 hit, our visits were ended due to New York state laws. He had a cell phone, so we would call every day, but we were incessantly worried he wasn't getting proper care. We learned he'd fallen and that he had bedsores. He spent holidays alone. It was an excruciating time for him—and for us.

When we finally saw him again in person, he had grown weaker, lost a lot weight, and complained of being in pain. I comforted him by holding his hand, rubbing his head, telling him jokes, and giving him three kisses on his forehead (like my grandmother used to do to us as kids). Anything to get his mind off the pain. During a candid talk, he told me that he wished to attend the weddings of my sister and me. I told him to stay strong, but knew I would never have that father-daughter dance all brides dream of.



Our family. From left: My sister, Jennifer, my father, Joel, me, my mother, Eva.

Days later, he slipped into coma again. I visited after my overnight shift at work—and my mom and sister came at other times. Every time the phone rang, my heart sank.

On May 15, 2021, my mother and I visited my dad. It was a hot, sunny day. The kind of weather he always enjoyed—especially since he got sick. He used to run hot, but when he suffered the stroke, he was always cold. Spending time outdoors in the sun with me, my mom, and my sister turned into his favorite pastime.

When my mom and I arrived, my dad was awake, on morphine. His speech was slurred, but I pretended to understand him. I cuddled up next to him, opened a book to read to him, and rubbed his head. When my sister and my dad's brother arrived, my mom and I headed out.

When we got home, the phone rang—and I knew. My sister said she had her hand on my dad's chest, and as soon as my mom and I left the room, my dad took his last breath.

We were so tired—ten years of illness was draining on us all. Even so, if I had to do it again to have him here with me, I would. The nightmare of losing my dad became a reality that day. Now, the four words that run through my mind over and over are, "I love my girls." And I love you, too dad—to infinity and beyond. Always.

STATE AFFILIATE NEWS

Delaware

The Brain Injury Association of Delaware (BIADE) is honored to host mask-painting workshops for brain injury survivors throughout the year allowing them to express how their brain injuries feel to them through art therapy.

The current group of painted masks pictured at the right have been displayed at PAM Health in Dover and at PeachTree Assisted Living located in Harbeson, Delaware.

Greg, a talented artist, and resident of PeachTree Assisted Living is featured below with his artwork. Greg shared the following thoughts with us: "I feel grateful for so much in my life, but I guess that the thing that I am the most grateful for would have to be this life itself. Think about it for a minute. There are all the things that I wish did not happen, but when I see the positive things that I've ended up with, I just smile."

BIADE hosts a free Educate Delaware Webinar Series each month geared toward brain injury survivors and their families. Visit Educate Delaware 2022 at biade.org/webinar to see the full schedule. BIADE also offers in-person and virtual support groups for brain injury survivors and caregivers. For more details, visit BIADE Support Groups at biade.org/support-group.



Greg, a resident of PeachTree Assisted Living.



A collection of masks created by brain injury survivors across all three counties in Delaware.

Indiana

Brain Injury Association of Indiana (BIAI) has had a very busy quarter! BIAI held its inaugural educational event as a part of its new live series with key topics identified by the community. Dr. Sachin Mehta presented on "Post-Acute Sequelae of COVID (AKA Long COVID)" followed by a live discussion and Q&A with the virtual attendees. The presentation was full of detailed information about what Long COVID may look like as well as the services and supports available to help individuals impacted by Long COVID. This presentation is the first of four virtual educational events this year based upon survey input received from individuals throughout the state of Indiana. The next event is scheduled for Sept. 15 on the important topic of "Anxiety after Brain Injury." Be on the lookout for more information.

"Popping the Myths Around Brain Injury" is a yummy fundraiser held by BIAI this quarter. BIAI sold popcorn from Popcornopolis during the entire month of July with a percentage of the proceeds going to help BIAI provide information, education, and supports for individuals impacted by brain injury. From the traditional butter to the extremely popular Zebra flavor, individuals all over the globe enjoyed some delicious popcorn while helping BIAI help others in need.

Be sure to SAVE THE DATE for the first BIAI wiffleball tournament on Saturday, Oct. 29! Visit biaindiana.org for more information on the event, including how to register to play, sign up to sponsor, details on our silent auction, and other fun games/contests at our event!



Louisiana

Throughout the summer, the Brain Injury Association of Louisiana (BIALA) has partnered up with Ski Dawgs Adaptive Water Skiing as a sponsor for their adaptive water skiing clinics. With the use of specialized equipment and expert instructions during these comprehensive clinics, Ski Dawgs opens avenues to greater independence and allows people to experience the excitement and thrill of water sports that many with disabilities did not think were possible. Over the past few years, Ski Dawgs has taught many skiers with a broad range of disabilities, including individuals with brain injuries, cerebral palsy, spinal cord injuries, spina bifida, muscular dystrophy, multiple sclerosis, and amputations. The water skiing clinics provide a unique and safe opportunity for individuals with disabilities to gain new recreation skills that enhance their overall well-being and improve their quality of life.

"Seeing the smiles on all the participants' faces, as well as their caregivers, and hearing the laughter and chatter really brings us great joy," said Kimberly Hill, executive director of BIALA. "Helping provide these opportunities for fun and fellowship and experiencing the thrill for those we serve to enjoy the freedom of adaptive water skiing is one of the most satisfying experiences we have the privilege of being a part of."





Participant at Ski Dawgs Adaptive Water Skiing Clinic in May.

Participant at Ski Dawgs adaptive water skiing clinic enjoys making a splash.



Maine

The Brain Injury Association of America – Maine's (BIAA-ME) 13th Annual Conference on Defining Moments in Brain Injury will take place on Sept. 27, 2022 in Portland at the Holiday Inn by the Bay. Kelly Lang, co-author of "The Miracle Child: Traumatic Brain Injury and Me," will give a keynote sharing her unique perspective as both a brain injury survivor and caregiver. The conference agenda is packed with two plenary sessions and 16 breakout sessions.

BIAA-ME recently wrapped up a collaborative project with Speaking Up For Us of Maine that provides education and support to the Maine brain injury community around selfadvocacy. In addition, BIAA-ME is offering two ongoing webinar series for Maine brain injury caregivers and support group leaders and is hosting Brain Injury Fundamentals and Certified Brain Injury Specialist (CBIS) trainings for individuals working in brain injury care and to individuals working in behavioral health. A monthly webinar series for brain injury professionals is also set to begin in August.



Michigan

With registered attendance of nearly 500 passionate, vocal supporters, and a picture-perfect afternoon under bright blue skies at Spirit Plaza in downtown Detroit, the Brain Injury Association of Michigan's Rally for Vlady indeed "lit the lamp" for Detroit Red Wings legend Vladimir Konstantinov and the 18,000 catastrophicallyinjured auto crash survivors directly impacted by one of the most heinous aspects of the state's new auto no-fault law – the retroactive application by insurers to survivors who were injured before the law changed. Calling attention to this injustice were fellow Red Wings legend Darren McCarty as well as a host of city officials



David St. Amant (seated) and his mother, Linda, hold signs that say it all.



Det. Red Wing legend and 4-time Stanley Cup champion Darren McCarty speaks on behalf of teammate Vladimir Konstantinov (left: seated) and 18,000 catastrophically-injured accident survivors.

and state legislators leading chants of "Contracts Matter; Contracts Count" and "Say NO to Retro," and joining our plea for justice from the Michigan Court of Appeals, which heard a landmark case (Andary vs. USAA) in early June seeking to declare this retroactive application illegal. The Court is expected to issue their ruling sometime in the coming weeks. Print, broadcast, and social media coverage of the rally was extensive and universal in calling for a fix to this growing humanitarian crisis of care.

Missouri

Bowling for Brain Injury – Missouri raised nearly \$27,000 to support the Brain Injury Association of Missouri (BIA-MO). Fundraising by teams, bowlers, donors, and sponsors will increase awareness about brain injury. Services of support, education, recreation, and advocacy will be provided for persons with brain injury and families. Teams had fun and generated friendly competition with their fundraising and during the Bowling for Brain Injury events. Silent auctions associated with the events resulted in \$552 and a 50/50 Raffle raised \$116. Please join us next year, June 2023, for Bowling for Brain Injury – Missouri.

The BIA-MO One-Day Regional Outdoor Camps were held in Columbia, Kansas City, Springfield, and St. Louis from June 12-27. Each camp featured activities such as arts and crafts, tie-dyeing, games, bingo, and s'mores. Missouri AgrAbility was the sponsor for the Planting Marigolds activity at each One-Day Camp. Participation was free, and about 100 survivors, family members, and supporters joined the fun, conversation, and activities.

For more information about these events in 2023, visit biamo.org.



Bowling is the activity. Brain injury is the reason. Participants enjoy BIA-MO's Bowling for Brain Injury event.



Outdoor fun for persons with brain injury of all abilities.

New Hampshire

The Brain Injury Association of New Hampshire (BIANH) held their 36th Annual Walk by the Sea and Picnic on a beautiful Sunday in June. The bright sunshine and warm ocean breeze added to the enjoyment of seeing each other after three years of this event being held virtually. Teams and individuals raised over \$26,000 for the brain injury community and awareness. Team Annjie was formed by family and friends in memory of Annjie Dow. Annjie and her family have been longtime supporters of the walk, and she worked for many years as the BINGO coordinator for BIANH.



NH Concussion earns Eldon Munson, III Team Spirit Award.

(continued on page 28)



Cognitive Rehabilitation Tool for Brain Injury Professionals

www.neuronup.us

(continued from page 27)

Annjie also worked with individuals with brain injury and truly loved her work and the individuals she supported. New this year was the Eldon R. Munson, III – Team Spirit Award. The award is in memory of our friend, Eldon R. Munson, III. Eldon was a strong supporter of the walk. No matter the weather, Eldon and his father were out along the route handing out the water and snacks that they had donated. Eldon was a member of the Walk planning committee, contributing his time and creative ideas to improve the walk. It is because of his unsurpassed enthusiasm and dedication to this event that Team NH Concussion was awarded this team spirit award.

The annual golf tournament was held Wednesday, Aug. 10 at The Oaks Golf Course in Somersworth, New Hampshire. Survivor Jason Schreck shared his story of rehabilitation and recovery.

Rhode Island

Brain Injury Association of Rhode Island (BIARI), the state's only not-for-profit dedicated exclusively to brain and head injury, will be hosting their 7th Annual Hidden Treasure Gala 2022. This culinary extravaganza will be held at one of Rhode Island's true "hidden gems" – Aldrich Mansion in Warwick on Thursday, Sept. 29.

Widely regarded as Rhode Island's premier charity culinary event, Hidden Treasure Gala pairs 18 of Rhode Island's top executive chefs and restaurant partners with the region's finest wineries and micro-breweries. These epicurean virtuosos share their prodigious culinary talents with more than 300 of the region's most philanthropic and generous individuals and companies whose taste buds burst when they experience the food samplings on offer.

Emerging from inside Aldrich Mansion, guests have an opportunity to bid on fabulous silent auction packages generously donated by area businesses. In addition to food and wine, a unique experience awaits attendees. Outside and "under the stars" in a 5,000 square feet tent, guests will have an opportunity to experience the magic and energy of emcee Sir Jeremy Bell, replete with bagpipes and dressed to "kilt" and who guides guests with humor and grace through the myriad of unique live auction packages, as well as Fund the Mission and Corporate and Individual awards, all in support of the life-saving work of the Brain Injury Association of Rhode Island.



Hidden Treasure Gala... a culinary fundraising event like no other.

Virginia

Spring 2022 was especially busy for us here at the Brain Injury Association of Virginia (BIAV)! We were able to host our first week-long Camp Bruce McCoy session since 2019. The week was filled with joy, connection, laughter, and support for survivors of brain injury and our counselors. Our campers' favorite night is the dance on Tuesday night, and they sure knew how to get down and boogie!

This spring we also hosted our Annual Legacy Celebration. The annual BIAV Legacy Celebration is held to celebrate advocates and trailblazers working to change the lives of Virginians impacted by brain injury.

Our award winners this year included:

- Karen Grazionale Member of the Year
- Lauren Carter-Smith The Weinstock Award
- Sen. Emmett Hanger Legislator of the Year
- Dr. Jeffrey Barth The Legacy Award



Our campers know how to boogie! Campers and counselors join hands and enjoy a dance together



We were honored to have two guest speakers. Camilla Herndon from the Virginia Department of Health presented on our collaborative domestic violence Screen and Intervene project. Maralee Teshima, a member of BIAV's Speakers Bureau, shared her story of her ongoing recovery from her brain injury, and the role that Camp Bruce McCoy played in her finding her new calling.

To learn more about us, Camp Bruce McCoy, and our Legacy Celebration, please visit biav.net.

Taken during our 2022 Legacy Celebration, our Executive Director, Anne McDonnell, poses with our four award winners. From left to right: Karen Grazionale, Dr. Jeff Barth, Anne McDonnell, Lauren Carter-Smith, and Senator Emmett Hanger

Let's Stay in Touch



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- 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/signmeup

UPCOMING WEBINARS

Business of Brain Injury Webinar

Neurobehavioral Challenges in Acquired Brain Injury: Embracing the Challenge with Dignity October 4, 2022, 1:00 p.m. ET/10:00 a.m. PT Dave Anders, MS, CCC-SLP, CBIST

Mitchell Rosenthal Research Webinar

Monitoring Brain Health in Individuals Exposed to Repetitive Head Impacts: Lessons Learned from Radiation Safety

October 13, 2022, 3:00 p.m. ET/ 12:00 p.m. PT Jeffrey J. Bazarian M.D., MPH

Butch Alterman Memorial Survivor Webinar

The Early Years After Brain Injury: A Way Through the Fog

October 22, 2022, 10:00 a.m. ET/7:00 a.m. PT Members of BIAA's Advisory Council: Paul Bosworth, Anne Forrest, Kelly Lang, Angela Leigh-Tucker, Kellie Pokrifka, and Carole Starr

To register, please visit shop.biausa.org/livewebinars.

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Did you enjoy reading this magazine or find a meaningful piece of wisdom? **Pass it on!** Share this copy with a friend or send them to biausa.org to read online.

Center for Neurologic Study-Lability Scale (CNS-LS) for Pseudobulbar Affect (PBA)

The CNS-LS is a short questionnaire that can help individuals with neurologic illness or injury identify the presence of PBA symptoms and their frequency. After a week of tracking, patients can share the questionnaire with their physicians.

| Patient assessment | Applies never | Applies rarely | Applies occasionally | Applies fre- quently | Applies most of the time |
|---|------------------|-------------------|-------------------------|-------------------------|--------------------------------|
| There are times when I feel fine one minute, and then I'll become tearful the next over something small or for no reason at all | 1 | 2 | 3 | 4 | 5 |
| Others have told me that I seem to become amused very easily or that I seem to become amused about things that really aren't funny. | 1 | 2 | 3 | 4 | 5 |
| l find myself crying easily. | 1 | 2 | 3 | 4 | 5 |
| l find that even when I try to control my laughter, I am often unable to do so. | 1 | 2 | 3 | 4 | 5 |
| There are times when I won't be thinking of anything happy or funny at all, but then I'll suddenly be overcome by funny or happy thoughts. | 1 | 2 | 3 | 4 | 5 |
| l find that even when l try to control my crying, l am often unable to do so. | 1 | 2 | 3 | 4 | 5 |
| l find that I am easily overcome by laughter. | 1 | 2 | 3 | 4 | 5 |

Source: Moore, SR et al. J Neurol Neuro J Neurol Neurosurg Psychiatry. 1997;63(1):89-93.

NOTES:



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 Carrie Mosher at 703-761-0750, ext. 640 or cmosher@biausa.org.













