

# Know *your* Rights



Pushing Back  
Against Unsafe  
Discharges

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The ABCs  
of Supporting  
Students in Schools

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Knowing Your  
Rights in  
the Workplace

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# FROM MY DESK

Greetings,

In the days, weeks, months, and years following a brain injury, there are an oftentimes overwhelming amount of choices that people with brain injury and those that care for them are faced with. On top of the physical, mental, and emotional changes that so often accompany brain injury, there are complicated landscapes to navigate, from advocating for safe and effective treatment in acute and post-acute healthcare and health insurance systems, to returning to work or school. And if your brain injury was caused by another entity, such as a car crash or medical malpractice, a legal proceeding could be on the horizon. That's why it's so important to know what your rights are as a person with brain injury.

Through our programs, publications, webinars, and resources – especially the National Brain Injury Information Center – the Brain Injury Association of America is committed to helping our community better understand those choices, what your rights are, and how to make your voice heard.

As I write this letter, we're less than four months away from Brain Injury Awareness Day. Before we know it, the Brain Injury Association of America will lead the brain injury community to gather for a rally on Capitol Hill on March 5-6, 2024, with the goal of winning reauthorization for the Traumatic Brain Injury Act. We want you to join us!

The Traumatic Brain Injury Act, which passed Congress in 1996 with bipartisan support and was signed into law by then-President Bill Clinton, is an immensely important piece of legislation for the brain injury community, providing much-needed funding to improve rehabilitation and community support for people with brain injury. Funding from the



Traumatic Brain Injury Act has been shown to improve the overall outcomes for people with brain injury. Unfortunately, it is set to expire in 2024.

We need your help to secure this important reauthorization. By attending our rally, we'll connect you with your member of congress and handle the logistics of scheduling a meeting. We'll provide training and equip you with best practices that can be used in your home state. You'll also be able to make connections with other members of the brain injury community from across the country. Join the movement and make your voice heard at the national level!

If you can't make it in person, we understand. There will be plenty of other ways to get involved. More information is coming soon, but be sure to visit our website or scan the QR code below to sign up for updates about Brain Injury Awareness Day 2024.

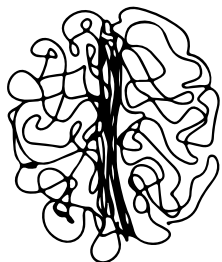
Sincerely,

A handwritten signature in black ink that reads "Rick Willis". The signature is fluid and cursive.

Rick Willis  
President and CEO  
Brain Injury Association of America



To join our cause and sign up for updates for Brain Injury Awareness Day 2024, scan the QR code or visit [biausa.org/awarenessday2024](https://biausa.org/awarenessday2024)



# PUSHING BACK AGAINST UNSAFE DISCHARGES

*By Lauren Moore, Marketing and Communications Manager, BIAA*

Depending on the severity of a person's brain injury, an extended hospital stay may be necessary in order to monitor the patient's condition and prevent further medical crises. The hospital will have social workers or case managers on staff to help the patient, their loved one, and their medical team determine options for discharge, such as whether a patient should be sent home or if the patient would benefit from transitioning to post-acute rehabilitation, such as a transitional/residential facility, or specialized rehabilitation such as a neurobehavioral unit or substance abuse treatment program, before returning home.

Actively participating in the decision-making process about discharge means the patient and their family or caregiver will be better prepared to make informed decisions and take advantage of the resources available to them.

Because external factors such as health insurance and a person's financial situation can heavily influence discharge decisions, it is imperative for the patient that their family and loved ones advocate for their well-being and push back against premature or unsafe discharges. Although hospitals may be under pressure to discharge patients quickly in order to make space for other sick or injured patients, existing patients who leave before they are healed, or without having proper accommodations in place for post-acute care, are at risk of further injury, delayed recovery, or being readmitted to the hospital.

Be sure to review any insurance coverage the patient has to see if home care, including home health aides, visiting nurses and physicians, or transportation assistance to inpatient, outpatient, or transitional/residential rehabilitation, is covered.

Some patients may be protected against premature or unsafe discharge under a patient's bill of rights. Many states, insurance providers, and health care facilities have their own patient bill of rights. For example, in New York State, patients have the right to identify a caregiver who will be included with their discharge planning and sharing of post-discharge care information or instruction, and to participate in all decisions about their treatment and discharge from the hospital. As well, the hospital must provide the patient with a written discharge plan and a written description of how to appeal a discharge. Patients who receive services via Medicare have the right to a fast appeal. With a fast appeal, an independent reviewer will decide if a patient's services should continue. A patient may be able to stay in the hospital while the reviewer looks over the case. The hospital cannot force a patient to leave before the reviewer reaches a decision.

A patient's bill of rights can vary from state to state or institution to institution, so it is important to determine whether or not the patient is covered by such protections and, if so, what those protections are.

## What to Ask

**When discussing the patient's discharge planning, it's important to be prepared and gather all the information necessary. Here are some questions to ask the hospital staff:**

- Who decides when my loved one is ready for discharge, and how is the decision made?
- Do you have an appeals process in place, and how does that work?
- What is my/our family's role in the decision-making process?
- What are all of the care options available to us now and in the coming weeks and months?
- What factors could extend or shorten the anticipated discharge date? If the date changes, what sort of notice will we be given?
- What happens if the patient's discharge option is not viable? For example, if the program or facility that is right for the patient has a waiting list, or if we are unable to provide care or modify the home to accommodate the patient's needs?
- How can I access a complete set of records for my files upon discharge? Is there a charge for this?

## What Pushing Back Can Look Like

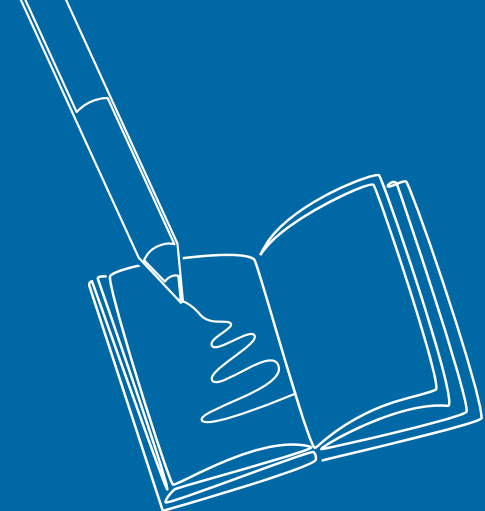
When a family member sustains a brain injury, things can feel overwhelming. Navigating a loved one's medical care and finances, making a home more accessible, and preparing for potential physical and behavioral changes is a lot to take on at once. Fortunately, the National Brain Injury Information Center, operated by BIAA, is available to help. Here's how NBIIC helped one mother advocate for her son's best interest:

In 2022, the mother of a young man who sustained a brain injury in a motor vehicle crash called the NBIIC hotline. She needed help understanding the medical terminology being used by hospital staff, and wanted to figure out what to expect in the days and weeks to come. NBIIC operators shared information that would help her understand more about brain injury.

A couple of weeks later, she called again. The hospital was pushing her to take her son home, but she was concerned that his needs were more than she could handle as a single parent. NBIIC suggested she tell the hospital that sending him home would be an unsafe discharge, and that she would work to find a suitable alternative.

The next time she called NBIIC, she thanked them, and said that getting advice from a trusted source helped her feel like she was doing the right thing for her son. The hospital found a facility nearby that could take him, giving the mother the opportunity to visit her son regularly and continue advocating for him. She also felt the additional therapies he would receive in a facility would allow him to improve enough to come home safely with her.





# THE ABCs OF SUPPORTING STUDENTS IN SCHOOLS

By Kelly Lang, BIAA Advisory Council Member



## A is for Advocacy

Experiencing a brain injury is traumatic, with so many questions and not enough answers. Once it is time for your student to return to or begin school following a brain injury, learning how to advocate for their educational needs can be overwhelming. If your child was treated in an inpatient rehabilitation hospital, hopefully an educational consultant or social worker explained the process of receiving services and assisted in starting the process. It is not a quick endeavor. Paperwork must be submitted along with medical documentation. Meeting dates are set with school administrators to determine if a child meets the eligibility requirements for assistance and, if so, which plan would best serve the student's needs.

### There are two options for accommodations:

- A 504 plan ensures a child who has a disability and is attending an elementary or secondary educational institution receives accommodations that will ensure their academic success and access to the learning environment.
- The Individualized Educational Plan (IEP) provides accommodations and specialized instruction for students in grades K–12.

A second meeting is scheduled 90 days later giving the school staff time to evaluate the child's abilities and determine the appropriate level of educational support. Appropriate educational support is a key component of the plan. If the child is 5 years old and reading and comprehending at a kindergarten level, there will be no justification for reading support. However, if the child is having difficulty reading or comprehending the information at the appropriate age level then it is deemed educationally necessary for additional support.

Parents know their children better than anyone else and must advocate for what they need and deserve. Sometimes that requires getting assistance outside of the school system through neuropsychological testing or other evaluations to demonstrate the need for additional services. Schools only provide accommodations that satisfy a student's educational needs and, in some cases, additional services such as speech, physical, occupational therapies, and tutoring if needed.



# B is for Build Relationships and Supports

Plans are re-evaluated each year and new goals are developed to ensure progress in their academics. Parents should build a relationship with the school and include all the teachers a student encounters. It is important for everyone to have all the necessary information and tools to assist students. There are times when learning the curriculum gets more difficult. If needed, ask for another meeting to revise the accommodation(s).

When my daughter started kindergarten, I met with all her teachers, including art, music, and physical education teachers as well as the case manager to explain her injury and how it impacted her. She has an invisible injury and tends to be quiet rather than draw attention to herself. I was concerned that she would get lost in the room.

These meetings gave the teachers time to absorb information and ask questions. I was very candid and told them what to expect. I also gave them examples of what to look for when she got overwhelmed and fatigue set in, and encouraged them to reach out to me if they had any questions or needed assistance.

Some of the relationships and support systems started when she was first injured at age 3. I maintained those relationships throughout her school years and relied on their expertise when I needed help. The schools are there to assist and, in my experience, will support us when they see involved families willing to collaborate with them.

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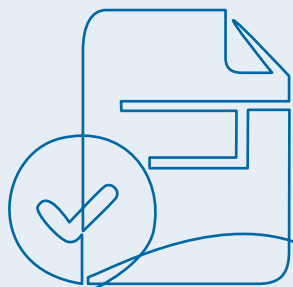


# Celebrating 40 years of comebacks.

At Hope Network Neuro Rehabilitation, improving patient outcomes has been our priority for decades. And, our goal remains the same: to provide high-quality, targeted, cost-effective care.



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## Possible Accommodations

- Extra time on homework, quizzes, and tests
- Reduction of the number of problems to show mastery of skills (especially important in math classes)
- Preferential classroom seating
- Breaks during the day
- A quiet space to rest in case of overload, fatigue, or headaches
- Reduced fluorescent lighting
- Textbooks at home
- Note takers to reduce the need to multitask; it is difficult to focus on a lesson and take notes simultaneously
- Allow the student to audio record lectures for later review
- Provide both oral and written instructions; clarify instructions
- Provide student with an outline or study guide when available
- In grading work, reduce emphasis on spelling and grammatical errors unless it is the intent of the assignment
- If two exams are scheduled on the same day, allow student to reschedule one for another day
- Assess knowledge using multiple-choice instead of open-ended questions
- Allow student to clarify and explain responses on exams and assignments
- Permit student to keep a sheet with mathematic formulas for reference, unless memorizing the formulas is required

## C is for Communication

I kept the communication open and would check in if I suspected there was an issue in accessing the curriculum. I also taught my daughter how she could advocate for herself. These meetings continued until she was a senior in high school.

Transitions can be hard for everyone but especially for those dealing with a brain injury. New routines, rules, and responsibilities tax our brain and it takes time to adjust. Allowing students time to learn new routines is key to success. When changing schools, ask to tour the school before the orientation day so other students are not present. It helps to have a quiet environment to learn their way around and acclimatize to the new space. Give them time to practice using a locker and walk their schedule if needed. We would do this several times until she understood the layout of the new building. Change is incredibly stressful, so minimize that anxiety and help maximize the education for the students. Students can't learn if they are under a lot of stress.

As the student progresses to middle and high schools, there are more classroom changes and the number of teachers they encounter increases. If you do not meet them, send an email introducing yourself and encourage them to let you know if there are problems. The sooner you can solve an issue, the easier it will be for everyone involved. Later, the skills students learn advocating for themselves will be helpful for when they move on to higher education and employment.

Brain injury recovery cannot happen without significant help. We need communities surrounding us with support to keep moving forward. There will be hard days, harder than you ever imagined, but there are also days filled with much joy and happiness. Strive for those days filled with hope and laughter.

**Are you 60 years or older?  
Do you have a history of brain injury?**

**You may qualify for a paid research  
study at the University of Illinois!**  
The study is completed remotely over Zoom

**Contact us for more information:**

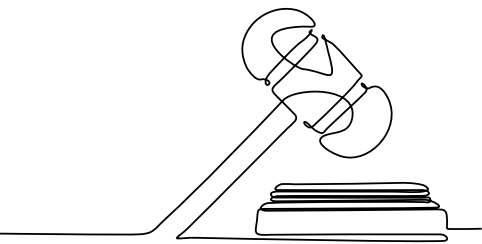
Email: [kch-hfa-enact@illinois.edu](mailto:kch-hfa-enact@illinois.edu)

Phone: 217-265-0885



IRB #20993





# SELECTING LEGAL REPRESENTATION

People who sustain brain injuries from vehicle accidents, medical malpractice, falls, defective products, or other incidents caused by another person or entity often find it helpful to talk to an attorney. Medical treatment like rehabilitation and long-term care services can be expensive and have the potential to span years, if not decades.

## Why Hire an Attorney?

Pursuing compensation from a person or corporation that caused a brain injury is a way to ensure justice and accountability and may also provide additional financial resources to aid with long-term care or rehab if the injury causes a chronic or permanent disability.

An attorney will seek to obtain full compensation for medical bills, lost income, and future care costs. The attorney may also seek damages for pain and suffering. Importantly, an experienced attorney can help to preserve any entitlements to federal and state benefits. Without careful planning, valuable benefits may be lost.

It's important to contact an attorney as soon as possible after a person is injured, as the attorney can help determine whether or not the plaintiff – the person bringing the suit – has a case. The plaintiff may be the person with a brain injury, or it may be their family, caregiver, or estate. The defendant, meanwhile, is the party or parties that caused the brain injury.

Determining who the defendant is may not always be clear cut, and a lawyer can help with determining who is legally responsible for the brain injury. For example, in a motor vehicle crash that results in a person getting a traumatic brain injury, there are several potential defendants, including the driver, the automobile manufacturer, the local government or its employees, could all be liable. If the driver was under the influence of alcohol, the bartender who served them could also be liable. If the crash occurred

at a work event, an employer may be liable as well. An attorney can investigate the case, determine what kind of case to bring against which defendant or defendants, and work on preparing the case, allowing the injured person to focus on recovery.

## Choosing the Right Attorney

When choosing an attorney, it's important to consider many factors, including education and training, knowledge of the consequences and treatment of brain injury, knowledge of how to structure and manage awards, and experience with similar cases.

An attorney must have the financial resources to try the case as well as access to the best experts. Most personal injury attorneys work under a contingent fee arrangement, which means the attorney does not receive a fee if the plaintiff is not compensated. As such, attorneys will often invest substantial time and money during the investigation, preparation, and resolution of the case.

The Brain Injury Association of America provides a list of Brain Injury Preferred Attorneys who have experience handling brain injury cases. BIAA's Preferred Attorneys have extensive knowledge and experience representing the brain injury community and understand the cognitive, physical, behavioral, and social difficulties that people with brain injury may experience. To find a list of BIAA's preferred attorneys and to locate one in your area, visit [biausa.org/preferredattorneys](https://biausa.org/preferredattorneys).

*This information originally appeared in the BIAA's Guide to Selecting Legal Representation for Brain Injury Cases.*

## Questions to Ask

**Preparing a set of questions ahead of your meeting with an attorney can help you ensure you're getting all of the information you need. Here are some questions you may want to ask a prospective attorney:**

- How much of your practice is dedicated to personal injury?
- What experience do you have with brain injury cases?
- How did you first get involved with brain injury cases?
- Based on the information you have about my case, what are the strengths and weaknesses you're seeing?
- What additional information about my case would be helpful for you to have?
- Who else in your practice would you involve in my case? What sort of role would they have?
- Who will be my primary contact with your practice?
- Have you been successful handling cases similar to mine in the past?
- What is your involvement with legal associations, local, state, or national brain injury associations, or other organizations?

# KNOWING YOUR RIGHTS IN THE WORKPLACE

## Understanding the accommodations available to people with brain injury

*By Lauren Moore, Marketing and Communications Manager, BIAA*



Starting a new job can be daunting. Understanding the nuances of team culture, learning new systems, meeting new people, even navigating a new commute can make a person feel anxious. Throw in the added complexity of starting a new job – or returning to an old one – while living with a brain injury, and the situation might feel overwhelming.

Many of the impairments people with brain injury experience, such as difficulty with attention, memory, communication, regulating emotions, or problem solving, as well as physical effects like impaired vision, fatigue, or persistent headaches, can interfere with their ability to find or keep a job.

After sustaining a brain injury and returning to work, some people find they cannot perform their job the same way they did prior to their injury. Others may realize that they cannot perform their job safely. And while many people may choose to seek other employment or withdraw from the workforce, others would prefer to stay in their positions. In many cases – although not all – the impacts of a brain injury may entitle these individuals to accommodations to ensure they are able to perform their responsibilities effectively, safely, and with dignity.

### What does “substantially limits” mean?

The term “substantially limits” is interpreted broadly and is not meant to be a demanding standard. Not every condition will meet this standard. For example, a mild allergy to pollen would not qualify.

The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against people with disabilities in everyday activities. The ADA defines a person with a disability as someone who has a physical or mental impairment that substantially limits one or more major life activities, has a history or record of such an impairment, or is perceived by others as having an impairment, and any person who falls into any of those categories is protected by the ADA. Businesses and employers are required to follow the ADA.

Some individuals living with brain injury may have impairments that qualify them for workplace accommodations under the ADA.

### Physical Impairments

It's not uncommon for people with brain injury to experience physical symptoms like seizures, fatigue, or photosensitivity. Others may experience reduced or limited mobility as a result of their brain injury, or in tandem with their brain injury. There are a number of workplace accommodation options for the physical impairments that accompany brain injury.

For those who experience fatigue, accommodations include reduced hours or a flexible schedule, telework options, ergonomic equipment, or hiring an assistant to help manage workload, while individuals dealing with photosensitivity may benefit from adjusted lighting fixtures or a change of office space or location.

Seizures can pose a serious safety risk, especially in certain jobs that require the employee to operate machinery or drive and may require the employee to shift their job responsibilities as a result. However, in

instances where the employee works in a low-risk environment, such as a desk job, accommodations may include developing a plan of action and designating responders in the event of a seizure, team training, the use of a service animal, modified lighting that is less likely to trigger a seizure, padded edging, protective gear, or a rest area or private space for recovery following a seizure. Workers who experience seizures as a result of their brain injury may also benefit from a flexible schedule or remote work, as well as transportation assistance if remote work is not a possibility.

As with seizures, reduced mobility may require people working in certain professions to alter the scope of their roles. In instances where a job may still be performed safely despite reduced mobility, some helpful accommodations may include grab bars, canes, walkers, scooters, wheelchairs, or a modified workspace.

## Cognitive Impairments

Individuals with brain injury can experience a variety of cognitive impairments, including difficulty paying attention or staying organized, reduced executive dysfunction, and reduced emotional control or stress tolerance. Some people may feel reticent to disclose their brain injury and the cognitive symptoms they live with, especially when starting a new position or with a new company. However, by working with a manager and/or company's HR department, there are plenty of opportunities for accommodation.

Depending on what triggers an individual's executive dysfunction, some accommodation options include changing an office space or desk location to reduce distractions, desk organization tools, noise canceling headphones or earplugs, establishing uninterrupted time blocks on a schedule, organizational software or apps, and offering additional time to complete tasks. Working with a job coach and having a supervisor or colleague offer clear verbal or written instructions and/or deadlines can also be helpful, as can offering the ability to work remotely so as to avoid in-office distractions like background noise or small talk.

Emotional control is important not only for the person with brain injury, but for colleagues and customers as well. In cases where emotional regulation is a factor, implementing disability training for the team, regular one-on-one communication with team members and supervisors, positive feedback, and counseling or



working with HR can be helpful. Some workplaces may also accommodate an emotional support animal or offer remote work options.

These accommodations are a starting point, and do not paint a complete picture of every accommodation available to people who are protected under the ADA. As well, sustaining a brain injury does not automatically qualify a person for accommodation. It is never a bad idea to speak with a disability rights advocate or attorney to determine the best course of action for a person's individual circumstances.





# Survivors Share Their Tips for Requesting Workplace Accommodations

BIAA reached out to people living with brain injury and their loved ones to share their suggestions for how to request workplace accommodations, as well as their experiences with disclosing their brain injury at work. Below are some of their tips for handling what can be a challenging or sensitive situation:

*"I believe that requesting accommodations at work after experiencing a brain injury can place a brain injury survivor in a challenging situation, as it may create the impression of weakness. Nevertheless, I firmly believe that it is crucial for a brain injury survivor to communicate openly with their employer about their limitations. Failing to do so at the outset could lead to difficulties later on, potentially causing friction between the survivor and their employer." – Trevor Turner*

*"It's all about the company who you work for. The company I worked for when I had my brain injury tried to make a place for me. Unfortunately, despite them trying I didn't know what I needed to succeed. My doctors were not giving me good suggestions on what accommodations to ask for, and the company was changing how they had always done things, leading to attitudes from other employees about my special treatment. Unfortunately, I did leave my dream job due to my brain injury. I then found myself part-time at a large brand hardware store. I walked in thinking, 'It's just a job. Just have to be here, do work, and get some money.' I have been there three years. In that time, I have healed so much. I have learned what works for me and what doesn't. The store I work for has not had to adapt much, as my job description is simple. I have kept my part-time hours at 15 but then added on an additional 10-15 hours at a company that is flexible on when I work. Some days I go there after my set hour job and if I have a bad day I know I can just go home and do my second job tomorrow. In a month is my five-year brain injury anniversary. My life has changed so dramatically from what it used to be and I never thought I would be working the jobs I am today. My best advice is to look for anything that might work for you. It doesn't matter where or what you are doing. Your skills can change and as you heal you may grow out of a position or two." – Michaela Powell*

*"We often recommend a ramp-up schedule for folks wanting to return to full time work - something like:*

- starting at three four-hour days for the first week or two,*
- then increasing to four four-hour days for the next two weeks,*
- then four six-hour days (leaving one day for ongoing therapies/medical appts),*
- etc. until progressing to full-time (with no overtime) within two months.*

*When an employer can see the stair-step moving towards the full-time goal, they're often very willing to accommodate the ramp-up schedule." – Jessica Miller*

## What is considered a "major life activity"?

**Major life activities are the kind of activities a person does every day, including the body's own internal processes. Examples include:**

- Actions like eating, sleeping, speaking, and breathing
- Movements like walking, standing, lifting, and bending
- Cognitive functions like thinking and concentrating
- Sensory functions like seeing and hearing
- Tasks like working, reading, learning, and communicating
- The operation of major bodily functions like circulation, reproduction, and individual organs

Note: Some answers have been edited for length and clarity.



# SPASTICITY, OR MUSCLE TIGHTNESS, OCCURS IN MANY<sup>1</sup> PATIENTS WHO HAVE SUFFERED FROM A STROKE.

The good news is there are treatment options available that can help.



Spasticity—a condition in which certain muscles are continuously contracted—is caused by a brain or spinal cord lesion and is one of the most disabling conditions resulting from a stroke<sup>2,3</sup>, affecting 17-38%<sup>4</sup> of patients who have suffered from one. This contraction causes stiffness or tightness of muscles and can interfere with normal movement, speech and walking<sup>2,4</sup>.

At Ipsen, patients are at the heart of everything we do. In Neuroscience, our ambition is to help patients suffering from highly debilitating and painful muscular disorders (such as post-stroke spasticity<sup>2</sup>).



**To learn more about a treatment option for post-stroke spasticity, scan this code.**



[ipsen.com](https://www.ipsen.com)





Caleb Clausen and his family



## BIAA IS YOUR VOICE

*Stephanie Cohen, MS, Development Manager, Brain Injury Association of America*

### **BIAA IS YOUR VOICE IN:**

**Advocating** for increased access to rehabilitation, choice in care, and more community-based services

**Educating** communities about increased incidences of brain injury due to domestic violence, the opioid epidemic, and complications from COVID-19

**Reaching** millions nationwide through interactive awareness campaigns

**Investing** more than \$200,000 in research seeking cures for chronic brain injury

The Brain Injury Association of America is in relentless pursuit of a world where everyone who sustains a brain injury is diagnosed, treated, and accepted. BIAA represents millions of voices demanding improved care, access to rehabilitation, services and support, and a greater investment in brain injury research.

Just one of these millions of voices is Caleb Clausen. Five years ago, Caleb was involved in a motor vehicle accident and sustained a TBI. Due to his injuries, the doctors didn't think that Caleb would ever be able to breathe on his own, eat on his own or walk or talk.

Caleb proved them all wrong. Three months later, Caleb was released and got to go home, welcomed by everyone in town. However, there is still a long road ahead and BIAA will be there every step of the way-advocating to make sure that Caleb and every other person living with a brain injury gets the treatment and support they need to live their best lives.

As we work to achieve a brighter future for people living with brain injury, every accomplishment is made possible thanks to generous, tax-deductible contributions from friends like you. With your help, we can extend our reach, aiding more survivors and their loved ones.

The effort to help brain injury survivors during hospital stays and after injury is unmatched by any other organization. Seeing how BIAA is trying to overcome the short falls shows me that my family is not unique in our experience. I see things are changing, but there is a tremendous amount of work yet that needs to be done for brain injury survivors and families. BIAA is doing that work.

— Michelle D., BIAA Amplifier



**Please support  
our work with a  
year-end donation.**

**There are three easy ways  
to make your year-end gift:**

1. Send a check made out to the Brain Injury Association of America using the enclosed envelope.
2. Call 703-761-0750 during regular business hours.
3. Visit [biausa.org/supportbiaa](https://biausa.org/supportbiaa) to make an online donation.

# 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).

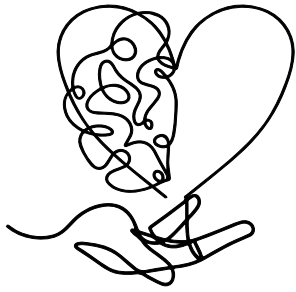
The bequest provides an unprecedented opportunity for BIAA to invest in strategic revenue growth and long-term stability. In honor of Dr. Sbordone's generosity, BIAA created the Robert Sbordone Memorial Lecture series on mild traumatic brain injury (mTBI) and concussion. These online lectures are led by licensed social workers, medical doctors, and other professionals in the field of brain injury.



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**Learn more by contacting the development department at [development@biausa.org](mailto:development@biausa.org) or 703-761-0750 ext. 645 or visiting [biausa.org/futuresfund](https://biausa.org/futuresfund).**





# HONOR ROLL OF DONORS

June 1, 2023 – August 31, 2023

This honor roll recognizes donations of \$100 and above received between June 1 and August 31, 2023. Contributions at every level are of great importance and will be acknowledged in the annual report.

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

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## THE FUTURES FUND LEGACY SOCIETY

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

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For more information about how you can be recognized as a member of the Futures Fund Legacy Society, contact Paula Eichholz, Senior Director of Development at (703) 761-0750, ext. 648 or [peichholz@biausa.org](mailto:peichholz@biausa.org).



# PUBLIC POLICY AND ADVOCACY UPDATE

*By Susan L. Vaughn, Policy Consultant, Brain Injury Association of America*

Congress and several federal agencies continue to celebrate the 50th anniversary of the passage of the Rehabilitation (Rehab) Act of 1973, and have held or scheduled events highlighting the various sections relating to employment, housing, and vocational rehabilitation. Federal agencies, including Departments of Labor (DOL), Justice (DOJ), Veterans Affairs (VS) and Health and Human Services (HHS), have updated policies and issued proposed regulations to ensure that websites and mobile applications are accessible in keeping with Section 508 of the Rehab Act.

On Sept. 7, HHS' Office for Civil Rights (OCR) published a proposed update to the HHS regulations implementing Section 504 of the Rehabilitation Act of 1973, which prohibits disability discrimination by recipients of federal funding. The proposed rule addresses discrimination in medical treatment regarding people with disabilities; accessibility of medical equipment; accessibility standards for websites, apps, telehealth, video platforms, and self-service kiosks to access health care; obligations to provide services in the most integrated settings; and to ensure that value assessment methods used for cost containment and quality improvement efforts do not discriminate against people with disabilities by placing a lower value on extending life.

## Proposed Legislation

### FY 2024 Appropriation

*The Fiscal Responsibility Act of 2023*, signed by President Biden on June 3, to raise the debt ceiling to pay for past spending included caps for future spending which was believed would pave the way for Congress to pass appropriation bills for fiscal year (FY) 2024. The Senate Appropriations Committee finalized appropriation bills in keeping with the debt ceiling bill agreement, but was unable to move the bills in the Senate. The House Appropriations Committee and Subcommittees, however, recommended deep cuts below the top lines authorized in the debt ceiling bill and was only able to pass one spending bill that did not make it through the Senate. Most programs for Americans with disabilities and brain injury were proposed to be maintained at current levels.

Congressional Brain Injury Task Force (CBITF) co-chairs Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.) circulated a letter to enlist support for increased TBI funding that was sent to House appropriators. Nearly 30 Representatives signed on in support. Senator Chris Van Hollen (D-Md.) circulated a similar letter in the Senate.



## Concussion

Senators Maggie Hassan (D-N.H.) and Shelley Moore Capito (R-W.Va.) introduced a bipartisan resolution recognizing National Concussion Awareness Day, which is recognized by the United States Congress as the third Friday of each September. The bipartisan resolution was cosponsored by Senators Richard Blumenthal (D-Conn.), Bob Casey (D-Pa.), Susan Collins (R-Maine), Van Hollen, and Ron Wyden (D-Ore.). The resolution was introduced in the House of Representatives by Congressional Brain Injury Task Force Chair Bill Pascrell (D-N.J.) and co-chair Don Bacon (R-Neb.).

## Long-term Services and Supports

### HCBS Relief Act of 2023

Sen. Casey is introducing the *Home and Community-Based Services (HCBS) Relief Act of 2023* or the *HCBS Relief Act of 2023* to address the need for additional Medicaid HCBS funding to states for two years to stabilize their HCBS service delivery networks, recruit and retain HCBS direct care workers, and meet the long-term service and support needs of people eligible for Medicaid home and community-based services. The funds can help decrease or eliminate the waiting lists for HCBS in the states.

The *HCBS Relief Act of 2023* is to be introduced during the fourth week of October. A House companion bill is expected to also be introduced.

### Skilled Nursing Facility (SNF) Coverage

On Aug. 4, Reps. Joe Courtney (D-Conn.), Glenn 'GT' Thompson (R-Pa.), Susan DelBene (D-Wash.), and Ron Estes (R-Kan.) re-introduced the bipartisan bill, *Improving Access to Medicare Coverage Act of 2023*, to ensure that patients qualify for post-hospital Medicare-covered care in a skilled nursing facility (SNF) when they are in a hospital for three or more consecutive days. Under current Medicare law, only time in the hospital that is classified as "inpatient" counts in the calculation of days. During the COVID-19 Public Health Emergency, the three-day requirement was waived, allowing patients to receive SNF care regardless of their hospital status. H.R. 5138 would ensure Medicare covers doctor-recommended, post-acute care by counting the time spent under "observation status" towards the requisite three-day hospital stay for coverage of skilled nursing care.



Senator Maggie Hassan (D-N.H.) is joined by Brooke Mills, a vocal advocate for concussion awareness and this year's Miss New Hampshire.

## Disability-Related Legislation

### Expand Access to the ABLÉ Program

On July 26, Sen. Casey introduced new legislation to expand access to the *Achieving a Better Life Experience (ABLE)* program. The proposed *ABLE MATCH (Making ABLE a Tool to Combat Hardship)* Act removes some of the financial barriers for low-income Americans with disabilities when enrolling in the ABLE programs. The *ABLE MATCH* Act helps people with lower incomes participate in the ABLE program by creating a federal dollar-for-dollar match for new and existing ABLE accounts held by individuals that make \$28,000 annually or less. Last year, legislation passed that extended eligibility to age 46 to participate in the ABLE saving program, which allows individuals to save money up to a certain limit without jeopardizing eligibility for certain federal programs.

### Expressive Communication Disabilities

Senators Casey, Bernie Sanders (I-Vt.), John Fetterman (D-Pa.), and Ed Markey (D-Mass.) have introduced S. 2904, *Augmentative and Alternative Communication Centers of Excellence and National Technical Assistance Act or the AACCENT Act*, to support national training, technical assistance, and resource centers, to ensure that all individuals with significant expressive communication disabilities have access to the augmentative and alternative communication options necessary to interact with others in order to learn, work, socialize, and take advantage of all aspects of life. Rep. Debbie Dingell (D-Mich.) introduced similar legislation, H.R. 5705. Rep. Mark DeSaulnier (D-Calif.) is a co-sponsor. similar bill, H.R. 2708, was introduced by Rep. Steve Cohen (D-Tenn.) along with 79 co-sponsors.



## P&A Services in Justice Systems

On Aug. 22, Rep. Deborah Ross (D-N.C.) introduced H.R.5258, the *Protection and Advocacy for Criminal Legal Services Act*, to authorize the Attorney General to make grants to protection and advocacy (P&A) systems to address the needs of individuals with disabilities involved in the local, state, and federal criminal justice system. Since 1975, P&A provisions have been added to federal legislation to assist individuals with disabilities receiving federal and state services, including the Protection and Advocacy for Traumatic Brain Injury (PATBI) program created in the TBI 2000 Amendments.

## Work and SS Benefits

Senate Finance Committee Chairman Ron Wyden (D-Ore.) and nine co-sponsors introduced S.2196, bipartisan legislation to empower Americans with disabilities to work without losing Social Security (SS) benefits. The *Work Without Worry Act* addresses Americans who sustain or incur their disability before the age of 22 and are eligible for the Disabled Adult Child benefit (DAC), which is based on their parent's Social Security earnings, in the same way that benefits of a child under age 18 would be. S. 2196 prevents an individual who chooses to work from losing his/her Social Security DAC benefit, if they have an eligible medical condition that began before age 22.

## Administration

### Administration for Community Living (ACL) TBI Program

In September, the U.S. Department of Health and Human Services' (HHS) Administration for Community Living (ACL) awarded two ACL Traumatic Brain Injury State Partnership Program (TBI SPP) grants, the University of Florida and the University of Wisconsin, that will end July 31, 2026. The TBI Act of 1996 authorized the grant program to assist states to increase access to rehabilitation and community services.

## National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)

In September, NIDILRR awarded 14 Disability and Rehabilitation Research Projects (DRRP) grants, including a DRRP on TBI Model Systems Centers Collaborative Research Project to the Trustees of Indiana University to conduct exploratory research to better understand angry and aggressive reactions that individuals with chronic TBI experience in response to their daily lives. The DRRP Projects for Translating Findings and Products into Practice also included funding for:

- *Employing Knowledge Translation Strategies to Promote Provider Adoption of the AAN-ACRM-NIDILRR Practice Guidelines on Management of Persons with Disorders of Consciousness Across the Care Continuum* – Spaulding Rehabilitation Hospital Corporation; and
- *TBI@Work Toolkit: Employment Resources for People with Traumatic Brain Injury* – American Institutes for Research in the Behavioral Sciences.

NIDILRR sought stakeholder feedback on its draft Long-Range Plan for Fiscal Years 2024-2028 during the summer with comments due Oct. 13. NIDILRR proposed a new national health goal focused on TBI recovery, which reflects the *Healthy People 2030* objective to "increase the percentage of adults who can resume more than half of their preinjury activities five years after receiving acute inpatient rehabilitation for TBI." The NIDILRR-funded TBI Model Systems database is the approved data source for monitoring progress toward the goal.

## National Institutes of Health (NIH)

NIH's National Institute of Minority Health and Health Disparities (NIMHD) has designated people with disabilities as a distinct health disparity population, along with racial and ethnic minority groups, people with lower socioeconomic status, and who are underserved rural communities, in recognition that people with disabilities often experience a wide and varying range of health conditions that lead to poorer health and shorter lifespan. BIAA advocated for this decision and to fund research examining the factors impacting the health and well-being of persons with disabilities at the intersections of race, ethnicity, and socioeconomic status.

BIAA has posted its *Policy Briefs* on its website [biausa.org](https://biausa.org), which can be accessed at any time.



# PBA Voices

Pseudobulbar Affect Voices

LAUGHING AT A  
FUNERAL. CRYING  
UNCONTROLLABLY FOR  
NO REASON.

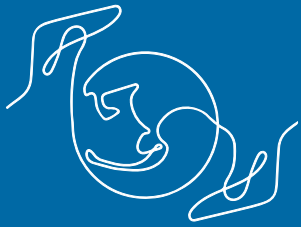
It's hard to understand if you don't know that it could be Pseudobulbar affect (PBA) – a neurological condition involving involuntary, sudden, and frequent episodes of laughing or crying.

PBA IS OFTEN MISUNDERSTOOD AND MISDIAGNOSED – BUT IT DOESN'T HAVE TO BE.

Awareness, education, and treatment can help people better manage PBA in everyday life. Find webinars, personal stories, and our self-advocacy toolkit at [pbavoices.org](https://pbavoices.org) to help.



Learn more at  
[pbavoices.org](https://pbavoices.org)



# STATE AFFILIATE NEWS

## Delaware

BIADE is proud of our 2023 Educate Delaware webinar series on preparedness. The past few years have taught us all that being prepared for the unexpected is crucial in a crisis. This series was designed to educate both survivors and caregivers.

BIADE had its largest attendance for a live webinar in early October. W. Wade W. Scott, Esquire, discussed "Legal Documents Everyone Needs to Be Prepared." Those who attended had an opportunity to ask Mr. Scott questions. Part of the discussion was focused on estate planning to care for the survivor after the death of a primary guardian. This very engaging webinar will help survivors and caregivers create a list of documents they need to have prepared for themselves and their families. This discussion will give you an overview of what questions to ask your attorney.

The 2023 series will end with topics that include how to be prepared for travel and having a disaster/emergency plan; then we team up with Easterseals DE and Maryland's Eastern Shore to discuss how we can utilize assistive technology and support to help navigate the medical systems.



These Educate Delaware webinars may be replayed on our YouTube channel ([youtube.com/@BIADE302](https://youtube.com/@BIADE302)) or our website ([biade.org](https://biade.org)). You can register to attend a Live Webinar by emailing us at [Admin@BIADE.org](mailto:Admin@BIADE.org).

Please save the date of March 14, 2024, for our second Brains in Bloom Survivor and Caregiver and Community Awards Luncheon. We look forward to celebrating some fantastic people of Delaware.

Visit [www.biade.org](https://www.biade.org) to learn more.

## Florida

The Administration for Community Living (ACL) has announced the awarding of a three-year Traumatic Brain Injury State Partnership Program grant to the University of Florida (UF), led by Dr. Michael Jaffee, Chair of Neurology at UF and Founding Director of the Brain Injury, Rehabilitation, and Neuroresilience (BRAIN) Center. The grant will be implemented in collaboration with Brain Injury Florida (BIF), the new BIAA state affiliate, in coordination with the existing Brain and Spinal Cord Injury Program (BSCIP), and will enhance support for individuals and families affected by brain injuries throughout the state of Florida.

Dr. Jaffee, a renowned expert in neurology and brain injury research, stated, "Access to services and resources is key to recovery following brain injury and we look forward to developing a plan that will improve outcomes for all Floridians recovering from these complex injuries." Dr. Nagele, Vice President, Brain Injury Florida, added, "We are excited to collaborate with the UF and the ACL in expanding our reach and providing much-needed support to individuals and their families affected by brain injuries. Together, we can make a meaningful difference in their lives by helping them to find the services and support they need."

## Indiana

Brain Injury Association of Indiana (BIAI) has been very busy with lots of exciting and impactful events in our state. Our members have been attending many events representing BIAI and promoting brain injury awareness and education. Some of the events include the IN BI Advisory Council, the Goodman Campbell Brain Bolt, the Rehabilitation Hospital of Indiana 2023 Sports Expo and various conferences across the state.

BIAI was scheduled to hold its second annual Wiffleball Tournament on Oct. 28. This fun-filled day raised funds to support the mission of the BIAI including upcoming projects and activities aimed at increasing awareness, advocacy, and support for individuals with brain injury in Indiana. Activities include wiffleball games and tournament, silent auction, fall-themed contests, and

crafts for all ages. Visit our website at [www.biaindiana.org](http://www.biaindiana.org) to learn more and get involved or contact BIAI directly at 317-410-3532 or [biassociationofindiana@gmail.com](mailto:biassociationofindiana@gmail.com).

We are excited to report that the BIAI Support Group Committee has developed a support group newsletter called the "BIAI Support Group Gazette." This bimonthly newsletter was created to communicate information from BIAI to IN BI support groups and continue to build this fabulous community. We will also "spotlight" an IN BI support group in every edition!

On behalf of Brain Injury Association of Indiana, we wish every a very happy and healthy Fall!

## Kansas

To bring services and information to the sparsely populated western area of Kansas, the Brain Injury Association of Kansas held a family and survivor seminar in Hays, Kan., on Saturday, Sept. 23 at Fort Hays State University. Professionals, as well as survivors and their families, were invited to participate in the event which included a light breakfast and lunch.

Seminar planning committee members from the Hays area developed a two-track agenda with topics that included brain injury diagnosis and management, forming new support groups, survivor stories, breakout sessions, and panel discussion, enabling healthcare professionals to earn CEUs for attending the event.

Healthcare organizations from across the state and the Hays area were also available to discuss their services with participants.



Seminar organizers reported that it was so gratifying to hear comments like, "I no longer feel isolated as this has validated so much of what I have been going through."



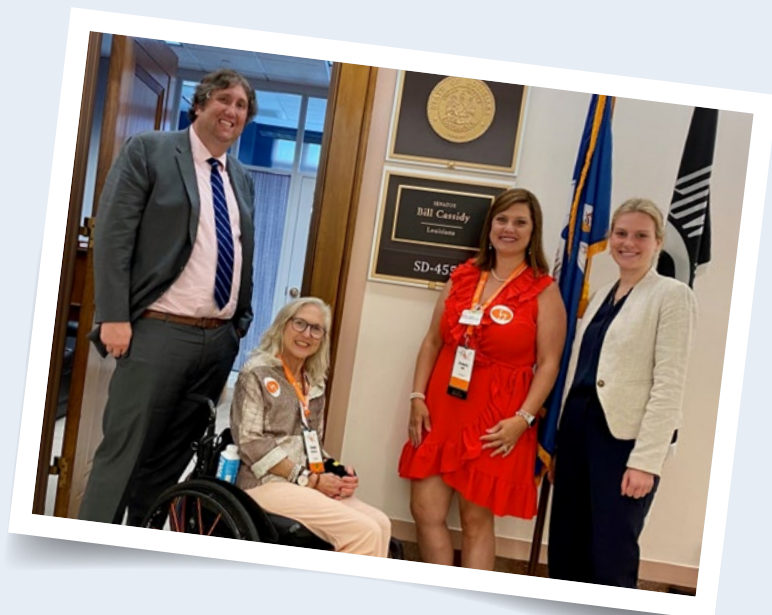
## Louisiana

The Brain Injury Association of Louisiana (BIALA) has been busy creating a new caregiver program, participating in advocacy efforts, and growing our ambassador program which is proving to be quite successful.

A caregiver program emerged through the newly created ambassador program by a simple act of kindness from caregiver and state ambassador Martha Boswell. Martha felt compelled to host a caregiver coffee, which was sponsored by BIALA, to bring caregivers together for support and fellowship. Due to the success of the caregiver coffee, others have hosted caregiver coffees around the state with more planned. Additionally, Baton Rouge Rehab Hospital has started an in-person caregiver support group, in conjunction with BIALA, and a virtual caregiver support group is in the works to begin in the next few months. Thanks to a charitable gift from the Oscar J. Tolmas Charitable Trust, 250 caregiver support bags are being assembled and will start being distributed by the end of the year.

BIALA participated in an advocacy event on Capitol Hill, bringing together over 200 advocates for this annual signature policy event that supports key advocacy priorities for the disability community. The event strengthens the voice of the disability community and ensures all people with disabilities are engaged in policies that impact their quality of life and independence.

The success of our ambassador program has been incredible. Our goal is to broaden our presence statewide so that everyone impacted by brain and spinal cord injuries can connect with our organization and benefit



from our established programs and services. Since January, our membership has increased by 20 percent, including many new members from rural areas of the state. Three new in-person support groups have been created including one in a rural area. More recreational events have been offered and attended by many new people connected with BIALA, and our social media presence has broadened. And, a new caregiver program has been established. We are excited to see what else comes about from our ambassador program.

Our ambassadors have been doing a fantastic job being the liaison between their state region and BIALA, and we are much obliged for their commitment and service.

To learn more about BIALA, please visit [www.biala.org](http://www.biala.org).

## Maine

The Maine Chapter of the Brain Injury Association of America was the recipient of New England Rehabilitation Hospital of Portland's Community Partnership Award. Developed in order to recognize an individual or organization who has supported the hospital and helped foster connections with the local community in a meaningful way, BIA-ME was recognized for its work increasing awareness of brain injury, providing information, resources, and support for individuals who have sustained brain injuries and their families, and advocating for prevention and improved funding and services across the state of Maine.

New England Rehab highlighted the Neuro Resource Facilitator Program, borne out of a collaboration with BIA-ME and the State of Maine DHHS Office of Aging and Disability Services (OADS) funded by a grant from the Federal Administration of Community Living

(ACL). Patients at the hospital complete an application to participate in the program via their case manager, giving the hospital the opportunity to collaborate with a NeuroResource Facilitator while patients are still in-house in order to create a seamless transition into the community. The program prevents patients from "falling through the cracks" when beginning to navigate the chronic, lifelong stage of brain injury. In particular, NeuroResource Facilitator Katy Bizier and Steve Wade, executive director of BIA-ME, were instrumental in developing this partnership and invaluable patient resource. In addition to this program, BIA-ME also has a robust network of support groups that service the entire state, as well as abundant resources for support group leaders. The resources provided by BIA-ME helped the hospital to launch our community stroke support group that began earlier this year.

## Massachusetts

The Brain Injury Association of Massachusetts (BIA-MA) testified on a panel before the Financial Services Committee in support of the Cognitive Rehabilitation Bill. The bill will require commercial health insurance plans to cover cognitive rehabilitation for individuals with an acquired brain injury.

State representative Kimberly Ferguson, a speech language pathologist, described her experience with cognitive rehabilitation to the Committee. Beth Adams, a neurotrauma rehabilitation specialist at Massachusetts General Hospital, explained how she has seen “countless patients fall between the cracks due to lack of insurance coverage for therapies.”

Dr. Victoria Harding, the vice president of development at NeuroRestorative, testified that medically necessary transitional (cognitive) rehabilitation is straightforward for people following their brain injury. “It simply requires insurance companies to add medically necessary comprehensive cognitive rehabilitation to their benefit designs. There is no new process to create nor new provider enrollment processes nor new codes to develop.”

Nicole Godaire, Chief Executive Officer, and Kelly Buttiglieri, Public Policy Manager, BIA-MA, updated the Committee on its advocacy efforts and how the



Acquired Brain Injury Commission recommended the bill's passage. The panel concluded by requesting that the Commonwealth require “healthcare insurance policies provide access to short-term, transitional, medically necessary rehabilitation following an acquired brain injury.”

## New Hampshire



*Jonathan D. Lichtenstein, PsyD, MBA*

The Brain Injury Association of New Hampshire (BIANH) announces that Jonathan D. Lichtenstein, PsyD, MBA, has been elected as the new president of BIANH's Board of Directors. He is currently the Director of Neurological Services at Dartmouth-Hitchcock Medical Center, where he also leads the Pediatric Neuropsychology and Sports Neuropsychology programs. He is an Assistant Professor of Psychiatry, Pediatrics, and the Dartmouth Institute for Health Policy and Clinical Practice at Dartmouth's Geisel School of Medicine, as well as an Adjunct Professor of Clinical Psychology at Antioch University.

On Wed., Nov. 8, BIANH sponsored the 17th Annual Coalition of Caregivers Conference. Keynote Speaker, Rebecca Rule was slated to share her thoughts and humor while speaking about *We Cried So Hard We Laughed: Stories from New Hampshire Caregivers*.



## New York

The Brain Injury Association of New York State (BIANYS) spent the beginning of 2023 focused on multiple advocacy priorities and are thrilled that two of those priorities – the Continuum of Care for Resource Facilitation Program and a Concussion Outreach Prevention and Education (COPE) program – were funded in the FY 2023-2024 New York State budget.

The Continuum of Care will establish a resource facilitation and care coordination program to address the needs of brain injury survivors, their families, and caregivers. Survivors, families, and caregivers will have the information they need and will be connected to doctors, rehabilitation services, and other community-based services, improving outcomes and preventing unnecessary hospitalizations and medical care.

COPE will be run in partnership with the New York State Athletic Trainers' Association, and the series of educational programs throughout the state will provide valuable information for educators, nurses, coaches, athletic trainers, students, and parents/guardians on how to create a plan for a successful return of a concussed student back to youth sports and the classroom as well as many ways to prevent concussions.



BIANYS is thankful to the support of state legislators and the hundreds of individuals that attended Advocacy Day, made phone calls, and sent letters to the legislature to push for this crucial funding.

## Ohio

"An Evening with Bernie Kosar," "Ohio Brain Injury Summit," and "Cere-bration: Walk, Roll & Run" events set the stage for a fantastic Fall season!

Volunteers and staff members at the Brain Injury Association of Ohio (BIAOH) have been hard at work preparing for four major events all within a three-week time frame. On Sept. 10, the "Walk, Roll & Run" event took place in Westerville on a beautiful sunny morning. Survivors, caregivers, and community members joined together to support BIAOH and raise over \$20,000. The most memorable moment of the morning, though, was when one of the TBI survivors who had been pushed in her wheelchair throughout the walk by family members and friends, transitioned to a walker and crossed the finish line by herself! Five days later, another "Walk Roll & Run" event was held in Akron on Sept. 15 at the Edwin Shaw Cleveland Clinic Rehabilitation Center.

On Oct. 5, BIAOH doubled up on events again to host a Brain Injury Summit during the day, and "An Evening with Bernie Kosar" at night. Kosar, an NFL player



and brain injury survivor, was the keynote speaker. In addition to dinner, guests could also opt in for a special "meet and greet" before the event. It was amazing to watch survivors, caregivers, medical professionals, and representatives from other organizations come together to learn more about acquired brain injuries and share their experiences.



## Pennsylvania

BIAPA is set to participate in Brain Injury Awareness Day in Harrisburg on Oct. 17. The primary goal of this event is to educate members of the Pennsylvania General Assembly on the needs of persons with brain injury and their families. Over the past four years, this event has seen significant growth, with up to 80 participants meeting with many legislators in both the House of Representatives and Senate.

The day's schedule includes a comprehensive agenda, featuring a rally in the Capitol Rotunda, individually scheduled meetings with legislators, a reception, and a brain injury panel.

This day is coordinated by Melissa Carmen and Kevin McDonald both survivors of brain injury, in conjunction with the Pennsylvania Brain Injury Coalition (PABIC). PABIC is a collaborative group including the Brain Injury Association of Pennsylvania, the Rehabilitation and Community Providers (RCPA), as well as persons who have experienced an acquired brain injury and family members. The PABIC has worked with members of the Pennsylvania Senate and House of Representatives to form Brain Injury Legislative



Caucuses in both chambers. The Caucuses promote issues of importance to Pennsylvanians dealing with the challenges of an acquired brain injury (ABI).

The Pennsylvania Brain Injury Coalition and members of the Brain Injury Legislative Caucuses in both the Senate and House work together to improve the lives of the many Pennsylvanians who are living with the challenges of an acquired brain injury. Together they have collaborated on many topics such as anatomical gifts, access to cognitive rehabilitation, safety in youth sports, concussion protocol for Pennsylvania State Police, carbon monoxide alarms, and medical marijuana.

## South Carolina



The Brain Injury Association of South Carolina (BIASC) in collaboration with the SC Brain Injury Leadership Council (SCBILC) hosted the annual Life with Brain Injury Conference in Columbia, S.C., on July 28.

This was the first time since the pandemic that the conference was held in person. We were ecstatic that we had a little over 200 people in attendance. Our keynote speaker was Kelly Lang from Virginia. She told her personal story of caregiving for her brain injured daughter as well as experiencing her own brain injury.

During the conference, BIASC recognized SC House of Representative Nathan Ballentine as Legislator of the Year. Representative Ballentine made the formal request for appropriations from the SC General Assembly and was successful in securing the funding. SC Representative Ballentine is a champion for BIASC, and we appreciate his support!

Also during conference, on behalf of the board of directors, Marty Van Dam, BIASC Board President, announced the creation and presentation of the Joyce Davis Impact Award to current BIASC Executive Director, Joyce Davis. In the BIASC's 25th year, the award was created by the Board of Directors to recognize impactful service and dedication to serving persons with brain injury in South Carolina.

# Virginia

The Brain Injury Association of Virginia (BIAV) held a series of four ECHO training webinars during September focusing on the intersection of domestic violence and brain injury. The virtual series was well attended and received great reviews. Thank you to Pink Concussions, Virginia Commonwealth University, and Community Brain Injury Services for your contributions.

In September, BIAV partnered again with the Richmond Area Bicycling Association (RABA) to help them with their annual Heart of Virginia Bike Festival. Close to 400 cyclists rode country roads between 18 to 100 miles raising awareness and funds for BIAV. BIAV volunteers staffed rest stops and kept the Gatorade and pickle juice flowing! BIAV has supported this event for many years and RABA donates 50 percent of the proceeds to us each year.

Virginia has been working on adding Targeted Case Management for Medicaid recipients with severe traumatic brain injury to the Virginia State plan. Over the past year, BIAV leadership, staff, and our partners have advocated for increased support for those living with brain injury. We are looking forward to seeing that plan become a reality in early 2024.

With a change of leadership comes many changes and BIAV has been able to fill some vital roles in the last few months. We welcome Liz Wilson, Director of Development, Keisha Walker, Director of Administration and Finance, and soon Kathy Baba, Communications and Marketing Specialist.

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.



## NeuroRehab Outpatient Therapies

- NeuroPsychological Evaluations
- NeuroFunctional Evaluations
- Cognitive Rehabilitation
- Speech & Language Therapy
- Occupational Therapy
- Physical Therapy

## Supported Living Services

- Community Residences
- Community Apartments
- Life Skills Training
- Recreation Therapy
- Care Coordination
- InSPIRE Structured Day Services

## Life & Health Management Services

- On-site Medical and Rehab Nursing
- Clinical Case Management
- Dietician & Nutrition
- Neurology
- Brain Injury Psychiatry

## Vocational Services

- Supported Employment
- Brain Injury Clubhouse
- NeuroVocational Evaluations
- BeechTree Enterprises



**Beechwood NeuroRehab Admissions**  
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 Phone: 215-750-4245 | 800-782-3299  
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[www.BeechwoodNeuroRehab@woods.org](http://www.BeechwoodNeuroRehab@woods.org)

Beechwood NeuroRehab's policies, procedures, and practices regarding staffing, client admission, provision of services, and referrals, prohibit discrimination on the basis of race, color, religious creed, disability, ancestry, national origin (including limited English proficiency), age, or sex.





# WHO AM I?

Hi. I'm Karen. I care for my husband who has traumatic injuries to his brain.

By Karen Grazionale



This is how I introduce myself at the beginning of a support group. It reminds me a bit of Alcoholics Anonymous as I go on to tell a short version of my caregiver story. It's meant to give others a sense of who I am as a caregiver. Of course, there's so much more to me than that.

When asked to introduce myself before my husband's accident, I would share my name and, if it was a work thing, my role and how it fit into whatever we were doing. For more personal encounters, I'd share that I'm a wife, mom, and grandmother. Now, the first thing that comes to mind and out of my mouth is that I'm a caregiver who supports my husband who was hit by a car ... you get it.



People's faces change when I say that, and they don't know how to respond. Some are curious and ask questions, while others share their sorrows. Amid this exchange, all those other things about me get lost or at least lose their importance. Not only to the person who may never know that I'm a

grandmother or big sister. It sometimes gets lost to me. I'm still aware that I fill all these other roles, but don't always have the energy to juggle all of them.

It feels like the role of caregiver hovers over everything, and I must periodically escape to find the other parts of myself. Depending on what's going on, that escape can look like walking the dog or an afternoon with my youngest granddaughters.

My walks are a bit like meditation where I can just observe and absorb my surroundings. It's very peaceful and I often feel refreshed afterwards. Time with the girls is high energy with lots of laughter. I learn so much from them and absolutely love seeing them evolve.

I realize that, as my husband and I age, the role that caregiving plays may very well increase. I know that for me to be all those things in a way that's fulfilling requires changing my perspective. Rather than escaping one

role to embrace another one, I need to develop the ability to be multiple things without totally exhausting myself. I want to blend those roles in a way that feels natural. Realizing that change begins with me, I must first think of all those other parts when asked to describe myself. In fact, it may be helpful if I don't even think of myself as a caregiver at all.

When my husband and I participated in a research study on the impacts of a brain injury to a marital relationship, we were fortunate enough to be in the group that received counseling. One of the things I learned in those counseling sessions was that I was much more focused on being a caregiver than on being a wife. So, I began to focus more on being a wife. The transition wasn't easy, as so many things about the way we interacted with one another had changed. I now needed to speak succinctly and pause periodically, so he could process what he'd heard. Our level of intimacy had changed. I focused on feeling and being his lover and allowing him to be mine. Those efforts brought us closer as a couple and reintroduced me to the woman I had forgotten.

I now feel more balanced as a person. I know that I am more than a caregiver, wife, and mother. I am a kind and giving individual. Helping others brings me joy. I am organized and disciplined. A clean house makes me smile. I am an introvert. Being alone with a good book and glass of wine comforts me. I fill many roles, while still being me.

## Hi. I'm Karen. Who are you?

Amid this exchange, all those other things about me get lost or at least lose their importance. Not only to the person who may never know that I'm a grandmother or big sister. It sometimes gets lost to me. I'm still aware that I fill all these other roles, but don't always have the energy to juggle all of them.



# Let's Stay in Touch



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

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



**[biausa.org/connect](https://biausa.org/connect)**

## EVENTS AND WEBINARS

**January 9, 2024, 3:00 p.m. ET**

Jeanne Hoffman, Ph.D., ABPP and Risa Nakase-Richardson, Ph.D., FACRM | Chronic Pain and TBI

**January 31, 2024, 3:00 p.m. ET**

Rita Lenhardt, DHSc, CCC-SLP and Mariah Bell, M.S., CF-SLP | Executive Functioning and Mild TBI: Assessment and Treatment Strategies

### **BIAA's Neuro Rehab Leadership Summit: Elevating Business Practices**

January 31-February 2, 2024

Westin San Diego Bayview, San Diego, CA

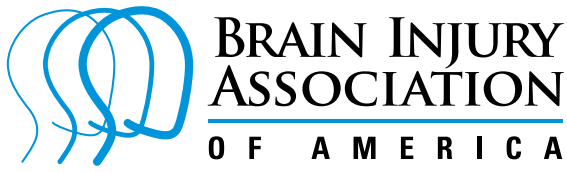
Formerly the Brain Injury Business Practice College, the Neuro Rehab Leadership Summit is the premier national conference for executives and professionals in neuro rehabilitation. Network with peers and attend sessions focused on industry trends, best practices, human resource management, and legislative topics.

Leaders from neuro rehabilitation programs, including, but not limited to, CEOs, Presidents, CFOs, COOs, Medical Directors, HR Executives, Executive Directors, Directors of Inpatient or Outpatient Rehab, Directors of Care Coordination, Clinical Directors, Inpatient Rehab Managers, Outpatient Program Managers, Home and Community Rehab Managers, and Residential Program Managers, are encouraged to attend.

To learn more, view the agenda, or register, visit [biausa.org/summit](https://biausa.org/summit).

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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](http://biausa.org/corporate) or contact Paula Eichholz at (703) 761-0750, ext. 648, or email [peichholz@biausa.org](mailto:peichholz@biausa.org).

