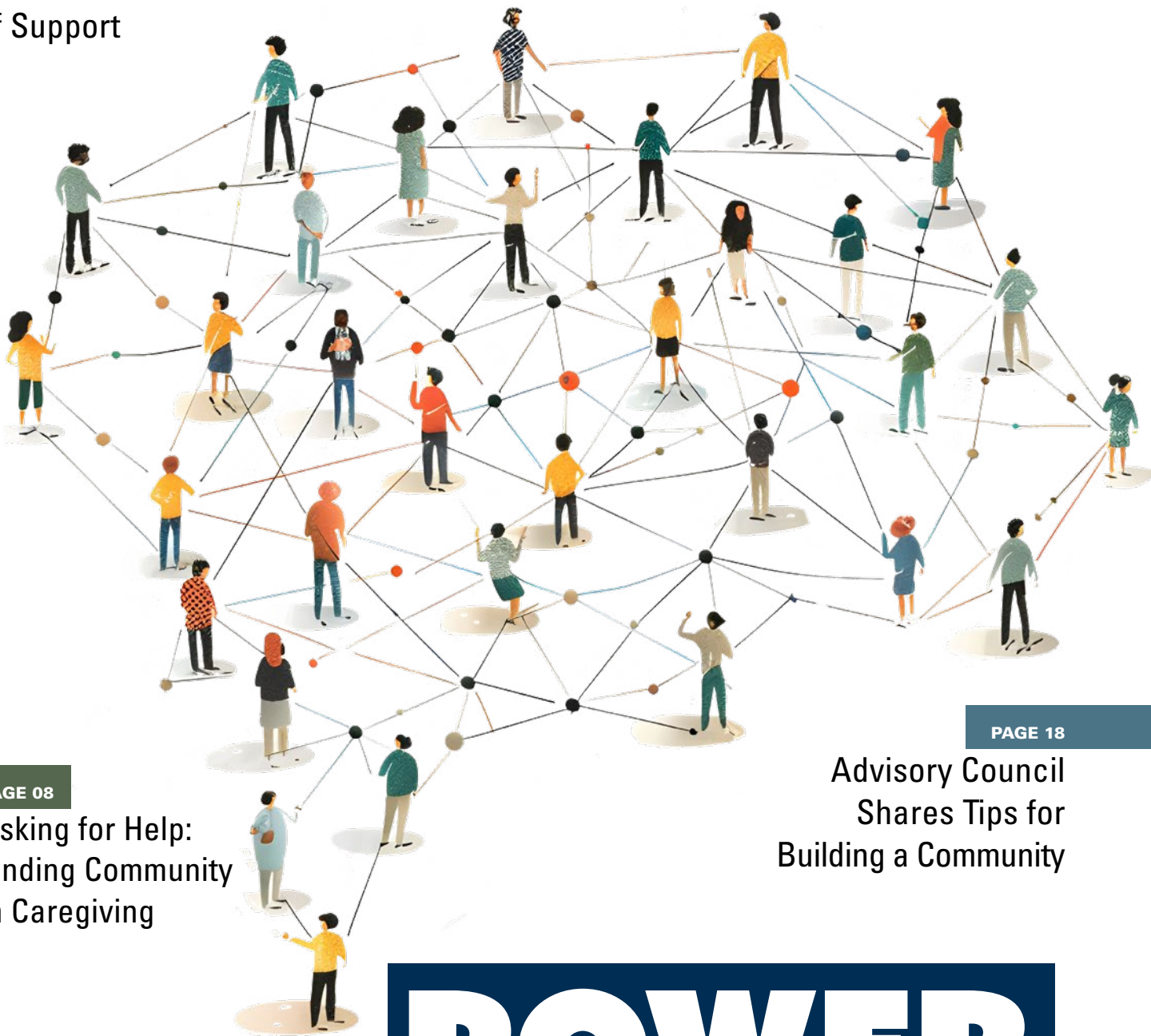


# THE CHALLENGE!

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of Support



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Finding Community  
in Caregiving

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Advisory Council  
Shares Tips for  
Building a Community

# The **POWER** of **COMMUNITY**

**NOVEMBER 2024**

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# FROM MY DESK

Greetings,

The theme for this issue of THE Challenge!, The Power of Community, is intended to shine a light on all of the ways that members of the brain injury community find connection, support, and camaraderie. By coming together in community, survivors and caregivers alike can find compassion and care, empathy and understanding, and in some cases, practical solutions to help with symptoms or struggles.

This theme feels especially timely in light of the agreement between the Brain Injury Association of America and United States Brain Injury Alliance to become a single, unified organization under the Brain Injury Association of America. This reunion will help us better serve the brain injury community – survivors and their loved ones; professionals and support staff who treat, care for, and support them; researchers who study treatments and cures for brain injury; advocates who lobby for greater recognition and access to care; and everyone else who makes up this unique, diverse group.

This effort, the culmination of two years' worth of collaboration and conversation, is a major milestone, one that perfectly illustrates the impact and importance of building a community. The Brain Injury Association of America is the nation's largest network of direct support and advocacy for people with brain injury across the United States, as we foster stronger connections and communication, align around a shared vision, and speak with one voice to change public perceptions of brain injury and advance policy that would benefit the quality of life of people living with brain injury.

As of this writing, we're about to host our first Affiliate Leadership Conference since reuniting with USBIA, and I am looking forward to meeting and spending time with the people who are leading the state affiliates that are joining our network, providing valuable and needed care in their local communities.

I would be remiss if I did not acknowledge the passing of Rep. Bill Pascrell, Jr., who was a fierce advocate in Congress for the brain injury community. He was the founder of the Congressional Brain Injury Task Force, serving as a co-chair since its inception, and frequently championed funding for programs at the Department of Defense that support traumatic brain injury research



and treatment. We are grateful for the tireless support he showed us over the years, and his loss is felt deeply within our community.

As we look forward to 2025, I invite anyone reading this to join us for our next **Brain Injury Awareness Day on Capitol Hill**, which will be held March 3-5, 2025 in Washington, D.C. On March 3, we will be hosting pre-conference activities and March 4-5 will be focused on awareness and advocacy. More details will be shared in the coming months. You can visit the URL below or scan the QR code to visit a Save the Date page to ensure that you are the first to know when registration is open.

To be sure, this community is growing. Evolving. Expanding. All of us at BIAA invite you to be a part of it.

Sincerely,

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

Rick Willis  
President and CEO  
Brain Injury Association of America

## Save the Date: Brain Injury Awareness Day 2025



Interested in learning more about BIAA's Brain Injury Awareness Day on Capitol Hill?

Scan the QR code or visit [biausa.org/brain-injury-awareness-day-2025](https://biausa.org/brain-injury-awareness-day-2025)



# COMMUNITIES of SUPPORT

## BRAIN INJURY SURVIVORS FIND COMPASSION, CAMARADERIE, AND COMPANIONSHIP IN SUPPORT GROUPS

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

Living with a brain injury can be isolating. Many of the long-term symptoms that brain injury survivors experience, such as cognitive fatigue, difficulty with vision or hearing, speech problems, unpredictable headaches or migraines, or becoming overwhelmed in dynamic settings, often makes it difficult to navigate social situations or return to a beloved hobby or career. There is also an all-too-common lack of understanding about how a brain injury can change a person's abilities, limits, and comfort levels, which can lead to frustration and make life after brain injury a lonely experience.



**I know it can feel quite scary to enter a room full of strangers and talk about the most vulnerable part of our lives, but once I attended and came to understand that everyone in the room knew exactly what I was experiencing, I no longer felt alone.**

ANGELA LEIGH TUCKER

"It's just so hard to create a community after something like this happens to you," said Theresa Galvin, a brain injury survivor from New York. "I lost most of my community in the process, and it was hard for me to create community in my world, where people don't understand what I'm going through. I went from being a functioning person, to not so much, to not being in the world at all."

But when she joined Life After Concussion, a monthly virtual support group, she felt a sense of belonging.

"People who haven't endured a brain injury don't understand. People in my family don't get it, my friends don't get it, but these are my people," she explained. "If I say something like, 'This strange thing happened to me and it only happens to me,' people in the group will say, 'Oh, this happens to me all the time.'"

Being part of a support group for people with brain injury offers survivors the chance to realize that despite their frustrations, losses, struggles, or negative experiences, there are others out there who can understand and empathize – and that they're not alone.

"It seems to be a real theme in our experiences – people with brain injuries don't feel seen or heard," shared Randi Levy, a former middle school teacher and brain injury survivor from Maryland. "I think it's very powerful for people with brain injury to realize they're actually not alone – because you're not."

Bryan Pugh, Executive Director of the Brain Injury Association of Maryland, who facilitates Check In Chat, the support group that Levy belongs to, said the knowledge that "you are not alone" is, in his opinion, the biggest benefit of being part of a support group.

"You are not alone in your experiences. You are not alone in your frustrations. You are not alone after the loss of family, friends, and work colleagues," Pugh explained. And, because the group consists of other people with brain injury, members don't have to explain things like fatigue, confusion, or angry outbursts. "You just see nodding heads," he pointed out. "Hearing about others with similar experiences and being able to speak your truth without judgment reduces feelings of isolation and stigmatization."

The idea of walking into a room full of strangers and talking about a traumatic experience can be daunting. But those who have found "their people" in support groups say taking the leap is worth it.

"I know it can feel quite scary to enter a room full of strangers and talk about the most vulnerable part of our lives, but once I attended and came to understand that everyone in the room knew exactly what I was experiencing, I no longer felt alone," said Angela Leigh Tucker, a member of BIAA's Advisory Council and brain injury survivor from North Carolina.

## Finding the Right Fit

Support groups are not one-size-fits-all. Some groups meet virtually, while others gather in-person. Some groups are geared toward a specific demographic: women-only support groups, support groups for veterans, groups for young adults, LGBTQIA support groups. Structure varies from group to group as well: some are more free-flowing, while others offer a bit more structure or someone to facilitate the meeting.

Ali Rheume, who started Life After Concussion in October 2022, said she was motivated to start the group because she wanted to create a support group that had a growth mindset. "It can be difficult to attend support groups if people only complain the whole time, but the struggle is also so real," she noted. "So, the goal was to offer a space where people could be real and vulnerable, receive love and encouragement, and also be provided with strategies and examples to help them move forward in their journeys as they are ready to."

Catherine Hes, another member of Life After Concussion, said that positivity-focused growth mindset helped her shift her thinking about her brain



Joining a support group can lead members to pursue other hobbies, such as art or meditation.



**It seems to be a real theme in our experiences – people with brain injuries don't feel seen or heard. I think it's very powerful for people with brain injury to realize they're actually not alone – because you're not.**

**RANDI LEVY**

injury. "I got brave enough to try new things, and if the experience didn't go well, I didn't berate myself. Instead, I just used Ali's phrase: 'I am not ready yet,'" she explained. The positive mindset exhibited by Rheaume and her fellow group members has helped her be more appreciative, celebrate her wins, and recognize the progress she's made. "With this thinking, I was able to manage my symptoms with more self-kindness and grace, rather than embarrassment," she said. It even helped her develop strategies to more comfortably travel via plane to visit her son, plan and host a birthday party for a friend, and embark on a new career.

## Sharing Solutions

Another benefit beyond the camaraderie and understanding that comes from gathering with fellow brain injury survivors is the sharing of strategies and resources.

"When we find a good doctor, we share that. When we find a good community center, we share that. We become resources for one another. We're veterans of a very particular type of injury," explained Betsy Bizarro, a brain injury survivor from Massachusetts.

Levy shared that a fellow support group member gave her the idea to organize her weekly schedule using a white board, after her previous attempts to use sticky notes and a planner weren't helping. "When he suggested it the first time, I was still in a lot of denial, but it worked," she said. "It helps me to organize myself."

Bizarro believes that providing help and support to fellow brain injury survivors is part of her healing process. "Being able to support other people in their healing journey gives us purpose," she said. "We want to be useful, we want to be able to help others, and being present in a support group is something we can still do."

## Branching Out

While support groups are an invaluable resource for camaraderie and community, they're not the only resource. Support groups like Life After Concussion and Check In Chat have led members to other groups and programs that have helped them explore new interests, hobbies, and practices. Bizarro, for example, runs a weekly meditation group, which Galvin joined and considers a game-changer for her brain injury-induced migraines. "My migraine activity has decreased as I continue to immerse myself in this mindfulness and meditative practice," she shared.

Tucker shared that her support group led her to a writer's group specifically geared toward people with brain injury.

And Pugh shared that several group members use art as therapy, which inspired some of the members to apply for and attend an arts festival to showcase their art and demonstrate what they were able to do with their brain injury. And, he added, "Several participants have started businesses, gone back to school, gotten their drivers licenses again, gotten their EMT certifications back based on the encouragement of the group."

If you would like to be connected to a support group in your area, reach out to the National Brain Injury Information Center at 1-800-444-6443. You can also find a list of virtual support groups at [biausa.org/supportgroups](https://biausa.org/supportgroups)

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

If you or someone you love has been diagnosed with Pseudobulbar affect (PBA), BIAA is here for you.

Visit  
[biausa.org/pba](http://biausa.org/pba)  
starting  
December 1 for  
access to helpful  
information and  
resources about  
living with PBA.



# ASKING FOR HELP: COMMUNITY IN CAREGIVING



Our neighbor Allen, who lives directly across the street, is tall, well over six feet. He carries his height on a solid frame. I see him out jogging from time to time and working in the yard.

My husband Steven is average height, about 5'8", and he weighs about 135 lbs. That in itself is not a problem. In fact, it is actually a good thing because due to Steven's health issues he can no longer walk. Now and then, especially during transfers from toilet to wheelchair, Steven's legs give out and he ends up on the cold tile floor. The confined space of our bathroom, designed before the ADA, makes these situations challenging and uncomfortable for Steven. In those moments, once I've ensured Steven's safety and provided comfort for his body, thoughts of Allen come to mind. Allen is often my lifeline in these situations, ready to help at a moment's notice.

## Dependable Neighbors: A Lifeline in Caregiving

Somehow, miraculously it seems to me, Allen is usually available when I need his help. Despite a busy travel schedule, he's at home more often than not when I call.

I've come to think of Allen as my white knight. He comes over at a moment's notice and with a few deft strokes manages to pick Steven up and return him to his wheelchair. There's no way that I can do it by myself. I've tried. At 5'1" and 109 pounds, I just don't have the strength or the leverage. It's such a comfort knowing that Allen lives across the street and is so willing to literally lend a hand. Everybody, or at least every caregiver, needs an Allen – someone to call on for immediate assistance in times of crisis.

If Allen isn't home, or I've called too often, I can turn to Tony next door. Tony isn't as tall as Allen, but he is younger and very strong. Tony is always willing to help at a moment's notice, which is most important.

When Steven's fever spiked to 102 degrees and he was too weak to move, I immediately called Tony at 6:30 a.m. Tony responded instantly, assisting me in getting Steven out of bed and into his wheelchair so we could rush to the emergency room. His prompt action and support were invaluable during that critical moment. He also called that night when he got home from work to find out how things were going.



## The Importance of Building a Support Network

One Sunday, Steven slipped from his wheelchair during a transfer, with neither Allen nor Tony available for help. It seemed we were the only ones at home on that lovely sunny Sunday. Bereft of neighbors (or at least those I felt comfortable enough asking), I called the fire department. If they're asked to get cats out of trees, I reasoned, surely they can help lift a man off the floor. Sure enough, three members of the rescue squad showed up within 15 minutes. "Any time ma'am" they said with a smile.

I've become very good at asking for help, in putting necessity first and pride last. I've learned caregiving requires a team effort and recognizing when tasks exceed individual capabilities is crucial. I've learned the vital importance of proactively establishing a support network, ensuring there are reliable people to call during emergencies. I've also learned it doesn't just happen. It requires an effort and a breaking down of barriers. You have to let people into your life, to tell your story, to let them see your vulnerability as well as your strength.

We didn't know Allen lived across the street when we bought our house. Tony moved in next door a few years ago. As Steven has become increasingly disabled, we've learned the importance of establishing a reliable support network. Every caregiver needs an Allen or a Tony. Every caregiver needs a few people to call on who can respond quickly in an emergency. Across the street or next-door is ideal, but even five or ten minutes away can work.



## Embracing Support: The Key to Caregiving

I've learned that many people do actually want to help. They need to be asked and then told what kind of help they can actually provide, and once they've provided it, they need to be heartily thanked.

We need to let other people into our lives, and perhaps that is the hardest part, to let them see the intimate difficulties with which we deal. But once we do, life isn't quite so scary anymore, and we don't feel so alone. For a caregiver, or at least for this one, that is very, very important. My wish for you is this – that you find the courage and the strength to reach out for help and find an Allen or a Tony to respond.



*This article was reprinted with permission from Caregiver Action Network.*

# FINDING COMMUNITY THROUGH YOGA AFTER BRAIN INJURY

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



The list of benefits from social connection and building meaningful relationships is long: less anxiety and depression, improved sleep, lower risk of chronic disease, better cognitive performance, longer and more satisfying lives. And yet, after brain injury, social isolation and loneliness are among the most common and devastating experiences. This happens for a variety of reasons—environments that trigger sensory overload, cognitive fatigue from social interaction, lack of understanding among friends and family, and heightened self-criticism that something is “wrong with me.”

---

Although research has identified important strategies for addressing loneliness, including improving social skills, enhancing social support, increasing social contact, and addressing maladaptive social cognition, the medical system faces major gaps in effectively supporting brain injury.

So, how can we do better?

The most effective approaches to building a sense of belonging are multifaceted, working both at the external level by connecting people together who have meaningful, shared experiences, while also at the internal level by addressing false narratives about our self-worth. That’s why mind-body activities like yoga have particularly strong potential as a pathway for community building after brain injury. You might wonder, how?

**Connection to Self** –When we turn inward through practices like yoga and meditation, we begin to see more clearly what’s happening in our minds, bodies, and hearts. Our thoughts shape our experience of life. So, if we have a habit of thinking negatively about ourselves, we’ll mistrust our abilities and incorrectly assume others don’t like us, which only furthers isolation. Research shows that when we become more aware of our self-talk, we’re better able to focus on thoughts that foster self-confidence, resilience, and relationships with others. Neuroscience shows that when we’re aware of how our body feels (known as interoception), we’re more able to empathize with the emotional experience of others. Matthew Sanford, a disabled yoga instructor who specializes in adapting yoga for people with disabilities, shares, “As you’re more in your body, you do feel more connected to people. You think about the importance of other life. You are here. It’s beautiful. It’s subtle. It’s all one big thing. And so I think that as you move back into your body or more deeply into your body, it makes you in contact with the world more. And when you’re part of the world, it’s much harder to not feel compassion about the world.”

► **Connection to Others** –When we feel seen, accepted, and valued by others with shared experiences or identities, we feel a sense of belonging that makes a big difference. Think about it for yourself – at times when you've felt your lowest, when you've connected with another person who “gets it,” what did that shift for you? This depth of connection is directly tied to our level of vulnerability. Because yoga is a practice of uniting the different parts of ourselves – our physical, emotional, energetic, and spiritual selves – it teaches us to accept our strengths and limitations and show up more fully, which is central to vulnerability. And, because yoga is highly adaptable, it's inclusive of all injury severity levels, which is important because receiving peer support from people at different stages in healing gives perspective and hope for what's possible. As Sanford shares, “Yoga can travel through any body. It's not about the perfect pose; it's not that. It's literally – it's a phenomenon that occurs at your mind's intent and your body's limits, and it – poof, it happens. And it travels through any body.”



*Kyla Pearce, CBIS, RYT, MPH, PhD, is the Senior Director of Programs and Research for LoveYourBrain, a national nonprofit that offers free, research-backed yoga and mindfulness programs for people with brain injury and caregivers.*

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# FINDING SUPPORT WHEN YOUR CONCUSSION SYMPTOMS PERSIST

Concussion survivor and activist shares tips in free BIAA webinar

By Lauren Moore, Marketing and Communications Manager, BIAA

Concussions can have a wide range of symptoms, including headaches, nausea, sensitivity to light or noise, dizziness, exhaustion, difficulty concentrating, and more. For some, those symptoms can last weeks, months, or even years after the initial injury. In addition to the physical toll these symptoms can take on a person, they can often lead to feelings of isolation and despair, making it important for sufferers to get the support they need as they navigate their post-concussion lives.

Allison Moir-Smith, a therapist, artist, public speaker, and concussion survivor and activist, presented “Finding Support When Your Concussion Symptoms Persist,” a free webinar offered by the Brain Injury Association of America.

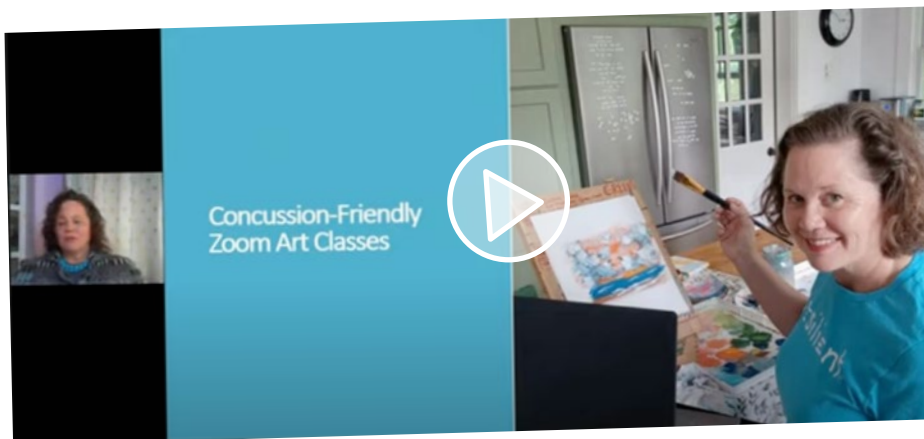
## An Accident Leads to a Concussion

Allison’s concussion story starts like so many others — with an accident. During a ski trip with her family, she slipped and hit her head. Unaware that she had just gotten a concussion, she stood up and joined her family further down the slope. She continued to take another run, then took the two-and-a-half-hour drive home.

Because she wasn’t exhibiting the most severe symptoms of a concussion (like being knocked unconscious or vomiting), she didn’t think she needed to be seen by a medical professional. Just as so many other concussion survivors — especially busy working moms like herself — have done following their injury, Allison went on with her day-to-day life. But the following week, she started to feel unwell — something that is especially common in women, whose symptoms tend to bloom slowly. “I started to get light and noise sensitivity, headaches, nausea, balance problems. I couldn’t read or write. I felt like I had fire in my veins, and I didn’t understand what was happening to me,” she recalled.

Weeks went by, and Allison lived on in darkness — literally. “I was wearing a hat and sunglasses inside the house because of my light and noise sensitivity,” she said. Allison kept calling her doctor, who advised rest and assured her the concussion would heal on its own. “I trusted her because I had to. Because I had a brain injury, and I didn’t know what was happening.”

Allison detailed the exhausting months that followed. “I was functioning, but I always longed to be on the couch, with my hat and



sunglasses, under my son's Star Wars blanket," where it was dark, quiet, and safe, she said.

That isolation took a huge toll. Under that blanket, she would ruminate, wondering why she wasn't feeling better. She wondered if she had a tumor, or early onset Alzheimer's. She was scared and depressed – and that depression grew into suicidal ideation.

Allison found herself withdrawing from her normal activities, including her exercise group and her church, where the singing and organ music were more than she could bear. She was even limited in how much she could support her children at their sporting and theater events. "I lost all of my normal supports. I lost joy, friendship, my identity of being a person out and about in the world," she recalled. As she watched her friends carry on with their lives, she felt forgotten, hurt, angry, abandoned, and deeply lonely. Although being around other people was too stimulating and draining, the loneliness was overwhelming, creating an impossible situation. "Loneliness is serious stuff, with enormous physical and mental health consequences," Allison acknowledged.

## Finding Relief, Support, and Community

Over time, Allison began to experience "small healings" – relying on her hat and sunglasses less, being able to sort her family's laundry, getting through the holidays. The bitterness she had felt for months started to wane. She also found support in "unexpected angels," the women who belonged to her church that sent cards, left cookies on her front porch, and checked in with her.

"Who is showing up in your life right now? Who checks in with you? Who helps you? Who takes the time, who remembers you, who reached out to you even when

you can't do your part in the relationship?" Allison asked. "I hope you can appreciate them, because they're probably not who you expect. Start embracing the people who are actually showing up in your life."

She also found relief in a supportive speech language pathologist, who validated her symptoms and worked with her to develop strategies that would help mitigate some of her symptoms. She also taught Allison how to calm her nervous system, which in Allison's case included spending time using a coloring book. Those daily coloring sessions grew into a love for watercolors, and provided a tangible example of how far she had come in her recovery.

“  
Loneliness is  
serious stuff, with  
enormous physical  
and mental health  
consequences.

ALLISON MOIR-SMITH

Allison's daily art practice led her to Instagram, where she shared the progress she had made in her art in an effort to inspire hope in other concussion survivors who were struggling. "Instagram has been a game changer in my concussion recovery," Allison said, explaining that what she found there was "an amazing community of people who have knowledge and who will help." She made friends, found work, sold art, and ultimately became a concussion activist thanks to the support she found within the Instagram concussion

community. "There's a wonderful world of concussion recovery just waiting for you to join us," she said.

However, she acknowledged, connecting with strangers, even online, can be intimidating. She shared tips for getting set up on Instagram, finding the concussion recovery community, and ultimately forging connections with survivors, activists, and others who can offer help and support during what is often a scary, painful, lonely experience. Allison offered suggestions for hash tags and concussion-related accounts to follow to get started, as well as tips for offering support to others who are struggling. "What you put out there will come back to you," she added.



SCAN THE QR CODE TO  
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Marilyn Price Spivack, right, with her husband, Dr. Martin Spivack, and her daughter, Deborah Lee Price

## A LIFELONG LUMINARY

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

Marilyn Price Spivack has made advocating for brain injury survivors her life's work.

Her efforts began in 1975, when her teenage daughter, Debby, sustained a severe traumatic brain injury. As Marilyn and her family managed the difficult days following Debby's injury, she soon realized that her daughter's needs – and the needs of countless others in a similar situation – could only be met by a nationwide organization dedicated to providing support to people with brain injury, with an ultimate goal of helping these individuals regain their quality of life.

Five years later, Marilyn and her husband Marty invited 17 family members and professionals who treated Debby to their home to discuss how to bring about meaningful change for individuals with brain injury. That pivotal meeting was the seed that blossomed into the National Head Injury Foundation – now the Brain Injury Association of America (BIAA).

Under Marilyn and Marty's leadership, BIAA spearheaded many important initiatives that advanced the conversation around brain injury, including generating awareness about and sharing the National Head and Spinal Cord Injury Survey, one of the first sets of statistics compiled related to brain injury; co-creation of the first standards of acute care rehabilitation for persons with brain injury; establishment of the Federal Interagency Head Injury Task Force; and countless advocacy efforts at the federal level that resulted in millions of dollars of funding for brain injury research. In the early days of BIAA, the first brain injury phone line (now the National Brain Injury Information Center) was established in the Spivack home to help provide a larger number of people access to the information and resources they had gathered. To this day, NBIIIC provides support, information, and resources for individuals and families that experience the life-changing effects of brain injury.

By the time Marilyn passed the torch in 1990, her efforts had resulted in BIAA's widespread recognition at a federal level – within the administration, in Congress, and among many federal agencies that have been integral to our mission and vision. In the 44 years since that fateful meeting in Marilyn's home, thousands of professionals, family members, and brain injury survivors have come together to share resources and advocate for changes that positively influence outcomes for this community.



## [ LU·MI·NARY ]

### a person of prominence or brilliant achievement

Luminary of the Year is an exciting new fundraising campaign that supports BIAA and our mission to improve the quality of life of people affected by brain injury. By supporting the Luminary of the Year campaign, you are helping us work toward a world where everyone who sustains a brain injury is recognized, treated, and accepted.

This inspiring, mission-focused event gives us the opportunity to highlight stories of resolve, determination, and compassion from the brain injury community. Luminaries are also known for diminishing darkness, lighting a path, and leading to a brighter future.

In honor of the incredible contributions Marilyn has made to the brain injury community, BIAA named her the inaugural Luminary of the Year, celebrating her lifetime of efforts and achievements at the Luminary of the Year celebration on November 15, 2024, in Washington, D.C.



**SCAN THE QR CODE TO SUPPORT MARILYN PRICE SPIVACK  
AS OUR INAUGURAL LUMINARY OF THE YEAR OR VISIT  
[GIVE.BIAUSA.ORG/FUNDRAISER/5547851](https://give.biausa.org/fundraiser/5547851)**

# 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](http://biausa.org/futuresfund).



# BIAA AMPLIFIERS

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

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# THE FUTURES FUND LEGACY SOCIETY

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

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To see the list of our donors,  
scan the QR Code

# ADVISORY COUNCIL SHARES TIPS FOR BUILDING A COMMUNITY

By Lauren Moore, Marketing and Communications Manager, BIAA

Recently, members of the Brain Injury Association of America's Advisory Council joined Greg Ayotte, Director of Consumer Services, for a live virtual event about building community after brain injury. During the event, Carole Starr, Cazoshay Marie, Kellie Pokrifka, and Paul Bosworth shared their experiences with building a community after brain injury, including the opportunities, challenges, and more. Read on for excerpts from the event:



## As a survivor, how have you built your community?

**Carole:** For me, it was a very step-by-step process, and it really started one on one for me. Groups, after my brain injury? It was just too much for me. Too many

people, too many stories, too much emotion. I could barely handle my own brain injury, I couldn't handle much from anybody else. But I was going to brain injury rehab, and I met one other survivor. And her story was similar to my story, she had been a teacher too. We started going to lunch together once a month, and we shared our stories. And that helped me to not feel so alone.

## How has having a community benefited or affected you?

**Kellie:** When you look fine, and a lot of people don't know much about brain injury and what's going on, there's a lot of comments saying, "Is it really that bad?" And you start to internalize it, and it feels absolutely horrible, because you need that support. You need people saying, "I believe you, I see you, I want to spend time with you, even if it is just staying on the couch all day, I want to be there for you." But, I feel like a lot of us don't necessarily always have that. And the loneliness and the losing people is so extremely difficult on top of what we're already going through with our physical and emotional symptoms. I would say that having community – once I had those people who have shown me that will stand by me – it strengthened my relationships with them so much.



**Paul:** We ran a support group for a very long time. In that process, I found folks meeting each other as family. They weren't family, but now they are, because we share that common bond – we've been there, we've done that, now what do we do? We can help the next person out.



## What are some of the challenges of building community with brain injury?

**Cazoshay:** I really think one of the biggest challenges is that level of vulnerability that it takes to build community. And when you have a brain injury, you're already feeling vulnerable in so many different ways. So to add something else, to have to put yourself out there, to be transparent, to show up as your authentic self rather than trying to be who you were, or not show how you're feeling, it does take a level of vulnerability and bravery, and that can be a challenge.



To watch the full recording, scan the QR code or visit [youtube.com/live/pRajdi3I8Yw?si=LbDg-A8AgWX52E7K](https://youtube.com/live/pRajdi3I8Yw?si=LbDg-A8AgWX52E7K)

# BRAIN INJURY ASSOCIATION OF AMERICA & US BRAIN INJURY ALLIANCE AGREE TO REUNITE



29th Annual Affiliate Leadership Conference

The Brain Injury Association of America (BIAA) and United States Brain Injury Alliance (USBIA) have agreed to reunite to better serve the brain injury community as one unified organization under the Brain Injury Association of America. The USBIA Board of Trustees voted unanimously on September 10, 2024 to start the process of dissolving the organization.

“We are excited to unite and speak with a single voice in order to better serve the brain injury community,” said Rick Willis, President and CEO, BIAA. “As a unified organization, we will leverage our collective influence to change public perceptions of brain injury and affect policy.”

“We have been working hard over the past two years to get to the point where we believe it is time to become one national organization again,” said Gavin Attwood, CEO of USBIA. “This decision will mean that most of the USBIA state-level affiliates will be joining the Brain Injury Association of America, forming the nation’s largest network of direct support and advocacy for people with brain injury across the US.”

This decision marks an important milestone for the brain injury community that promises deeper impact for brain injury survivors and their loved ones by:

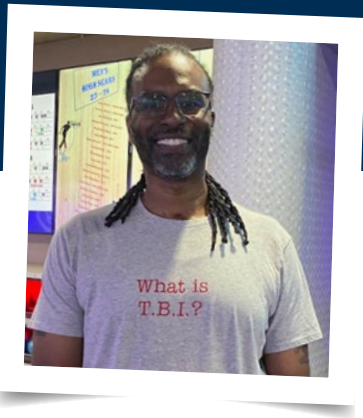
- ▶ **Aligning around a shared vision:** Driving toward common objectives builds momentum and enables a scalable movement to advance prevention, awareness, research, treatment, education and advocacy.

- ▶ **Speaking with one voice:** Standing together we leverage our collective influence to change public perceptions of brain injury and affect policy.
- ▶ **Elevating shared learnings:** Working hand-in-hand, we foster stronger connections and communication so we can learn from one another and improve our overall effectiveness.

Survivors, caregivers, healthcare providers, donors, and supporters will continue partnering with their local state affiliates on a day-to-day basis. As part of a new, unified national brain injury network, they may also expect to receive added resources and support, information about educational opportunities, invitations to gather with the community at events and conferences, and alerts and communications to keep them informed of important progress and developments.

The addition of USBIA Affiliates to BIAA will take place based on the unique circumstances and planning needs of each individual Affiliate.

# STATE AFFILIATE NEWS



## Delaware

The Brain Injury Association of Delaware (BIADE) is officially joining forces with the Brain Injury Association of America. Starting December 2024, we'll be known as the Brain Injury Association of America – Delaware Chapter. Local Councils will be created to make a difference in Delaware. The Chapter will look for an Executive Director and continue to provide community outreach, answer calls, offer education, and connect survivors and caregivers with the help they need, including support groups. Stay tuned as we grow, evolve, and continue to make a lasting impact in Delaware. Here's to a bright future and even more opportunities to provide help, hope and healing!

## Florida

Brain Injury Florida (BIAF) recently hosted its inaugural Bowling for Brain Injury fundraiser in Tampa. One participant, 21-year severe TBI survivor Rodrick Frazier, shared his thoughts on participating in the fun-filled event: "This was an easy fundraiser to stand behind due to my love of bowling. I think when you love what you're doing and who it is for, it never feels like hard work! ... It was a great event and I promise to do more to bring survivors out in the future! Thanks to our brain injury survivors, allies, bowling teammates, and my loving spouse for their support! We are just getting started and I want to build this exceed expectations! To my fellow survivors in Florida, be on the lookout for us coming to a city near you! If we come to your town, please do your best to come out and say hello! If you need a ride or something else, let me know! I've learned that my existence today is no longer about me, but is about everyone else, but me!"

## Indiana

The Brain Injury Association of Indiana (BIAI) has had a busy summer and beginning to fall.

BIAI held our very first "Stroll for your Lobes" event in July! "Stroll for your Lobes" is a new series from BIAI intending to promote brain health and wellness for those impacted by brain injury. Our first event of this series was held in a beautiful park with an accessible walking trail in Indianapolis. Dr. Sachin Mehta, physical medicine and rehabilitation physician, spoke about the benefits of exercise on the brain. We were then led by physical therapist Elliott Cohee through some simple stretching and warm up exercises before we ventured out on the trail and discussed what we learned and socialized with each other. We are in the planning stages for our next "Stroll for your Lobes" event so be on the lookout for upcoming information.

We also launched our "Brain Blitz" informational series on our BIAI website. Our website series is made up of short videos with various people speaking about important topics and providing information about resources both locally and nationally. Visit [biaindiana.org/brain-blitz](https://biaindiana.org/brain-blitz) to see what we have so far.

We are super excited about our Third Annual Wiffleball Tournament coming up on October 26! We have fantastic wiffleball games, fall-themed costume contests, raffles, a virtual silent auction, incredible door prize, vendors, family-friendly activities, and more planned for this year. To learn more about how you can participate in our fun-filled event, visit [givebutter.com/c/2024BIAIWiffleball](https://givebutter.com/c/2024BIAIWiffleball).

Wishing you a beautiful autumn filled with so much beauty and joy!

## Kansas

Throughout the spring and summer, the Brain Injury Association of Kansas and Greater Kansas City's (BIAKS) Executive Director Heather Pilkinton and Program Director Julie Luttmann embarked on a road trip across Kansas to expand awareness and make connections through each region of our state. Their efforts were aimed at connecting Kansas healthcare facilities, providers, and community partners with BIAKS. Kansas is comprised of 105 counties, some of which have population numbers smaller than 1,500. Our vision at BIAKS is to support people living with brain injury to live their lives to the fullest.

As part of the road trip outreach program, Heather and Julie visited 22 hospitals, rehab facilities, councils on independent living centers, mental health organizations, and area agencies on aging, many in far-flung areas of the state, meeting staff, most of whom did not know there was a state-wide organization that could help brain injury survivors.

"We've learned about services available to survivors, the communities they serve, and the challenges they face. Our work on this project is far from over.



This is just the beginning, we are thrilled to make these connections, and to expand our reach. This has been a wonderful opportunity to link BIAKS with the dedicated professionals who work tirelessly to provide quality care for individuals and their families affected by a brain injury," Heather noted. "We consider our tour of Kansas a great success and will continue these efforts as we move into the fall months."

## Louisiana

The Brain Injury Association of Louisiana (BIALA) filled the summer building a sense of community by hosting and sponsoring recreational opportunities statewide for individuals living with brain injuries, spinal cord injuries, and caregivers. The good times rolled at our adaptive bowling event, and many enjoyed learning line dances at our silent dance party. Creativity was blooming at our art event at a local pottery studio as well learning mindfulness and chair yoga at a three-day workshop. Our Unmasking Brain Injury art exhibit now highlights 40 new masks that were painted as we visited numerous post-acute residential brain injury centers around the state. Adaptive sports activities were in full swing during Ski Dawgs Adaptive Water-Skiing clinics throughout the summer. And we cheered the Cajun Crushers to victory during their competitions at the Endeavor Games. While summer activities are winding down, we look forward to offering more community events in the coming months.



In September, BIALA was honored to be the beneficiary of proceeds raised at the Mande Milkshakers 6th Annual Polka Dots and Pearls Ball and Charity Auction. BIALA was chosen as the Mande Milkshakers charitable partner for this year and next, and at the ball, a check was presented to BIALA for \$25,400. Not only was the ball successful in raising money but also helped raise awareness about BIALA's programs and services as well as educate and inform the community about brain injuries. To learn more about the Mande Milkshakers, visit: [facebook.com/MandeMilkshakers](https://facebook.com/MandeMilkshakers). And to learn more about BIALA, visit [www.biala.org](http://www.biala.org) and follow us on social media at [www.facebook.com/braininjuryla](https://www.facebook.com/braininjuryla) and [www.instagram.com/biala.lachapterusa](https://www.instagram.com/biala.lachapterusa).

## Maine

The Brain Injury Association of Maine (BIAA-ME) hosted the 15th Annual Defining Moments in Brain Injury Conference on September 30, in Portland. Maine brain injury survivor, author, and advocate Carole Starr gave her keynote, "Silver Learnings: Lessons from 25 Years of Living with Brain Injury;" Maine brain injury survivor Jenn Williams gave the Beverley Bryant Memorial Lecture, and the day was packed with 16 breakout sessions.

In collaboration with the Maine Office of Aging & Disability Services and under the Administration for Community Living grant awarded to Maine, BIAA-ME has been working with three behavioral health programs across the state to implement screening for a history of brain injury using the OBISSS tool from the National Association of State Head Injury Administrators. Staff from the pilot programs are participating in trainings and building capacity to support individuals with co-occurring brain injury, mental health, and substance use disorder challenges. The pilot project also links those who many benefit from additional resources and services with NeuroResource Facilitation services for additional support.



## Massachusetts

The Brain Injury Association of Massachusetts (BIA-MA) was awarded a Home and Community-Based (HCBS) Workforce Development grant from the state's Executive Office of Health and Human Services to address the need for specialized training with respect to acquired brain injury (ABI) and professional development as a critical workforce need.

In collaboration with experts in the field of brain injury, both an introductory and continuing education credit series was developed and designed to provide professionals, as well as those who may be new to the field of brain injury, with an understanding of acquired brain injury and their consequences.

The free virtual courses were designed to enhance the knowledge, expertise, and skills of nurses, case managers, behavioral health, and rehabilitation clinicians, as well as other professionals.

BIA-MA began offering the courses in the Fall of 2023 and they will continue each month through March 2025. For more information visit [biama.org/forprofessionals/](https://biama.org/forprofessionals/).

## Missouri

The Brain Injury Association of Missouri (BIA-MO) held four One-Day Regional Outdoor Camps in St. Louis, Springfield, Kansas City, and Columbia in Fall 2024. Activities included tie-dyeing shirts, rock painting, bingo, cornhole, and other games. Survivors of brain injury and families enjoyed nature, lunch, and connecting with others at this free event.

For professionals, the BIA-MO 20th Annual Statewide Conference was held on November 7 and 8. Sessions included Better Living Through Brain Stimulation, Vocational Rehabilitation Research within the NIDILRR TBI Model Systems, Missouri Brain Injury Resource Facilitation, Guide to Becoming an Effective Advocate for Policy Change, Pushing Through Recovery Survivor Panel, and more. It was a great opportunity for professionals to network with colleagues and gain information to improve outcomes for their patients, clients, and consumers.

On November 9, the BIA-MO Survivor and Family Seminar was held in St. Louis. Topics included Brain Injury 101, Reduce Social Isolation and Loneliness Through Relationships, Work and Purpose, and Getting



Social Security Following Brain Injury. Let's Talk breakout sessions encouraged survivors of brain injury to share experiences of life with brain injury in a facilitated discussion.

The BIA-MO Annual Awards Luncheon was also held on November 9. Volunteers, supporters, and survivors were honored for their efforts to create better futures for individuals with brain injury and their families.



*Photo credit Michelle Kellen*

## New York

The Brain Injury Association of New York State (BIANYS) was thrilled to host its Annual Conference in beautiful Saratoga Springs, N.Y. Professionals, caregivers, service providers, and brain injury survivors came from all over the state for the educational and inspirational event.

Award-winning author, artist, and brain injury survivor, Ashok Rajamani, took the stage as the

conference keynote speaker, moving everyone with his personal experiences. He discussed his near-fatal brain hemorrhage at the age of 25 that left him with permanent bisected blindness, epilepsy, distorted hearing, erratic transient amnesia, metal staples in his brain, and ultimately, a carved skull courtesy of open brain surgery. His resilience in recovery led him to author his first book, "The Day My Brain Exploded: A True Story," and become an advocate for others with brain injuries.

Additionally, three individuals were recognized for their efforts and impacts on New York's brain injury community in support of the organization's mission. Dina Pagnotta, PT, MPT, MPH, strategic initiatives, Rusk Rehabilitation, and co-chair of The Concussion Initiative, received the Marie Ivancich Memorial Award, Kara Moran, a three-time brain injury survivor and activist from Buffalo, received the Frank Pierce Champion Award, and Quantum Rehabilitation and Nursing received the Ted Weiss Consumer Advocacy Award.

## Ohio

In August, thanks to a grant from the Synthomer Foundation and a collaboration with Cleveland State University, the Brain Injury Association of Ohio (BIAOH) offered a three-day “NeuroSparks: Brain Injury Camp” for brain injury survivors who are two to three years post injury and have reached a general plateau of physical, mental, and emotional recovery. After meeting with survivors to identify needs, CSU professors and graduate students in areas including Speech and Language Therapy, Physical Therapy, and Occupational Therapy worked directly with each brain injury survivor and created individualized therapy plans to “spark” new skill development in an interactive, engaging, and positive way. Daily sessions were also offered for caregivers to help them learn more about local resources and connect with others.

Just a few weeks later in September, “Cere-bration: Walk, Roll & Run” events were held in Columbus, Akron, and Cleveland. Brain injury survivors, caregivers, family members, and friends gathered together to celebrate the courage of brain injury survivors and raise over \$20,000 for statewide



programs. As an extra bonus, Brutus the Buckeye, mascot for Ohio State University, surprised participants in Columbus to show his support!



## Pennsylvania

The Brain Injury Association of Pennsylvania (BIAPA) is thrilled to announce the return of its popular program, ReDiscover U! This innovative program offers individuals with brain injury the opportunity to develop new skills or rediscover past interests through engaging and supportive interactive information sessions, all while fostering social connection. ReDiscover U provides a wide range of inclusive and diverse educational opportunities. These classes are led by a team of staff and community members, ensuring participants receive valuable, enriching experiences. The program’s virtual format means it’s accessible to participants statewide, with classes held year-round on

Monday nights. All Pennsylvania based persons with brain injury are welcome to join. More information can be found at [biapa.org/programs/rediscoveru](http://biapa.org/programs/rediscoveru).

On August 29, BIAPA, the Fighting Back Scholarship Program and PGA Reach held their annual All Abilities Golf Clinic at Penn Oaks Golf Club. This year, 50 participants and volunteers came out to learn about the game and just have a good time. This year we also were thrilled to have the G.A.P Adaptive join us to feature the SoloRider and other equipment which helps make the game accessible to all. Thanks to our sponsors – ReMed: a Collage Rehabilitation Partner, Oliver Heating and Cooling, NJM Insurance, Penn Oaks Golf Club, and Geis Realty Group who have supported this event for years; to our Golf Professionals, Jesse Hallett, Doug Hendricks and Joel who provided excellent instruction to all of our participants; and to Joanne Finegan for her leadership and coordination! The clinic was a resounding success, with attendees enjoying the opportunity to connect, learn, and have fun. Everyone left with improved skills and a stronger sense of community—an unforgettable experience for all!



## South Carolina

The Brain Injury Association of South Carolina (BIASC) in collaboration with the South Carolina Brain Injury Leadership Council (SCBILC) hosted the annual Life with Brain Injury Conference in Columbia, S.C., on July 26 with 193 people in attendance. Our keynote speaker was Eric Washington who is a former football player for the University of Minnesota and for the University of Kansas. He shared his personal journey as a person with a spinal cord and brain injury who experienced homelessness and how he found his voice with his contribution of valuable expertise for The National Center on Advancing Person-Centered Practices and Systems (NCAPPS).

We continue to have great success with our Brain Injury Friendly Art Classes and Adapted Yoga Classes that are conducted online. During the September art class, participants painted poppies to honor those who serve or served in the military. We increased the number of yoga classes to twice a month to



emphasize the importance of mental and physical health through exercise. We will also offer the second Brain Injury Fundamentals class beginning in November to caregivers and professionals.



Dan Reeves

## Virginia

The Brain Injury Association of Virginia (BIAV) is excited to welcome Daniel Reeves as our new Executive Director! With his extensive 15 years of experience in key nonprofit roles, both internationally and within the United States, Dan is set to bring a wealth of knowledge to our team.

Thanks to the advocacy efforts of many, BIAV secured an additional \$223,000 in state funding, supplementing the approximately \$600,00 previously approved. This will enable us to enhance our services across Virginia. Over the summer, we continued to advocate at the state capitol for traumatic brain injury long-term care to be offered within our state.

Camp Bruce McCoy once again provided a joyful experience for campers and a respite for families and caregivers. Campers participated in various outdoor activities, socialized with peers, and celebrated with a lively end-of-week dance.

BIAV also received a grant from DARS to help us connect with underserved and unserved populations. This initiative strengthens our commitment to reaching more people impacted by brain injury, including domestic violence and encouraging them to seek help. Our messaging is expanding, and we are collaborating with more community members to share our messaging through strategic marketing. Additionally, our website is more accessible, with translation options and features designed to reduce language barriers and accommodate those with disabilities.

# CONCUSSION AWARENESS NOW NEWS



The Brain Injury Association of America is a co-chair of the Concussion Awareness Now coalition. Concussion Awareness Now includes a braintrust of partners, including organizations that determine guidelines for concussion care, advocate for patients, and work with communities that are vulnerable to concussions.

We are thrilled with the great participation in this year's National Concussion Awareness Day, which took place on September 20 this year. With the partnership of CAN coalition members and awareness champions, we work together to create a future where every person with a concussion receives the right diagnosis, the best possible care, and the resources and information they need.

This year's campaign theme asked champions and supporters to start the #ConcussionConversation in their communities and with their networks, friends, families and constituents, either online, offline, or both!

We had great participation and many #ConcussionConversations taking place! Be sure to visit the CAN social media channels (Facebook, Instagram, and LinkedIn) to learn more about the creative ways champions participated in the campaign.

## A few examples of the ways champions participated included:

- ▶ **Giving** #ConcussionConversation presentations in schools and community groups
- ▶ **Organizing** a concussion awareness event at hospitals and workplaces
- ▶ **Distributing** the #ConcussionConversation quiz at meetings, classrooms, and with family and friends
- ▶ **Sharing** CAN stickers with kids wearing helmets on the bike trail
- ▶ **Inviting** friends, family, and colleagues to sign up as a concussion awareness Champion
- ▶ **Sharing** statistics, myths, and facts about concussion on social media
- ▶ **Recording and sharing** a personalized awareness video

With the help of our supporters, we were able to welcome more than 2,500 new champions to our network. We also reached hundreds of people through our social media, website, and webinar activities.

We are thrilled with the results from our National Concussion Awareness Day campaign, and we are grateful for the support of our coalition partners and champions to make it a success!

We also know that raising awareness of concussions is a year-round job! If you want to continue the #ConcussionConversation, our resources are always available. Visit [concussionawarenessnow.org/spread-the-word](http://concussionawarenessnow.org/spread-the-word) to download our Awareness Toolkit.



# CONNECTING YOU TO THOSE WHO NEED YOUR EXPERTISE TODAY

The Brain Injury Association of America's Preferred Attorney Program connects individuals who have sustained brain injuries and their families to qualified attorneys experienced in personal injury, civil rights, and financial matters.

## WHY BECOME A BIAA PREFERRED ATTORNEY?

BIAA's Preferred Attorneys know how the carelessness of others can change lives in an instant. If you have demonstrated skill in representing brain injury victims, amassed the resources necessary to sustain a claim, and your reputation and standing in the legal, medical, and lay communities are stellar, you are eligible for inclusion in a select group of lawyers serving individuals with brain injury and their families.

## PROGRAM BENEFITS

- Your hyperlinked name and firm profile are prominently displayed in the Preferred Attorney database on BIAA's website. The site attracts more than 1.5 million visitors per year and boasts the best SEO ranking for brain injury information nationwide.
- Your profile page includes contact information and case history and presents the firm photograph and video. The online form allows potential clients to contact you directly.
- Your name and firm are listed as a resource in BIAA's National Brain Injury Information Center, a toll-free service connecting brain injury victims to experts every day.



## ABOUT THE BRAIN INJURY ASSOCIATION OF AMERICA

The Brain Injury Association of America (BIAA) is the nation's oldest and largest brain injury advocacy organization.

**CONTACT US**

[PREFERREDATTORNEY@BIAUSA.ORG](mailto:PREFERREDATTORNEY@BIAUSA.ORG)

# ADVOCACY UPDATES

## TBI Act Reauthorization Efforts Still Underway

The House of Representatives has passed H.R. 7208, the House bill representing the Dennis John Benigno Traumatic Brain Injury Program Reauthorization Act of 2024. H.R. 7208 reauthorizes critical federal funding for TBI research and services, and renames the program's national surveillance system and registry programs in honor of Rep. Bill Pascrell, Jr., founder and co-chair of the Congressional Brain Injury Task Force. The newly renamed "Bill Pascrell, Jr. National Program for Traumatic Brain Injury Surveillance and Registries" will continue to fund research, treatment initiatives, and data collection through key federal agencies, including the Centers for Disease Control and Prevention (CDC) and the Administration for Community Living.

In addition to extending the funding, H.R. 7208 directs the Department of Health and Human Services to study designating TBI as a chronic condition. The bill passed by the House also reduces the state match requirement for TBI state grants, expanding access to federal funding for states struggling to meet financial obligations to widen the reach of essential TBI services nationwide.

*As of press time, the TBI Act is with the Senate.*

## BIAA Holds Congressional Brain Injury Task Force Briefing



From left, Rick Willis, President and CEO of the Brain Injury Association of America; John Corrigan, PhD., National Research Director, BIAA; Page Melton Ivie, BIAA Board Chair; and David Harrington, BIAA Vice Chair, spoke during a Congressional briefing on Capitol Hill, where they educated members of Congress on the incidence of brain injury in the United States and the needs of the brain injury community.

**Scan the QR code to watch a recording of the briefing or visit [bit.ly/3Yr8Ji6](https://bit.ly/3Yr8Ji6).**



## Rep. Bill Pascrell Jr., Congressional Brain Injury Champion, Dies at 87

U.S. Rep. Bill Pascrell Jr. (D-N.J.), co-chair of the Congressional Brain Injury Task Force, passed away on August 21, 2024, at the age of 87.



"We are deeply saddened by the news that Rep. Pascrell has passed away," said Rick Willis, President and CEO of the Brain Injury Association of America (BIAA). "For decades, Rep. Pascrell has been a leader in advancing brain injury policy on Capitol Hill. He was a true ally to the brain injury community, and continuously helped our advocates push for greater access to care, expanded brain injury research and resources, and increased congressional awareness of important brain injury issues. BIAA will always be extremely grateful to Rep. Pascrell for his tireless support for the brain injury community. Our thoughts go out to his family, loved ones, and dedicated staff."

In 2001, Rep. Pascrell co-founded the Congressional Brain Injury Task Force and had served as co-chair since its inception. The Task Force works to increase awareness of brain injury in the United States, supports research initiatives for rehabilitation and potential cures, and strives to address the effects these injuries have on all Americans. Rep. Pascrell also championed funding for programs at the Department of Defense that go towards traumatic brain injury research and treatment, such as the Psychological Health and Traumatic Brain Injury Research Program, the Defense and Veterans Brain Injury Center, and the National Intrepid Center of Excellence. Most recently, Rep. Pascrell was the champion and House sponsor of the Dennis John Benigno Traumatic Brain Injury Program Reauthorization Act.

## Centers for Medicare and Medicaid Services Recognize TBI as a Chronic Health Condition

In a victory for the brain injury community, the Centers for Medicare and Medicaid Services (CMS) has recognized traumatic brain injury (TBI) as a chronic health condition.

CMS has added TBI to its list of chronic conditions for chronic special needs plans (C-SNPs) through its Medicare Advantage program effective for the January 2025 plan year. The Brain Injury Association of America (BIAA) will continue to fight to expand coverage for all types of brain injury with the ultimate goal of greater coverage across all forms of public and private insurance.

“We are thrilled that CMS agrees with our stance that brain injury is a chronic health condition, and has provided official recognition,” said Rick Willis, President and CEO of the Brain Injury Association of America. “This is an important first step in our fight to expand coverage for brain injury beyond acute care and helps us to make our case that brain injury should be treated by healthcare providers as a chronic condition like heart disease or diabetes.”

The addition of TBI to the list of chronic conditions was included in a rule published in the Federal Register earlier this year. Getting official recognition of TBI as a chronic condition from CMS is a significant step forward and provides validation that brain injury should be more broadly recognized as a chronic condition.

Earlier this year, BIAA published a position paper calling for CMS, along with the Centers for Disease Control and Prevention (CDC), to designate brain

injury as a chronic condition. Formal recognition, the paper states, has the potential to provide several advantages for people with brain injury, including the allocation of additional public health resources to focus on the lifelong effects of brain injury as well as health insurance plans, primarily Medicare and Medicaid, providing additional benefits and other supports as they do for other chronic health conditions. The greatest benefit, however, would be an increase in public awareness of the long-term effects of brain injury that affect the estimated 5 million Americans with a brain injury-related disability.

“When we talk about recognizing, treating, and covering brain injury as a chronic condition, that last piece of it is making sure there are resources there to continue providing support once a person with a brain injury leaves the acute care setting,” said Page Melton Ivie, Chair of the BIAA Board of Directors. “There is a lot of support in the hospital, but once you walk out the door, you’re on your own. We need to make sure we are continuing to support survivors and their families, because they are going to have a lot of needs that won’t be covered.”

BIAA is working to equip its affiliates and individual advocates with the tools they need to articulate how healthcare needs to change in order to reflect this recognition, including making sure that providers start treating TBI as a chronic condition.

In September, BIAA hosted a live Q&A session explaining what this designation means and outlining the next steps we can take to increase access to care. In case you missed it, scan the QR code or watch a recording on our YouTube channel: [youtube.com/@bia\\_usa](https://youtube.com/@bia_usa)

**Scan the QR Code to watch the Q&A Session**



## Save the Date: Brain Injury Awareness Day

**Mark your calendars:** Brain Injury Awareness Day 2025 will take place March 3-5, 2025, in Washington, D.C. Every year, BIAA hosts a Brain Injury Awareness Day on Capitol Hill during Brain Injury Awareness Month in March. This year, we are hosting a convention at the Hilton Arlington National Landing in Arlington, Va., where members of the brain injury community can come together to learn about brain injury, advocate for brain injury causes, and more! More information and registration for the event will be available soon. Sign up to receive updates at <https://www.biausa.org/brain-injury-awareness-day-2025#updates> or scan the QR code.



# 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 22-24, 2025

#### 2025 Neuro Rehab Leadership Summit: Elevating Business Practices

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The BIAA Neuro Rehab Leadership Summit is the premier national conference for executives and professionals in neuro rehabilitation. Network with your peers and attend sessions focused on industry trends, best practices, human resource management, and legislative topics.

Leaders from neuro rehabilitation programs, including 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. **Learn more at [biausa.org/summit](https://biausa.org/summit).**

### March 3-5, 2025

#### Save the Date: Brain Injury Awareness Day 2025

**HILTON ARLINGTON NATIONAL LANDING | ARLINGTON, VA**

Every year, BIAA hosts a Brain Injury Awareness Day on Capitol Hill during Brain Injury Awareness Month in March. This year, we are hosting a convention as well, where members of the brain injury community can come together to learn about brain injury, advocate for brain injury causes, and more. Scan the QR code and be the first to know when registration opens.



To learn more about Brain Injury Awareness Day 2025, scan the QR code or visit [biausa.org/brain-injury-awareness-day-2025](https://biausa.org/brain-injury-awareness-day-2025)

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[pknockstead@biausa.org](mailto:pknockstead@biausa.org) | 703-761-0750, ext. 640

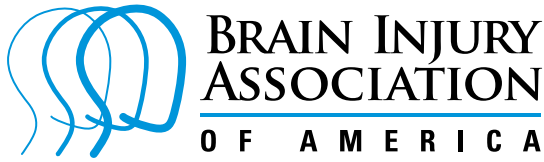
# Have you or a loved one had a brain injury?



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

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

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1-800-444-6443**



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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and education programs. BIAA is grateful to the Corporate Partners for their financial contributions and the many volunteer hours their companies devote to spreading help, hope, and healing nationwide.

For more information on how to become part of the Brain Injury Association of America Corporate Partners Program, please visit [biausa.org/corporate](http://biausa.org/corporate) or contact Peter Knockstead at (703) 761-0750, ext. 640, or email [pknockstead@biausa.org](mailto:pknockstead@biausa.org).

