



# Awareness AAdvocacy



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#### Greetings.

Every year, the Brain Injury Association of America leads the nation in recognizing Brain Injury Awareness Month in March, starting with our annual trip to Capitol Hill. These visits give the brain injury community face time with their Congressional



representatives and their staff as they advocate for federal funding and legislation that will improve the quality of life for people with brain injury. This year, we've decided to expand the program to include a national conference, featuring breakout sessions focused on how to tell your brain injury story, survivor meet and greets, a keynote address, a panel discussion, and an overview of this year's rallying point for our Capitol Hill meetings.

In years past, we've rallied for reauthorization of the Traumatic Brain Injury Act, funding the Centers for Disease Control and Prevention's TBI program and the TBI Model Systems of Care, and supporting legislation that would benefit the brain injury community. This year, we will be advocating for a National Plan of Action. This effort seeks to establish a comprehensive framework for improving outcomes for brain injury survivors through enhanced research, care, and community support. You can read more about the National Plan of Action on pages 4-5.

We're continuing our My Brain Injury Journey awareness campaign this year, encouraging people with lived experience to share their stories about their unique brain injury journeys. No two brain injury survivors will have the same experience, and every member of this community deserves to have their story heard. Brain injury survivors from across the country have shared their stories through our My Brain Injury Journey campaign, and we are looking forward to hearing more of your stories as the campaign continues.

It's been nearly 25 years since BIAA last conducted a public opinion survey about brain injury. In this poll, we explored public perception and knowledge of brain injury, people's experiences with injuries, and whether or not people have different views on brain injuries versus head injuries. I'm excited to announce that this year we will be sharing the findings of a new public opinion poll conducted by The Harris Poll, one of the longest running surveys in the U.S. that tracks public opinion, motivations, and social sentiments. We will have more information soon about the poll findings, which we'll be using to help our community tell our story to Congress, educate the public about the realities of living with brain injury, and promote awareness.

President and CEO Brain Injury Association of America

### **HARRIS POLL FINDINGS:** An Exclusive Preview



#### Brain Injury Association of America Publishes National Report on Public Perceptions of Brain Injury

By Lauren Moore, Marketing and Communications Manager, Brain Injury Association of America

The Brain Injury Association of America (BIAA) is excited to share our national report on the public perceptions of brain injury ahead of Brain Injury Awareness Month in March.

BIAA last conducted a public opinion poll in 2000, commissioning Harris Poll, one of the longest running surveys in the U.S. tracking public opinion, motivations, and social sentiments. This year, we are once again partnering with Harris to utilize original public opinion research to publish a national report on public perceptions around brain injury.

Through this report we'll better understand what people know about brain injury, identify the greatest knowledge gaps, and influence public discussion with data-backed evidence. A working group consisting of brain injury survivors, professionals working in brain injury and neurorehabilitation, and BIAA staff worked alongside Harris to develop the themes and questions for the survey.

Below are some of those themes and a few examples of what we'd like to know more about.

- Misconceptions about brain injury Do people know the signs and symptoms of a brain injury? What do people think are the leading causes of brain injury?
- Gender, racial, and ethnic disparities Are women or men more likely to seek care?
- Barrier to help/treatment Are people being asked about their history of brain injury by their primary care doctor? If someone is not seeking care after a head injury, what is the reason why?
- Invisible Disability Are people familiar with the term invisible disability? Do they consider brain injury an invisible disability?

In the coming weeks and throughout Brain Injury Awareness Month, BIAA will share the findings of the poll. You can view the National Report on the Public Perceptions of Brain Injury by visiting our awareness page on the BIAA website. Visit biausa.org/awareness to learn more.

To stay up to date on the latest news from BIAA, including our findings from our new poll, visit https://biausa.org/ ioin-our-community or scan the QR code.





#### BUILDING A NATIONAL PLAN OF ACTION

By Lauren Moore, Marketing and Communications Manager, Brain Injury Association of America

During the Brain Injury Association of America's (BIAA's) annual trip to Washington, D.C. in March, we will be launching a National Plan of Action – a groundbreaking effort to prioritize the voices, experiences, and needs of brain injury survivors. This ambitious plan seeks to establish a comprehensive framework for improving survivor outcomes through enhanced research, care, and community support.

These efforts follow in the footsteps of other groups that advocate for communities affected by chronic health conditions, explained Denver Supinger, BIAA's Director of Advocacy and Government Relations. "This is a needed step for the federal government to take brain injury seriously and put it on the national agenda. We have bipartisan support for brain injury and brain injury systems, and we believe this will be well-received by members of Congress," she said. "In coordination with our trusted partners, BIAA hopes to be a leading lobbying and federal voice

around this, to create spaces in which various agency heads and leaders can hear and see the concerning gaps in our brain injury community to further support the need for the plan."

The National Plan of Action calls for the creation of an advisory council of federal agencies, advocacy organizations, and people with lived experiences that would advise the Secretary of Health and Human Services on how to create a federal government structure that puts brain injury survivors first. Through this, the Secretary of HHS, in conjunction with their federal agency partners, would look at existing resources, cost, and barriers.

"Historically, we've advocated for the TBI Reauthorization Act, which funds programs in certain siloed agencies," Supinger explained. While federal organizations like the CDC, Administration for Community Living, Department of Defense, Veteran's Administration, National Institutes of Health, and Centers for Medicare and Medicaid Services, all touch the brain injury community, there's little linkage of data, on-the-ground experiences, and progression within these agencies. "The National Plan of Action hopes to thread all that we're doing across the nation into one space, so we can work in a more collaborative and effective manner," Supinger added.

### The National Plan of Action has several key components, including:

- Recognizing both traumatic and non-traumatic brain injuries that occur post-birth, reflecting the diverse experiences of survivors
- Pocusing on improving survivor care, access to resources, and the coordination of services across the country
- Including brain injury survivors and caregivers alongside medical experts to ensure survivor perspectives shape the plan's actions and recommendations
- Requiring annual evaluations of programs and outcomes, centering survivors' well-being and reducing financial and emotional burdens on families
- Collaboration among federal agencies in providing comprehensive data, enabling better care and policy decisions that directly benefit survivors
- 6 Ensuring the plan delivers measurable outcomes by 2030, prioritizing survivors' urgent needs

This effort places brain injury survivors at the heart of a coordinated national plan, addressing critical gaps in care, recovery, and support systems, and ensures survivors' voices and experiences guide research, policy, and services. It will be the core focus of our legislative ask on March 5, as attendees of the National Brain Injury Conference and Awareness Day meet with their representatives on Capitol Hill. The conference will include a session led by BIAA about what to expect during meetings with Congressional representatives and their staffers, as well as tips for making your message heard.

Supinger said that it's important for advocates to bring their passion and support for the National Plan of Action to their representatives' local offices. "You have a more intimate touch in your own backyard," she explained.

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In coordination with our trusted partners, BIAA hopes to be a leading lobbying and federal voice around this, to create spaces in which various agency heads and leaders can hear and see the concerning gaps in our brain injury community to further support the need for the plan.

DENVER SUPINGER

DIRECTOR OF ADVOCACY AND
GOVERNMENT RELATIONS, BIAA



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# THE BRAIN INJURY SURVIVOR'S GUIDE TO BRAIN INJURY AWARENESS DAY

By the Brain Injury Association of America's Brain Injury Advisory Council

Brain Injury Awareness Day is an event dedicated to anyone interested in brain injury. We gather on Capitol Hill, Washington, D.C., during Brain Injury Awareness Month each March to meet and discuss information about brain injury from across the United States. We learn from each other. To help new attendees get the most out of Brain Injury Awareness Day, the Advisory Council has put together some helpful tips based on their collective experience attending this event as brain injury survivors.

#### What to Expect During Brain Injury Awareness Day

Brain Injury Awareness Day on Capitol Hill is a crucial event for advocacy at the federal level. Attending this event is educational, empowering, validating, and rewarding; it could also be extremely challenging given the realities of living with brain injury. It can be an exhausting day for anyone. We have put together a few strategies that can make the day easier for you.

During Awareness Day there are sounds, lights, crowds, lines, and stress – a recipe for cognitive overstimulation. BIAA works hard to make this event as survivor-friendly as possible by advocating for a quiet room and other accommodations. However, logistics are incredibly difficult to arrange due to the volume of events on Capitol Hill, so nothing is guaranteed.

For those of us making the journey to Capitol Hill, here are a few tips on how we have made it through this event and managed our symptoms at the same time.



#### What to Pack

- Comfortable clothes! Yes, it is important to dress the part. However, know that it is a day of walking, standing, and being on your feet. Make sure you have a jacket or blazer in case the rooms are chilly, and bring comfortable footwear to change into if necessary. You'll also want to prepare for a variety of weather conditions (Washington, D.C. in March can be snowy, rainy, or unseasonably warm).
- Write/print out extra copies of your personal schedule.
- -Include room numbers where applicable
- -Map out where the buildings are ahead of time. Learning the layout of Capitol Hill is not a lastminute cram session.
- Map of Capitol Hill
- Cellphone charger
- ID for security lines
- Empty water bottle to fill inside of the Capitol building, as you are not permitted to bring in food and drink
- Personal ways to share your story with representatives, such as photos or written statements. Be succinct since time is of the essence.
- Thank you cards to write on the trip home while the appointments are still fresh in your memory. They are key to building relationships and reminding the elected official or legislative aide of key points that you discussed in your meeting.

#### **Tips for Representative Meetings**

- Maintain a high level of respect: When advocating for brain injury, remember that each member of Congress may disagree with you. Do not feel discouraged. They are there to help us, any disrespect has the potential to burn bridges and prevent future progress.
- Legislative aides are assigned to certain aspects of the elected official's job. Expect to get time with the aide, and then be thrilled to gain time with the actual congressperson.
- You do not have to be an expert to conduct meetings. Just talk about your experiences and what

- you know. This educates representatives and makes a difference. Your story matters and there is no need to be intimidated.
- BIAA creates packets of information called issue briefs to drop off with the Congressperson. These are talking points to start your advocacy conversation. You can pick up these packets at the BIAA table during the event or print them off on the BIAA site beforehand.
- It is critical to ask for accommodations if you need them. For example, delegation meetings are occasionally held in the hallways, but you can request to meet inside of an office space, so a seat can be made available.
- Consider opening each meeting by asking if the representative is personally connected to anyone living with a brain injury.

#### **What to Say During Congressional Meetings**

- Begin with a personal story explaining how you are connected to brain injury. Although this can be challenging for those of us who are long-winded, try to keep it relatively brief (2-3 minutes.)
   We recommend practicing ahead of time.
- Ask your representative if he or she has a personal connection with brain injury.
- Ask your representative if he or she is willing to join the Brain Injury Task Force
- Tell the person you're meeting with what you need to live life better. Try to be specific and keep it short.

#### **Additional Things to Keep in Mind**

- Anticipate lines at building entrances.
- Restrooms and courtyards work as handy chill out spaces on the go since they contain less noise.
- On the back of each business card you receive, write down the date and any personal notes to help remind yourself of that interaction. Be specific when making notes, the more detail in the moment will last a lifetime.
- Take breaks throughout the day.
- It is easy to get lost in these buildings, so stay aware of your time and surroundings.

Survivors' voices are powerful, and they are necessary. However, we must prioritize our own health as best we can. If you feel you cannot attend the in-person event, there are many ways to advocate on this day, and every day. Of course, we do not need to travel to Washington D.C. to have our voices heard. Social platforms are a great way to let your voice be heard. Calling and writing your representatives is also effective. The Advisory Council wishes you a safe and rewarding experience on National Brain Injury Awareness Day.

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#### CONCUSSION NOW 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.

In December, we were thrilled to acknowledge the milestone of Concussion Awareness Now's second anniversary. In our second year of CAN, we built upon the great foundation of the coalition's launch in 2022 in order to expand our reach to additional CAN champions and healthcare professionals.

In 2024, CAN reached thousands of people, providing them with valuable information about concussions and the importance of seeking an accurate diagnosis and effective care. We also worked hard to generate greater awareness about concussions with healthcare professionals and provide them with the tools and evidence-based resources that provide information about every stage of a concussion patient's journey.

We led a robust campaign in recognition of National Concussion Awareness Day, held September 20, 2024. We had more than 1,300 people register for our Campaign Kickoff and Champion rally webinars, gained more than 1,100 new followers on our social platforms, and launched several new resources for our CAN Champions.



We are grateful to our concussion advocates, especially Dr. Brooke Mills, founder of National Concussion Awareness Day; Cazoshay Marie, disability advocate, influencer, and content creator; and Julie Kobak and Erin Bain of Thiel College, for amplifying our awareness efforts and presenting at our webinars. We'd also like to give special thanks to all of the CAN champions who hosted events, provided presentations, distributed stickers, and used CAN awareness tools to start the #ConcussionConversation! We are also deeply grateful to our coalition partners for helping us to share our message and resources with consumer and professional audiences alike.

This year, we are excited to launch our Organization Champions program during Brain Injury Awareness Month. Scan the QR code or visit **concussionawarenessnow.org/join-our-cause** to sign up for our newsletter and learn more about this exciting new initiative!



Use this sign to help share your story about your brain injury journey. Feel free to tear this sign out of the magazine, use a few words to describe your brain injury journey, and share a selfie of you holding up your sign! If you share your selfie on social media, be sure to tag BIAA in your post, reel, or story, and use the hashtag #MyBrainInjuryJourney.









## Your brain injury journey can inspire hope and raise awarness.

Join us in saying, 'I'm a voice for Brain Injury' this Brain Injury Awareness Month by starting a fundraiser.

#### It's easy to get involved:

- 1. Set up your personal fundraising page in just a few minutes.
- 2. Share your story what makes you a voice for brain injury?
- 3. Spread the word through social media, email, or even a community event.



Visit <u>biausa.org/voice</u> or scan the QR code to start your Brain Injury Awareness Month fundraiser.



Fundraisers
who raise
\$100 or more
will receive
an exclusive
brain injury
awareness
t-shirt!



# 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:

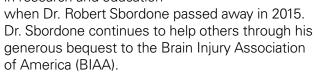
- Retaining control and use of your assets during your lifetime
- The ability to modify your bequest if your circumstances change
- Tax exemptions as gifts to BIAA from your estate are exempt from federal estate taxes

#### 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



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

Learn more by contacting the development department at <a href="development@biausa.org">development@biausa.org</a>
or 703-761-0750 ext. 645 or visiting <a href="mailto:biausa.org/futuresfund">biausa.org/futuresfund</a>.

\*\*\*\*GHALLENGE! | 11



**NOVEMBER 15. 2024** 

The Brain Injury Association of America (BIAA) held our inaugural Luminary of the Year celebration on November 15, 2024, during which 250 members of the brain injury community came together to honor Marilyn Price Spivack, BIAA's co-founder and first-ever Luminary of the Year honoree.



From left, David Storto, Storto Healthcare Strategies; Rick Willis, President and CEO of the Brain Injury Association of America; Luminary of the Year honoree Marilyn Price Spivack; Dr. Greg O'Shanick, Medical Director-Emeritus of the Brain Injury Association of America and President and Medical Director of the Center for Neurorehabilitation Services; and Dr. Nathan Zasler, Founder, CEO, and Medical Director of the Concussion Care Center of Virginia, Founder and Medical Director of Tree of Life, and Emeritus Chair of the International Brain Injury Association

The event, held at the National Press Club in Washington, D.C., raised more than \$460,000 to benefit the Brain Injury Association of America's programs, research initiatives, and advocacy efforts. It was also an opportunity for the community to celebrate Marilyn, who was described by Dr. Mel B. Glenn of the Spaulding Rehabilitation Hospital and Harvard Medical School as "the most influential person in the history of brain injury rehabilitation.

#### A Letter from our Inaugural Luminary of the Year

I was so humbled and incredibly honored to be chosen to be the Brain Injury Association of America's Inaugural Luminary of the Year awardee.

The evening was a joyous reunion for those of us who have dedicated ourselves to making a difference in the lives of people with brain injury. Many of the attendees were pioneers and creators of the numerous accomplishments in the early years, all of whom became dear friends and amazing supporters whenever I made a request of them which was often!

For those who could not attend, a sincere thank you for your donations and support. In particular, to those who could not be in attendance due to age or illness, and for those who have passed away: you are never forgotten. They taught and mentored those of us who are still here. and if you have heard them lecture or read their work, then count yourselves fortunate. They were generous to me and to our community's efforts. They helped give credence and support to a fledgling organization as they recognized its value in the long run.

My only regret is that Martin L. Spivack, MD, PhD – Marty, my husband, soulmate, and partner – and my daughter, Deborah Lee Price, who inspired the brain injury movement, were not there to share that evening.

To the rest of my family: I am forever grateful that you were there to share in my honor and my joy.



Deborah Lee Price and Martin L. Spivack

I would be remiss if I didn't call out two events from this year that have made me incredibly happy: one, that BIAA and the US Brain Injury Alliance have come back together again as one voice, and that the Center for Medicare and Medicaid Services has announced that traumatic brain injury is being recognized as a chronic health condition. These are amazing accomplishments for the brain injury community.

My best to all, Marilyn

#### THANK YOU TO OUR **FUNDRAISING CHAMPIONS**

In our inaugural year, we had 20 Fundraising Champions from around the country take an extra step to support the mission of the Brain Injury Association of America. They hosted fundraising cocktail parties, held art and jewelry sales around the country, asked their friends and family for support, and shared their stories online in their social networks. Thank you to this incredible group for setting and accomplishing big goals. Collectively, they raised more than \$40,000.

#### FUNDRAISING CHAMPIONS

Susan Boles	
Danielle Brazan	
Eric Ganci	
Jennifer Guillory	
Kaitlin Hinzman	
Natalie Holcroft	

Katherine Kimes

Amy Kemp Adam Massey Maryam Mohit Katie Montovan Florence Murray Joseph Poduslo Dani Rosenblad James Deanna Savage Ashley Scanlan Scott Shields Mark Steinhubl Kristy Tenbus Erica Walker



Mark Steinhubl of Waxahatchie, Texas, was our top Fundraising Champion this year.



Danielle Brazant of Marion, Iowa was one of our top Fundraising Champions

Joseph Poduslo of Washington, D.C.,

one of our top Fundraising Champions



Scott Shields of Arlington, Virginia was one of our top Fundraising Champions

#### THANK YOU TO OUR SPONSORS

#### **GOLD**

Centre for Neuro Skills NeuroRestorative

#### **SILVER**

**Encompass Health** Rehabilitation Hospital of Braintree The Family of Robert Melton Save Our Air Medical Resources

Abbott Aretech **Bioness** 

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**Partners** 

Chaikin, Sherman, Cammarata & The Cohen Family

Community Works, INC and Minds Matter, LLC

> Concussion Care Centre of Virginia

Craig Hospital De Caro and Kaplen, LLP

**BRONZE** 

Joanne Finegan and Dr. Eli DeHope Friends and Colleagues

of Marilyn Hinds' Feet Farm

Hope Network Neuro Collage Rehabilitation Rehabilitation

Cindy Ivanhoe and Flora Hammond

The Ohio State University

On With Life

Paradigm

Owen Perlman, MD RT Specialty

Rusk Rehabilitation

The Spivack Family

**David Storto and** Shelley Mogil

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For more information on the Luminary of the Year Fundraising Champions, or to learn how to nominate someone or self-nominate for 2025, contact Paula Eichholz, Senior Director of Development, at peichholz@biausa.org or 703-761-0750, ext. 648.

#### STATE **AFFILIATE** NEWS

#### Colorado

The Brain Injury Association of Colorado will host the Leading the Way Brain Injury Conference in March in Arvada, Colo. The Leading the Way Brain Injury Conference is designed for professionals working with survivors of brain injury. The conference will address the intersections between brain injury, mental health, homelessness, legal involvement, employment, and military service, featuring speakers who are Leading the Way as experts in these fields. Attendees will leave with tangible knowledge on how to support survivors experiencing these challenges. The conference includes six CE, breakfast, lunch, and networking happy hour. Registration is now open at www.biacolorado.org/conferences.



#### Delaware

On December 11, the Brain Injury Association of Delaware marked the transformative milestone of making the official transition to becoming the Brain Injury Association of America – Delaware Chapter (BIAA-Delaware Chapter).

For over 40 years, BIAA has been a steadfast national voice for brain injury survivors, caregivers, and professionals. By joining this dynamic national network, we are unlocking new opportunities to deliver expanded resources and programs to support Delaware's brain injury community; advocate with greater impact, influencing policies and services both locally and nationally; and amplify our collective voice in vital discussions shaping the future for survivors and their families.



This exciting new chapter was celebrated at the Dover Public Library, where an inspiring gathering of survivors, caregivers, community stakeholders, and board members came together. Special guests Rick Willis and Paula Eichholz from BIAA shared valuable insights about the vision for the Delaware Chapter and explored ways our community can unite to build a stronger, more impactful network.

We are energized by this alignment and the promise it holds for Delaware's brain injury community. Together, we're stepping into a future of greater support, advocacy, and connection.



#### **Rehab Without Walls**

Working together to provide the Neuro Care Continuum





#### **RESIDENTIAL-DAY NEURO THERAPY**

After a neurological injury or diagnosis, some patients aren't able to go home. Our patients are immersed in resources focused on maximizing physical, mental, and social potential. Each day begins with a specially formulated, individualized, plan for success. Let us be the home away from home on the path back to independence.

#### **Residential Services and Amenities**

(varies by location)

- 24-Hour Personal Care
- Physical, Occupational, Speech Therapies
- Cognitive Therapy
- Educational Programming
- Daily outings and activities focused on development of neurological skills
- Comprehensive DME and HME Assessment
- Barrier-Free Room and Board
- Counseling and Mentorship
- Community Outings
- Medical Director
- Nursing Services

#### **Day Neuro Services and Amenities**

- Transportation to and from the center
- Physical, Occupational, Speech Therapies
- Cognitive Therapy
- Educational Programming
- Daily outings and activities focused on development of neurological skills
- Comprehensive DME and HME Assessment
- Drivers Re-Education (in select locations)



#### **HOME AND COMMUNITY NEURO THERAPY**

Our home and community neuro rehabilitation is a CARF accredited program that builds a therapy program around our patients, moving individuals outside the walls of institutional settings and into their natural home and community environment through a continuum of care.

Home and community neuro therapy is appropriate for both adult and pediatric patients who need an interdisciplinary team, including:

- Physical, Occupational, Speech, Recreational Therapies, Care Coordination
- Have suffered a recent medical event resulting in a complex injury
- Need complex problem solving related to home accessibility or a desired return to community level participation
- Have pain or endurance limitations that make travel to therapy difficult

By providing care in the home, community, workplace, or school, RWW promotes greater health through the recovery process, all with industry-leading outcomes that dramatically improve functional skills and independence for patients.



#### **OUTPATIENT NEURO THERAPY**

Rehab Without Walls provides specialized, interdisciplinary and outcome-based care in both one-on-one sessions and group settings. We want to help you achieve a personal level of independence and success through design, access, therapies, and resources.

To achieve the best results for each patient, we create an intensive, customized therapy plan that addresses their unique medical. physical, cognitive, psychosocial, and educational needs.

Our outpatient clinics are equipped with state-of-the-art equipment and open gyms, where patients can practice everyday living skills.

#### Services

- Speech Therapy
- Physical Therapy
- Occupational Therapy

**Contact us for more information p)** 844.243.4998

RehabWithoutWalls.com



#### Indiana

The Brain Injury Association of Indiana (BIAI) has had a busy few months! We held our third annual BIAI Wiffleball Tournament on October 28, and are thrilled to report that this year was our biggest tournament yet. We had 10 teams made up of survivors, family members, and professionals batting and running the bases to raise money and awareness for brain injury. We had incredible, fun-filled activities, costume contests, vendor tables, and food, as well as an amazing silent auction. We are so grateful to all of our

attendees and very generous sponsors who made our event the best wiffleball tournament yet. We are already in the planning stages for our 2025 Wiffleball Tournament so stay tuned for more information.

We are working on the details for our next "Stride with a Specialist" event to be held in March in correlation with Brain Injury Awareness Month. The BIAI "Stride with a Specialist" series and related happenings are intended to promote brain health and wellness by having a specialist speak on a topic related to maximizing our brain while we walk/jog/roll together as a community. Be on the lookout for upcoming details on our March meet-up.

Our next "Brain Blitz" video will be on the topic of internet safety. This specific video will be a primer for a live interactive one-hour webinar to come in 2025. Our Brain Blitz series is made up of videos with various people speaking about important topics and providing information about resources both locally and nationally. Visit biaindiana.org/brain-blitz/ to see what we have so far in our library.

BIAI is also looking forward to attending the National Brain Injury Conference and Awareness Day in Washington. We will meet with our Indiana legislators to bring them brain injury awareness and education and advocate for continued and additional funding, services and supports both locally and nationally.

#### Missouri

The Brain Injury Association of Missouri (BIA-MO) 20th Annual Statewide Conference was held on November 7 and 8. It was a great way for professionals to connect with other colleagues and gain information to improve outcomes for their patients, clients, and consumers. Session topics included Better Living Through Brain Stimulation, Vocational Rehabilitation Research within the NIDILRRTBI Model Systems, Missouri Brain Injury Resource Facilitation, Guide to Becoming an Effective Advocate for Policy Change, Pushing Through Recovery Survivor Panel, and more.

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

On December 3, BIA-MO participated in Giving Tuesday, raising nearly \$1,500. This Global Day of Giving was a great way to highlight charitable giving during the holiday season and make a difference for survivors and families living with brain injury.

#### New Hampshire

The Brain Injury Association of New Hampshire (BIANH) held its 18th annual Coalition of Caregivers Conference on November 13. Keynote speaker Susan McKeown, APRN(Ret), CPS, MFA,



spoke on the topic "Introducing the Balance Wheel and Determining What Areas of Life Might Need Some Attention."

BIANH is saddened to share the news about the passing of John Richards. John was well-known in the brain injury community, and dedicated his life and work to improving the lives of others, especially those with brain injuries, disabilities, and chronic illness. John was a board member for BIANH for over 30 years. He held the position of president for the Board, served as president of Residential Resources, Inc., and also served as Executive Director for the Governor's Commission on Disability in the state. John was very active in facilitating and working with various support groups for the Association. A tireless advocate for persons living with brain injury, John will be sorely missed by all of us.

#### Iowa

2024 kept the Brain Injury Alliance of Iowa (BIAIA) busy as our organization provided personalized assistance to more than 1,200 individuals and families through the Brain Injury Resource Facilitation program; provided training and educational opportunities to more than 500 individuals that experience brain injury, caregivers/ family members, and professionals across the state; and continued to work to expand our outreach to under and unserved populations with a pilot program engaging with child welfare.

In 2025, lowa will launch a campaign to re-join the Brain Injury Association of America as an affiliate to continue on the-plus years spent working to serve lowans with brain injury, their families, caregivers and the professionals engaging with them. In addition, BIAIA looks forward to our 33rd annual conference in March and invite you to consider attending or sharing the event link: https://bit.ly/4j6MSpC

#### Maine

On Thursday, March 20, the Brain Injury Association of Maine (BIAA-ME) will host the 2025 BIAA-ME Brain Injury Resource Fair at the Augusta Armory in Augusta, Maine. The resource fair is BIAA-ME's big event for Brain Injury Awareness Month, and it provides an opportunity for Maine's brain injury community to gather and explore resources and supports.

BIAA-ME continues a pilot project to increase capacity to support individuals with co-occurring brain injury, mental health, and substance use disorder challenges in Maine. Through this project, BIAA-ME continues to work 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 and link those who may benefit from additional resources and services with NeuroResource Facilitation services for additional support. This project is being completed in collaboration with the Maine Office of Aging & Disability Services under the Administration for Community Living grant awarded to Maine.

#### **New York**

The Brain Injury Association of New York State (BIANYS) has teamed up with the New York State Athletic Trainers' Association to help further concussion education and prevention. The program, called COPE (Concussion Outreach Prevention Education), includes in-person sessions and online educational modules. COPE programs are offered at no cost and supported by funding provided by the New York State Department of Health, in collaboration with the New York State Senate.

Sessions are open to anyone engaged with student athletes – parents, athletic trainers, school administrators, educators, nurses, coaches, and youth sports organizations. In each session, attendees learn about the symptoms and management of concussions, crucial insights into recognizing and treating this common head injury, essential information on preventing concussions, updated guidelines for returning to sport after a concussion, and strategies for a successful return to academics following a concussion.



In addition, BIANYS also offers COPE Modules: free, online learning opportunities presented by renowned concussion expert and Medical Director of the University at Buffalo Concussion Management Clinic Dr. John Leddy. Through the recorded, on-demand modules, Dr. Leddy will provide the latest evidence-based information and strategies for assessing and managing concussion patients. Continuing education credits are included with each of these free modules.

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#### Pennsylvania

The Brain Injury Association of Pennsylvania (BIAPA) Conference Planning Committee is excited to announce that the 2025 Annual Conference will take place June 30-July 1 at the Lancaster Marriott at Penn Square in Lancaster, Pa. This year's theme, "Celebrating an Empowered Brain Injury Community: A Conference for Survivors, Care Partners, and Professionals," reflects our commitment to fostering connection and growth. We are pleased to, once again, offer a limited number of full conference scholarships to eligible caregivers and survivors.

This year's keynote address, "How to Navigate Life After a Brain Injury," will be delivered by Jennifer Lynn Robinson, Esq. A former litigation attorney, Jennifer's life took a transformative turn following her traumatic brain injury. Today, she is a sought-after professional speaker, communications expert, and TEDx presenter. Her TED Talk can be viewed at ted.com/talks/jennifer\_lynn\_robinson\_from\_fighting\_for\_breath\_to\_fighting\_for\_life.

For the latest updates on the conference or to elarn about scholarship opportunities, visit biapa.org/2025conference.

On October 7, advocates gathered at the Pennsylvania State Capitol for a powerful day of brain injury advocacy, focusing on House Bill 1682 and Senate Bill 1094. These bills aim to secure access to Post-Acute NeuroRehabilitation, including Cognitive Rehabilitation Therapy (CRT), through commercial insurance. The Brain Injury Association participates in advocacy efforts on behalf of the brain injury community by participating in the Brain Injury Coalition and serving in an advisory capacity on policy issues. It was a successful and enriching day for all who made the trip to Harrisburg!









#### South Carolina

The Brain Injury Association of South Carolina (BIASC) started the new year off in a physical office located in the state's capital city of Columbia. Since the pandemic, staff have been working remotely so we are excited to be in an office again. The address is 4400 St. Andrews Road, Ste. E, Columbia, SC 29210.

During Brain Injury Awareness month, BIASC will be collaborating with the South Carolina Department of Disabilities and Special Needs (SCDDSN), Head and Spinal Cord Injury Division (HASCI), on a community project called "Headstrong Hits." SCDDSN is the state's lead agency on TBI. Headstrong Hits will be an inspiring soundtrack curated by brain injury survivors, each song symbolizing a unique aspect of their recovery journey. From moments of struggle to breakthroughs of resilience, this soundtrack will represent the healing power of music and the strength of the human spirit. Every track will reflect

the personal experiences, emotions, and triumphs of those who have faced and overcome life-altering challenges. Headstrong Hits won't be just a playlist, but a reminder that you're not alone.

We will again host the Statewide Walk, Run and Roll during Brain Injury Awareness month. The event will be held March 23-29 with a kickoff event on March 23 at the Riverwalk in Columbia.











#### Every Hour, Every Day, CNS is Redefining Rehabilitation

For more than 40 years, Centre for Neuro Skills has established itself as a renowned leader in intensive post-acute community-based brain injury rehabilitation. With clinics in California and Texas, our expert teams of highly-trained, CBIS-certified staff provide outcomedriven medical treatment, therapeutic rehabilitation, and disease management services for individuals recovering from acquired and traumatic brain injury.

Independence is our Goal. Lifelong Recovery is our Legacy. For more information visit neuroskills.com or call 800.922.4994.



# THE ROAD TO REDISCOVERY: MY JOURNEY AFTER A BRAIN INJURY

By Anthony Falsone

If I had to summarize my brain injury journey in one word, it would be "Resilience." Over the past year, I've faced profound changes to my physical, cognitive, and professional life, yet I continue to adapt and push forward, learning to navigate a reality I never expected.

On February 22, 2023, my life was irrevocably altered by a car accident. Initially, I thought my injuries were minor, but as time passed, the true extent of the damage revealed itself. Now, over a year later, the lingering effects have become part of my daily life.

#### **Physical Challenges**

The physical pain has been one of the most consistent reminders of my accident. I deal with neck pain every day. It's not just discomfort—the cracking sounds from my neck are a near-constant companion. I've also developed neuropathy. My hands are numb most days, and now my shoulders have joined in, often causing pain three out of seven days a week. On those days, the shoulder pain surpasses the numbness in my hands.

Headaches come and go, but the tinnitus in my left ear never leaves. The persistent ringing is exhausting, a constant soundtrack to my life that I've yet to learn how to tune out.

#### **Cognitive Struggles**

Beyond the physical, the cognitive challenges are equally significant. I find myself forgetting things more often. Despite using multiple lists to stay organized, tasks slip through the cracks. This has been particularly frustrating, as I used to pride myself on being efficient and detail-oriented.

Communication has also become more challenging. I often struggle to convey my thoughts and feelings clearly. This is one of the reasons I'm writing this story — to organize my thoughts and reflect on my journey. I believe these issues stem from the concussion I sustained in the accident, and while I'm working on strategies to improve, it's a slow process.

#### **Professional Shift**

Before the accident, I was an enterprise sales executive with a \$24 million yearly quota, earning a six-figure income. My work was demanding but rewarding, and I thrived under the pressure. Today, my career looks completely different.

I now juggle multiple part-time jobs. Most involve driving: one for Uber and Lyft, which I've adapted to easily thanks to GPS, and another driving for a crematory, where I transport urns and deceased individuals. It's a far cry from my previous life, but it's work I can manage.

I've also taken on a commission-based sales role, but I haven't made a sale in months. It's disheartening but not surprising given the cognitive challenges I'm facing. Still, I'm holding onto hope that this role may grow into something more sustainable.

#### Lessons Learned and Advice

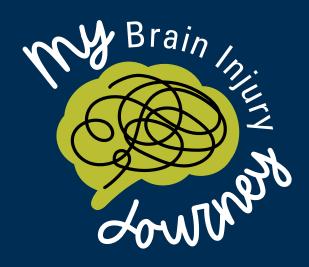
If I could go back to the immediate aftermath of my accident, I would've sought out more specialized care sooner. Understanding brain injuries and their long-term effects would've prepared me better for the journey ahead. For anyone newly experiencing a brain injury, my advice is to be patient with yourself. Recovery isn't linear, and it's important to celebrate small victories along the way.

Also, I would avoid screens! Phones, PCs, TVs, etc. Seek quiet and read often. The most important thing I've learned and would like to share is to avoid multitasking at all costs!! My own research and testing has proved (to me at least) that focusing on one task at a time aids cognition, retention and overall satisfaction.

One common misconception I've encountered is that people assume I'm "fine" because I look the same. Brain injuries are invisible, but their impact is profound. Educating others about this has been both a challenge and a necessity.

#### **Moving Forward**

While my life has changed dramatically, I'm learning to embrace this new version of myself. The road ahead is uncertain, but I'm determined to keep moving forward, one step at a time. Resilience has defined my journey so far, and it will continue to guide me as I rebuild and rediscover my life after a brain injury.



#### **SHARE YOUR STORY**

Add your voice to the hundreds of brain injury survivors who have shared their stories about their brain injury journeys. Visit biausa.org/ personal-stories or scan the QR code to submit your story to BIAA. We are always looking to amplify stories from brain injury survivors on our social media channels and in THE Challenge!



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### Let's Stay in Touch



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

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



biausa.org/connect

#### **EVENTS AND WEBINARS**

APRIL 3, 2025, 3 P.M. ET

Social Security Benefits Overview TRISHA MENTZER

This Carolyn Rocchio Caregivers webinar will cover eligibility for Social Security benefits, how to file for benefits, disability and survivor benefits, Medicare, and the future of Social Security. Session objectives include explaining the eligibility and entitlement factors for Social Security benefits, including the difference between Social Security Disability (SSDI) and Supplemental Security Income (SSI); describing the application process for Social Security benefits; and discussing the online services available and the future of Social Security. This webinar is available free of charge.

Register at shop.biausa.org/products/livewebinars.

#### APRIL 10, 2025, 3 P.M. ET

Won't You Be My Neighbor? How Neighborhood Factors Affect Life After Traumatic Brain Injury RAJ G. KUMAR, PH.D., AND SHANNON B. JUENGST, PH.D., CRC

Drs Kumar and Juengst will discuss how environmental factors, specifically characteristics of a person's neighborhood, affect outcomes after TBI. They will highlight findings from a forthcoming issue of the Journal of Head Trauma Rehabilitation on this topic and discuss how attending to these environmental factors is essential to considering TBI through the lends of a social model rather than a medical model - of disability.

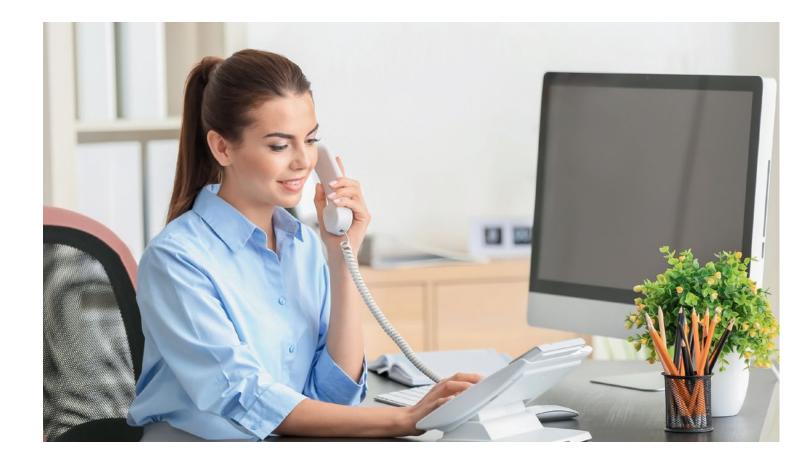
Register at shop.biausa.org/products/livewebinars.

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National Brain Injury Information Center	23

**Interested in advertising in THE Challenge?** 

Contact Peter Knockstead, Director of Corporate Partnerships 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 guestions about treatment and rehabilitation options, coping with changes in personality or physical capabilities, access to counseling or legal assistance, and so much more.

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

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



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



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

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







