

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 19, Issue 2

# THE CHALLENGE!



# BRAIN INJURY

## *at every age*

PAGE 3

Embracing  
the Journey

PAGE 6

Stroke Risk  
on the Rise

PAGE 8

Brain Injury  
Awareness  
Day Recap

PAGE 14

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Please recycle this issue.

## TABLE OF CONTENTS

|   |           |
|---|-----------|
| Brain Injury at Every Age                                     | <b>3</b>  |
| Embracing the Journey:<br>Parenting a Child with Brain Injury | <b>6</b>  |
| Stroke Risk on the Rise                                       | <b>8</b>  |
| Concussion Awareness Now News                                 | <b>11</b> |
| Donor Profile   | <b>13</b> |
| Brain Injury Awareness Day Recap                              | <b>14</b> |
| Affiliate News  | <b>16</b> |
| Event Calendar  | <b>22</b> |

Greetings,

As I'm writing this letter, the Brain Injury Association of America and our advocates are mobilizing to protect funding for federal brain injury programs. A document with proposed budget priorities for the Department of Health and Human Services, which plays a central role in delivering programs, research, and services that support the brain injury community, reflects devastating cuts to key brain injury and disability programs. Among the casualties would be all traumatic brain injury (TBI) initiatives under the Centers for Disease Control and Prevention, including the HEADS UP Concussion Education and Prevention Program, the Core State Injury Prevention Program, and the National Concussion Surveillance System.



In addition, the proposal calls for the dissolution of the Administration for Community Living, with its programs reassigned across HHS. Most concerning is the complete elimination of the National Institute on Disability, Independent Living, and Rehabilitation Research, the federal government's primary engine for rehabilitation science, innovation, and independent living research. This includes the elimination of all 16 TBI Model Systems, which serve as national centers of excellence for rehabilitation and long-term outcome tracking.

Right now, the document is only a proposal. BIAA is pushing for a meeting with HHS Secretary Kennedy with the goal of preserving these programs, and working with our allies on Capitol Hill, including the Co-Chairs of the Congressional Brain Injury Task Force, to secure bipartisan support for brain injury programs.

The theme of this issue is Brain Injury at Every Age, and these brain injury programs support, protect, and benefit people of all ages – not only those who are currently living with brain injury, but those who may sustain one in the future. HEADS UP is a cornerstone of concussion education. Eliminating this program would strip thousands of communities of the only national concussion guidance for youth. The National Concussion Surveillance System is the only ongoing federal system tracking the incidence of concussion and brain injury across age groups, and guides policy, research, clinical protocols, and local resource allocation. The TBI Model Systems are conducting the nation's only long-term studies on moderate to severe TBI outcomes, providing us with critical recovery metrics and insights into the chronic nature of brain injury.

Brain injury doesn't always have an end date. Some people live with lingering effects for years, if not the rest of their lives. We know this news is deeply concerning, but please be assured: we are mobilizing the full power of BIAA's advocacy network to educate congressional leaders, fight for the programs that support brain injury through every stage of life, and preserve the federal commitment to brain injury care and recovery.

Sincerely,

Rick Willis, President and CEO  
Brain Injury Association of America

# BRAIN INJURY *at every age*

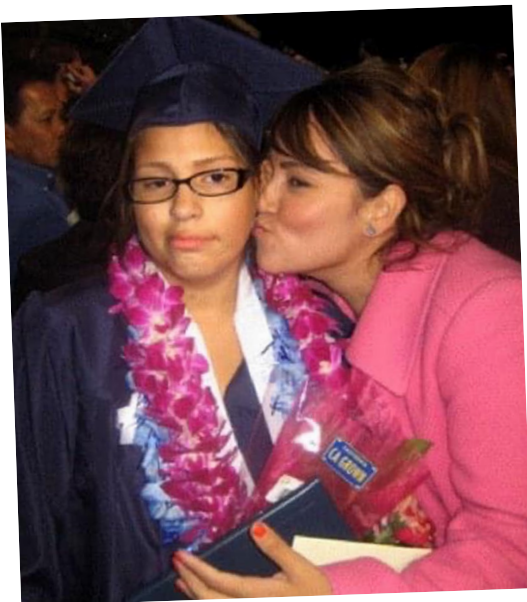
By Kylie Chang, Media Coordinator,  
Centre for Neuro Skills

While some health conditions are more common within a specific age bracket, brain injuries can happen to anyone – children and teens, young adults in college, middle-aged parents, or the elderly. The Centre for Neuro Skills, a network of neurorehabilitation clinics in California and Texas, has treated brain injury patients of all ages since its founding in 1980. Meet just a few of the resilient CNS patients who sustained brain injuries at different points in their lives.

## Sabrina Schiermeyer

**AGE AT TIME OF INJURY: 10**

**INJURY: Medulloblastoma**  
(cancerous brain tumor)



## Sabrina's Journey:

In fourth grade, Sabrina suffered from headaches, dizziness, and nausea and the school nurse would call her mother every week. After several tests, Sabrina was diagnosed with a cancerous tumor in the cerebellum at the age of 10. Sabrina underwent two brain surgeries and extensive chemotherapy and radiation.

After her brain surgeries, Sabrina suffered left-side paralysis on her face, arm, hand, and leg. Through intensive physical therapy and cognitive rehabilitation, Sabrina relearned how to walk, returned to her studies, and strengthened the left side of her body.

Sabrina went on to graduate high school along with her peers, obtained an associate degree in social work, and has a full-time job. Now 20 years out from her initial diagnosis, Sabrina recently took a solo cruise in celebration of her 30th birthday, as well as commemorating her life of independence after the obstacles she faced as a result of her illness and brain injury.





## Emily Silver Owen

**AGE AT TIME OF INJURY: 22**

**INJURY: Traumatic Brain Injury (TBI)**

### Emily's Journey:

Emily was in her last semester of college when she was hit by a drunk driver during an evening walk with her dog, Teddy. Teddy tragically passed away, and Emily, who fell into a near-coma, was rushed to the hospital. She had sustained multiple hematomas and a diffuse axonal injury, a severe type of TBI. Emily was confined to a wheelchair, had limited mobility in her right arm, and cognitive deficits that impacted her memory and reading abilities.

One week into her post-acute therapy, the COVID-19 pandemic shut down the clinic where Emily had been admitted to a day treatment program. Undeterred, Emily participated in telerehabilitation during the pandemic, using tools and equipment within her household to regain her strength and independence. She began documenting her recovery journey as well, first by speaking aloud then by writing and typing as she regained her dexterity.

Within six months, Emily was able to walk independently, strengthened her right hand, and saw her cognition improve. Two years later, Emily was able to move into her own apartment.

Emily is now a published author. Her debut book, "The Best of the Worst: My True Story of Surviving and Thriving After a Traumatic Brain Injury," chronicles her experience surviving and navigating life with TBI. Emily still lives independently and hopes to spread awareness to other young TBI survivors, and is working on her second book.



## Nicole Paredes

**AGE AT TIME OF INJURY: 31**

**INJURY: Stroke**

### Nicole's Journey:

When Nicole was seven months pregnant with her third child, she started having chest pains. She was rushed to the emergency room where it was discovered that she had experienced a stroke as a result of pre-eclampsia, a condition that can develop during pregnancy and causes high blood pressure and organ damage.

Due to her stroke, Nicole had to deliver her child prematurely. The stroke left Nicole unable to walk, speak, use her right arm, or care for her daughter in the first couple of months of her life.

Nicole worked closely with therapists to practice caring for her new baby. She relearned how to walk and care for herself while simultaneously relearning how to change diapers, dress, and carry a baby.

Seven years after her stroke, Nicole homeschools her three children and is able to manage all household chores on her own. After beginning her recovery with the use of a wheelchair, Nicole now walks comfortably with an ankle-foot orthosis, she has regained her confidence and proudly helps her children with their schoolwork.





## Dr. Michael (Mike) Petersen

**AGE AT TIME OF INJURY: 54**

**INJURY: Stroke**

## Dr. Petersen's Journey:

Dr. Petersen, a father of three with over 20 years of health industry experience, was living an active lifestyle, attending workout classes three times a week and working full-time as a chief medical officer. But one day, his son found him lying on the floor of his bedroom with a headache. Dr. Petersen had suffered a stroke, and was rushed to the hospital for an emergency craniotomy.

The stroke left Dr. Petersen in a wheelchair with limited mobility in his right hand and leg, along with cognitive deficits and double vision issues. Through daily therapy, Dr. Petersen was able to correct his vision, relearn how to walk without any assisted devices, and relearned how to multi-task through work simulation drills.

One of Dr. Petersen's biggest goals was returning to work – a goal he accomplished just eight months after his stroke. He has resumed his work duties with a renewed sense of purpose and commitment, and enjoys traveling and spending time with his wife and children.



## Carol Meyer

**AGE AT TIME OF INJURY: 73**

**INJURY: Stroke**

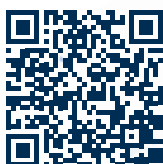
## Carol's Journey:

Following a successful career in corporate business, consulting, and accounting, Carol Meyer had retired and was preparing to travel internationally with her husband. But when she began to notice irregular sleep patterns on her Fitbit tracker, she made an appointment with her doctor. She was diagnosed with heart arrhythmia – a major risk factor for stroke. Carol underwent a successful cardio ablation procedure to address the heart arrhythmia, but suffered a stroke soon after.

The stroke severely impacted Carol's speech, leaving her with expressive aphasia, a language impairment that affects speech and cognitive processing. She also had right hemiplegia, or weakness on one side of the body.

Carol worked closely with physical therapists and speech therapists five days a week, determined to regain her speaking ability and to be able to attend her granddaughter's wedding in England.

Carol is now able to express her needs verbally, continues to improve her speech abilities, and has resumed her travels with her husband. And yes – she made it to her granddaughter's wedding.



The Brain Injury Association of America's awareness campaign, **My Brain Injury Journey**, highlights the unique experiences and stories of people living with brain injury. Share the story of your brain injury journey with us! Visit [biausa.org/brain-injury/community/personal-stories](https://biausa.org/brain-injury/community/personal-stories) or scan the QR code.

# Embracing the Journey

## PARENTING A CHILD WITH A BRAIN INJURY

*By Kelly Lang, BIAA Advisory Council Member*



No parent anticipates the words “brain injury.” The uncertainty, the agonizing wait. Yet, it happens, leaving families adrift in a sea of medical jargon and unanswered questions. Doctors offer no certainties, just a terrifying wait.

This is a reality for families daily, plunged into a nightmare with little guidance. Even after the initial improvement, the journey is far from over. Families grapple with special education, therapies, and a “new normal” that’s often far from it. Support systems dwindle just when they’re needed most, leaving parents overwhelmed by insurance, school, and the constant, unpredictable nature of brain injury. Every milestone is hard-won, every symptom a potential red flag.

How does a family cope with so much uncertainty? It may sound trite, but the answer is one second, one hour, and one day at a time.

In the beginning, we sit beside our child in a hospital. For some of us, we’re hoping they will wake up from a coma. Once they are awake, we wait for an assessment of their physical, emotional, and cognitive abilities. Recommendations are made, but it is up to us to make the right decisions for our child and family.

Parents have so many questions but find it difficult to find the “right” answers. There is a common saying in

the brain injury world: “If you’ve seen one brain injury, then you’ve seen one brain injury, because no two are alike.” This simple saying is accurate. Therapies that work for one may not help another. There are a lot of trial and error while searching for a treatment that works best for the individual.

The age of the child at the time of injury also plays a large part in the recovery process. If a child is injured when they are under 5 years old their recovery may not be the same as a child injured at 15. There are so many factors to consider when searching for appropriate care. Brain injuries are dynamic, and many do not fully recover.

## Finding the Right Support

It is important to get a team of professionals that can help guide you along the journey. When my daughter was young, I kept searching for a gatekeeper – someone who could hold all her medical files and information, and research alternative therapies and medical specialists. I never found one, so I became the gatekeeper and the navigator of her care. Parents know their child best and have a special intuition or gut feeling of what is most appropriate. I always recommend, if it doesn't seem to be working then look elsewhere or seek out other options.

Building a support circle consisting of a medical team, educators, supporters, and family will be imperative as you move forward. It is cliché but it really does take a village of support. Lean into them when you need extra resources. Ask as many questions as possible.

Parenting a child with a brain injury can be an isolating place as you are focusing a lot of energy on getting your loved one the services they need and deserve. Many of your friends and family will not understand all that you are dealing with, and it is helpful to find or build a support network you can rely upon. There will be days you need assistance with childcare for your other children, or getting dinner for the family. When that happens, seek out help as soon as possible. I did not do this enough. I wanted to be Super Mom, and it didn't always work out so well.

This community of support will rally around you in times of need, and you will be able to give back to them once you and your family are in a more stable environment.



**How does a family cope with so much uncertainty? It may sound trite, but the answer is one second, one hour, and one day at a time.**

## Brain Injury Through the Years

Each season will bring about different challenges and victories. Sometimes these occur simultaneously, but don't forget to celebrate the victories. It is important to honor them and give them the glory they deserve. Over time the family will need to heal as well. It's a shock to everyone when a loved one sustains a brain injury. It was approximately 12 years into my family's journey

before a medical professional asked me how I was doing. I burst into tears because she was showing me empathy and said, "You have been through so much and have done everything you can for your daughter." It shouldn't have taken so long for someone to acknowledge our pain.

Once a child sustains a brain injury there is time of adjustment for the child, parents, and siblings, and it takes time as the family recalibrates and adapts. Seek counseling as you deal with a lot of struggles and grief. Grief for the child you lost. There is ambiguous loss as well. Your child is still here, thankfully, but they are different and require intense care for a while. Your dreams for them may be altered.

It is alright to grieve the loss.

American writer Joseph Campbell said, "We must let go of the life we have planned, so as to accept the one that is waiting for us." I think his quote sums up living with brain injury. We learn to let go of the past and embrace our future because there are good things on the horizon.



# STROKE RISK ON THE RISE

## CDC FINDS RATE OF STROKE IS INCREASING IN YOUNGER ADULTS

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

In May 2017, Maddi Niebanck was gearing up for life after college. She had just graduated from Georgetown University and already had a job lined up for her in a new city that would start the following fall. She was looking forward to spending her summer months relaxing and hanging out with friends.

She was also planning to use that time to recover from brain surgery. After suffering from debilitating migraines throughout her childhood and teenage years, a neurologist discovered she had a rare arteriovenous malformation (AVM) in her brain's right occipital lobe. She opted to have brain surgery after graduating college to remove any risk of it potentially rupturing.

Ten days after her graduation, Maddi checked into the hospital for her surgery. However, a pre-operative

procedure caused a blood clot to form and burst in her brain, resulting in a massive hemorrhage.

"I have a high tolerance for pain, and I was crying. I had never felt pain this bad in my entire life," she said. She lost consciousness and was rushed into surgery.

When she woke up, she was completely paralyzed on her left side – her dominant side. The burst blood clot caused a stroke, leaving her unable to speak, swallow, or walk.

## SUSPECT A STROKE? ACT **F.A.S.T.**

The body gives signals when a stroke occurs. The American Stroke Association developed an easy-to-remember acronym, **FAST**, to remember these signals:



**FACE**

Stroke can cause sudden drooping on one side of the face. Ask the person to smile. Is their smile uneven?



**ARMS**

One arm may feel weak or numb. Ask the person to raise both arms. Is one arm drifting downward?



**SPEECH**

Stroke can cause slurred or confused speech.



**TIME**

**TIME TO CALL 911:** When a stroke happens, it's an emergency – one where every minute counts. If you suspect a stroke, call 911 immediately, and note the time when symptoms first appeared.

“

I had the common misconception that strokes only happen to older people.

MADDI NIEBANCK



maddistrokeofluck

Follow

Message

692 posts

91.3K followers

1,117 following

Madeline Niebanck - Stroke Survivor

maddistrokeofluck

Author

Hi I'm Maddi - young stroke survivor and advocate.

Fast Fwd Summits to connect with survivors

My book Fast Fwd: The Fully Recovered Mindset

linktr.ee/maddistrokeofluck

## Strokes on the Rise

Strokes in people Maddi's age – who was just 22 years old – are fairly uncommon. However, last year, a report from the Centers for Disease Control and Prevention (CDC) found that the rate of young people having strokes has increased. While adults 65 and older still have the highest rates of stroke, the risk of stroke among Americans younger than 65 has increased by approximately 15 percent when compared to rates from a decade ago.

"I had the common misconception that strokes only happen to older people," Maddi said. "I didn't even know a stroke could happen to someone who's 22 years old."

Strokes occur when a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot, bursts, or ruptures. When that happens, part of the brain cannot get the blood and oxygen it needs.

For some individuals, like Maddi, stroke can be caused by uncontrollable risk factors. In her case, her stroke was the result of AVM. Other conditions like atrial fibrillation and sickle cell disease can also pose a risk of stroke, as can an individual's sex, race, or family history of stroke.

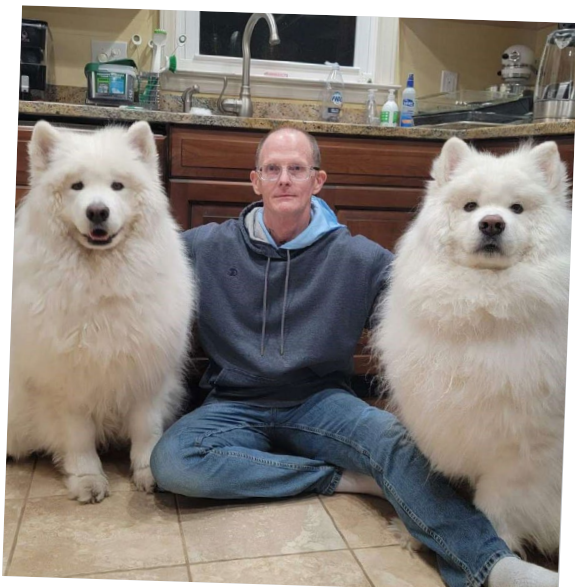
However, other risk factors for stroke such as high blood pressure, smoking, obesity, diabetes, high cholesterol, sedentary lifestyle, and a diet high in saturated or trans fats, can be controlled. And these controllable risk factors are, in many cases, the reason for the rising number of younger people having strokes, the CDC report noted.

"The morbidity and mortality from 'lifestyle diseases' – diabetes, hypertension, obesity – it's enormous," explained Brent Masel, MD, Executive Vice President for Medical Affairs with the Centre for Neuroskills and BIAA's National Medical Director. Making a conscious effort to be physically active, control your blood pressure, eat a healthy diet, and abstain from smoking are all steps people should take to lower their risk of having a stroke, he stressed.

But sometimes, strokes can occur without any apparent risk factors.

In 2011, Steven Nape was a 42-year-old husband and father of two. He and his family had recently moved to Radford, Virginia, where Steven had secured a job as Vice Provost at Radford University. In addition to building his career – Steven wanted to be a college president – Steven was an endurance athlete, having completed numerous races that included 12-mile swims, long runs, and triathlons. He did not drink, smoke, or use drugs. "I would describe myself as a healthy, fit, hard worker who was having a successful career," Steven reflected.

Despite his healthy and active lifestyle, Steven suffered a stroke that left permanent damage on both sides of his brain. "Presently, I am walking around having had a stroke which came out of the blue with no known cause," he said. Steven underwent medical testing that found certain anomalies that could potentially be risk factors – "but I can't prove that," he explained.



Steven continues to live with symptoms of his stroke, including right side weakness and right side facial droop. In 2017, Steven sustained a TBI when a truck struck his car and pinned him between his car and a guardrail. The TBI exacerbated his pre-existing issues from his stroke, and created additional deficits. He deals with mood issues, including anxiety, depression, and PTSD, as well as problems with his vision and memory.

## Strokes and Our Brains

Strokes are deadly – they’re the fifth leading cause of death in the United States, and a leading cause of disability. They can affect every part of the body, but they especially impact the brain.

“Strokes are generally focal, meaning a very specific part of the brain is involved,” Dr. Masel explained. The effects on the brain and a person’s functioning will depend on where a clot occurs or a blood vessel ruptures. For Maddi, it affected her speech and mobility, particularly the left side of her body.

In the days, weeks, and months after her stroke, she had to relearn how to sit up and use a wheelchair, progressing toward walking with the use of a cane, and eventually walking without a mobility aid. She went through cognitive and speech therapy, and worked toward improving mobility in her left hand and arm.

Eight years later, Maddi is a stroke advocate. She has published two books, runs a popular Instagram account (@maddistrokeofluck), lives independently,

“  
I have been through a lot,  
and I’ve learned a lot. I’ve  
had horrible lows, but I  
have regained a certain  
level of normalcy in my  
life. I’ll never be what I  
was, but I can live with  
who I am on most days.

STEVEN NAPE

and operates summits designed for stroke survivors and caregivers, with the next event taking place this September in Los Angeles.

“I can do a lot of things that I hadn’t considered or given myself enough credit that I can do,” she said. “I think as brain injury survivors, we don’t always give ourselves enough credit for the things we have done. We get so caught up in, ‘oh, I can’t do this yet, I haven’t achieved all this stuff that I want to,’ but I think it’s also important to take a second to pause and realize how far we have come in our journey and our process. That’s just as important.”

Steven was unable to return to the workforce after his injuries, but in the past few years has found opportunities to volunteer and participate in activities within the brain injury community. He has been a member of the Virginia Brain Injury Council for the past two and a half years, and volunteers as a featured ambassador with the Model Systems Knowledge Translation Center. He credits his case manager at Brain Injury Solutions, a Virginia-based organization that helps people living with brain injury reintegrate into their communities, with 9 helping to connect him with these opportunities.

“I have been through a lot, and I’ve learned a lot. I’ve had horrible lows, but I have regained a certain level of normalcy in my life. I’ll never be what I was, but I can live with who I am on most days,” he said.

The Brain Injury Association of America has a new stroke hub on our website. Visit the hub at [bit.ly/3Rm3VaE](https://bit.ly/3Rm3VaE) or scan the QR code.





# CONCUSSION AWARENESS NOW CORNER

Despite being relatively common occurrences, concussions are still widely misunderstood, with misconceptions about their causes, symptoms, diagnosis, and treatment potentially preventing people from seeking the care they need. To continue to narrow this knowledge gap, during Brain Injury Awareness Month, Concussion Awareness Now (CAN) set out to start the concussion conversation by busting concussion myths.

During March, CAN hosted a “Busting Concussion Myths” webinar, where panelists Dr. Beth McQuiston, a neuroscientist and medical director for Global Neuroscience Research at Abbott; Dr. Drew Nagele, a neuropsychologist and board-certified rehabilitation psychologist who’s worked for over 40 years in brain injury rehabilitation; Katherine Snedaker, a licensed clinical social worker and founder of Pink Concussions, a non-profit focused on awareness and advocacy around brain injury in women; and Kellie Pokrifka, a brain injury survivor and member of the Brain Injury Association of America’s Survivor Council, came together to compare the persistent concussion myths with the facts:

**MYTH:** Sports are the leading cause of concussions

**FACT:** Falls are the leading cause of concussions. “Gravity is actually the biggest cause of concussions,” Dr. McQuiston said, pointing out that while certain age groups, particularly older adults, are more susceptible to falls, anyone can fall at any time.

**MYTH:** Concussions present the same way in everyone

**FACT:** Just as concussions can be sustained in a variety of ways, symptoms can appear differently from person to person—and even differently in the same person across multiple concussions.

**MYTH:** Concussions affect men and women similarly

**FACT:** Research shows significant differences in how concussions manifest in males versus females, both in causes and symptoms. Snedaker noted that while data suggests men experience concussions at twice the rate of women, many cases in women may go unreported. Dr. McQuiston noted that there are also biological factors that can make concussions more problematic for women as well.

**MYTH:** CT scans and MRIs always detect concussions

**FACT:** Many people believe that if diagnostic imaging comes back clear, they don’t have a concussion. According to the panel, this is false. “The vast majority of head CTs are going to be negative. So even if you had a concussion, 90 percent of those CTs are going to be negative. That doesn’t mean you didn’t have a brain injury. That just means that you didn’t have a brain bleed or a skull fracture,” Dr. McQuiston said.



To view the full webinar, visit [bit.ly/4j6ADJh](https://bit.ly/4j6ADJh) or scan the QR code.



# 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

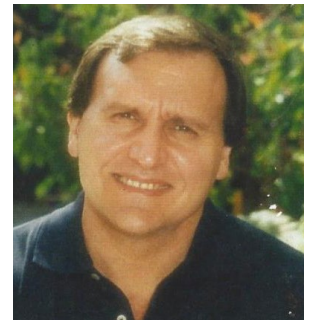
## Let Us Thank You: Futures Fund Legacy Society

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).**

# BRAIN INJURY AWARENESS MONTH 2025: HEROES DON'T ALWAYS WEAR CAPES

By Peter Knockstead, Director of Corporate Partnerships, Brain Injury Association of America

March, which is Brain Injury Awareness Month, is always a special time for the Brain Injury Association of America (BIAA). It's an opportunity for us to spotlight the lived experience of brain injury survivors and our community.

During this year's Awareness Month, thousands of volunteers joined our efforts to promote brain injury awareness and education by participating in a peer-to-peer fundraising campaign, soliciting donations while sharing information about the complex nature of brain injury.

We are grateful to the BIAA partners that formed fundraising teams. Here are just three stories of the many individuals and teams that made our 2025 Brain Injury Awareness Month Campaign a success.



Ilana Kleinfeld and Dr. Arielle Resnick

## Team Kessler Rehab and Select Specialty Hospital of Northern New Jersey

As part of Select Medical, both campuses – each with their own professional teams who help brain injury survivors, and their families

navigate the challenges of recovery after brain injury – joined forces and went above and beyond to support our Awareness Month campaign.

Led by co-captains Ilana Kleinfeld, an occupational therapist and clinical liaison at Select Specialty hospital, and Dr. Arielle Resnick, an advanced clinical specialist and director of the Neurologic Physical Therapy Program at Kessler, the team organized bake sales and other fundraisers, collecting donations of \$1,017.

## Team Gateway Clubhouse, Raleigh, North Carolina

Team Gateway Clubhouse is a member driven space where brain injury survivors come to participate in work-ordered days with staff that are “deeply invested in the cause of brain injury awareness.”

Stephanie Vinson, director of brain injury services, was Clubhouse's team leader. When asked about the secret sauce that drove her team to triple their fundraising goal to support BIAA, Stephanie gladly shared her advice to promote brain injury awareness and solicit donations: “Boy, will you be surprised at how many respond! Do not be afraid to ask for support, and make sure you share your passion with enthusiasm and excitement. It is contagious.”



Stephanie Vinson



The Learning Services team

## Team Learning Services of Northern California

Lyndsay Blakely and her teammates at Learning Services of Northern California (part of Collage Rehabilitation Partners), a community-based neurorehabilitation program, were glad to

form a team to participate in this campaign for a cause

that hits close to home. It was “all hands on deck – clients (TBI survivors), staff, friends, families, doctors, and community supporters working together to raise funds for brain injury awareness month,” she said.

With an initial goal of raising \$1,500, their collective effort soon skyrocketed to \$5,000. They organized a “Walk and Roll” where participants received a donation for each lap completed. Other fundraising activities included a car wash and bake sale, and the team enlisted the help of clients and staff when accepting payment donations, using the opportunity to promote cognitive tasks related to providing change and money management.

**If you are interested in hosting a workplace fundraiser for the Brain Injury Association of America, email [development@biausa.org](mailto:development@biausa.org) or call 703-761-0750, ext. 645**



# ADVOCACY, EMPOWERMENT, COMMUNITY

## BIAA Hosts First-Ever National Brain Injury Conference and Awareness Day

*By Lauren Moore, Marketing and Communications Manager, Brain Injury Association of America and Wendy Waldman, BSW, CBIST, President, Brain Injury Association of Indiana*

The Brain Injury Association of America hosted its first-ever National Brain Injury Conference and Awareness Day event March 3-5, where nearly 400 survivors, caregivers, advocates, professionals, and friends came together in Washington, D.C. for an event celebrating advocacy, empowerment, and community.

While BIAA has historically celebrated Brain Injury Awareness Day with an annual trip to Capitol Hill, where attendees have an opportunity to meet with their congressional representatives and advocate for policies, legislation, and funding that would improve the quality of life for people living with brain injury, this year's event was expanded to include a national conference.

This year's events provided an impactful platform for education, advocacy, fellowship, and community engagement, including informational sessions, social and networking opportunities, and an in-depth overview of BIAA's current legislative priorities.

A keynote address from BIAA Board of Directors members Dr. John D. Corrigan and Dr. Michael Jaffe featured insights on the latest research, treatment advancements, and rehabilitation strategies for brain injury survivors, as well as the need for brain injury to be recognized as a chronic health condition rather than

a one-time event. Both speakers addressed the need to manage brain injury over the course of a person's lifetime.

The conference also featured advocacy training sessions to help attendees who would be meeting with their representatives effectively communicate their experiences and needs.

We hope that the momentum from this year's National Brain Injury Conference and Awareness Day will continue throughout the rest of the year. We encourage everyone to stay engaged by:

- ▶ Educating themselves and others about brain injury
- ▶ Supporting legislative efforts to improve care and access to services
- ▶ Participating in awareness events and fundraising activities
- ▶ Volunteering or donating to support brain injury programs and research



**364**

**ADVOCATES  
JOINED US ON  
CAPITOL HILL**



**43**

**NUMBER  
OF STATES  
REPRESENTED**



**284**

**MEETINGS HELD WITH  
HOUSE AND SENATE  
REPRESENTATIVES**





- 1) Advocates pose for a photo in the U.S. Capitol Building ahead of their congressional meetings.
- 2) Brain injury advocates from Alabama stand outside Sen. Tommy Tuberville's offices.
- 3) The National Brain Injury Conference and Awareness Day gave attendees an opportunity to meet other survivors, caregivers, and advocates from around the country.
- 4) Advocates took a photo on the steps of the Capitol ahead of their legislative meetings.
- 5) Advocates from New Jersey stop for a photo outside Sen. Cory Booker's office.
- 6) Members of the Virginia delegation grab a photo in between meetings on Capitol Hill.

- 7) BIAA Board Chair David Harrington, far left, moderated a panel of brain injury survivors and caregivers who shared their brain injury stories with attendees.
- 8) BIAA's President and CEO Rick Willis snaps a selfie during the General Session at the National Brain Injury Conference and Awareness Day.
- 9) The National Brain Injury Conference and Awareness Day gave attendees an opportunity to meet other survivors, caregivers, and advocates from around the country.
- 10) Members of BIAA's Advisory Council pose for a photo during the National Brain Injury Conference.

- 11) Members of the Florida delegation meet with their representatives on Capitol Hill.
- 12) The National Brain Injury Conference and Awareness Day gave attendees an opportunity to meet other survivors, caregivers, and advocates from around the country.



**STAY UPDATED  
ON BRAIN INJURY  
ADVOCACY BY  
SCANNING THE  
QR CODE OR VISITING  
[BIT.LY/30PMEUW](https://bit.ly/30PMEUW)**



# STATE AFFILIATE NEWS



## Indiana

It's been an exciting and productive quarter for the Brain Injury Association of Indiana (BIAI)! In January, we began planning our 2025 Wiffleball Tournament. This year's event will be taking place on Saturday, October 25! We will be hosting teams from all over the state of Indiana and putting on all kinds of amazing activities, games, and crafts for all ages! Be sure to save the date and watch for more information to come.

We also began planning our lineup for our Brain Blitz videos that we will add to our BIAI site this year. Our Brain Blitz series features various speakers sharing on important topics related to living with brain injury. Keep an eye out for new Brain Blitz videos covering subjects such as concussion awareness, school after brain injury, vision health, and more. Visit [biaindiana.org/brain-blitz/](https://biaindiana.org/brain-blitz/) to learn more.

In March, BIAI attended the National Brain Injury Conference and Awareness Day in Washington D.C. hosted by BIAA. Nearly 400 members of the brain injury community gathered from across the country to connect, share, and raise awareness on brain injury. BIAI met with and engaged our Indiana

state policymakers, urging them to support the reauthorization of the Traumatic Brain Injury Act and to increase funding for brain injury programs, services, and support.

BIAI had the honor of meeting with state representative Sue Errington, a passionate, dedicated and committed community leader working to bring people together in Indiana. Representative Errington championed a proclamation with BIAI recognizing March as Brain Injury Awareness Month, a significant step forward for advocacy in our state. BIAI will continue working with Representative Errington and other policymakers to support and advocate for Hoosiers affected by brain injury.

BIAI is incredibly excited to announce we have been chosen by Hickory Hall Polo Club to host an evening of brain injury awareness and fundraising as you watch a thrilling game of polo. We invite you to join us on Friday, July 18 at 6 p.m. ET for an unforgettable evening! More details and information to come soon.

Happy Spring to all!



## Louisiana

During Brain Injury Awareness Month, the Brain Injury Association of Louisiana (BIALA) hosted its 16th annual conference, “The Power of We.” Over the course of two days, more than 200 attendees, including allied health professionals, caregivers, and individuals living with a brain and/or spinal cord injury, came together to deepen their understanding, exchange valuable insights, and build meaningful connections with others who share similar experiences and challenges. Healthcare professionals had the opportunity to expand their expertise on the latest advancements in brain and spinal cord injury rehabilitation, including innovative therapies, cutting-edge services, and emerging treatment options, while survivors and caregivers gained knowledge to support their recovery and daily lives.

A dedicated survivor track offered engaging, hands-on presentations and interactive activities such as poured art making, music therapy, adaptive yoga, and Tai Chi, along with inspiring talks designed to motivate and empower. After the sessions, participants came together for a lively Survivor Social, where they not only enjoyed exciting giveaways but also had the chance to laugh and form meaningful connections in a fun and supportive environment.

The exhibit hall buzzed with energy as 44 sponsors and exhibitors enthusiastically showcased the latest products, services, and resources, creating an engaging and informative environment.

A highly anticipated part of the conference each year is the powerful collaboration between BIALA and Tulane University’s Department of Theatre and Dance Documentary Theatre. Through this service-learning project, students engage deeply with the realities of brain injuries by conducting interviews with survivors, caregivers, and rehabilitation professionals. These firsthand accounts provide invaluable insight into the lived experiences of those affected.

The students then transform these interviews into a compelling documentary, capturing the emotions, challenges, and perspectives of the individuals they spoke with. To further amplify awareness and foster a deeper understanding, the documentary is adapted into an impactful live performance, where students “bring to life” the voices and stories they encountered. This year’s performance centered on the themes of advocacy and invisible disabilities, shedding light on the often-unseen struggles faced by individuals with brain injuries while emphasizing the importance of empowerment and awareness.

## Maine

On March 20, the Brain Injury Association of America-Maine Chapter (BIAA-ME) held the 2025 BIAA-ME Brain Injury Resource Fair at the Augusta Armory in Augusta, Maine, with over 50 exhibitors and 250 participants. 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 come together 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, as well as additional efforts to increase the scope and reach of NeuroResource Facilitation services for Mainers. The pilot project is being completed in collaboration with the Maine Office of Aging & Disability Services under the Administration for Community Living grant awarded to Maine.



The next brain injury conference in Maine will be the annual BIAA-ME Conference on Defining Moments in Brain Injury on Sept. 15 in Portland, Maine.

## Massachusetts

The Brain Injury Association of Massachusetts (BIA-MA) is proud to celebrate the recognition of its founder and Board Member, Marilyn Price Spivack, as the Patriots Foundation's "Difference Maker of the Week." This prestigious award, part of the Celebrate Volunteerism initiative, honors individuals who have made a profound impact on the New England community. In recognition of Marilyn's dedication, the Patriots Foundation and Gillette contributed a generous \$10,000 donation to BIA-MA.

For over 50 years, Marilyn has been a relentless advocate for individuals with brain injuries and she remains an unwavering pillar of support, actively serving on BIA-MA's Board of Directors and participating in BIA-MA annual events.

Marilyn played a crucial role in the creation of the Statewide Head Injury Program (SHIP), which serves approximately 1,200 individuals annually. She also championed the passage of the Traumatic Brain Injury Act of 1996, the first federal legislation addressing TBI prevention, research, and service delivery.

On Jan. 5, Marilyn received her award at Gillette Stadium in Foxborough, Mass. during the Patriots vs. Bills football game. Reflecting on her journey, she expressed gratitude for the recognition, emphasizing



her lifelong commitment to improving the lives of brain injury survivors. Congratulations, Marilyn, on this well-deserved honor!

## Missouri

The Brain Injury Association of Missouri (BIA-MO) held our Concussions: Facts, Fallacies, and New Frontiers Seminar on Feb. 14. This seminar was a concussion education "refresher" for youth sports and school personnel. Topics included physical activity, concussion management, protective equipment, fear avoidance behaviors, and resources. Session recordings are available for anyone interested.

BIA-MO Survivor and Family Seminars were held March 22 in Springfield, Mo., and April 26 in Kansas City, Mo. These seminars provide information for understanding and living with brain injury. Topics included Build Understanding for Better Communication, Discovering Hobbies and Passions to be Active in the Community, and Embracing Music for Memory, Coping, and Healing. The Seminar will return on Nov. 8 in St. Louis, with the same sessions.

Bowling for Brain Injury will be held in June. Teams in Springfield, St. Louis, and Kansas City will enjoy bowling with others as they reach their team goal of \$500 or more. "Spare the Alley, Join the Rally" is available throughout June for fundraising only and no bowling.

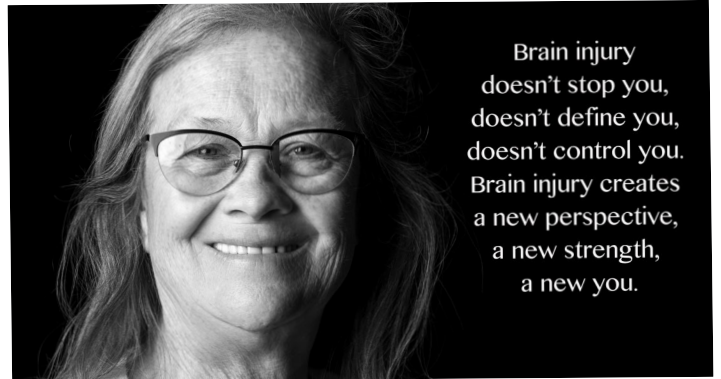
The One-Day Regional Outdoor Camps will be held in September, with locations in St. Louis, Springfield, Kansas City, and Columbia. The 21st Annual Statewide Conference will be held on Oct. 21 and 22.



## Nebraska

The Brain Injury Association of Nebraska hosted its annual statewide conference on March 13–14 in Kearney, NE bringing together professionals, survivors, and families to learn, connect, and share stories. This year's conference featured a special tribute to four families who participated in *Forever Shaken*, a powerful documentary raising awareness about the global impact of abusive head trauma. Their stories continue to inspire prevention efforts worldwide. Watch the film [here](#).

We also partnered with A Peace of My Mind, led by award-winning photographer and storyteller John Noltner. Through interviews and portraits captured at the conference, attendees shared personal stories about the impact of brain injury. This moving exhibit is available to view and share at [apeaceofmymind.org](http://apeaceofmymind.org).



Brain injury  
doesn't stop you,  
doesn't define you,  
doesn't control you.  
Brain injury creates  
a new perspective,  
a new strength,  
a new you.



## New Hampshire

The Brain Injury Association of New Hampshire (BIANH) held its 41st Annual Brain Injury and Stroke Conference on Wednesday, May 14. Keynote Speaker Ali Rheame shared her story of road to recovery after two brain injuries, the challenges she had to work through, overcoming multiple hardships, and finding joy she finds in helping others. Over 200 conference attendees enjoyed her presentation of "The Blank Paper." Workshop topics included sessions on the long-term impact of trauma, substance use and brain injury, neurologic music therapy, nutrition, and more.

Keeping the ongoing tradition for several years, BIANH continued to provide free bike helmets to any interested police department in the State of New Hampshire. On average each year, BIANH provides 1,500 helmets and educational materials to more than 60 different departments. Many departments hold bike safety sessions at local schools or bike rodeos in their townships and give the helmets to children and youth who attend.

Looking ahead, BIANH will hold its 42nd Annual Golf Tournament in August, and the 19th Caregiver's Conference in November.



## New York

March is always an exciting and impactful month in New York, especially for the brain injury community. The Brain Injury Association of New York State (BIANYS) led a series of initiatives to raise awareness and strengthen advocacy across the state. Highlights included Advocacy Day in Albany, where survivors and supporters met with lawmakers to push for critical policy changes. BIANYS also delivered six Concussion Outreach Prevention Education sessions, reaching over 265 individuals with vital safety information. A dedicated webinar for caregivers provided essential tools and support for those caring for individuals with brain injuries. Throughout the month, BIANYS amplified its message via social media, ensuring important brain injury information reached thousands. The month culminated in the annual Go Blue! for Brain Injury fundraising campaign, benefiting the BIANYS Annual Conference Scholarship Program. These efforts reflect BIANYS's commitment to empowering voices, supporting families, and supporting the brain injury community in New York.



## Ohio

Over 130 brain injury survivors, caregivers and local professionals gathered together at the Ohio Statehouse on Monday, March 10, to celebrate Brain Injury Advocacy Day. The event began with breakfast (made possible through a grant from Community Fund Ohio) and an awards presentation. The Impact Leadership Award was presented to Senator Mark Romanchuk for his unwavering commitment to helping people with disabilities through policy, support and resources. The Advocate Pioneer Award was presented to Dr. DeAnna Frye whose compassionate expertise as a Neuropsychologist has elevated the standard of support for brain injury survivors and forged new pathways for

collaboration throughout northeast Ohio. Throughout the day, brain injury survivors and caregivers met with state representatives and legislators to increase awareness, discuss why continued funding is essential, and share their inspiring stories.

## Pennsylvania

The Brain Injury Association of Pennsylvania (BIAPA) Conference Committee is excitedly preparing for our annual conference! This two-day event, taking place June 30-July 1 in Lancaster, Pa., promises to be a valuable opportunity for learning and networking. The theme for this year's conference is "Celebrating an Empowered Brain Injury Community: A Conference for Survivors, Care Partners, and Professionals."

Designed for professionals, survivors, and caregivers, some of the key highlights of the conference include CEU and CE Opportunities, exhibits and poster presentations, networking and social events, a silent auction benefiting our scholarship fund, a survivor coffee house and open mic, and yoga and tai chi sessions.

For the second consecutive year, we will be hosting dedicated group sessions for pediatric professionals and caregivers, including an opportunity for pediatric caregivers to meet one another and develop a support network. Pediatric sessions will be held on July 1. A full listing of conference sessions, plus keynote and plenary speaker information, can be found at [biapa.org/2025conference](http://biapa.org/2025conference).

BIAPA was proud to host a Brain Safety Fair this spring, continuing our mission of brain injury prevention. Held at Westmoreland Mall on March 22, the event was a big success, thanks to the incredible energy and participation of all involved.



The Fair offered a range of brain education activities, including coloring pages that depicted the brain, a neuron and correct helmet position, as well as interactive games that taught about brain functions and helmet safety. Educational and sponsor booths featured hands-on experiences such as sensory games where participants moved beads to different brain sections, perception challenges such as writing with a mirror or wearing gloves, and helmet protection demonstrations, all designed to engage children in learning about the importance of brain health and safety. We look forward to hosting more family-friendly events like this and spreading awareness about the importance of safeguarding our brains!

## Texas

Pate NeuroRehabilitation hosted a 5k on March 29 during Brain Injury Awareness month to raise money for the Brain Injury Association of America (BIAA) and to increase community attention to brain injury. With the support of participants, donors, and event sponsors, we were able to raise \$4,800 for the BIAA-Texas Chapter!



# EVENTS AND WEBINARS

**July 16, 2025, 3 p.m. ET**

## Vestibular Rehabilitation in Brain Injury: Assessment and Management of Vestibular System Dysfunction

**WHITNEY L. CHUMBLEY, PT, DPT, CBIS, CSRS**

This David Strauss Clinical Webinar will provide a basic understanding of the vestibular system, the resulting difficulties upon identifying dysfunction within the system, and the potential avenues for treatment and rehabilitation. Attendees will learn the plans of care required for the management of disorders with an emphasis on the role of physical therapy.

**July 24, 2025, 3 p.m. ET**

## Acquired Brain Injury: A Transdisciplinary Approach to Inpatient Rehabilitation

**ANNA RITCHIE, PT, CBIS; CARA YETLEY, OTD, OTR/L; AND ERIN WIND**

The close coordination of care between therapy, nursing, medical staff, psychology, and case management is required to make the greatest impact on patients and their families. In this presentation, a team from the Sheltering Arms Institute will share the inner workings of their transdisciplinary system of care.

**August 14, 2025, 3 p.m. ET**

## Home-Based Strategies to Support Cognition After Brain Injury

**BRIANA ELSON, MS, OTR/L, BCPR, CBIS**

Home and activity modifications can provide support for those with cognitive impairments as a result of their brain injury. In this Carolyn Rocchio Caregivers webinar,

we will review current literature and evidence-based interventions that facilitate success during activities of daily living to help promote independence and reduce caregiver burden.

## Last Chance!

The following webinars will be removed from the BIAA bookstore this summer. If you'd like to download a recording, visit [shop.biausa.org/products/recordedwebinars](https://shop.biausa.org/products/recordedwebinars)

**Expiring July 31**

## Self-Awareness After TBI

In this David Strauss Memorial Lecture webinar, Whitney Neal, Ph.D., CCC-SLP describes the presentation of self-awareness deficits in individuals with traumatic brain injury.

## Realities of the Recovery Journey After Pediatric Brain Injury

What happens after pediatric brain injury? Jennifer P. Lundine, Ph.D., CCC-SLP, BC-ANCDs reviews research describing realities of life following pediatric brain injury, based on the perspectives of caregivers, youth with brain injury, and medical and educational providers.

**Expiring August 31**

## Emotional and Behavioral Changes after Pediatric Brain Injury

In this webinar, Dr. Danielle Ploetz, ABPP-CN, discusses emotional and behavioral issues that can follow brain injury in childhood and adolescents. She focuses on outcomes and also discuss strategies for helping individuals and their caregivers manage these challenges.

## Estate Planning for Families of Individuals with Brain Injury

What are important considerations for future planning when you are caregiver to a loved one with a brain injury? Keith Miles, Esq., MBA, LL.M., discusses estate planning, special needs trusts, and ABLE accounts.

# AD INDEX

| Advertiser and Website | Page |
|------------------------|------|
| NBIIC                  | 23   |

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Contact Peter Knockstead,  
*Director of Corporate Partnerships*  
[pknockstead@biausa.org](mailto:pknockstead@biausa.org)  
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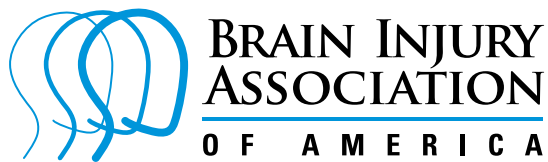
# Have you or a loved one had a brain injury?



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

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

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



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



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

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

