THE
VOICE
OF BRAIN INJURY
HELP, HOPE, AND HEALING
Cathy sustained a brain injury while on a work trip. Multiple healthcare providers missed her diagnosis of a traumatic brain injury (TBI). Using her frustration to fuel her search for treatment, Cathy looked to the Brain Injury Association of America’s National Brain Injury Information Center. On the website she found information on terminology, diagnosis, and treatment options. The stories of others living with a brain injury made her feel validated, realizing her symptoms were common among survivors. For Cathy, BIAA was there when she needed it the most.

No one ever thinks that they or a loved one will sustain a brain injury, but when it does occur it can be absolutely devastating. I was blessed to have BIAA’s resources and support early in my journey.

— Cathy, educator, consultant, and person living with a brain injury

Brain Injury Fact:
MORE THAN 3.6 MILLION adults and children acquire brain injuries each year, but the total incidence is unknown.
Imagine not knowing the difference between a hairbrush, a toothbrush, and a paintbrush. Or forgetting which goes on first: your shoes or your socks? A brain injury can change the way a person moves, talks, thinks, and acts. Brain injury can lead to physical, communicative, cognitive, and behavioral impairments that can be lifelong.

BRAIN INJURY IS NOT AN EVENT OR AN OUTCOME.
It is the start of a misdiagnosed and misunderstood neurological condition that can cause or accelerate other diseases.

EVERY 9 SECONDS, SOMEONE SUSTAINS A BRAIN INJURY

Every day, more than 9,000 lives are changed forever by brain injury, with a ripple effect that impacts tens of millions of families, workplaces, and entire communities. The total number of brain injuries is on the rise due to complications from COVID-19, increased incidence of domestic violence, and the opioid epidemic.

What is a Brain Injury?

AN ACQUIRED BRAIN INJURY (ABI)
is any injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma.

Typical causes of ABI include electric shock, infectious disease, lightning strike, oxygen deprivation, seizure disorder, stroke, substance abuse/overdose, toxic exposure, trauma, and vehicle accidents.

A TRAUMATIC BRAIN INJURY (TBI)
is a type of ABI that is caused by trauma to the brain from an external force.

Typical causes of TBI include slips and falls, automobile crashes, assaults, sports injuries, and blasts from explosives.
THE VOICE OF BRAIN INJURY

"The Brain Injury Association of America is helping survivors and families return to as normal a life as possible, providing hope and benefits they need. BIAA is at their side all the time."

— Brent Masel, M.D., Volunteer National Medical Director

Founded in 1980 by a grassroots group of volunteers, families, survivors, caregivers, and professionals, the mission of the Brain Injury Association of America is to advance brain injury awareness, research, treatment, and education and to improve the quality of life for all people affected by brain injury.

BIAA is the primary authority on medical diagnosis and treatment, disease management, research, and life challenges associated with brain injury. The Association is a leading influencer of public awareness and policy change and an incubator of brain injury research.
THE VOICE OF BRAIN INJURY

BIAA’s Vision: Everyone who sustains a brain injury is diagnosed, treated, and accepted.

With a nationwide network of state affiliates, local chapters, and support groups, BIAA serves as the voice of brain injury for survivors, their families, and the professionals who provide care, treatment, and expertise to the brain injury community.

BIAA works relentlessly to:

• Improve care and support for individuals with brain injury and their families.
• Increase awareness and understanding of brain injury and the Association.
• Accelerate research for treatment and a cure.
• Increase the Association’s impact commensurate with the size of the community.
PROVEN, EFFECTIVE, AND TRUSTED

The Brain Injury Association of America makes a difference in the lives of millions of people living with brain injury every day.

96% OF THOSE SERVED plan to use BIAA programs and services in the future.

94% OF THOSE SERVED are willing to recommend the BIAA to a friend or colleague.

BIAA needs your help to keep pace with the ever-increasing demand for services, supports, and research. The speed at which patients and their families can make well-informed decisions about medical care is directly related to the quality of their recovery. You can help by funding game-changing investments that will allow BIAA to reach more survivors, assist more families, train more specialists, and identify cures for chronic brain injury.

WITHOUT YOU, the Voice of Brain Injury could be silenced.
MEET RENEE, A VOICE OF BRAIN INJURY

Renee found the Brain Injury Association of America when she was looking for answers about her son’s brain injury. She was comforted in knowing she was not alone. She learned about how damage to the frontal lobe affects a person and how important it is to find support and ways to cope. Most meaningfully, she found people who understood and she no longer felt alone or judged.

“Brain injury is sudden, life changing, and can happen to anyone. Supporting BIAA makes it possible for services to be there when you need them.”

— Renee, mother and caregiver to a person living with a brain injury

Brain Injury Fact:

1 OUT OF EVERY 60 PEOPLE in the U.S. lives with a traumatic brain injury (TBI) related disability.
BIAA CORE SERVICES

National Brain Injury Information Center (NBIIC)

Operated nationwide in collaboration with state affiliates, NBIIC assists thousands of individuals and families who experience the life-changing effects of brain injury. Compassionate and knowledgeable brain injury specialists assist in locating medical, rehabilitative, legal, financial, and other local support services critical to maximizing recovery.

Academy of Certified Brain Injury Specialists (ACBIS)

ACBIS is a voluntary training and credentialing program for clinicians and direct support personnel who specialize in brain injury. Since the program’s inception, the Association has certified more than 20,000 professionals, improving the quality of care for individuals with brain injury.

Research

Scientific research is essential to developing better treatments for people living with brain injury. The need to better understand brain injury, the impact it has as a chronic disease, and its role in causing other conditions diseases like Parkinson’s, Alzheimer’s, and multiple sclerosis has never been greater. BIAA funds the best and brightest investigators seeking answers to these important questions.
BIAA CORE SERVICES

Affiliate Services

BIAA provides leadership, technical assistance, operational best practices, and individualized fundraising training and consultation to a nationwide network of chartered state affiliates, divisions, local chapters, and support groups across the country to meet the needs of those living with brain injury.

Public Awareness

BIAA leads the nation in recognizing March as Brain Injury Awareness Month. The goal of awareness activities is to demystify brain injury and empower survivors to define themselves. BIAA’s award-winning website, social media, and print publications are essential parts of its outreach and education. Survivors, caregivers, and professionals also learn through on-demand and live webinars on a range of topics.

Advocacy

By influencing public policy at the federal level, BIAA has secured millions of dollars for research, public awareness, and prevention. Key accomplishments include establishing the TBI Model Systems of Care, supporting the TBI Act and its subsequent reauthorizations over the last 20 years, creating the bipartisan Congressional Brain Injury Task Force, adding provisions for service members with TBI in the National Defense Authorization Act, and including rehabilitation as an essential health benefit in Patient Protection and Affordable Care Act.
BIAA has worked relentlessly over the past four decades to assist survivors, caregivers, family members, and professionals by successfully delivering award-winning and nationally recognized services and supports. To meet the ever-evolving needs of the brain injury community, BIAA must continue to innovate and elevate programming to reach more people, in more places, and in more ways.
An avid concertgoer and lover of music, Dylan has been at the microphone for brain injury for many years. Navigating roadies, managers, and venue red tape, Dylan is relentless in getting permission to speak up about brain injury at concerts across the country. He has been defying the odds since high school, when a car crash put him in a coma that doctors called “unsurvivable.” Dylan walked out of the hospital ten weeks later and has been a voice for brain injury ever since.

“Music is still a very big part of my life thanks to the Brain Injury Association of America. I am in an ideal position to spread awareness about brain injury and to help individuals who are struggling with brain injury.”

— Dylan, musician, philanthropist, and person living with a brain injury

**Brain Injury Fact:**

150 PEOPLE DIE EACH DAY because of a traumatic brain injury (TBI) related disability.
When it comes to recovery after brain injury, getting the right information when it is needed is critical. The speed at which patients and their families can make well-informed decisions about medical care is directly related to the quality of their recovery. Therefore, BIAA must expand services to reach more people, in more places, and in more ways. The following projects will allow the Association to connect with survivors, caregivers, and families as soon as possible, increasing the chances of a quality recovery.

The sooner survivors and families connect with BIAA’s National Brain Injury Information Center, the better the potential outcome.
Helping Survivors Help Each Other

Building a support system, connecting with those who have a similar experience, and having access to a knowledgeable peer are essential parts of the recovery process. Establishing a nationwide peer-mentoring program will connect people living with brain injury with each other, providing one-on-one access to trained volunteers, allowing people to find community resources and emotional support.

Project cost: $100,000

On-Demand Assistance 24/7

Creating BIAA Connect, an intuitive, dynamic application available 24 hours a day, 7 days a week, will support individuals facing the challenges of brain injury anywhere at any time. The result is an instant lifeline and virtual community where survivors and families can establish meaningful, lifelong relationships regardless of the type or severity of brain injury. Content creation, program moderation, volunteer training, and platform construction are necessary to produce this state-of-the-art resource.

Project cost: $150,000

Help Extend Our Reach

Connecting and Supporting Caregivers

Creating a virtual caregiver conference allows participants from around the country to come together to better understand the resources available to them and their loved one. Funding provides ongoing on-demand resource delivery on a variety of relevant topics. Participation in the program would be completely free of charge to the caregiver.

Project cost: $50,000

Help When It Is Needed The Most

The speed at which an individual with brain injury is connected to community-based resources and supports after injury has a direct impact on the quality of their recovery. Aggressive outreach to trauma centers nationwide, expansion of call center hours, professional resources, and case management assistance will connect more survivors to NBIIC when help is needed most.

Project cost: $500,000
Laura and Lance have spent more than forty years together serving the brain injury community. Laura, an occupational therapist active in BIAA’s Academy of Certified Brain Injury Specialists, helped design the resource facilitation model used nationwide. Lance is a neuropsychologist and recipient of BIAA’s Berrol Clinical Service Award for improving the quality of care, professional training, and education in the field of brain injury.

“While we have seen a lot of positive changes during the course of our careers, we still have a long way to go in understanding brain injury. The future will be defined by our youth, attracting the brightest young professionals into brain injury is critical.”

— Laura and Lance, brain injury professionals

Brain Injury Fact:

1 IN 3 PEOPLE INFECTED WITH COVID-19 have long-term neurological symptoms.
HELP EXPAND SPECIALIZED TRAINING

The Brain Injury Association of America’s Academy of Certified Brain Injury Specialists (ACBIS) is the largest and most respected national program providing education, training, certification, and ongoing resources for multi-disciplinary specialists in the brain injury community.

Providing up-to-date training and education to the many professionals and family members responsible for the direct care of people living with a brain injury requires state-of-the-art curriculum, custom content, and the ability to connect in a variety of settings. The following projects will allow BIAA to educate and certify caregivers, extending reach into new communities.
Help Expand Specialized Training

**More Brain Injury Specialists in Underserved Communities**

The direct costs associated with applying, preparing, and testing to become certified as a brain injury specialist are often out of reach for care professionals working in underserved communities. By providing scholarship support to qualified CBIS candidates, BIAA is able to improve care to targeted markets and ultimately increase the quality of rehabilitation and chances of recovery. Scholarships provide funding to cover the candidate’s application for the certification, study materials, test preparation and study course, test administration, and one year of fees.

*Project cost: $50,000*

**Access to Concussion Certification**

More than 6 million people in the U.S. sustain a concussion each year. The Certified Concussion Specialist Program includes curriculum, exam, and certification from BIAA’s Academy of Certified Brain Injury Specialists. Certification provides tools to qualified health care professionals to oversee concussion diagnosis, assessment, treatment, and management. Support of this opportunity will extend certification in underserved communities by using scholarship funds to cover the cost of certification, suggested study materials, test preparation and study course, and test administration.

*Project cost: $100,000*

**Spanish Speaking Direct Care Providers NAMING OPPORTUNITY**

The nationally recognized Brain Injury Fundamentals Training and Certificate Program provides essential information to those caring for people with brain injury including non-licensed direct care staff, first responders, family members, friends, and others in the community. The training course covers essential topics such as cognition, medical complications, and medication safety and management. More than one million Spanish-speaking caregivers could benefit from advanced training, ultimately improving outcomes for people with brain injuries.

*Project cost: $250,000*

**Family Caregivers NAMING OPPORTUNITY**

Millions of Americans serve as unpaid caregivers for a family member or friend. Caregiving can include, depending on the severity of the brain injury, operating a Hoyer lift, assisting with toileting and personal care, understanding medical complications, and safely managing medication, among many other diverse needs. Family members are often unprepared for the physical, emotional, and medical demands required of caring for their loved one. This opportunity will allow BIAA to modify and disseminate the Brain Injury Fundamentals Training and Certificate Program specifically for family caregivers who will receive the training they need to improve the quality of care of their loved one free of charge and available on demand.

*Project cost: $250,000*
Laurie is an advocate, a counselor, and the kind of person who sees a problem and does something about it. When she feared that the brain injury community was underrepresented during the 2020 U.S. Census, Laurie started a campaign to improve response rates. Noting that accessibility was an issue for the disability community during the recent election, she led an online movement to get out the vote.

“I can tell my voice is heard, which is so critical for those who are often dismissed. As just one of the millions of others whose lives have been deeply affected by brain injury, I feel that BIA has our back.”

— Laurie, advocate and person living with a brain injury

Brain Injury Fact:

1.6 MILLION WOMEN have sustained brain injuries as a result of intimate partner violence, but the total incidence is unknown.
BIAA is the voice for millions demanding greater access to care, expanded brain injury research, adequate resources for state programs, and increased congressional awareness of brain injury issues. BIAA’s efforts have greatly influenced what resources currently exist for brain injury rehabilitation. The following projects will allow BIAA to build on this successful history and increase resources for all living with brain injury.

**A Permanent Seat at the Table**

Powerful coalitions of patient advocacy organizations and healthcare providers seek to improve the quality of healthcare for Americans, influencing the resources available to assist recovery. It is critical that the brain injury community have a permanent voice as an equal partner in these important groups. Membership fees, assessments, and other associated costs make participation possible and provides access for the brain injury community.

**Project cost: $50,000**

**Marilyn Spivack Public Policy Fellow**

Named in honor of the Association’s co-founder, funding supports the direction of BIAA’s government affairs programming, engaging in regulatory activities with federal agencies, and legislative advancements with congressional lawmakers, linking the grassroots with policy makers. The fellow would provide training for advocates and support to affiliate leaders in their federal advocacy work.

**Project cost: $150,000**

**Nationwide Coverage for Brain Injury Rehabilitation NAMING OPPORTUNITY**

Comprehensive, intensive rehabilitation is the only standard of care after brain injury, proven to slow the progression of chronic disease after injury. With rehabilitation, individuals and families have hope. Funding will allow BIAA to provide a comprehensive legislative action plan and resources to states that would advocate for mandatory brain injury treatment, extending rehabilitation services nationwide.

**Project cost: $300,000**
Dr. Kumar grew up visiting his mother in her laboratory. Watching her work on experiments inspired him to pursue a career in public health focusing on important questions in TBI research. His post-doctoral research project entitled “The Epidemiology of Comorbidities and Associations with Functional Outcome among Adults with TBI” was funded by the Association’s generous donors.

“...This is the golden age of brain injury research, with many new, highly trained investigators entering the field. Organizations like BIAA are fundamental to our progress, playing an integral role in equipping researchers with the requisite resources to conduct their research."

— Raj Kumar, Ph.D., brain injury research scientist

Brain Injury Fact:

HALF OF ALL PEOPLE receiving treatment for substance misuse have a history of at least one brain injury.
Imagine a world where we learn how to heal the brain, where people do not live with the lifelong effects of brain injury, and where, rather than accelerating a disease, we can slow its progression or even stop it in its tracks.

The need to better understand brain injury, the impact it has as a chronic disease, and its role in causing other conditions has never been greater. BIAA is leading the way by investing in projects with potential for cures while encouraging the best and brightest investigators to devote their careers to brain injury research.
Dissertation Grant

BIAA recognizes outstanding doctoral dissertation projects that contribute to our understanding of chronic brain injury and its causes, consequences, and methods of mitigation by providing financial support to a future brain injury researcher. Dissertation Grants are funded up to $5,000 total for up to two years.

Seed Grant

Young Investigator Seed Grants support the background work needed to establish a line of research for a new investigator. Applicants are expected to use the seed grant to prepare for larger funding from the National Institutes of Health or other public or private source.

Brain Injury Scholar Seed Grants support principal investigators who wish to supplement an existing project by testing a new hypothesis, adding an additional cohort, or conducting additional statistical analyses of existing data. Brain Injury Scholars have a record of published articles in peer-reviewed journals or other demonstration of scientific inquiry.

Seed Grants in both categories are funded up to $25,000 total for up to two years.

Naming opportunities are available in both categories when an endowed fund is established.
None of this work will be possible without your help. To meet the ever-evolving needs of the brain injury community, the Association must continue to innovate and elevate programming.

Help BIAA expand services to reach more people, in more places, and in more ways.

Please consider a gift today.
MAKE AN IMPACT

Help extend BIAA’s reach by providing more resources and supports to the brain injury community.

Funding from donors and gifts of all sizes are essential. There are many ways to support brain injury services:

- Make a gift increasing BIAA’s current annual commitment to programs, services, and research;
- Contribute to one or more of our special project needs advancing our reach by making a single year or multi-year commitment or in perpetuity though an endowment;
- Transform BIAA’s ability to fund services by considering a planned gift or remembering the Association in your will or estate plan.

For more information about the Brain Injury Association of America or the projects described in this document, please contact Robbie Baker, Vice President & Chief Development Officer, at (703) 761-0750 ext. 648 or via email at rbaker@biausa.org.