

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 15, Issue 4

THE CHALLENGE!



LIFE AFTER BRAIN INJURY

DECEMBER 2021

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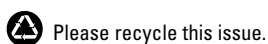


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FROM MY DESK



It is hard to believe another year has almost come and gone. The end of the year marks a busy time for the Brain Injury Association of America (BIAA) and for me personally. I take stock of all that BIAA has accomplished and begin planning for the year ahead. I am reminded to thank those who make BIAA's mission possible – our board of directors, state affiliates, committee volunteers, corporate sponsors, individual donors, and our incredibly talented and hard-working staff. I am grateful to the thousands of people who power our work.

The end of the year is also a time to reflect on our losses. COVID-19 has claimed more than 700,000 lives since the start of the pandemic in early 2020. As I write this message, more than 47 million people have been infected in the United States. Thankfully booster shots are now available in many areas, and Pfizer is developing an oral antiviral treatment. Let's hope we get control of this pandemic in 2022 and that life goes back to normal or at least a new normal.

Just like the thousands of families who have lost loved ones to COVID-19, families of loved ones lost to brain injury may also be grieving as the holidays draw near. If you've not done so lately, I urge all Challenge readers to Google "How to Deal with Grief During the Holidays." The Psychology Today website offers nine coping strategies that might really work. My favorite suggestions were "Do Something Kind for Others" and "Ask for Help." Perhaps we will all remember those ideas when we feel ourselves spiraling downward.

For now, I wish Challenge readers and everyone in the brain injury community a very happy and healthy holiday season and a prosperous new year.

May all your dreams come true!

A handwritten signature in black ink that reads "Susan H. Connors".

Susan H. Connors, President/CEO
Brain Injury Association of America

A Message from the Editor: My name is Dianna Fahel and I've been editor-in-chief of *THE Challenge!* since June 2016. This marks my 23rd and final issue as editor. I have loved planning, writing, curating, and proofreading every issue of this newsmagazine over the last five years. It has been an honor to help the Brain Injury Association of America serve and represent the brain injury community. Happy reading!



Unpredictable Laughing and Crying?

YOU CAN TAKE BACK CONTROL!

*By Susan H. Connors, President/CEO,
Brain Injury Association of America*

Imagine yourself at a funeral or other solemn occasion when a gentleman in the pew next to you suddenly bursts out laughing. Other mourners turn and stare while embarrassed family members hide their eyes. There's nothing funny about the situation, but the man is unable to control his emotions. He may have pseudobulbar affect or PBA.

PBA is a medical condition causing sudden, frequent, uncontrollable crying and/or laughing that doesn't match how a person feels. It is common among people who have experienced neurologic injury or illness, such as brain injury, stroke, multiple sclerosis, Alzheimer's disease, and ALS (amyotrophic lateral sclerosis). There may be as many as two million people living in the U.S. with PBA.

For more than a decade, the Brain Injury Association of America (BIAA) has been learning about PBA, the proportion of people with brain injury who experience PBA, and how to get control over the condition. In our first survey of individuals with brain injury and their caregivers, conducted in summer 2010, we learned approximately half of the 248 respondents exhibited PBA symptoms frequently or often. Two-thirds of those who experienced PBA said the episodes were burdensome, reporting that it interfered with

friendships and social activities and contributed to becoming housebound. One survey respondent stated: "I have found myself staying inside, avoiding interaction with others, high anxiety when participating in family activities due to knowing I may break out in tears... Makes others very uncomfortable, and I do not want others to feel sorry for me or have my injury be the center of all communications with others."

In autumn 2018, BIAA conducted another survey about PBA. This time, 151 respondents described the condition as "frustrating," "embarrassing," "unpredictable," and "misunderstood." The majority of respondents discussed their PBA with a neurologist or primary care physician, but almost one-quarter did not discuss it with a doctor, claiming it was too embarrassing or nothing could be done about it. About one-third of respondents said they talked to a psychologist or psychiatrist about their PBA, suggesting their belief that PBA is a mental health disorder and that the laughing or crying outbursts are somehow willful. More than half of the survey participants said they had not received treatment for their PBA.

It was time to find out why!

BIAA conducted a third survey in September 2021. A total of 110 respondents reported having experienced PBA. Slightly more than half were male and age 50 or older. The primary causes of injury were motor vehicle accidents (40%), falls (14%), and strokes (14%). The vast majority of respondents sustained moderate or severe injuries. The PBA symptoms appeared anytime immediately following the injury to 2 or more years later. One respondent explained: "I was having a lot of uncontrollable crying/breakdowns for no reason. After I would be like, why was I crying over something stupid? Or the laughing was really bad, certain times it's not appropriate and I couldn't control that."

In this year's survey, the majority of people with brain injury (or their loved ones) talked with a clinician about the PBA symptoms, but 25% of respondents did not. Of the majority who did talk about the condition, many found it was difficult to get an accurate diagnosis, much less treatment. As one person stated, "Doctors never mentioned it. Learned about PBA & Nudexa from an NPR story."

Of those who did discuss the condition with their physicians, 21% were referred for psychological counseling, but most said that treatment didn't work. About 55% of respondents said they were prescribed an antidepressant for their sudden, frequent, uncontrollable crying and/or laughing, and 73% of them still take the medication. Those who discontinued the treatment said they did so because the antidepressant didn't work or the side effects were intolerable. As one respondent explained: "It took 4 different doctors before being referred to a psychiatrist, who then properly diagnosed me with PBA. Other doctors just kept trying me for depression, even though I explained I was not depressed. I am still having trouble accessing a Medicaid waiver and have been on a waiting list for 3 years... There is not enough awareness & understanding about how debilitating PBA can be. PBA is more than laughing & crying; it affects my ability to organize, remember things, multitask, or control emotional outbursts."

Of the 110 survey respondents who said they had experienced PBA symptoms, 18 had been prescribed Nuedexta®. Of those who were prescribed the medication, slightly less than half (47%) still take it. More than half (65%) of respondents who received Nuedexta for their PBA symptoms said it improved the quality of their life. One respondent explained: "When I was taking Nuedexta, my brain felt more clear – clarity and focus, not overtaken by the desire to cry or laugh or even my depression and severe anxiety. It enabled me to act, to move, to execute plans and trust my brain, which had been unreliable and very noisy until then. Nuedexta lowered the noise and improved my confidence and tolerance, which also improved the suicidal ideation."

Those who stopped taking Nuedexta did so for a variety of reasons, including because it was no longer covered by insurance. In fact, 44% of survey respondents were denied insurance coverage for Nuedexta despite the positive results the medication produced. As one person said, "I wish I could get the medication again. It was beyond helpful – it was life changing."

Of those who were denied, 75% appealed, but the results were mixed. Many were denied a second time; some are still waiting for the results.

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In our survey, respondents' insurance varied widely: Medicare (15%), Medicare Advantage (18%), Medicaid (18%), Employer or Individual Health Plan (28%), Uninsured/Self-pay (9%). Individuals with brain injury and their loved ones are familiar with being denied access to necessary treatment regardless of the type of health plan/insurance coverage they may have.

BIAA has decided to fight back!

Please join us for two free educational webinars. Visit shop.biausa.org/livewebinars to register.

Assess Your Need

At the end of this article, readers will find the Center for Neurologic Study-Lability Scale (CNS-LS) for Pseudobulbar Affect (PBA). The CNS-LS is a short questionnaire that can help individuals with neurologic illness or injury identify the presence of PBA symptoms and their frequency. After a week of tracking, patients can share the questionnaire with their physicians.



Looking for brain injury information?

Check out BIAA's Online Resource Center!

From free webinars and research updates to timely articles and stories from survivors, our Resource Center has something for everyone.

Visit biausa.org/resource-center to find what you need.

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Center for Neurologic Study-Lability Scale (CNS-LS)

Patient assessment	Applies never	Applies rarely	Applies occasionally	Applies frequently	Applies most of the time
There are times when I feel fine one minute, and then I'll become tearful the next over something small or for no reason at all	1	2	3	4	5
Others have told me that I seem to become amused very easily or that I seem to become amused about things that really aren't funny	1	2	3	4	5
I find myself crying easily	1	2	3	4	5
I find that even when I try to control my laughter, I am often unable to do so	1	2	3	4	5
There are times when I won't be thinking of anything happy or funny at all, but then I'll suddenly be overcome by funny or happy thoughts	1	2	3	4	5
I find that even when I try to control my crying, I am often unable to do so	1	2	3	4	5
I find that I am easily overcome by laughter	1	2	3	4	5

Source: Moore, SR et al. J Neurol Neuro J Neurol Neurosurg Psychiatry. 1997;63(1):89-93.

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LIVING WELL AFTER BRAIN INJURY: TIPS FROM BIAA'S BRAIN INJURY ADVISORY COUNCIL

*By Paul Bosworth, Anne Forrest, Darcy Keith, Kelly Lang, Kellie Pokrifka, Carole Starr, and Angela Leigh Tucker,
BIAA Brain Injury Advisory Council Members*

Collectively, the members of the Brain Injury Advisory Council have been living with brain injury for 130 years! That's a lot of hard-won wisdom about how to live well after brain injury. Read on for some of their perspectives and strategies.

There's always something you can do.



Brain injury often takes away activities we used to do and changes who we are. The more we focus on all the losses and what we can't do, the worse we feel about ourselves. Yes, it's important to grieve the losses, but make sure you also spend time learning about the new you. Explore something that brings you joy! Start with a small activity, find success, and gradually build on it. Trying new things can be a path to increasing your self-esteem and self-confidence. Experiment with new activities and know that it's OK and expected that you will make mistakes along the way – they are part of the process.

There are multiple solutions for working around our deficits.



If plan A doesn't work for your brain, try plan B, C, D and beyond. Set up at least two plans. If forecasting is challenging for you, try reaching out to someone you trust for support. When things don't go according to plan, be gentle with yourself and know that you're doing the best you can. Sometimes the biggest setbacks can be the biggest opportunities for growth. Persistence and practice are key. Know your limits. Recognize what you do and don't have control over. Keep moving forward; you've got this!

Living with brain injury means learning how to manage symptoms.



To thrive with a brain injury, we must learn to recognize our triggers and adapt to factors that make our symptoms worse. When your "brain battery" only has so much "charge" it's important to know what activities will drain your energy and how to mitigate those feelings. One example is eating at a restaurant, which is one of life's pleasures that can be challenging after brain injury. Eliminate the stress of decision-making by reading the menu ahead of time, deciding on your order, and writing it down for when you arrive. If car sickness affects you, arrive early to allow yourself time to recover before socializing. You can also try positioning your seat to accommodate for your needs. If visual stimuli are difficult, for example, sit facing a wall to help reduce things in your visual path or sit outside or by a window to reduce the strain of fluorescent lighting. If auditory stimuli make you feel worse, try sitting with the wall behind you to reduce noise. Don't forget to bring your brain injury toolkit – things like ear plugs, sunglasses, and medications can make it easier to be out and about. It's all about knowing what your brain needs.

Optimize your brain for long time periods.



Returning to meaningful activities, whether that's paid work or a volunteer position, requires a lot of thought and consideration of how much energy will be required. Identify whether mornings, afternoons, or evenings are best for you. If you want to tackle an activity that lasts



all day, take a break at lunch in a quiet place to recharge. Set a timer on your phone, dim the lights, and rest your head. Afterward, go back to your activity when your break is over. It's hard to focus on doing a job when you're hungry, so make sure to take a healthy snack break every few hours. You can reduce distractions by turning off things that may bother you, closing the door, and setting up an appropriate area for you to work. Finding a rhythm enables productivity.

Take ownership of your recovery and be open to new therapies.



"I've tried everything, nothing works." If you've said this to yourself, it's time to try something new. As much as we want our doctors to have all the answers, it's still up to us to learn as much as we can. There are more therapies than meet the eye. Two things to keep in mind: insurance doesn't cover every expense and each brain injury recovery is different. Start with the belief that healing can happen. We may not be able to return to our former selves, but progress is possible. Try exploring music, massage, yoga, and oxygen or cranial sacral therapies if appropriate. Persistence and trying new things will pave the way to enable a better day.

Living well after brain injury means recognizing the role of caregivers, too.



Family is the first line of support. Brain injury impacts more than just the survivor; the entire family and support network feels it, lives it, and walks through it together.

We always talk about the survivor's feelings, therapies, progress, and frustrations, yet the family and caregivers are experiencing those things as well. Just as survivors are doing their best in a challenging situation, so too are our caregivers. It is important for caregivers to take care of themselves so they can give quality support to their loved ones. Relying on one another is vital to the continued recovery and healing of the entire family.



Wellness is within your reach.

So much of brain injury recovery is out of our control; however, the most important basic tools to healing are accessible to each of us. These include sleep, exercise, hydration, nutrition, and meditation. Getting enough sleep and exercising can improve our energy, hydration can help mitigate some symptoms, eating nutritious foods can improve overall health, and meditation can calm a busy brain. Starting with just one of these habits can transform your continued recovery and help you maintain a balanced life.

For more tips from the Brain Injury Advisory Council, visit biausa.org/livingwell.

Faster Care, Better Recovery:

Why Air Ambulances Are Crucial for Brain Injury Patients

By Christina Kanmaz, SOAR Campaign



Every nine seconds, someone in the United States sustains a brain injury.

Due to their unpredictable nature, brain injuries can happen anywhere and at any time. Air ambulances play a critical role in helping those who sustain brain injuries get the care they need quickly, especially in rural and underserved areas where the closest trauma center could be hundreds of miles away. Air medical flight bases stand at the ready 24/7 year-round and are staffed with highly trained medical professionals, critical care nurses, and emergency responders. This level of preparedness allows them to deploy at a moment's notice – as soon as a car crash, drowning, stroke, seizure, or other medical emergency takes place. They can arrive at the scene of an emergency in a fraction of the time it takes a ground ambulance.

For those who sustain brain injuries, time is of the essence. The faster a patient arrives at a trauma center and receives continuous neurological care, the better their outcome. Each year, 2.8 million people sustain a traumatic brain injury, requiring immediate medical attention. Unfortunately, access to care is limited in certain parts of the country.

Since 2010, 136 rural hospitals have closed across the U.S., with 20 rural hospitals closing in 2020 alone, making it a record year for closures. This threatens a rural hospital's ability to maintain access to services and, if they close, it puts the roughly 60 million Americans who live in rural areas at risk.

Your ZIP code should never determine the level of care you receive.

Protecting access to air ambulances is vital to ensuring patients who live far from a hospital or trauma center can be transported there quickly in emergencies. With more than 75% of the nation's ICU beds full, hospitals and patients are increasingly reliant on air medical services for quick transport to hospitals and emergency rooms with open beds, which can sometimes be located hundreds of miles away in a different state.

Even though air ambulances have been crucial during the pandemic, a majority of emergency air medical providers continue to be reimbursed far below the

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The SOAR Campaign is dedicated to preserving access to emergency air medical services.



The Problems:

- **More than 130 rural hospitals have closed since 2010**, exacerbating the problem where **85 million Americans** live more than an hour away from the nearest Level 1 or Level 2 trauma center best suited for treating brain injuries.
- COVID-19 cases continue to overwhelm hospitals and **three-quarters of ICU beds across the country are full**, leading to increased air ambulance transports.
- **70% of transports** are patients with Medicare, Medicaid, or other government insurance, which **reimburse far below the cost of service**.
- Without proper reimbursement, air medical bases are **forced to reduce services or shut down entirely**.

The Solutions:

- Air medical providers must receive **fair reimbursement rates** to continue providing lifesaving care.
- The Department of Health and Human Services (HHS) must fairly implement the No Surprises Act to **differentiate between independent non-hospital providers and hospital-based providers** to account for the completely different cost and reimbursement structures.
- Insurers must work with air medical providers to **go in-network** and reimburse for these life-saving services.

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actual cost of transport because more than 70% of their patients have Medicare, Medicaid, other government insurance, or are uninsured. Medicare reimbursement rates have not been updated in more than 20 years, and they only cover approximately 50% of transportation costs.

If air medical providers do not receive proper reimbursement, they could be forced to shut down their bases, further reducing access to care.

Private insurers have a responsibility, too. Patients should never be left with a bill they cannot afford, so private insurers must bring providers in-network with rates that are negotiated fairly. If large insurers refuse to bring independent air medical providers in-network and cover the true cost of services, millions could lose access to lifesaving care.

The recently passed No Surprises Act of 2020 takes a step in the right direction by putting patients first and removing them from the middle of billing disputes. Unfortunately, the U.S. Department of Health and Human Services (HHS) is proposing to implement this

new law in a way that favors insurance companies over patients. If providers do not receive a fair reimbursement for providing medical care, they will be forced to reduce services or close their doors altogether. This would be devastating, particularly in rural areas where access is already a challenge.

While HHS reviews public comment on this new rule, we need patients to raise their voices to say that the No Surprises Act rule is unfair and threatens access to lifesaving care. You can learn more by heading to soarcampaign.com.

Brain injuries do not come with a warning – they can happen at any time and, when disaster strikes, air ambulances must be there to respond. The air medical industry must be preserved for the millions of patients who rely on the swift transport of air ambulances to get them safely to the nearest and most appropriate medical facility.

Christina Kanmaz is the national spokesperson for the Save Our Air Medical Resources (SOAR) Campaign



GET JUSTICE.

BIAA PREFERRED ATTORNEYS UNDERSTAND BRAIN INJURY

LEARN MORE AT BIAUSA.ORG/ATTORNEYS

HAS A TRAUMATIC BRAIN INJURY CHANGED WHO YOU ARE?



The image depicted contains models and is being used for illustrative purposes only.

A CLINICAL RESEARCH STUDY FOR BEHAVIORAL CHANGES RESULTING FROM A TRAUMATIC BRAIN INJURY (TBI)

If you or someone you care for are experiencing **aggression, agitation, or irritability**, and these behaviors began after suffering a traumatic brain injury (TBI), consider participating in a research study that is evaluating an investigational drug for the potential treatment of behavioral changes resulting from a TBI.

To be eligible for this study, a potential participant must:

- ✓ Be between 18 and 75 years old.
- ✓ Have been diagnosed with a TBI for 6 months or more.
- ✓ Have a history of aggression, agitation, or irritability that was not present before the TBI.
- ✓ Have a reliable study partner.

Additional criteria will be assessed by the study doctor. All study-related visits, tests, and study drug will be provided at no-cost. In addition, reimbursement for study-related travel may be provided.

To learn more about this TBI study, please contact
1-855-915-0497, or visit **www.TBItrials.com**.

“She Looks Fine”

Reflections from a Caregiver



*By Kelly Lang, Brain Injury Association of America
Advisory Council Member*

If only I had a dollar for every time I’ve heard those three words. Of course, I am thrilled my daughter does not have scars or other physical signs following her traumatic brain injury, but that doesn’t mean she doesn’t have challenges. Surprisingly, her appearance has become an issue.

Olivia’s injury is the result of a horrific motor vehicle accident that happened in November 2001, when she just was three years old. She was not expected to survive; her pediatric neurologist called her a “miracle child.” After reviewing the MRI, the doctor commented to me he had seen many brain injuries over the years and that hers was catastrophic. He’d worked with patients who had less severe injuries and never learned to eat, walk, or talk again. I’m proud to say that she has learned all those things and more.

She does not remember her “before.” This, too, is a curse and a blessing. At three, she just started attending preschool two mornings a week and loved to play with figurines and Barbie dolls. She had just begun learning her letters and the concept of sharing. She does not have

any memory of those times now, and I am not sure if that is due to the injury or the fact that she was only three.

While in kindergarten, following two years in the special education preschool, Olivia did not stand out amongst her classmates. She was in a program for kindergartners who needed a bit of extra help learning, but other than that she fit in. Issues began once she reached first grade and her learning difficulties became more apparent. Her processing issues slowed her down and the social issues started escalating. As the years went on, these issues would continue and, in some cases, get worse before any improvement.

I always made a point to meet with her teachers before the beginning of the school year for the purpose of explaining why she had an Individualized Education Plan (IEP) and how her disability affected her. A number of these teachers and case managers approached me during the year and commented on how helpful it was to have that information given that Olivia walked into classrooms trying to blend in as much as possible. Once they got to know her, the issues became more apparent.

She graduated high school in June 2017, which was a huge accomplishment. She has taken a few classes at the local community college, and many of her professors have asked her why she has accommodations. We had to meet with the director of disability services at her school. After Olivia left to get to class, the director said, “Wow, she can communicate so well!” I did not have a response. I walked out, incredulous that the director of disability services would make that comment – especially to her parent.

Unfortunately, having an invisible disability has been a detriment to her over and over throughout the years. Peers have a difficult time communicating with her because she cannot process the information. She becomes forgetful and does not respond to messages, she will not be able to drive, she is fearful of loud noises, etc. I could go on and on.



Kelly Lang, left, stands with her daughter, Olivia.

When a doctor or therapist comments about her “looking fine” after an appointment, I am bewildered. These are the “experts” and I need them to understand her ability and disability. I realize they only see her for a fraction of her day and she is on her best behavior, always eager to make a good impression. I need them to listen closely for the clues that indicate she is not fine. She is struggling; her family is struggling.

During a recent family vacation, we hiked in the Smoky Mountains. The climb to a waterfall was beautiful and the trail was not very crowded. The descent was a different experience. The trail dropped off a bit to the right if you walked a few feet from the path. Olivia was afraid to walk. I walked on the right side giving her more room to navigate away from the drop off. Our system was working well until another hiker or group came along walking up the trail. It was narrow and only allowed for two or four people, depending on the width. Olivia did not want to move to her right for fear of falling down the cliff. I tried to help, but we received a lot of dirty looks. I wished we had something to indicate she has a disability and could not walk securely.

I am eternally grateful Olivia did not suffer any noticeable physical impairments. There are some but not any visible to someone who does not know her well. My goal is to educate others about brain injury and the effects it has on the survivor as well as the family. I hope others will learn things are not always as they seem.

Three Tips from A Caregiver's Perspective

1. No one knows your loved one as well as you do. Follow your instincts and listen to your gut – it's often right.
2. Doctors do not know everything. As we all know, each brain injury is different. Medical professionals can give you a prognosis, but it is only an estimate.
3. Keep advocating for your loved one. If you think something isn't working, speak up, get second and third opinions, and ask questions. Speak to other caregivers to get support and guidance and never give up.



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**In memory of
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Mrs. Carolyn Rocchio

In memory of Scotty
Dr. Debra Luczkiewicz

**In memory of
Ed Siegel, beloved stepfather**
Ms. Sheryl Stolzenberg

**In memory of
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In support of Pass the Bass
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(continued on page 18)

FACEBOOK FUNDRAISERS

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THANK YOU!



Thank you to our recurring donors. Their support helps form a predictable source of income we can count on to fund services for people living with brain injury and their caregivers. For more information about how you can become a BIAA Amplifier, visit biausa.org/biaa-amplifier.

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THE BANNER HOUSE STORY

Photo credit: Debra Myrent

By Margaret (Peggy) Harris, MPH, CBIS, Retired Founder of Banner House

In 1992, my sixteen-year-old daughter, Jennifer, was injured in a car accident. In a coma for three months, Jen received inpatient rehabilitation services for almost a year. Our family, which included Jen's two younger sisters and her father, welcomed her home. All too quickly, we learned that Jen's injury had affected her behavior, perhaps permanently. Her bursts of anger were disruptive and unpredictable. Jen would refuse to take her medications. Unfortunately, it became clear that Jen's recovery with us at home was no longer an option. After nine months, I sought out rehabilitation facilities that included housing.

I found residential communities that offered rehabilitation services, but most were far away from our home. Jen lived at three different facilities in Apple Valley, California – more than two hours away from family. While she improved and made advances, like obtaining a special education high school diploma at 21, it was clear that she needed a well-staffed home to

meet her many needs. We knew Jen needed to be close to home, yet have some independence, and be with caregivers trained to assist her. I studied everything about rehabilitation and therapies for Jen. I wanted to train staff to reinforce her good behaviors and ignore the worst. Cognitive behavioral therapy techniques with consistent responses to behaviors seemed to work best. Since I felt the need, I trusted that others would also see the benefit of a well-designed and well-staffed adult residential facility (ARF) for adults living with brain injuries. "Build it, and they will come," was the phrase a friend used for an article about Banner House.

In 2007, I found a home in Ventura that I believed could be modified to be a residential facility for adults living with brain injury. It took close to a year to remodel the house, providing four bedrooms and a staff office. Among the many improvements made, the house needed a sewer system. The half-acre Ventura property on a large flat street was lined with houses using septic tanks.

I ran a sewer line to a large line that crossed the back of the property. In many ways, I re-built the house for its future purpose. I kept going on a dream of building a beautiful home. I had to move the kitchen to improve functionality and give it a garden view. A detached outbuilding became serviceable as a living space by the addition of plumbing. The trip to the laundry facility involves a walk through the garden. I wanted to create a home where people would want to live.

I enrolled in classes to fulfill California regulations and learned the basics of running a California-based home for up to six adults. I became an ARF Administrator and later sent administrative staff through the same training to become ARF Administrators. We had two residents who could not control their eating, but we could not lock the refrigerator due to state code. Dishwashing detergent could not be accessible for a resident who liked doing the dishes. It had to be locked. I was working for the resident's best interests, but sometimes this got me into trouble with the California Department of Social Services. This home was specifically designed for brain injury survivors.

I also sought certification as a Certified Brain Injury Specialist (CBIS) from the Brain Injury Association of America, which enabled me to have a quantifiable knowledge of the spectrum of medical and social issues. With the CBIS accreditation, my years of acquired knowledge gained validation.

Landscape design has been a passion and my vocation for many years. Banner House provided an opportunity for me to create a pleasing outdoor setting for Jen and her housemates. With the help of the residents and staff, we keep a healthy blend of drought-tolerant plants here in water-stressed Southern California. Organic vegetables were served from the garden until California regulators ruled that we could not serve backyard-grown food. It was a lovely place to live and work.

Caregivers, volunteers, and professional staff were all part of the village that made Banner House possible. Early on, I sought out the Brain Injury Center of Ventura County (BICVC) for their support and expertise. BICVC support groups met at Banner House and volunteers helped with some of our remodeling projects. After Banner House opened with residents, we created a "Friday Night Club," which was an open house and

dinner, extending a permanent invitation to all brain injury survivors in the area to attend. Banner House became a place to visit for help with homework, friendship, and support for survivors in the community. Friday Night Club later morphed into a first Saturday of the month outdoor lunch. We also made sure that Banner House residents attended support groups and events, sponsored by BICVC.



Jen Harris, left, with Peggy Harris enjoying a sunny day at Banner House.

Photo credit: Debra Myrent

In addition to BICVC, I relied on wonderful support from friends, family, and the brain injury community. My youngest daughter, Dr. Caitlin Harris Hwang, became an ARF Administrator and worked at Banner for several years before she entered medical school. The Brain Injury Association of America, the Brain Injury Association of California, and Dr. Mark Ashley and the Center for Neuro Skills in Bakersfield have all been steady sources of knowledge and support.

Today, Banner House is providing a secure and supportive environment for five residents under the management of the nonprofit Brain Injury Center of Ventura County. Each resident, including Jen, is very much an individual, living to his or her fullest, and sharing in the responsibilities of Banner House. To learn about Banner House, visit braininjurycenter.org. ●



ADVOCACY UPDATE

By Susan Connors, President/CEO, Brain Injury Association of America

President Signs Infrastructure Law

President Joe Biden signed the Infrastructure Investment and Jobs Act, a \$1.2 trillion investment in America's infrastructure and competitiveness. The bipartisan law will rebuild America's roads, bridges, and railway system. It will expand access to clean drinking water and high-speed internet. The law addresses climate change, advances environmental justice, and invests in communities that have too often been left behind.

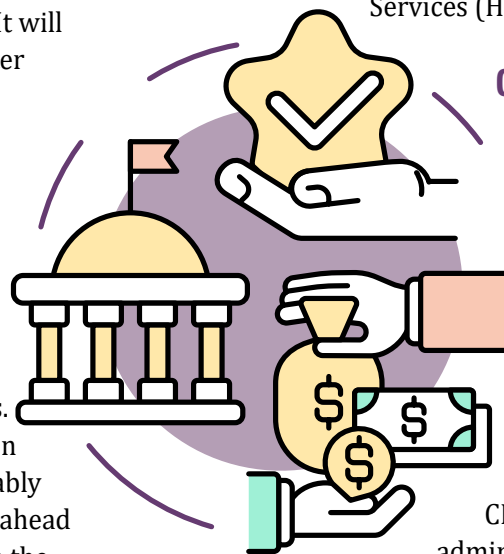
The law is expected to help ease inflation and strengthen supply chains by improving our nation's transportation and delivery systems. It will bring about good-paying union jobs and grow the economy sustainably and equitably so that everyone gets ahead for decades to come. Combined with the President's Build Back Framework, it is expected to add 1.5 million jobs per year for the next 10 years.

President Releases Build Back Better Framework

After meeting with Democratic leadership and the Progressive Caucus in the House of Representatives, President Biden announced a \$1.75 trillion framework for the Build Back Better reconciliation package known as the "human infrastructure" bill.

The framework includes universal pre-school and child care subsidies, expanded home care for seniors and people with disabilities, and an extension of the child tax credit through 2021. It also would expand Medicare to cover hearing benefits, extend Medicaid coverage to 4 million people, and reduce premiums under the Affordable Care Act.

The \$1.75 trillion package left out some priorities that had been targeted such as free community college, dental benefits for Medicare beneficiaries, and paid family leave. The pared-down bill still includes \$150 billion for Medicaid Home and Community-based Services (HCBS), referred to as home care.



CMS Launches Webpage on State HCBS Spending Plans

The Centers for Medicare & Medicaid Services (CMS) launched a new "one-stop shop" for state Medicaid agencies and stakeholders on Medicaid.gov to advance transparency and innovation for Medicaid home and community-based services (HCBS) for individuals with disabilities or for older adults.

CMS encourages stakeholders and state administrators to visit Medicaid.gov to view states' programs and activities. The site includes information on states' spending plans for the enhanced federal match – Federal Medical Assistance Percentages (FMAP) – in accordance with the American Rescue Plan.

CMS has received HCBS spending plans from 50 states and the District of Columbia. Forty-eight states have been fully approved to claim the HCBS FMAP increase retroactively to April 1, 2021, and to begin implementing activities in their spending plans and narratives. Additional information has been requested from three states. States are using the enhanced federal match to support provider increases; to expand services to new populations, such as brain injury; and to recruit and to retain direct care workers. The spending plans also include information about how the state involved stakeholder engagement with regard to the priorities for the increased funding. About half of states administer separate brain injury HCBS waiver programs.

NIH Releases Rehabilitation Research Plan



The National Institutes of Health (NIH) released its Research Plan on Rehabilitation, NIH Pub. No. 21-HD-8171, October 2021. The Plan was developed by the National Center for Medical Rehabilitation Research (NCMRR), in consultation with the Eunice Kennedy Shriver National Institute of Child Health and

Human Development, the NIH Medical Rehabilitation Coordinating Committee, and the National Advisory Board for Medical Rehabilitation Research.

The Plan reports the agency's progress since 2016 when the last plan was released and presents the revised research objectives. It is organized into six priority areas: 1) Rehabilitation Across the Lifespan; 2) Community and Family; 3) Technology Use and Development; 4) Research Design and Methodology; 5) Translational Research; and 6) Building Research Capacity and Infrastructure. The Plan also describes collaborations with other agencies and highlights the significant increase in NIH rehabilitation research investment, which grew from \$514 million in 2015 to \$847 million in 2020.

The following statement was excerpted from the Foreword on COVID-19 and Health Disparities:

"The COVID-19 pandemic has created an environment in which virtual work, school, recreation, worship, and healthcare experiences are more common, almost expected. This dramatic shift may have large repercussions on accessibility and inclusion of people with disabilities in their communities and schools. Despite the immense potential of these expanded opportunities, accessibility and access to virtual environments are not guaranteed. Moreover, this new virtual era only heightens the need to overcome barriers to inclusion and accessibility not only in society and medicine, but also in research and community services."

COVID-19 Task Force Releases Recommendations

The Presidential COVID-19 Health Equity Task Force released its Final Report and Recommendations October 2021. As of the publication date, COVID-19 had killed more than 700,000 people in the U.S. and infected tens of millions. All Americans have been affected, but not equally.

Individuals from communities of color and other underserved populations have been disproportionately affected and, as a result, have borne the brunt of this pandemic. To reverse this trend, the Report offers 55 recommendations for change within five broad priority areas:

1. Invest in community-led solutions to address health equity
2. Enforce a data ecosystem that promotes equity-driven decision making
3. Increase accountability for health equity outcomes
4. Invest in a representative health care workforce and increase equitable access to quality health care for all
5. Lead and coordinate implementation of the COVID-19 Health Equity Task Force's recommendations from a permanent health equity infrastructure in the White House

The Brain Injury Association of America is pleased with the Rehabilitation Research Plan and the Health Equity Task Force Report, having submitted comments to NIH and the Administration, respectively, as part of its role as a member of the steering committee of the Disability and Rehabilitation Research Coalition.

TBI Objective in Healthy People 2030

The U.S. Department of Health and Human Services (HHS) is updating the Healthy People 2030 objectives. TBI is one of three new objectives being proposed. The new objective would be stated as: "Increase the percentage of adults who can resume 50 percent or more of preinjury activities (with or without supports) 5 years after receiving acute inpatient rehabilitation for traumatic brain injury." The TBI Model Systems database, administered by the National Institute on Disability, Independent Living and Rehabilitation Research, will be the data source for measuring achievement of this goal. ●



STATE AFFILIATE NEWS

KANSAS

The Brain Injury Association of Kansas and Great Kansas City (BIAKS-GKC) has had a very busy fall, offering two virtual conferences for professionals along with a family and survivor Seminar in November.

The professional conferences included sessions on neuropsychology, pediatric brain injury, and mental health, criminal justice, domestic violence, and racial and cultural inequities affecting TBI services. Conference participants received continuing education credits and could view recorded sessions at a later date. More than 100 health care professionals attended each conference.

BIAKS-GKC held its first in-person Family & Survivor Seminar in more than two years. The seminar, "Moving Forward with a Brain Injury," was a day-long event that brought attendees from throughout Kansas and the metro area. Presentations during the day covered aging with a brain injury, available tech devices, and employment opportunities. Exhibitors attended the conference and provided additional information on available services.

For more information about BIAKS-GKC, visit biaks.org.

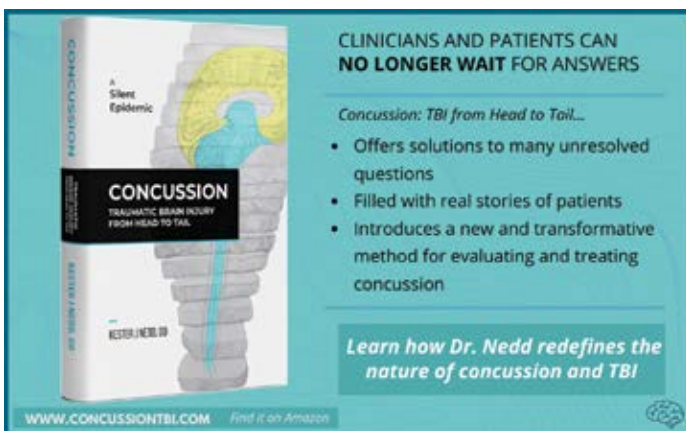
LOUISIANA

Over the past few months, the Brain Injury Association of Louisiana (BIALA) has worked to raise awareness of brain injury through community events and assisted with disaster relief efforts from Hurricane Ida.

Before Hurricane Ida struck Louisiana, our Resource Center was busy sharing valuable information on emergency preparedness with those we serve. We provided emergency preparedness backpacks to support group leaders and rehabilitation hospital case managers statewide. We also assisted with critical evacuation efforts and connected individuals to much-needed resources after the storm.



In October, we recognized Domestic Violence Awareness Month to raise awareness of domestic violence as a cause of brain injury for women in particular. We sponsored and participated in the Mande Milkshaker's 3rd Annual Walk a Mile in Her Shoes® Mandeville event. Participants, especially men, walked a mile wearing ladies' shoes. Not only did the event raise great about domestic violence, but it also helped raise \$11,200 for Safe Harbor, a domestic violence program. To learn more about brain injury and community events in Louisiana, please visit biala.org.



MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held the 12th annual conference on Defining Moments in Brain Injury virtually Oct. 13. Gary Seale, Ph.D., gave his two-part keynote titled “Self-Care Strategies and Advances in Brain Injury Treatment,” and stroke survivor and aphasia advocate Thomas Broussard, Ph.D., gave the Beverley Bryant Memorial Lecture. Presentations covered a variety of topics including Maine brain injury resources, the intersection of intimate partner violence and brain injury, alternatives to guardianship, and virtual service delivery.

BIAA-ME also continues to partner with Speaking Up For Us (SUFU) of Maine to provide outreach and education on self-advocacy to the Maine brain injury community.

Guy Pilote, a Maine stroke survivor, reached Mount Katahdin in late October after hiking the Appalachian Trail from Georgia to Maine to raise awareness of brain injury. Though he and his family had to turn around 1.5 miles from the summit due to hazardous conditions, Guy’s hike is an incredible accomplishment. Guy has also been using his hike to help support the Maine brain injury community by raising money for BIAA-ME. BIAA-ME is grateful to Guy and his family for all they have done to raise awareness. To learn more about his story or to donate, visit biausa.org/guypilote.



Guy Pilote hikes the Appalachian Trail to raise awareness of brain injury and funds for BIAA-ME.

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) held its annual conference Oct. 7-8 in St. Louis. Sessions focused on health disparities, inequities for persons with brain injury, and the increase in stroke risks for COVID-19 patients. The Survivor and Family Day of the conference included sessions on assistive technology, relationships, understanding types of doctors, and navigating the workforce. Recordings of these topics are available at biomo.org.

BIA-MO honored Clayton Fenter with its BIA-MO Lifetime Achievement Award 2021. Clayton’s 20-year involvement with BIA-MO includes participation in the Donald Danforth Jr. Wilderness Camp, survivor and family seminars, Finance Committee, board of directors and more.



Clayton Fenter receives BIA-MO Lifetime Achievement Award 2021

(continued on page 26)



NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) held its 38th Annual Golf Tournament Aug. 3 at The Oaks Golf Course in Somersworth, New Hampshire. Northeast Rehabilitation Hospital Network has been Title Sponsor for our golf tournament for several years, and Robin Hill Farm and BIANH have partnered together on this tournament for more than 30 years! This year, we had a record number of 116 golfers with clubs in tow enjoying the picture perfect day together. The sponsorships were the highest we've seen in several years.

The keynote speaker was Kurt "KC" Christensen of Campton, New Hampshire. Only months before his injury in a car accident in 2008, he had successfully passed the Professional Golf Association's (PGA) Player Ability Test and had been working as an assistant golf professional at the Owl's Nest Golf Course while studying for the final certification test. Now, nearly 13 years later, KC is still an avid golfer; he teaches adaptive golf through the New England Disabled Sports' program and works at the Owl's Nest Golf Course. To learn more about BIANH, visit bianh.org.

Kurt "KC" Christensen gives the keynote address at the 38th Annual Golf Tournament.

(continued on page 28)



The philosophy of **Beechwood NeuroRehab** is to maximize each individual's ability to participate in meaningful roles within their community. We accomplish this by providing specialized, brain injury rehabilitation for people who have sustained any kind of acquired brain injury. Beechwood NeuroRehab uses a person-centered, transdisciplinary approach, utilizing innovative treatment concepts, applied technology, and evidence-based research to help each individual to achieve a fulfilling life.



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



Have you or your loved one had a brain injury?

Call our toll-free number to speak
with a brain injury specialist.
Monday through Friday
9 a.m. to 5 p.m.

1-800-444-6443



Receive individualized, confidential
resources and support.

We understand.

We know what can happen when someone experiences a blow or jolt to the head. Perhaps the injury was caused by a fall, motor vehicle crash, sports mishap, violent behavior, or was the result of stroke, near drowning, or infection. No matter the scenario, a brain injury is not simply an event or an outcome – it is often a misunderstood diagnosis. A person with a brain injury may have physical problems or trouble remembering things. Sometimes, there is a change in the person's behavior and it may be hard to think clearly.

We can listen.

You need accurate and reliable information regarding brain injury.
You are not alone.

We can help.

The National Brain Injury Information Center is a toll-free telephone service for getting information, resources, and services in your community.

We provide information about:

- Local treatment and rehabilitation options
- Public funding programs
- Legal issues and access to Preferred Attorneys
- Resources for veterans
- Returning to school and work
- Coping with changes
- Planning for your future
- Counseling services
- Respite care
- Living with brain injury



For general information about brain injury, visit biausa.org.

PENNSYLVANIA

Over recent months, the Brain Injury Association of Pennsylvania (BIAPA) partnered with the Pennsylvania Department of Health and the Moss Rehabilitation Research Institute to study the feasibility of and satisfaction with cognitive rehabilitation services delivered through a video-conference platform. The project included 27 individuals with TBI enrolled in the Pennsylvania Head Injury Program. After six months of treatment, participants provided feedback regarding the usability of the TeleRehab system and their satisfaction with treatment they received through TeleRehab. Therapists also rated the system usability and reported on how the TeleRehab platform supported their delivery of various aspects of treatment.

Findings through the project, which concluded in July 2021, support the feasibility and potential benefits of cognitive rehabilitation provided via remote delivery. Most participants were able to connect to the video conference platform with only minimal technical assistance. Both clients and therapists found the TeleRehab easy to use. In fact, therapists indicated that they were able to accomplish even more than they expected during TeleRehab sessions. Client satisfaction with TeleRehab was also highly rated. Our findings offer strong support for the use of TeleRehab as a cost-effective alternative to home visits, which could expand service access to remote areas.



This project was conceptualized before the COVID-19 pandemic with a view to expand access to services for Pennsylvania residents, but took on even more meaning and relevance during this time of barriers to in-person treatment. As a result of this project, the Pennsylvania Department of Health will continue to fund cognitive rehabilitation treatment provided through TeleRehab indefinitely. A follow-up qualitative study is in process to gather detailed information about how therapists use TeleRehab. Visit biapa.org for more information.

SOUTH CAROLINA

The Brain Injury Association of South Carolina (BIASC), in collaboration with the South Carolina Brain Injury Leadership Council, hosted the 2021 Life with Brain Injury Conference in July via Zoom. BIASC was able to provide 19 scholarships for brain injury survivors and caregivers to attend at no cost. Our keynote speakers were Sheldon Herring, Ph.D., Roger C. Peace Rehabilitation Hospital, Prisma Health, in Greenville, S.C. and Tina Campanella, director and CEO of Quality Trust for Individuals with Disabilities in Washington, D.C.

BIASC continues to work with the Level I Trauma Centers across our state in providing SC Visibility

Resource bags to new individuals with severe brain injuries and their families. These bags provide resource information about rehabilitation providers, disability services, Medicaid and waivers, brain injury support groups and BIASC's toll-free help line.

We are gearing up for a very busy 2022 winter and spring. We are hosting Brain Injury Fundamentals classes in February for caregivers and direct service providers as well as CBIS Training in March for professionals. We will also be hosting a Virtual 5K across the state during March for Brain Injury Awareness Month. Watch out 2022 – here we come!

VIRGINIA

The Brain Injury Association of Virginia (BIAV) is heading into winter with fond memories of summer and excitement for what's next. Our highlight of the summer was Camp Bruce McCoy, which took the form of day camps this year. Campers at two different Virginia locations enjoyed horseback riding and canoeing, arts and crafts, games, and archery. Other fun activities included a camp-wide sing-along and Camp Olympics.

We hope to return to week-long camps in 2022. Our popular internship program is in full gear! To our delight, two summer interns asked to continue working with us this fall to assist with various critical data projects that will help us create and deliver current, meaningful, multimedia resources while also improving internal operations. A third intern will assist with our "Screen and Intervene" domestic violence project, which has just been funded for a second year thanks to the success demonstrated in its first year. To learn more about us and our programs, please visit biav.net.



Camp Bruce McCoy camper, left, joins in one of the camp's many activities.



Camp Bruce McCoy campers and BIAV staff enjoy all the day camp had to offer.

NEWS & NOTES

CALLING ALL VOLUNTEERS! Connect With BIAA

Forty years ago, a small group of volunteers – including survivors, family members, caregivers, and healthcare professionals – decided to do something about brain injury. That's why the Brain Injury Association of America (BIAA) exists today. Help carry on this tradition and volunteer your time for BIAA. Visit biausa.org/connect for the most up-to-date opportunities or email publications@biausa.org if you're interested in learning more.

SAVE THE DATE: Brain Injury Business Practice College



Mark your calendar for January 26-27, 2022 from 12-5 p.m. ET each day. The College is presented annually for business owners, c-level executives, and marketing professionals from the nation's top brain injury rehabilitation programs and long-

term care facilities. This year's program will focus on payer relations and employee retention and wellness. Register for the conference at biausa.org/businesspracticecollege. We hope to see you there!

Congressional Brain Injury Task Force Co-chairs Schedule Awareness Day

Co-chairs of the Congressional Brain Injury Task Force, Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.) are making plans to celebrate Brain Injury Awareness Day Wednesday, March 16, 2022, in Washington, D.C. The Rayburn Foyer has been reserved for the fair and the Gold Room for the briefing and the reception. Of course, should the COVID-19 pandemic prohibit meetings in person, other arrangements will be made. Meanwhile, please save the date and visit biausa.org for further information as it becomes available. ●

UPCOMING WEBINARS

David Strauss Memorial Clinical Lecture Webinar – Pseudobulbar Affect (PBA) in Patients with Traumatic Brain Injury (TBI)

January 13, 2022, 3 p.m. ET/12 p.m. PT

Justin Rash, PharmD, BCGP, Senior Medical Science Liaison, Avanir Pharmaceuticals

Carolyn Rocchio Caregivers Webinar – Fight for What You Need

January 19, 2022, 3 p.m. ET/12 p.m. PT

Jane Boutte, Director of Operations, Baylor Institute for Rehabilitation

Butch Alterman Memorial Survivor Webinar – Creativity Throughout Brain Injury Recovery

March 3, 2022, 3 p.m. ET/12 p.m. PT

Ali Rheume

To register, please visit shop.biausa.org/livewebinars.

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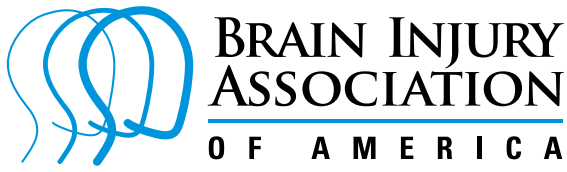
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For more information on how to become part of the Brain Injury Association of America Corporate Partners Program, please visit biausa.org/corporate or contact Carrie Mosher at 703-761-0750, ext. 640 or cmosher@biausa.org.

