

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 17, Issue 1

# THE CHALLENGE!

Understanding  
Behavior Changes  
After Moderate to  
Severe Traumatic  
Brain Injury

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Coping with  
Behavior  
Problems after  
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## *Behavior After Brain Injury*

TBI Survivor  
Uses Running  
As a Way to Aid  
Her Recovery  
and Give Back  
to BIAA

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## MARCH 2023

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# FROM MY **DESK**

Greetings,

I'm delighted to be writing to you as the Brain Injury Association of America's new president and CEO. While I started in December of 2022, some of you may be hearing from me for the first time, so I wanted to take an opportunity to tell you a bit about myself.

I joined this organization because I saw a community with incredible opportunity on the horizon. It is clear to me that BIAA makes a real difference in the lives of individuals with brain injury and those who love them. From advocacy to awareness to research to education, BIAA is the Voice of Brain Injury, and I am proud to build upon our tremendous legacy – the legacy that is due in no small part to each of you.

What drives me? I'm dedicated to making a daily difference for persons with brain injury and their caregivers, and I believe in the power of community to make that daily difference. Community is where those who need help on their journey find hope and where together we take action to speak with one voice to fight for a better tomorrow. That's why I'm excited to accelerate how we reach people and grow, because I believe that community is at the center of all that we do.

As you read this issue of The Challenge!, you'll see practical examples of ways to navigate changes in behavior as a result of brain injury and updates about Brain Injury Awareness Month and our affiliates. You'll also read many stories that share our community's perspective from survivors and caregivers. We are always looking for more opportunities to highlight many different perspectives and experiences, so if you would like to share something that you wrote, please send us an email at [publications@biausa.org](mailto:publications@biausa.org).



Finally, I want you to know that I am passionate about the same things you are: increasing access to healthcare for individuals with disabilities, promoting critical research initiatives to find treatment and cures, and empowering professionals to better understand the people they serve.

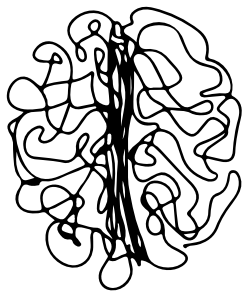
When I look at the horizon, I see a lot of opportunity, and I'm eager to build on it with you.

Sincerely,

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

Rick Willis  
President and CEO  
Brain Injury Association of America





# UNDERSTANDING BEHAVIOR CHANGES

after moderate to severe traumatic brain injury

by Sean Hollis, PhD; Phillip Klebine, MA; Risa Nakase-Richardson, PhD, FACRM; Tom Novack, PhD, ABPP-CN; and Summar Reslan, PhD, ABPP-CN, in collaboration with the Model Systems Knowledge Translation Center.

## What are some possible behavior changes?

People who have a moderate or severe traumatic brain injury (TBI) may have changes in their behavior.

People with a TBI and their families encounter some common behaviors:

- **Problems managing emotions.** People with a TBI may have a sudden change in mood; they also may have an extreme emotional response to a situation. They may raise their voice, cry, or laugh.
- **Restlessness.** People with a TBI may fidget, pace, or move in a repetitive way. For example, they may sway at an unusual pace.
- **Problems with social behavior.** People with a TBI may avoid others, interrupt others, or say things that do not fit the situation or are hurtful. They also may make sexually inappropriate comments.
- **Refusing to do things.** People with a TBI may say “no” to doing something, such as going to therapy or doing other activities.
- **Feeling unmotivated.** People with a TBI may have difficulty engaging in an activity even though they know the benefit of doing it or why it needs to be done. This is not caused by fatigue or laziness.
- **Difficulty starting tasks.** People with a TBI may have trouble starting tasks or conversations, even if these are things they want to do.



## Who is at risk for behavior changes?

Behavior changes (also called personality changes) are common for people with a moderate or severe TBI. These changes often occur soon after the TBI and may change across time. The types of changes people have and how long they last depend on where their injury is, how severe it is, and other factors. People with a severe TBI are more likely to have behavior changes that last for a while. The good news is that behavior changes can get better as time passes.

This article talks about why changes in behavior happen. It also includes tips for what to do when problem behaviors occur. It includes a framework that people with a TBI, their families, and others can use to help manage changes in behavior caused by TBIs.

## Why do changes in behavior happen?

Changes in behavior after TBI happen for many reasons, including changes in the way the brain works. The following are some of the most common changes in some people with TBI.

- Some people with a TBI may have **problems with focusing, thinking, or communicating**. They also may have issues with how long it takes to process information and respond to it. These issues can make it hard to **keep up** with a conversation or **understand a situation**. As a result, people with a TBI may appear to be uncooperative. They also may appear “off-task” or out of sync with what is happening in a fast-paced situation. They may avoid social situations because they feel uncomfortable or embarrassed when they are with other people.
- People with a TBI may have **problems with thinking skills**. These problems may make it hard for them to understand why some things happen or what to do when they happen. This can make the person feel irritated, refuse to do things, or not do things that they agreed to do. They also may have a hard time making choices.
- People with a TBI may have **poor impulse control**. This can make it hard for them to filter their thoughts or actions. They may not think about or understand the effect of what they say or do before they say or do something inappropriate or unsafe.

- People with a TBI may not be fully **aware** of their current issues. This can cause them to refuse to use a walker or wheelchair. They also may refuse to take part in therapy. Some people with a TBI may not follow recommendations or restrictions that are meant to help them be independent, keep them safe, and help them recover.
- Keep in mind that people with a TBI cannot always control their behavior, which is especially true in situations that are highly stressful. The **A-B-C framework** discussed later in this article includes strategies to help people with a TBI prevent problem behaviors. If the behavior does occur, the framework includes techniques to distract the person or help them relax.
- People with a TBI often have an **emotional response** to their injury. They may feel a sense of loss because of less independence, changes to their role within the family, and a lack of control over their situation. The following factsheets (available at [msktc.org](http://msktc.org)) may help in these situations (see Depression after TBI; Relationships After TBI, Emotional Problems After TBI; Understanding and Coping With Irritability, Anger, and Aggression After TBI). The following sections address problem behaviors.

## What can I do to identify problem behaviors?

### Identify problem behaviors

The goal of the A-B-C framework is to keep the problem behavior (the “B”) from occurring. Other strategies involve changing the things that happen after a behavior occurs, which can help change how intense, severe, or frequent the behavior is.

- The first step is to identify the behavior. Make a list of behaviors that you see that are a problem.
- Work with a professional to review the list to identify the behavior(s) that need to change. Keep in mind that a specific behavior may not be a problem to everyone. Ask family and friends for their input.
- Update the list as new behaviors come up and old ones are no longer a problem.

Follow the A-B-C approach to better understand problem behaviors

The A-B-C framework can help you understand the approach a professional may use to figure out when and why a behavior or emotional response may occur. This section discusses the framework. You may have a family member or friend assist with this exercise. If you have questions, you can contact a professional with experience in managing behavior after TBI before using.

**A. Antecedent.** An antecedent is what happens right before the problem behavior occurs. Take notes on everything you remember; it may not be clear what the “trigger” was for the behavior. Your notes can help you find patterns. From them, you will come up with ideas about triggers or causes of the problem behavior; triggers may include pain, fatigue, noise, or light sensitivity. The following are some questions to help you identify antecedents.

- Who is or is not present before the problem behavior happens?
- Where does the problem behavior take place?
- What desired items (e.g., television, video game, cell phone) are present or absent just before the problem behavior takes place? What about undesired items?
- What events took place before the problem behavior occurred?
- What time of day does the problem behavior happen?
- Is there a root cause for the behavior? Causes such as poor sleep, a reaction to medicine, changes in schedule, and diet changes set the stage for problem behaviors throughout the day.

**B. Behavior.** Take a close look at the problem behavior or behaviors on your list. Make notes. Describe the problem behavior in as much detail as you can. Here are some questions to understand problem behaviors.

- What does the behavior look like?
- How often does the behavior happen?
- How long does the behavior last?
- How intense is the behavior?

**C. Consequences.** This is what happens right after the problem behavior occurs. Take notes on all changes you see within a few minutes of the behavior. It is not likely that things that happen several minutes, hours, or days after are causing the problem behavior. The following questions should help.

- What happened right after the problem behavior?
- How did people react?
- Did the person get something from the behavior? For example, did they get attention (either good or bad)?
- Was something taken away or avoided because of the behavior?
- Did the environment change because of the behavior? For example, did the person leave a situation or place?

## Identify and Change Antecedents (to Prevent Problem Behavior)

Spend time identifying a list of triggers and ways to prevent a problem behavior. If you cannot avoid triggers, find ways to decrease the impact of those triggers. You can organize your notes in a chart to make it easier to track your results.







## What are some realistic goals for behavior change?

- Aim to reduce the number of times that problem behaviors happen and their intensity. Do not expect to prevent all problem behaviors.
- Aim to make small changes across time. Changing behavior takes time. Do not expect changes to happen quickly.
- Focus first on behaviors that are easy to recognize and occur often. As you build your confidence and make progress changing behavior, you can focus on more challenging behaviors.

- Problem behaviors can be exhausting for everyone. Take time for yourself. Get help from others.
- As you start to see success in changing behavior, slowly reduce positive reinforcements. At first, you will likely use positive reinforcements each time you see good behavior. Your goal is to reach a point when you need to use only positive reinforcements from time to time and they are not expected every time. Using the A-B-C chart to track changes across time may be helpful.

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*This article is an abbreviated version of an article originally published by the Model Systems Knowledge Translation Center, reused with their permission. A full-length version is available on our website at [biausa.org](http://biausa.org).*





# BIAA CELEBRATES

## Brain Injury Awareness Month

*By Steve Walsh, Brain Injury Association of America*

The Brain Injury Association of America (BIAA) is celebrating Brain Injury Awareness Month this March by putting a spotlight on the experiences of brain injury survivors. For the third year, BIAA will continue its More Than My Brain Injury campaign, which centers the stories of brain injury survivors to increase understanding, reduce stigma, improve care and showcase the diversity in this community.

"BIAA is proud to continue to lead the nation in observing Brain Injury Awareness Month," said Rick Willis, BIAA's president and CEO. "Too often brain injury survivors are defined by an injury, and our goal with this campaign is to change that perception. An individual with a brain injury is more than a brain injury. They are a unique person with their own unique experiences."

The campaign provides a platform for educating the public about the incidence of brain injury. As part of the More Than My Brain Injury campaign, survivors, caretakers, professionals, family members and advocates are invited to participate on a personal level through storytelling, social media posts, custom apparel, media outreach, and legislative advocacy.

BIAA is leading a number of events and activities throughout the month. A calendar of events as well as information on how to get involved, including educational material and downloadable collateral is available on our Brain Injury Awareness Month page at [biausa.org/raiseawareness](http://biausa.org/raiseawareness).



*Greg Ayotte joined members of the Brain Injury Advisory Council Paul Bosworth and Darcy Keith to talk about brain injury and Paul and Darcy's experiences getting involved in their communities.*

Many people with disabilities have their lives defined for them. The More Than My Brain Injury campaign gives individuals a chance to overcome those definitions, allowing them to tell their own stories and change the narrative of their lives.

BIAA works year-round to educate the public about brain injury and support survivors and their families. For more than three decades, BIAA has proudly led the nation in observing Brain Injury Awareness Month every March.



Learn more about Brain Injury Awareness Month at [biausa.org/raiseawareness](http://biausa.org/raiseawareness).

# CALENDAR

## of Events

MAR  
01

### Kickoff to Brain Injury Awareness Month

BIAA's Director of Consumer Services, Greg Ayotte, was joined by members of the Brain Injury Advisory Council to have a conversation about ways to get involved for Brain Injury Awareness Month.

WEEK  
OF  
MAR  
06

### Brain Injury Awareness on Capitol Hill

Throughout the week, BIAA will be facilitating meetings with advocates and their members of congress. We'll also be sharing our 2023 Legislative Issue Briefs.

WEEK  
OF  
MAR  
13

### Concussion Awareness Now!

Concussions can happen to anyone, anywhere, at any time. To help spread awareness, share your concussion story with us. Tag us in your post or share it on your own social channels with the #ConcussionAwarenessNow hashtag.

WEEK  
OF  
MAR  
20

### How to Become an Advocate

Later in March, Greg Ayotte, will be joined by Heather Matty, BIAA's Information and Resource Specialist to discuss how individuals can get involved with brain injury advocacy. This event will be hosted over Facebook Live.



# CONCUSSION AWARENESS NOW

## Spokeswoman Rebel Wilson debuts public service announcement

*By Concussion Awareness Now Coalition*

A concussion is a traumatic brain injury, yet over half of people who suspect they have a concussion never get it checked. That's why Rebel Wilson partnered with Concussion Awareness Now – to change how society views concussions.

In a new public service announcement for the Concussion Awareness Now coalition, Rebel highlights the importance of seeking care for a concussion as she accidentally wreaks havoc on a fictional movie set. She can be seen throwing knives, carelessly flinging cups of hot coffee, and playing with a flamethrower.

While she is causing chaos, Rebel reminds people of the importance of seeking care after a concussion and imparts the very serious wisdom that if you hit your head, you should get it checked.

The campaign has been featured prominently on many social media channels, and its intent is to reach people who may not consider concussions a big deal. In order to do that, Concussion Awareness Now is using humor to get the attention of the general public.



“Once, when I slipped and hit my head, I did do something rebellious,” Wilson says as she drives a golf cart into a stack of boxes marked ‘fragile.’ “I didn’t try to tough it out like most people do. I went and got it checked. Lucky I did because I had a concussion that could have caused serious damage.”


According to a survey conducted by the coalition, more than 50 percent of people who believe they may have suffered a concussion never get it checked. Ignoring the symptoms of concussion has both short- and long-term consequences. Stubbornly ignoring a possible concussion means it takes your brain and your body longer to recover and you may not be able to carry on like normal, even if you think you can.

The goal of the PSA is to get people to take concussions seriously. After all, a concussion is a brain injury and when your brain is hurt, it needs time to recover. Seeking care for a concussion also offers protection for the future if you ever end up hitting your head again.

The campaign directs people to explore resources on the coalition’s website, which includes a symptoms checklist and information about how to seek care. These resources were developed by BIAA, Abbott, and other coalition members. You can check it out yourself by visiting [concussionawarenessnow.org](http://concussionawarenessnow.org).

## Want to follow the campaign?

If you use social media, make sure that you are following Concussion Awareness Now on Facebook and Instagram.

 [facebook.com/ConcussionAwarenessNow](https://facebook.com/ConcussionAwarenessNow)

 [instagram.com/ConcussionAwarenessNow](https://instagram.com/ConcussionAwarenessNow)

The Concussion Awareness Now coalition was founded by Abbott and the Brain Injury Association of America and includes nearly 20 partners focused on educating people about the seriousness of concussions and the importance of getting checked after experiencing a hit or jolt to the head.

”

# BE A REBEL. IF YOU HIT YOUR HEAD, GET IT CHECKED.

I do lots of adventurous things, but got a concussion from something totally boring—slipping on wet grass!

When people hit their heads, there’s an expectation to blow it off and keep going. So, I did something rebellious. I went to a doctor, got my head checked and got the treatment I needed.

—Rebel Wilson



# COPING WITH BEHAVIOR PROBLEMS

## after brain injury

By Claude Munday, Ph.D., William Lynch, Ph.D., and John Haller, Traumatic Brain and Spinal Cord Injury Project; and Carol Welsh, MPA, CBIS, Services For Brain Injury, San Jose, CA.

## Identifying Behavior Problems

People with brain injuries may experience a range of neuropsychological problems following a traumatic brain injury. Depending on the part of the brain affected and the severity of the injury, the result for any one individual can vary greatly. Just as no two brains are alike, no two injuries are the same. Your loved one's deficits following brain injury are completely unique, which makes a specific prognosis for recovery challenging.

Personality changes, memory and judgement deficits, lack of impulse control, and poor concentration are all common issues. Behavioral changes can be stressful for families and caregivers who must learn to adapt their communication techniques, reestablished relationships, and change expectations of what the impaired person can or cannot do.

In some cases, extended cognitive and behavioral rehabilitation in a residential or outpatient setting will be necessary to regain certain skills. A neuropsychologist also may be helpful in assessing cognitive deficits and behavioral issues. However, over the long term both the person with a brain injury and any involved family members will need to explore what combination of strategies work best for them to improve the functional and behavioral skills of the individual with a brain injury.

## Personality Changes

Even a person who makes a "good" recovery may go through some personality changes. Family members must be careful to avoid always comparing the impaired

person with the way s/he "used to be." Personality changes are often an exaggeration of the person's pre-injury self, in which traits become intensified. Some changes can be quite striking. It may be, for example, that the person with a brain injury used to be easygoing, energetic, and thoughtful and now seems easily angered, self-absorbed, and unable to show enthusiasm for anything. Nonetheless, try not to criticize or make fun of the person's deficits. This is sure to make the person feel frustrated, angry, or embarrassed. *Always try keep in mind that the behavior of the person with a brain injury – although seemingly willful or intentional – is not fully in their control due to damaged brain cells.*





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.



### NeuroRehab Outpatient Therapies

NeuroPsychological Evaluations  
NeuroFunctional Evaluations  
Cognitive Rehabilitation  
Speech & Language Therapy  
Occupational Therapy  
Physical Therapy



### Supported Living Services

Community Residences  
Community Apartments  
Life Skills Training  
Recreation Therapy  
Care Coordination  
InSPIRE Structured Day Services



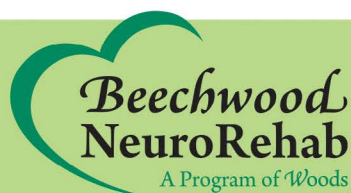
### Life & Health Management Services

On-site Medical and Rehab Nursing  
Clinical Case Management  
Dietician & Nutrition  
Neurology  
Brain Injury Physiatry



### Vocational Services

Supported Employment  
Brain Injury Clubhouse  
NeuroVocational Evaluations  
BeechTree Enterprises



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## Memory Problems

People with brain injuries may experience short-term memory problems and/or amnesia related to certain periods of time. In general, pre-injury knowledge is more easily retained. In contrast, *new learning* presents the greatest challenge to memory or remembering. Consistent repetition of new information, or repeated engagement in an activity, is most helpful to enable the person to retain the learning. Real-time learning (or learning about something when you need it) – with an actual problem and consequences – is much more meaningful than *discussion about a problem or situation*.

- The ability to focus and concentrate are keys to addressing some short-term memory problems.
- Keep distractions (e.g., music, noise) to a minimum. Focus on only one task at a time. Give one command at a time.
- If memory impairment is severe, without condescending, have the individual repeat the name of a person or object after you.
- Whenever possible, have the person write down key information (e.g., appointments, phone messages, list of chores).

- Keep to routines. Keep household objects in the same place. Use the same route to walk to the mailbox or bus stop. Changes in environment or routines are much more disruptive to the person with a brain injury as they work to accommodate new information.
- If getting lost is a problem, you can label or color-code doors or hang arrows to indicate directions. When going out, the person should be accompanied initially to ensure the route is understood and can be repeated. A simple map can be sketched from the bus stop to the house. And make sure that the person always carries his/her address and emergency phone numbers.

## Establishing Structure

A structured environment is essential in helping a person with a brain injury relearn basic skills. A written, routine schedule of activities and repetition make it easier to remember what's expected and what to do next. The schedule may need to be as specific as the time for dressing in the morning, getting ready for bed at night, and when to eat and take medications.



## Lack of Emotion

After a brain injury, a person may lack emotional responses such as smiling, laughing, crying, anger, or enthusiasm, or their responses may be inappropriate. This may be especially present during the earlier stages of recovery.

Try not to take it personally if the person does not show an appropriate response. Above all, always remember this is not willful or consciously directed at you, even though it may seem that way. It is a consequence of the injury to the brain and its functional ability.

Encourage the person to recognize your smile at a humorous situation (or tears if you are sad), and to take note of the proper response.

## Emotional Lability

In some cases, neurological damage after a brain injury may cause emotional volatility (intense mood swings or extreme reactions to everyday situations.) Such overreactions can be sudden tears, angry outbursts, or laughter. It is important to understand that the person has lost some control over emotional responses. The key to handling emotional lability is recognizing that the behavior is unintentional.

Caregivers should model calm behavior and try not to provoke further stress by responding in-kind, being overly critical, arguing or demanding. Be in the person's world first. Then work to gently bridge the gap to help him/her recognize what is currently happening in the moment. The key is to help the person relearn behavior (or modifications to that behavior). It's important to remember that relearning behavior or behavior with modifications is not actually "relearning", since these behaviors are now new. Work to support/reinforce the techniques that produce emotional responses which are under the person's control, while respecting their current feelings. Seek out the help of a neuropsychologist if emotional behaviors become too stressful, problematic, aggressive or violent.



## Learning to Cope/ Getting Support

Coping with behavior problems after a brain injury requires identification and acknowledgment of the deficits of the individual with a brain injury. A comprehensive neuropsychological assessment is recommended. This will help both the person with a brain injury and the family to better understand neurological and cognitive deficits and behavioral issues. The neuropsychological evaluation provides trained rehabilitation professionals – neuropsychologists, psychologists, speech and occupational therapists – with a "map" of where compensatory strategies and behavior modification should be directed. Oftentimes families or caregivers can recognize personality changes and cognitive deficits but find it difficult to resolve the issues. A treatment plan developed from a neuropsychological evaluation can more efficiently uncover deficits and enable professionals to help the person and their caregivers resolve them.

Finally, it is critical that family members seek and receive support from other family members, friends, support group, and/or counselor as they deal with their own emotional responses to caring for a person with a brain injury.

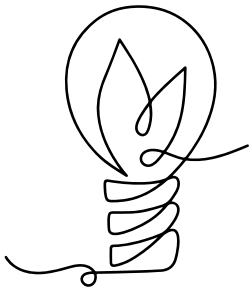
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*This article is an abbreviated version of an article originally published by the Family Caregivers Alliance, reused with their permission. A full-length version is available on our website at [biausa.org](http://biausa.org).*

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*Tom Hunter on release day in 2015.*



# SELF AWARENESS, INSIGHT, AND IDENTITY

## after traumatic brain injury

*By Tom Hunter*

### Who am I now?

If asked for advice for TBI or severe TBI sufferers, I would suffer from having too large a set of possibilities. There are more symptoms and hazard zones for TBI recovery than I had imagined. Similarly, there are lots of practical tools and life-hack solutions such as having more patience, and doing more planning, and what I'd describe as better anticipation along with environmental controls. I have not chosen to suggest those, or the many others, which I will describe with scare quotes "aphasia tactics," "conflict avoidance," or "the bodyguard." None of these are scary, nor are

they actual professional jargon, they are just the terms I used to describe my own recovery tools in my notes over time.

Anyhow, my primary advice is to trust the people who love you, and who are trustworthy, and who know you best. If you lack such persons, seek a counselor, therapist, or doc with experience in helping people who have undergone large changes in identity or in family structure. I suggest that because post-TBI my biggest adaptive and rehabilitative challenge has been believing and adapting to the significant changes in my own internal identity. Similarly, there are changes through some exaggerated aspects of my pre-injury personality.

I was mature and nearly 50 at the time of my injury. I had plenty of education, experience in a couple professional career arcs, and I had a job position which had room, even at that relatively late period in life, for career and personal professional growth. Generally I was somewhat quiet among people whom I did not know. As a person who could get off-track on complex tasks, I was practiced at avoiding distraction when necessary. My anger socially was not explosive or disruptive generally, I think it would more likely be described as becoming tense or stressed.

I was not at all prepared for what I now call post-TBI re-adolescence.

When my longtime friend David asked me, 12 weeks after my severe TBI, “do you notice any changes in yourself, like in your personality or behavior?” my response was nearly instantaneous. “No, I’m exactly the same. I’m just worse at some stuff.” Sure, I might have perceptible “surface” issues with aphasia, emotional outburst, and acquisition of new information, but I was on a curve back to being the very same person. I thought that my new impulses to make off-topic comments, or to answer inquiries with unhelpful sarcasm, or my much increased difficulty with minor trespasses of behavior by others, were mask-able, temporary, and not of the essence of my core personality. I was the same, and I intended to prove it in short time.

It took a longer time—in fact a few years. And instead of proving I was the same, I had to accept that I am not quite the same, no matter how much I had believed that I was. And no matter how much I wish for it now.

I would advise a person in recovery that all of the small surface differences or issues, they go farther and deeper than you yourself perceive, especially early in the recovery curve. A crucial aspect of how one’s personality and overall persona are perceived and judged by the rest of the world involves the consistency and reliability of a person’s behavior. That consistency becomes predictability for those who love you, and who need to trust you, and who want to rely on you. But the net effect of the small changes you may have acquired in your interactions and behavior have actually changed who you are, both in function and in manner, and you might just not realize it yet. Cumulatively, they are big.

As a patient in recovery, I lacked perceptual insight regarding my behavioral symptoms, especially in the first two years. I did feel just like the old me, with just some declining difficulties doing identifiable cognitive or language related things. I would advise people “in my shoes” to listen with care to any information, comment, criticism or advice they can obtain from their family, loved ones, and friends. They will know, and they may not want to tell you, for fear of discouraging you.

The information that is received from family, friends, and carers may not assist you in returning to your pre-injury self. It may still be necessary to accept who you are now, and what you can do now, and to be who you can be now. For me, I am closer to the old me, but no, I am not the same. My own awareness of a (permanent?) distinction between my pre-injury and post-injury selves could be very jarring. And it can be painful. During one of the many times of difficulty and conflict during my re-adolescence, my spouse of over 15 years finally expressed part of her own frustration very simply: “you are not the person I married.” This was not in anger, it was sad but it is true, I think. She has very good judgment, and also is an actual professional in working with TBI patients. After years working hard to prove to the world I was the same, or could become the same, I believe her.

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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

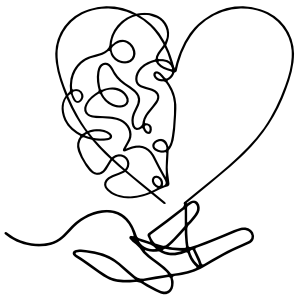
The world of brain injury lost an authority and leader in research and education

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.



**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).**



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October 1, 2022 – January 31, 2023

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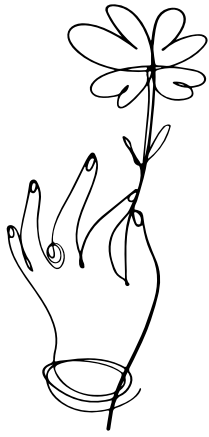
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# TBI SURVIVOR USES RUNNING AS A WAY TO AID HER RECOVERY

and give back to BIAA

*By Stephanie Cohen, MS, Development Manager, Brain Injury Association of America*

Kodi Churchill has proven herself to be a fighter, but she also acknowledges how hard it can be. Kodi's advice to someone going through what she did is "just because you can't do something right now doesn't mean you can't ever do it. Have hope and stay strong. If you can fight through a brain injury and keep going, you can overcome anything in life."

Kodi suffered a traumatic brain injury in the fall of 2018. She fell backward in a parking garage and cracked the occipital bone of her skull. Doctors believe she had a seizure due to stress and lack of sleep, but they aren't sure. The neurosurgeon

admitted he had only seen six occipital bone fractures in his career and her fracture was the second worst he's ever seen. They referred to Kodi as the "miracle on the floor" because there is no medical explanation on how she survived. After a month in the hospital, she was released home. Her parents quickly realized that she wasn't ready to be out of the hospital and paid out-of-pocket for an inpatient care facility. Because of that experience Kodi is concerned about how many patients are released before they are ready and therefore do not receive the proper time and treatment required.





During Kodi's long road to recovery, she faced the reality of the stigma and misunderstandings related to brain injury. Her ex-husband filed an emergency motion to take away her son, claiming that her brain injury was a threat to him. Kodi simultaneously testified in court to prove she was a good mother and participated in cognitive and physical therapy. Kodi wants people to understand that every single brain injury is unique. No single brain injury is the same. "People either know something and assume they're all the same, or they Google and jump to conclusions."

”

I wanted to get more involved in BIAA because of what I've experienced, because of the help they have provided for my parents and because I want to give hope to others that recovery can happen. We all have our own experiences and stories – but miracles are possible. I want society to better understand how brain injuries can happen, how we can try to prevent it, the importance of support of friends and family and to have hope that miracles do occur.

One symptom Kodi still suffers from is neurofatigue. It sneaks up on her when she has a lot going on with work, and even on busy days as a single parent. She also struggles when there are multiple things going on because she cannot focus on all of them. She also works on a daily basis to improve her balance.

She also found that running has really helped her recovery. "When I run, it's how I manage my stress and anxiety," Kodi said. "I am an emotional person, and I am also very hard on myself. When

I need a boost of self-confidence or have a rough day, running has the power to change your mind by releasing endorphins. The longer runs are peaceful to me."

Like many individuals with brain injury, Kodi found goal setting fills her with purpose and helps her work harder, focus more, and continue to work on herself. She has participated in various races and looks forward to BIAA's first Facebook challenge this May. The 62-mile May Challenge is a great opportunity to set a goal for yourself while also spreading awareness and raising funds for BIAA. Kodi's reason for participating is because "the organization provides awareness, education, helps with research and can make a difference in the lives of the caregivers and those who sustain a brain injury. We know a lot about the brain but every single one of us has a unique one—so we don't know enough. We need to keep educating ourselves and others to make recovery happen more, foster hope and provide healing."

JOIN THE NATIONAL ACADEMY OF NEUROPSYCHOLOGY

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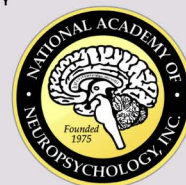
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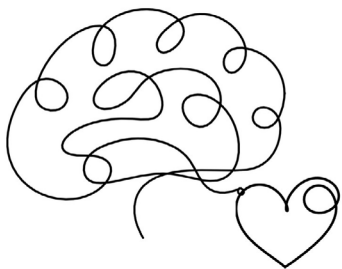
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# ADVOCACY UPDATE

*By Susan L. Vaughn, Policy Consultant, Brain Injury Association of America*

January marked the beginning of the 118th Congress, which will meet over the next two years taking up issues that impact people living with a brain injury and their families.

As the U.S. House of Representatives was late in electing new leadership, there have been delays and changes in operations, including the solidification of the annual March Awareness Day activities sponsored by the Congressional Brain Injury Task Force (CBITF). Therefore, the Brain Injury Association of America (BIAA) and its partners, the National Association of State Head Injury Administrators (NASHA) and the U.S. Brain Injury Alliance (USBIA), has made alternate plans for advocates to educate members of Congress in March.

”

Do what you can, with what  
you have, where you are.

– Theodore Roosevelt





*Rick Willis, BIAA president and CEO, introduces Rep. Bill Pascrell at a kick off event for Brain Injury Awareness Day.*

BIAA and stakeholders are flying in to Washington, D.C., March 7-8, 2023, to advocate for increased funding for brain injury surveillance, research and community services and supports, and other issues of importance. Meanwhile, the President's proposed budget for the next fiscal year (FY), FY 2024, is to be released March 9, which is later than usual. The President's budget will contain the Administration's recommendations for funding federal programs that is sent to Congressional leadership.

As this is a new Congress, there are new Members and new people in leadership positions. We encourage you to ask your Representative and Senators, whether newly elected or not, to become a member of the Congressional Brain Injury Task Force (CBITF). The CBITF has been critical in educating their peers about brain injury and annually circulates sign on letters to Members to enlist support for increased funding for brain injury programs. Congressional Members who wish to join the Task Force may contact Rep. Bill Pascrell, Jr. (D-N.J.), CBITF Co-chair, by contacting Nicole Howell at [Nicole.Howell@mail.house.gov](mailto:Nicole.Howell@mail.house.gov).

To learn more about your Representative you may go here ([house.gov](https://www.house.gov)) and about your Senators, here ([senate.gov](https://www.senate.gov)). BIAA has posted its Policy Briefs on its website ([biausa.org/public-affairs](https://biausa.org/public-affairs)), which can be

accessed at any time and used throughout the year to inform policymakers. Representatives/Senators have webpages with instructions for communicating on-line, which provides an opportunity to introduce yourself and to explain how brain injury has impacted you and your family. Be sure to include your contact information and to thank them for considering your request. Offices also have staff dedicated to health and/or disability issues should you wish to call.

Meanwhile, BIAA is advocating for increased funding for FY 2024 for brain injury programs within the U.S. Department of Health and Human Services, as follows:

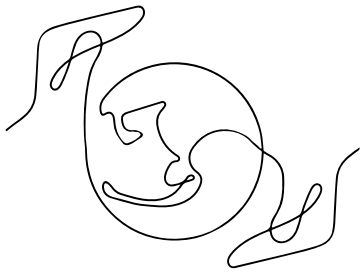
### **Administration for Community Living (ACL)**

- \$19 million, an increase of \$11M over FY 2023, for the ACL Federal TBI State Partnership Program to fund all states and territories.
- \$6 million (level funding) for the ACL Protection & Advocacy for Individuals with Brain Injury (PATBI) program.
- Increased funding for the National Institute on Disability, Independent Living, and Rehabilitation Research's (NIDILRR) TBI Model Systems by \$6.3 million annually.
- Increase the number of multi-center TBI Model Systems (TBIMS) Collaborative Research projects from one to three, each with an annual budget of \$900,000 (an additional \$1.8M) and
- Increase the number of competitively funded TBIMS from 16 to 18, while increasing the per-center support by \$200,000 annually (an additional \$4.5M annually).

### **Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (NCIPC)**

- \$5 million total, an increase of \$3.5 million over FY 2023, for the National Concussion Surveillance System, as authorized by the TBI Program Reauthorization Act of 2018.
- \$6.75 (level funding) for the NCIPC's TBI Program.

For more information, please visit BIAA's public policy section of the website ([biausa.org/public-affairs/public-policy](https://biausa.org/public-affairs/public-policy)) where you can view our 2023 Legislative Issue Briefs.



# STATE AFFILIATE NEWS

## Delaware

### Portrait of Strength

Selfless, determined, compassionate, strong, and relentless are all words to describe Barbara, but the love she has for her daughter Rachel is something that words could never express. Rachel sustained an anoxic brain injury caused by Sheehan's Syndrome on August 25, 2006. Sheehan's Syndrome is postpartum hypopituitarism caused by necrosis of the pituitary gland and is usually the result of massive blood loss during or after delivery.

Since then, Barbara, who was a Registered Nurse for more than 40 years, has been Rachel's primary caregiver and has faced many challenges the greatest being distance. Barbara lives in New Castle DE and Rachel is in Virginia. Due to the complexity of her condition, finding a facility closer to home that can meet Rachel's needs has been difficult. Barbara has traveled back and forth to VA weekly and has been



That really is the biggest reward of them all, watching her happily live her best life within the limits of her disability.

her daughter's caregiver, advocate, and voice. Barbara fought for Rachel's right to visit with her daughter after her ex-husband refused to let them visit. Rachel is now able to see her daughter six times a year, which was enough to keep their relationship alive. "The most rewarding part of being a caregiver is seeing her

smile and watching her continue to grow. There are ups and downs, but every small achievement is a victory. She loves her daughter, looks forward to her visits, and knows who she is even though she has grown. The smile on her face on the rare occasion when she sees her siblings is priceless."

Barbara still is working to bring Rachel home to Delaware so she can be closer to family and friends. "The biggest barrier the distance has presented is the inability of family and friends to see her and support her. Most of the outings we had with Rachel were to the mall, McDonald's, and Pizza Hut but those have stopped since COVID. She loved being out with people and listening to music. That really is the biggest reward of them all, watching her happily live her best life within the limits of her disability."



## Kansas



March is Brain Injury Awareness Month and the Brain Injury Association of Kansas and Greater Kansas City (BIAKS-GKC) is once again sponsoring a Brain Injury Advocacy Day and Pie Rally. The event will be held on March 14, 10 a.m. – 2:30 p.m. at the Kansas State Capitol in Topeka.

Individuals who've been affected by brain injury are encouraged to be at the rally and meet with their representatives to share their stories. Healthcare agencies from around the state will also be in attendance to provide information about their services. The pie day rally offers BIAKS-GKC an opportunity to meet elected officials (who love getting a piece of pie) and discuss important issues. This year BIAKS-GKC will ask legislators to support efforts to:

- Increase wages for direct care workers on all waivers, which will ensure a vibrant workforce caring for individuals living at home.

- Expand Medicaid to allow approximately 150,000 additional Kansans to receive essential services in their home and community.

BIAKS-GKC, whose mission is to provide ongoing brain injury advocacy, education and resources, is the only non-profit in Kansas that provides referral and resource information, support group coordination, ongoing education for professionals working with individuals who have sustained traumatic brain injuries and prevention programming.



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## Kentucky

The Brain Injury Association of Kentucky (BIAKY) has been busy the last quarter building a functional resource for those impacted by brain injury in the state of Kentucky.

We are delighted to announce that our new chapter website has officially launched, thanks to the amazing Tommy Tredway, board member and web designer. Our team has been working for the last couple of months to deliver an accessible resource, so survivors and supporters alike can enjoy the best possible user experience.

It looks fantastic! We now have a landing page where individuals can locate services, check in on recent news and education, donate, find teasers of upcoming events, and so much more. Please take a look at [biaaky.org](http://biaaky.org) and share it with your friends!



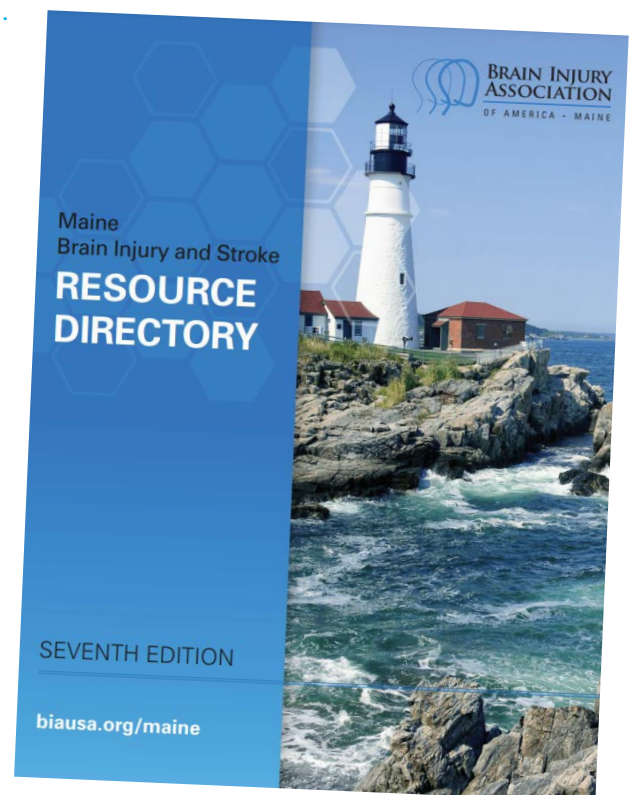
## Maine

BIAA-ME published the 7th edition of the Maine Brain Injury and Stroke Resource Directory in print and digital formats.

During Brain Injury Awareness Month, BIAA-ME will hold the 2023 BIAA-ME Brain Injury Resource Fair in Augusta on March 23, 2023. The event will feature exhibitors from across the state representing services, resources, and opportunities for Maine brain injury survivors, family members/caregivers, and professionals.

BIAA-ME continues to offer an ongoing webinar series for Maine brain injury professionals, caregivers, and support group leaders. BIAA-ME is also partnering with the State of Maine's Department of Health and Human Services in implementing Maine's Administration for Community Living State Partnership Program grant by offering specialty trainings for Maine's substance use disorder and behavioral health workforces.

The Brain Injury Association of Missouri (BIA-MO) recently hosted its Sports Concussions: Facts, Fallacies, and New Frontiers Seminars in-person and online. The Seminars included sessions on Concussion Signs and Symptoms, Myths, Research Updates, Teaching Others about Concussions, Concussion Care Continuum, and Advocating for Concussed Youth. Participants included youth sports coaches, school personnel, recreational league staff, licensed athletic trainers, and more.





## Missouri

For Brain Injury Awareness Month, BIA-MO partnered with Missouri AgrAbility to conduct a Brain Injury Fact of the Day social media campaign. Each day, a unique Brain Injury Fact is posted on news, weather, health, agriculture, and Veteran social media and websites. Postings encourage individuals and organizations to visit [biamo.org](http://biamo.org) to learn more.

As part of the BIA-MO social-recreational programs, survivors of brain injury and families were excited to cheer on the St. Louis Ambush professional soccer team. Tickets were courtesy of Swanner's Corner Program.

Upcoming events include the BIA-MO Survivor and Family Seminars and our Camp. Community engagement will continue with activities such as sporting events and theater performances for fun and socialization among persons with brain injury.

For more information, or to register, visit [biamo.org](http://biamo.org).



## New Hampshire

The Brain Injury Association of New Hampshire has been involved in an ongoing initiative to educate the public about the co-occurrence of brain injury and substance use disorder (SUD). We received a two-year contract from the State of New Hampshire, Bureau of Drug and Alcohol Services to provide trainings, create/distribute printed materials for professionals, family members, and those dealing with SUD/BI, and updates to our existing SUD/BI website page, [bianh.org/substance-use-disorder](http://bianh.org/substance-use-disorder). We also entered into a two-year pilot program with St. Joseph Hospital's Emergency Department to identify brain injury in patients with SUD. This project will help us to educate providers in identifying these patients so that they can receive the appropriate services. Additionally, our 14th edition Resource Directory has been updated to include resources related to substance use.

On May 10th, BIANH will hold its 39th annual Brain Injury & Stroke Conference with keynote speakers, Tim and Tod O'Donnell. Tod O'Donnell is a brain injury survivor and advocate. He is the subject of the documentary *THE HOUSE WE LIVED IN*, as well as the inspiring short ESPN film *No Quit*. His son, Tim, is an Emmy-nominated filmmaker and the director of the documentary.





## New York

The Brain Injury Association of New York State was thrilled to host the first in-person Journey of Hope Gala since the beginning of COVID-19 in November 2022! Held at the Midtown Loft & Terrace in New York City, the gala was a wonderfully-attended event, celebrating the brain injury community of New York.

"The gala is our way to honor those that have made significant advances in the field of brain injury. You could tell by the electricity and emotion of those in attendance that everyone was grateful to finally be back together in celebration of such a great cause," said Eileen Reardon, BIANYS executive director.

A big congratulations to the award winners of that night, Kyle Menglekamp (Penny Marshall Award), Barry Dain (Champion of Hope Award), The Goldsmith Family (Philanthropy Award), and Upstate University Hospital Concussion Center (Corporate Citizen Award).



Thanks to the efforts of our award winners, sponsors, participants, and donors, the Journey for Hope Gala raised \$80,000 to help fund programs and services delivered directly to brain injury survivors."



## Virginia

The Brain Injury Association of Virginia partnered with other brain injury providers and community advocates for Brain Injury Awareness Day 2023 on January 30. This year, BIAV asked the Virginia Legislature to invest in the brain injury community through investing in people and services.

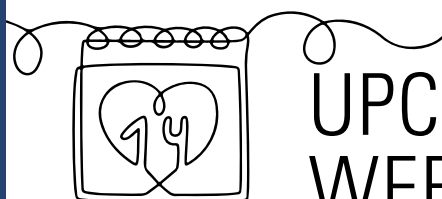
Over 75 brain injury advocates called on 25 Senators and 30 Delegates. Brain injury survivors, program staff, and caregivers visited everyone on the House and Senate decision-making committees who will be voting on our amendments. These dedicated supporters told us they had a great time and this event was empowering!

We are excited to welcome our new Executive Director, David DeBiasi! David is joining the BIAV team with over 20 years of non-profit experience in Virginia. We are delighted to have him a part of our staff!

To learn more about our programs, please visit us at [BIAV.net](http://BIAV.net).



# Let's Stay in Touch



## UPCOMING WEBINARS

**April 5, 2023, 3:00 p.m. ET**

Mark Bender, Ph.D. | Barriers to Rehabilitation Engagement and Strategies to Overcome Them

**April 24, 2023, 2:00 p.m. ET**

Jesse Fann, M.D. | TBI and Anxiety

**May 10, 2023, 3:00 p.m. ET**

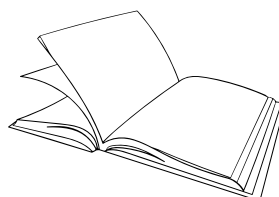
Maureen Miner, M.D., APC | Medication Management for Caregivers and Survivors

**May 24, 2023, 3:00 p.m. ET**

Rita Lenhardt, DHSc, CCC-SLP | Communication Disorders after Brain Injury

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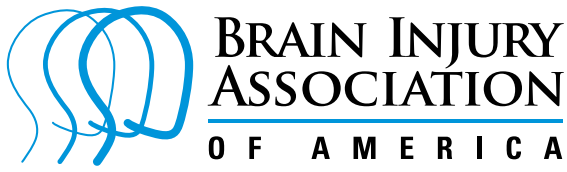
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- **ADVOCACY** – Action alerts and our weekly Policy Corner newsletter
- **EDUCATION** – Information about upcoming webinars, conferences, and other learning opportunities
- **GENERAL** – Brain injury resources, BIAA updates, and even digital copies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



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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](http://biausa.org/corporate) or contact Carrie Mosher at 703-761-0750, ext. 640 or [cmosher@biausa.org](mailto:cmosher@biausa.org).

