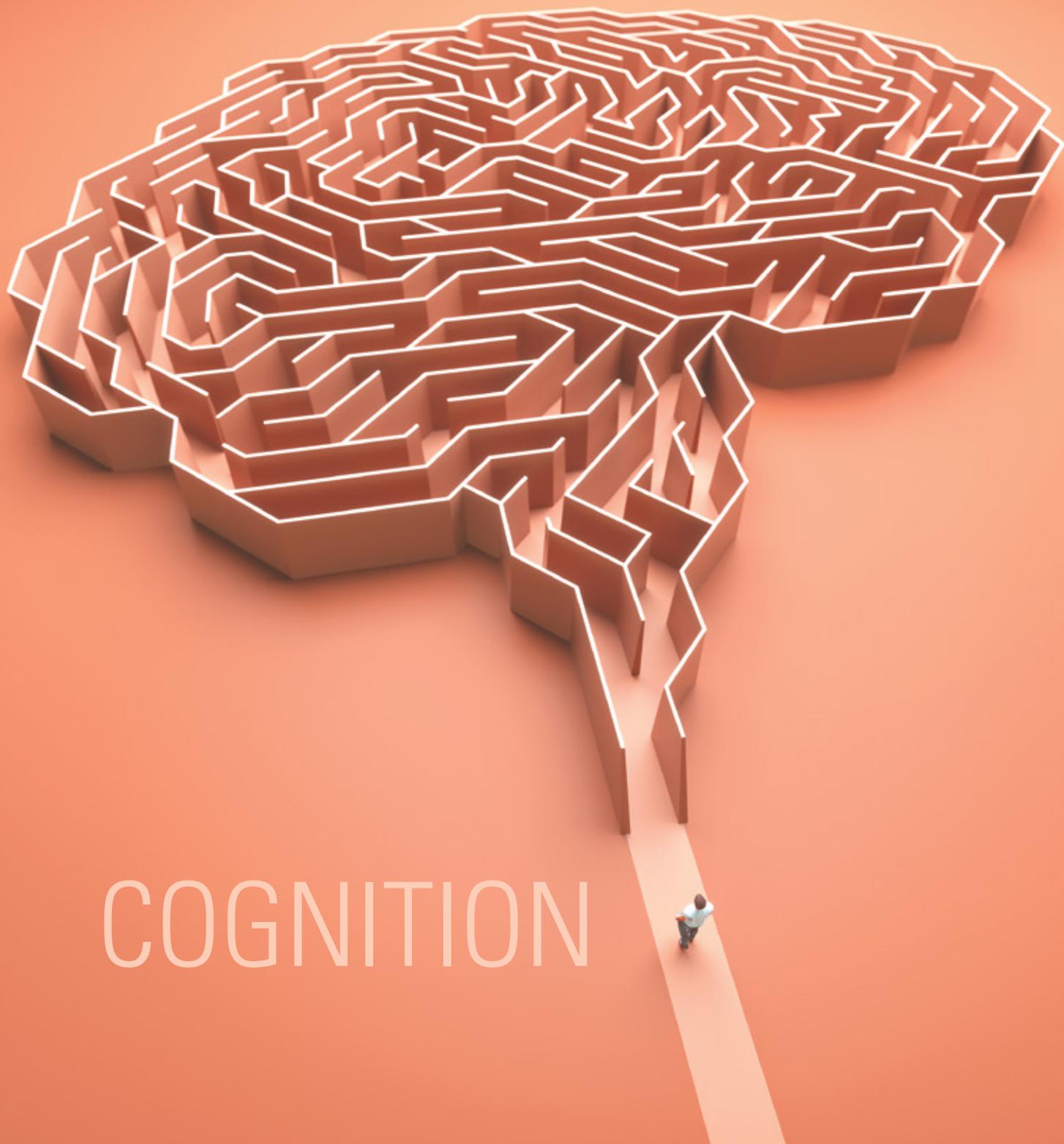


BRAIN INJURY ASSOCIATION OF AMERICA | Volume 15, Issue 1

# THE CHALLENGE!



## COGNITION

**MARCH 2021**

*THE Challenge!* is published by the Brain Injury Association of America. We welcome manuscripts on issues that are important to the brain injury community. Please send submissions in a standard Microsoft Word® document to [publications@biausa.org](mailto:publications@biausa.org).

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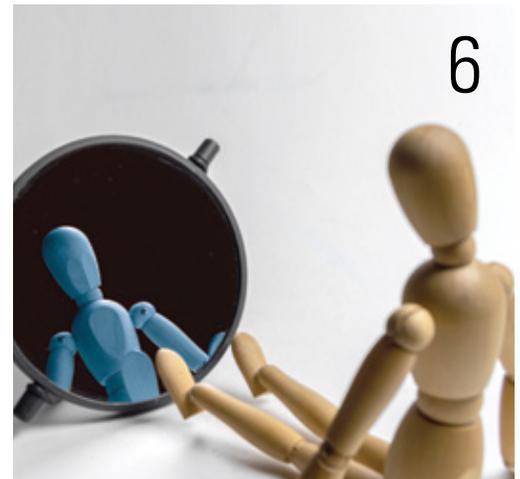
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**B**y the time this issue of *THE Challenge!* reaches your doorstep, the Brain Injury Association of America (BIAA) will have launched a new three-year campaign celebrating March as Brain Injury Awareness Month. The theme is #MoreThanMyBrainInjury. Our goal is to destigmatize the injury and help the public understand that individuals who sustain brain injuries – whether acquired or traumatic and regardless of severity – have many other roles in life. Individuals who've been injured may be mothers, fathers, sisters, or brothers. They may be athletes, advocates, employees, entrepreneurs, veterans, or volunteers. Please visit [biausa.org/raiseawareness](http://biausa.org/raiseawareness) to download fact sheets, posters, and other campaign materials. And be sure to check out our new fundraising program called **Do More** for Brain Injury at [biausa.org/domore](http://biausa.org/domore).

Participating in an awareness campaign relies, at least in part, on a person's cognitive, or thinking, skills. This issue of *THE Challenge!* includes several valuable articles on executive skills, such as self-awareness, initiation, and social and pragmatic communication. It also includes an article about the new CrashCourse Concussion Story Wall, released in partnership with TeachAids March 1. I am pleased to welcome Abbott as BIAA's newest corporate partner. Abbott is a leader in point-of-care diagnostic technology that may be critical in identifying concussions/mild brain injuries.

This issue of *THE Challenge!* also features our research winners: Coleen Atkins, Ph.D., University of Miami Miller School of Medicine; J Bryce Ortiz, Ph.D., University of Arizona College of Medicine – Phoenix; Kathryn Lenz, Ph.D., The Ohio State University (Psychology); and Dana Lengel, Drexel University. BIAA is deeply grateful to Chaikin, Sherman, Cammarata & Siegel, P.C., and Dr. and Mrs. Lance and Laura Trexler for their direct support for two of this year's grantees.

We are pleased to welcome three new directors to our Board: Joanne Finegan, Steven Schneider and Tony Strickland. The Association is very fortunate to have an outstanding group of leaders serving as volunteer officers: Shana De Caro (Chairwoman), Page Melton Ivie (Vice Chairwoman), Maureen Cunningham (Secretary), and Kent Hayden (Treasurer).

Last, but definitely not least, I want to take this opportunity to thank the BIAA staff and the volunteer leaders and staff professionals in our state affiliates and local chapters. They have all done an absolutely remarkable job amidst the coronavirus pandemic. I urge them and the entire brain injury community to remain vigilant in the months to come.

Stay well!

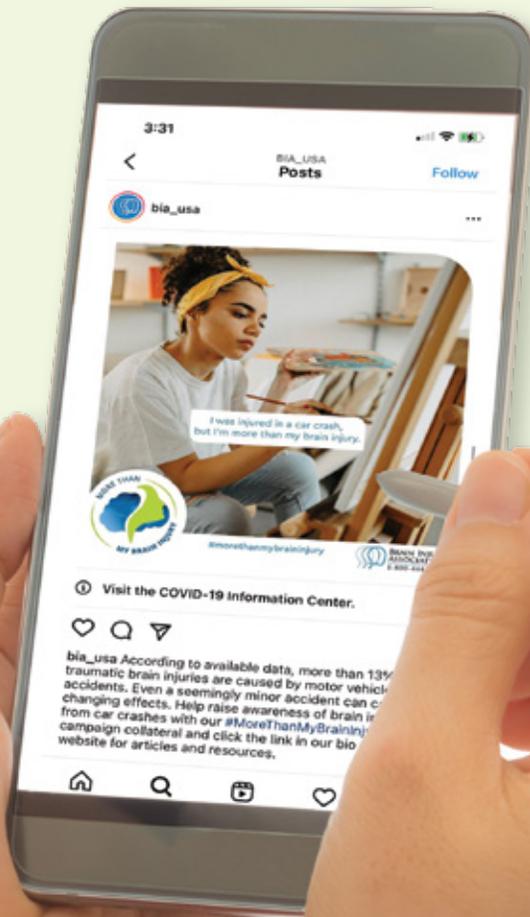
A handwritten signature in black ink that reads "Susan H. Connors". The signature is fluid and cursive.

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

# BIAA Launches New Brain Injury Awareness Campaign

By Dianna Fahel, Director of Marketing & Communications, Brain Injury Association of America

The Brain Injury Association of America (BIAA) revealed its new, survivor-focused awareness campaign for 2021 via special announcement on Instagram in early February. The More Than My Brain Injury campaign aims to destigmatize the injury, highlight the diversity of the brain injury community, and empower those who have survived.



For more than three decades, BIAA has proudly led the nation in observing Brain Injury Awareness Month every March. The Association has consistently worked to educate the public and reduce the stigma for the 5.3 million Americans who live with brain injury-related disabilities. “Too often, people are defined by their disabilities,” offered Susan H. Connors, BIAA’s president and chief executive officer. “The More Than My Brain Injury campaign gives individuals a chance to overcome those definitions, allowing them to tell their own stories. It was inspired by all the amazing survivors we know – and their determination not to let brain injury define them.”

An acquired brain injury (ABI) is any injury to the brain that is not hereditary, congenital, degenerative, or induced by birth trauma. Brain injuries – from things like trauma, stroke, oxygen deprivation, and neurotoxic poisoning – are a serious public health issue in the United States, where more than 3.6 million children and adults sustain ABIs each year. This number is likely higher due to the amount of brain injuries that go undiagnosed, unreported, and untreated.

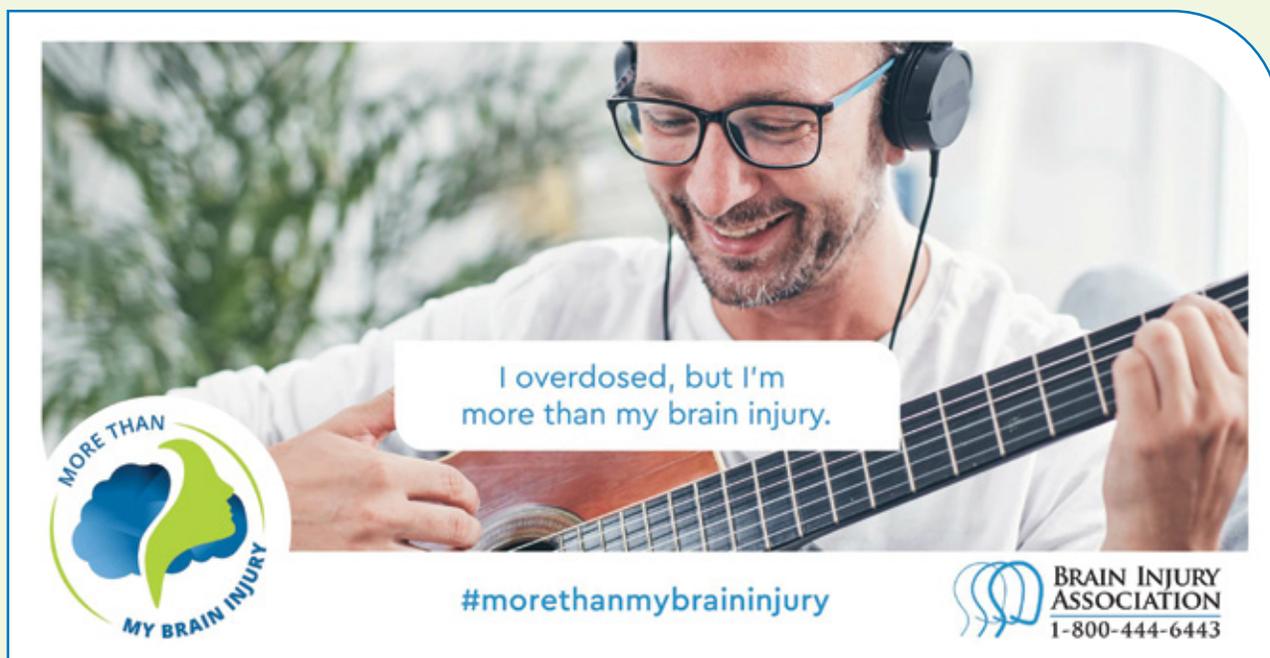
The campaign was designed with help from support group leaders, advocates, and people living with brain injury. In creating the collateral, we wanted to draw attention to the various mechanisms of injury – like concussion, stroke, overdose, and abuse – as well as the incredible diversity and strength in our community. After all, brain injuries don't discriminate; they can happen at any time and in a number of different ways.

The More Than My Brain Injury campaign is a three-year initiative that includes posters, public service announcements, and shareable graphics for social media. Throughout Brain Injury Awareness Month in March, the response to the digital campaign was incredible. Advocates all over the country attended virtual events by BIAA and its state affiliates; shared their stories through writing, song,



video, and art; and raised thousands of dollars to support the Association's mission. You can view the inspiring response by searching for the #MoreThanMyBrainInjury hashtag on Instagram, Facebook, Twitter, LinkedIn, and YouTube.

To view and download the campaign materials, visit [biausa.org/raiseawareness](http://biausa.org/raiseawareness). If you'd like to have your story and photo featured in next year's materials, email [communications@biausa.org](mailto:communications@biausa.org).



# Self-Awareness Issues After Traumatic Brain Injury



*By Kayela Robertson, M.S., and Maureen Schmitter-Edgecombe, Ph.D., Washington State University*

## **What is self-awareness?**

Self-awareness is the ability to recognize changes in one's cognitive abilities, such as memory and judgment, that are important for completing everyday tasks.

## **What are self-awareness issues?**

Difficulties with self-awareness are quite common, especially in the initial stages of recovery from traumatic brain injury (TBI). Self-awareness issues can result in decreased motivation to work on problem areas due to lack of recognition of the difficulties and compromised safety due to poor decisions or unrealistic goals.

## **What causes difficulties with self-awareness?**

Research has shown that everyone has problems with self-awareness to some extent; we simply are not very good at estimating our own abilities.

Self-awareness can worsen following TBI because of damage to structures in the brain that give us the ability to self-monitor. For example, based on prior experiences we can typically judge whether we will perform a task well or whether we will experience difficulties that may require using an organizational strategy (e.g., writing a reminder) or seeking assistance to complete the task. Persons with TBI can lose the ability to monitor their performance of such tasks, resulting in difficulty adjusting their idea of what they can and cannot do. Although damage to the brain is thought to be the main cause of self-awareness difficulties following TBI, emotional coping and adjustment are other issues that can also impact self-awareness.

## **Can difficulties with self-awareness be improved?**

A neuropsychologist, speech therapist, occupational therapist, or other trained professional can facilitate self-awareness training. Inpatient and outpatient

therapy have been shown to be helpful in improving self-awareness. It is important to keep in mind that self-awareness training is a slow process, and that the techniques provided may not work for individuals who have significant difficulty learning new information.

### Common training techniques:

- › Videotaping an individual while he or she performs a task. With the help of a clinician, the individual can then evaluate his or her own performance after the fact. The clinician can assist the individual in identifying difficulties that he or she is having and help develop compensatory strategies to use.
- › Identifying the individual's strengths and weaknesses. A clinician can help an individual connect how his or her strengths and weaknesses may impact performance of everyday tasks.
- › Having a clinician give direct feedback about performance while the individual does a particular task. Often the individual will be asked to estimate how he or she will perform beforehand and then will be asked to re-evaluate his or her estimation once the task is finished.
- › Treatment with a clinician aimed at improving mental health and reducing any emotional

### How can caregivers help facilitate self-awareness?

- › Be patient and do your best to understand that your loved one's brain injury is causing difficulties with self-awareness; it's not something that the individual can quickly change.
- › Remind your loved one multiple times that he or she is not able to do something that they were able to do prior to injury. Do your best to give direct feedback, but remember that the brain injury makes it challenging for your loved one to understand their difficulties and they may not remember the difficulties moments later (especially if they have significant problems with memory).

- › As your loved one recovers, you might be surprised at what he or she can do with a little guidance. Allow your loved one to be involved in safe activities as much as possible to build self-confidence. Encourage him or her to do things independently. When a mistake is likely or danger is possible, provide guidance to help correct behavior rather than completing the task for him or her.
- › Demonstrate a task before your loved one attempts to complete the activity alone.
- › Set realistic goals with your loved one and continually re-evaluate the goals as you see improvement.
- › Before completing a task, have your loved one estimate his or her performance. Provide your loved one with gentle corrective feedback as he or she does the task and talk about ways to improve performance in the future.

### Things to keep in mind as a family member or caregiver of someone with a TBI:

- › Healing takes time and often goes beyond just the initial year of recovery. Issues with self-awareness are usually worst in the beginning stages of recovery and tend to dissipate as the brain heals. Depending on the type and severity of injury, however, difficulties with self-awareness may be a long-lasting problem for some individuals.
- › Learn to adjust to a "new normal." When a family member sustains a TBI, a number of adjustments must be made within the family structure. If an individual experiences long-lasting impairments, it will take some time to fully understand these changes and how they impact the person with TBI and the family. Part of this is accepting the changes, grieving the loss of the person you once knew, and getting to know the person as he or she is now.
- › Self-care is important to you and to your loved one's recovery process. This is a stressful time for everyone involved, which can result in frustration and impatience. Be sure to take time for yourself.

Visit [biausa.org/selfawareness](http://biausa.org/selfawareness) for a list of suggested resources.

# Understanding Social and Pragmatic Communication Following a Brain Injury



By Rebecca D. Eberle, M.A., CCC-SLP, BC-ANCDS, FACRM, Clinical Professor, Speech, Language and Hearing Sciences, Indiana University

**W**e all demonstrate social and pragmatic communication skills that are uniquely ours. This may be illustrated by our use of humor, sarcasm, play on words, facial expressions, and gestures, among other characteristics. These communication behaviors ultimately become synonymous with our personality and general character; for example, “she is a good listener” or “he shows me he really cares!” After a brain injury, it is common to experience alterations in social and pragmatic communication. This can impact a person’s ability to maintain relationships and develop new ones. It can also impede positive vocational and community re-entry success.

**Communication** is an umbrella term that encompasses many subskills such as speech, language, and comprehension. Social and pragmatic communication, however, should not be confused with speech or language. Speech refers to the motor aspect of making speech sounds and producing words or sentences. Language is the ability to both express our ideas in words and sentences as well as understand the words and sentences spoken by others. This comprehension component of communication is not related to “hearing” the sounds, but rather understanding the words and the word order.

**Social communication** is a dynamic process that includes receiving and interpreting simple and complex messages from others and sending messages to others that convey intent. These messages can be verbal, including actual written or spoken words, or nonverbal. This may include changes in tone, vocal volume, word stress, gestures and facial expressions, proximity, and body postures. *How* a message is communicated can be more powerful and communicative than the words produced. We can say a simple sentence for which the meaning can vary greatly based on a person’s use of facial expressions, volume, or tone. For example, the simple sentence, “I have a new neighbor,” can carry the intent that I am excited, unhappy, or that I don’t care,

based on the associated use of tone and body language. The inability to understand emotional spoken tone and facial expressions is called **emotion perception impairment**. A person with brain injury may see and hear these non-verbal aspects of communication, but not interpret them correctly.

Impairments of **pragmatic communication** may include disruptions in staying on topic, organizing thoughts when speaking, and taking turns in conversation, among other difficulties. Pragmatic communication impairments may also be secondary to other cognitive impairments. Attention deficits, for example, may affect one’s ability to listen to others’ messages. Executive dysfunction may lead to impairments of self-awareness and self-regulation, resulting in the loss of a social filter and causing an individual to over-share feelings or thoughts inappropriately. These impairments typically result in problems with social relationships, fewer employment opportunities, poorer quality of life, and reduced community integration due to social isolation.

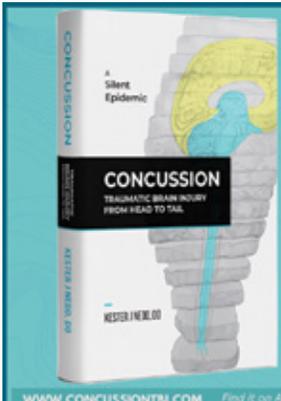
Fortunately, understanding and treating these impairments after brain injury has been an area of aggressive research over the past decade. As a result, we have more viable assessment and intervention options.

Specific measurement tools have been developed that assist with identification of the nature of the social challenges. Effective intervention can only be achieved after a thorough assessment, which helps identify the specific skill disruptions leading to the functional communication problems. After this detailed detective work, clinicians can collaborate with clients and their families to choose appropriate interventions.

Researchers have published several systematic reviews of the available interventions for social communication and pragmatic impairments, providing recommendations for therapists. The research indicates that specific, scientifically proven interventions result in positive changes in social communication, pragmatic conversation skills, and enhanced emotion perception skills. Like other aspects of cognitive rehabilitation, therapy interventions are most effective when contextual factors such as individual work history and personal aspirations, cultural and personal beliefs, and support systems are included in the treatment planning and implementation. Family education about the nature of the impairments and family participation in the treatments enhances the outcomes. Treatment models are available for family and caregiver training, and these models have proven to assist with both positive functional outcomes and generalization into salient environments.

In summary, we now have unequivocal evidence at the highest level for social communication treatment. Assessment tools and outcome measures are available to assist the diagnostician and therapist define areas of impairment and focus therapy. Lastly, we understand that impairments of social communication and pragmatic skills can serve as a significant barrier to long-term outcome if not addressed; therefore, it is necessary to include these treatments in the overall rehabilitation treatment plan.

For references, visit [biausa.org/socialcommunication](http://biausa.org/socialcommunication). ●



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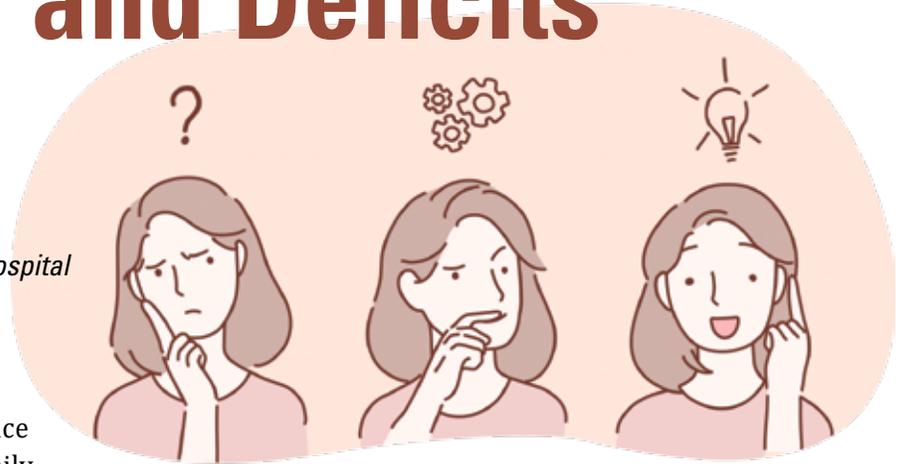


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# Brain Injury and Deficits in Initiation

By Taylor Sustarsic, M.S., CCC-SLP, CBIS,  
Prisma Health-Roger C. Peace Rehabilitation Hospital



Individuals with brain injury may experience a number of challenges that can impact daily efficiency. More noticeable deficits – such as visual impairments, memory and balance issues, difficulty with problem solving, etc. – frequently receive greater attention during the recovery process. Initiation, on the other hand, can be less obvious and as a result often goes unidentified and unaddressed. Decreased initiation can be present in a person’s physical, social, cognitive, and/or emotional abilities. Failure to identify and treat initiation deficits can negatively impact a person’s independence and quality of life.

Damage to the frontal lobe of the brain may result in myriad deficits. An injury to this area is frequently associated with changes to one’s executive skills, which involve the planning, coordination, and execution of daily tasks. Initiation is part of this skill set, and it normally involves your “internal monitoring system” identifying the need to act and then letting you know when it’s time to get started. Tasks can range from simple to complex and can include things like starting a new project, quickly going from sitting to standing up if the doorbell rings, taking a turn in conversation, or even calling 9-1-1 in the event of an emergency. When a brain injury occurs, this system can be interrupted. While one may understand and be able to state what needs to happen next, it may be difficult to actually do what needs to be done. An example of this might be hearing the doorbell ring, verbalizing or acknowledging the doorbell rang, but not physically getting up from the couch to go answer the door. Problems with initiation can have a negative impact on a person’s ability to live alone, complete activities of daily living, and engage socially with friends.

**In order to understand what initiation is, it is also important to understand what it is not.**

Decreased initiation is not an unwillingness to do something or defiance against the person making the request. Although it might appear this way on the surface, initiation deficits are not due to a lack of understanding of what needs to be done or how to do something. The lack of initiation often gets labeled as a person being “unmotivated,” but this incorrectly implies that a person is actively and independently making a decision about whether or not to complete a task. Initiation is an organic deficit that is a direct result of a traumatic brain injury.

What can you do if you or a family member is struggling with decreased initiation? Here are a few strategies that may help:

- **Creating routines.** Establish repeatable routines and schedules and make as little deviation from them as possible. Having a morning routine or a bedtime routine can help increase independence with initiating the next step. For example, each night before bed, build a routine such as changing into pajamas, brushing teeth, taking medications, and then laying down. Keeping the routine the same allows for someone to initiate the next activity without having to decide what should come next.
- **Setting alarms.** Use a timer or a cell phone to set alarms to help trigger the individual to start or switch a task. These can serve as useful reminders that prompt initiation.

It is also important to identify other factors that can impact initiation, such as significant depression.

If you notice problems with initiation, consider screening for and possible treatment of depression or other conditions.

- **Using visual reminders.** Use signs, pictures, to-do lists, or written schedules that can help identify the next steps involved in tasks throughout the day.
- **Being patient.** Provide increased wait time for the person to complete a task or to respond in a conversation. This will allow their brain time to process the next step or the question they were asked.
- **Trying self-monitoring techniques.** Questions to ask oneself to prompt initiation might include “What am I doing now?” and “What needs to be done next?”

While these are helpful strategies, additional resources might include participation in rehabilitation. Working with an interdisciplinary team of brain injury specialists including a physical therapist, occupational therapist, and speech language pathologist can help identify and treat specific deficits in initiation. Importantly, an interdisciplinary team would be able to develop strategies unique to the person and the goal as well as train and educate caregivers for increased carry-over of these strategies.

Through increased awareness of initiation issues, one can learn and apply strategies to regain a sense of independence and continue to live a fulfilling life. Additional resources for life after brain injury, including family and caregiver support, can be found through national and state Brain Injury Associations. ●

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# BIAA Awards Second Annual Grants Through Research Fund



By Stephani Kelly, Education Program Specialist, Brain Injury Association of America

**T**he Brain Injury Association of America (BIAA) announced the winners of its 2020 Brain Injury Research Fund competition. Coleen Atkins, Ph.D., University of Miami Miller School of Medicine, Kathryn Lenz, Ph.D., The Ohio State University (Psychology) and J Bryce Ortiz, Ph.D., University of Arizona College of Medicine – Phoenix, were awarded seed grants of \$25,000 each; Dana Lengel, Drexel University, was granted a dissertation award of \$5,000.

The Brain Injury Research Fund offers support to studies contributing to our understanding of brain injury as a chronic disease. “We are pleased to make these awards with the hope that talented young researchers, as well as more experienced scholars, will test new ideas for curing the chronic effects of brain injury,” said BIAA Research Committee Chair John D. Corrigan, Ph.D. “We could not be more pleased with the interest shown in our research program and the quality of proposals we’re privileged to support.”

BIAA established its research grant program in 2019 with a generous bequest from the estate of Linda Redmann and an allocation from the Association’s reserves. Through the Brain Injury Research Fund, BIAA offers two types of funding: Dissertation Awards, funded between \$3,000 and \$5,000, and Seed Grants, funded up to \$25,000.

Thanks to the generosity of donors of all kinds – individual contributors, businesses, foundations, and those giving to community-based special events – BIAA is able to fund more investigators who are working to increase our understanding of brain injury. For our community, funding a grant provides the opportunity to change the future of brain injury research while honoring a loved one or recognizing a milestone through a donation.

We would like to send a special thank you to the following benefactors who have lead the way with their gifts to the Brain Injury Research Fund:

Chaikin, Sherman, Cammarata & Siegel P.C.; Dr. Lance and Laura Trexler; Michael’s Mission in memory of Michael Seguin; John Rivard; Jennifer and Erik Kirk; Angela Caveness Weisskopf; Dr. and Mrs. Brent Masel; and an anonymous friend. For more information about the Brain Injury Research Fund or becoming a Research Champion, please contact Robbie Baker, Vice President & Chief Development Officer, at (703) 761-0750 ext. 648 or [rbaker@biausa.org](mailto:rbaker@biausa.org). Download our research brochure at [biausa.org/supportresearch](http://biausa.org/supportresearch).

BIAA would also like to thank its Research Committee Members:

- John Corrigan, Ph.D., Ohio State University (Chair)
- Lisa Brenner, Ph.D., VA/Rocky Mountain MIRECC, University of Colorado
- Susan Connors, Brain Injury Association of America
- Wayne Gordon, Ph.D., Icahn School of Medicine at Mt. Sinai
- Jasmeet Hayes, Ph.D., Ohio State University
- Brent Masel, M.D., University of Texas Medical Branch
- Stacy Suskauer, M.D., Kennedy Krieger Institute, Johns Hopkins University
- Michael Whalen, M.D., Harvard/Mass General
- Zachary Weil, Ph.D., West Virginia University

**The Association will accept Letters of Interest (LOIs) for the 2021 awards this spring.**

*(continued on page 14)*



# MICHIGAN'S LEADING NO-FAULT INJURY ADVOCATES

Liss, Seder & Andrews takes great pride in providing tenacious, expert legal representation to auto crash survivors. Through our work, we improve the lives of brain injury survivors and their families by securing the benefits and care they deserve.

We are honored to be recognized by the Brain Injury Association of America as part of the Preferred Attorney program, a testament to our lifelong commitment to our clients and their advocates.

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## FUNDED PROJECTS

### The Effects of Early Life Stress on Outcome after Mild Traumatic Brain Injury



#### Seed Grant of \$25,000

**Grantee:** Coleen Atkins, Ph.D., University of Miami Miller School of Medicine

#### Project Summary:

Mild traumatic brain injury (mTBI) is a significant health problem in the US. Although most people with mTBI recover within a few weeks, a subset

have persistent symptoms. The factors that contribute to persistent symptoms after mTBI are unknown. One potential factor identified in a study of mTBI patients is pre-exposure to stress in early development. Early life stress is highly prevalent and causes immune dysregulation in adulthood. This proposal will determine if early life stress limits recovery after a mTBI and test if an anti-inflammatory drug improves recovery after mTBI and stress.

### Analyses of the Relationship between Growth Hormone and Sleep after Pediatric TBI



#### Seed Grant of \$25,000

Supported by Chaikin, Sherman, Cammarata & Siegel, P.C.

**Grantee:** J Bryce Ortiz, Ph.D., University of Arizona College of Medicine - Phoenix

**Mentor:** Rachel Rowe, Ph.D.

#### Project Summary:

TBI can lead to dysfunctions of the growth hormone (GH) axis and disrupt the sleep-wake cycle in children. Here, using advanced biological, analytical, and statistical methods, we will determine the relationship between the GH-axis and the sleep-wake cycle using a pediatric TBI animal model. We will also determine how hypothalamic nuclei that control the GH-axis are changed following TBI. These studies will inform us of novel research directions and potential treatments to help treat and care for pediatric TBI survivors.

### Pediatric TBI Effects on Long-term Myelination: Sex Specificity and Neuroimmune Modulation



#### Seed Grant of \$25,000

**Grantee:** Kathryn Lenz, Ph.D., The Ohio State University (Psychology)

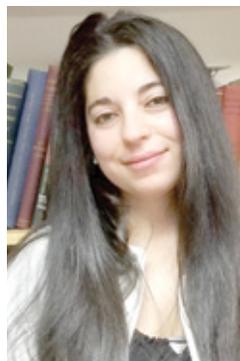
**Mentor:** Jonathan Godbout, Ph.D.

#### Project Summary:

TBI is the leading cause of pediatric emergency room visits. Boys are more likely than girls

to experience early-childhood TBI, which can lead to sex-specific risks for subsequent psychiatric disorders. Neuroimmune cells mediate healthy brain development, are sexually dimorphic, and their function is perturbed by TBI. Using a preclinical rat model of TBI, we will assess sex-specific inflammatory function and determine how brain myelination and motivated behavior are impacted, to discover new potential strategies to treat or prevent long-term outcomes of childhood TBI.

### The Role of FK506-binding Protein 51 (FKBP5) in Long-term Psychosocial Outcomes of Pediatric TBI



#### Dissertation Grant of \$5,000

Supported by Dr. Lance and Laura Trexler

**Grantee:** Dana Lengel, Drexel University

**Mentor:** Ramesh Raghupathi, Ph.D.

#### Project Summary:

Childhood TBI results in increased risk for psychosocial disorders

that can emerge in adolescence and adulthood. This vulnerability may be due to the susceptibility of developing neural stress circuits to TBI. In this proposal, we investigate the role of FK506-binding protein 51 (FKBP5), a co-chaperone of the glucocorticoid receptor (GR) and psychiatric risk factor, in behavioral and neuroendocrine effects of social stress following pediatric TBI. Targeting the GR system through FKBP5 may be able to mitigate the risk for psychosocial disorders following childhood TBI.



# Has traumatic brain injury changed what's inside you or a loved one?

Please visit  
[www.TBIbehaviorstudy.com](http://www.TBIbehaviorstudy.com).

If you or someone you care about has experienced traumatic brain injury (TBI) and is showing symptoms of **aggression, agitation, and irritability**, learn more about this research study of an investigational drug for behavioral problems due to TBI.

To pre-qualify for this study, subjects must:

- Be between 18 and 75 years old
- Have been diagnosed with TBI for 6 months or more
- Have a history of aggression, agitation, or irritability that was not present before the injury
- Have a reliable participant study partner who interacts with the participant at least 2 hours a day for at least 3 days a week

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



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*(continued on page 18)*

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**THANK YOU!**

# Lance and Laura Trexler: Investing in the Future of Brain Injury Research

By Robbie Baker, Vice President and Chief Development Officer, Brain Injury Association of America

Lance and Laura Trexler have spent decades together serving the brain injury community not only in their home state of Indiana, but also by impacting care and treatment nationwide. In celebration of this commitment, they have made a major gift to the Brain Injury Research Fund through their support of a dissertation grant. The grant will be awarded annually, giving a young researcher a leg-up while advancing discovery. Their motivation is twofold: recognizing the need to sustain the field of brain injury and to advance it at the same time. “The future will be defined by our youth; attracting the brightest young professionals into brain injury is critical,” shares Laura.



Laura, an occupational therapist and Certified Brain Injury Specialist, helped design the current resource facilitation model used across the country. “We have a strong passion for what we do for a living, and our lives have been very much enriched by knowing individuals who show courage day in and day out through their recovery,” explains Laura. Lance is an award-winning neuropsychologist who received the Brain Injury Association of America (BIAA) Sheldon Berrol, M.D. Clinical Service Award in 2020 for his work to improve the quality of care, professional training, and education in the field of brain injury. He adds, “While we have seen a lot of positive changes in 40 years of service, we still have a long way to go in understanding brain injury.”

It was their shared commitment to the brain injury community and passion for bettering lives that brought Lance and Laura together in a clinical setting in the 1980s. Since then, both have logged countless volunteer hours, mentored many young professionals, and driven needed change. This includes recognizing brain injury as a chronic condition, challenging private and public health care systems to work together, and improving the ability of schools to recognize the impact of brain injury earlier. “You do not have to accept that the cognitive, physical, and behavior effects of brain injury are permanent and that nothing can be done about it,” Lance asserts. Laura agrees, noting, “We make a lot

of negative assessments about people because of brain injury. I wish people took time to think before they made quick judgements and understood what got them there.”

When thinking about ways they could support the future of their profession, Lance and Laura kept coming back to the same challenges. The cognitive disability associated with brain injury is substantially greater than any other neurological disease, and they wanted to give relative to the need. Brain injury is underfunded, which has resulted in a staggering social and economic cost. This compelled them to consider a gift in support of the Brain Injury Research Fund and BIAA. “We are aligned with the mission and know

*(continued on page 30)*



## Project Euphonia

Our goal is to train computers and mobile devices to **better understand people who have impaired speech**. We hope to enhance independence and social inclusion by improving voice activated products for everyone.

Significant improvements to automated speech recognition are possible with more examples to learn from. So, our first step is to record voice samples from people who have difficulty being understood. Our research scientists use these recordings to teach speech recognition systems.

Learn more by visiting our website:

[g.co/euphonia](https://g.co/euphonia)





# ADVOCACY UPDATE

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



**E**ach year, the Brain Injury Association of America (BIAA) releases legislative issue briefs detailing the critical public policy issues of importance to individuals with brain injury. Advocates are encouraged to use these issue briefs when working with national, state, and local government officials to educate them on topics ranging from access to care, research, TBI Act appropriations, and information about the Congressional Brain Injury Task Force. Keep reading for the content from this year's issue briefs or download them as individual handouts by visiting our website at [biausa.org/2021issuebriefs](http://biausa.org/2021issuebriefs).

## Ensure Patient-Centered Access to Rehabilitation

When an individual sustains a brain injury, life-saving treatment is only the first step in recovery. Post-acute rehabilitation of sufficient scope, duration, and intensity delivered in inpatient rehabilitation hospitals and units (IRFs), residential/transitional rehabilitation facilities, and community-based outpatient programs is vital for regaining health, function, and independence. Each day it becomes more difficult for patients with individual and group health insurance plans as well as Medicare and Medicaid beneficiaries to access the rehabilitation they need.

### Ways to Overcome Barriers to Access:

- Oppose efforts to restrict access to rehabilitative services and devices in all settings of care.
- Reform the use of prior authorization in Medicare Advantage by passing H.R. 3107; the Improving Seniors' Timely Access to Care Act, and reject the use of prior authorization for IRF patients.
- Oppose the proposed Medicare demonstration project that seeks to impose pre-claim or post-claim review of 100% of IRF claims.
- Ensure that efforts to design and implement a Medicare uniform post-acute care (PAC) payment

system do not negatively impact access for people with brain injury and other complex conditions.

- Continue the tele-rehabilitation flexibilities after the COVID-19 public health emergency ends while ensuring that access to in-person care is maintained and improved.
- Develop a permanent fix for the reimbursement cuts to therapists and other providers under the 2021 Physician Fee Schedule.
- Revise the so-called "three-hour rule" to expand access to all appropriate skilled therapies provided in IRFs (Access to Inpatient Rehabilitation Therapy Act).

## Build Knowledge on COVID-19-Related Brain Injuries

Congress has appropriated significant funding to the National Institutes of Health (NIH) to study the coronavirus. Some individuals who have survived COVID-19 have significant, long-term complications and functional losses that must be studied and addressed. Access to medical and cognitive rehabilitation is critical to positive outcomes in this population of COVID survivors. Congress should direct the NIH to conduct focused research to explain the mechanisms of brain injury and resulting cognitive impairments resulting from the virus and to discover how people with existing brain injuries may be uniquely affected.

## Fully Fund TBI Model Systems of Care

The TBI Model Systems are a collection of 16 research centers receiving grants administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) housed within the Administration for Community Living at the Department of Health and Human Services. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury across the lifespan. These long-term research findings are critical to identifying and designing future improvements in brain injury treatment. The Model Systems are a key source of evidence-based medicine and serve as a “proving ground” for future researchers. TBI Model Systems sites work closely with the Department of Veterans Affairs on research to improve the treatment of Veterans with brain injuries.

BIAA urges Congress to increase funding by \$15 million over the next five years to expand the TBI Model Systems program from its current funding level of less than \$9 million. This funding increase would:

- Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to three, each with an annual budget of \$1 million;
- Increase the number of competitively funded centers from 16 to 18 while increasing the per-center support by \$200,000 annually;
- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed over their lifetime; and
- Provide “line-item” budget authority to the TBI Model Systems within the broader NIDILRR budget to ensure accountability and reliability of these funds.

## Allocate Federal Resources

### Coordinate Federal Programs

The Department of Health and Human Services (HHS) Administration for Community Living (ACL) funds programs impacting individuals with brain injury and families, including Aging and Disability Resource Centers, Assistive Technology, Independent

Living Centers, Lifespan Respite Care; and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

- Support HHS in carrying out its mandate to develop a plan for coordinating Federal activities impacting TBI service delivery.

## Increase TBI Act Funding

ACL administers the TBI State Partnership Grant Program to help states increase access to services and supports for individuals with TBI throughout the lifetime and the Protection and Advocacy (P&A) TBI Grant Program to provide advocacy services for people with brain injury. Currently only 24 states receive TBI State grants, and all the P&A grants are severely under-funded.

- Appropriate \$19 million to the Federal TBI State Grant Program to increase the number of state grants to \$300,000, and appropriate \$6 million to the P&A Grant Program.

## Fund CDC TBI Program

The TBI Act of 1996, as amended, authorizes the Centers for Disease Control and Prevention (CDC) to collect data and conduct public education and research. The TBI Program Reauthorization Act of 2018 further authorized the establishment of a national concussion surveillance system.

- Support the TBI national concussion surveillance system at \$5 million as part of a total allocation of \$11.75 million and continue to include brain injury across multiple CDC programs, including Steadi, opioid misuse prevention, intimate partner violence and others.

## Join the Congressional Brain Injury Task Force

The mission of the Congressional Brain Injury Task Force is to further education and awareness of brain injury and support funding for basic and applied research, brain injury rehabilitation, and development of a cure. Advocates are urged to request their senators and representatives join the Task Force to help make life better for individuals with brain injury and their families. Congressional offices can reach out to Rep. Bill Pascrell, Jr. (D-N.J.) or Rep. Don Bacon (R-Neb.).



# STATE AFFILIATE NEWS

## INDIANA

The Brain Injury Association of Indiana (BIAI) created its first newsletter, Indiana Brain Beat, and sent the first issue out in January with great success! Email [biassociationofindiana@gmail.com](mailto:biassociationofindiana@gmail.com) to make sure you receive future issues.

Over the last year, we hosted many different virtual events. BIAI offered support groups virtually, and we look forward to continuing to have a virtual option available for attendees in the future. We held our first art therapy collaboration with the Indiana University Neuroscience Art Therapy Program. Those who attended appreciated the chance to express themselves through an artistic medium. We also held our first FUN-raiser with an exciting night of virtual trivia!

We have made several important updates to our website, showcasing various new initiatives. We created a brain injury advocacy page with information on ways to advocate for increased funding, supports, services, and resources – locally and nationally. We've also started listing volunteer opportunities online. Lastly, we are so excited to report that we have brought back BIAI membership to our organization! We depend on our members to help us to advance our vision that people with brain injury and their caregivers are well served, understood, empowered, and supported in living full, meaningful lives. For more information or to become a member, visit [biaindiana.org](http://biaindiana.org).

## LOUISIANA

The Brain Injury Association of Louisiana (BIALA) has been busy brainstorming ways to connect with our more than 500 members in this new virtual world. In the first quarter of 2021, our virtual support groups continued with guest speakers scheduled each month. Topics included neuroplasticity, setting goals, creating hope after brain injury, cognitive health, and a question-and-answer session with a neuropsychologist. In addition, we offered monthly virtual exercise groups led by Maryann Vicari, physical therapist, and Nicole Marquez, BIALA board member.

In collaboration with the Louisiana Assistive Technology Access Network (LATAN), we are hosting a free virtual conference on how the use of technology can improve quality of life. The conference will highlight engagement in recreational and leisure activities and feature live demonstrations by people living with brain and spinal cord injury. In August, we will host our 13th annual conference, "Together Toward Tomorrow." For more information, visit [biala.org](http://biala.org).



Maryann Vicari and Nicole Marquez debut a new virtual exercise series offered through BIALA.

## MASSACHUSETTS

Despite the pandemic, the Brain Injury Association of Massachusetts (BIA-MA) continues its advocacy efforts to require commercial health insurance plans to cover cognitive rehabilitation for individuals with acquired brain injury. In December, the state legislature adopted an omnibus health care bill that requires commercial, state employee insurance plans and Medicaid to cover cognitive rehabilitation specifically for individuals experiencing neurological complications associated with COVID-19.

Our new program, “The Journey: Healing through Self-Expression,” was an idea whose time had come when a pandemic forced us all to stay home. This weekly, virtual program is an opportunity to inspire through survivor and family-led creative self-expression presentations. Open to all, the program contains wisdom, resilience, and respect for the challenges of living with brain injury. Sessions so far have included topics such as writing, photography, fairy gardens, coaching, volunteerism, music, painting, and so much more. Attendees have an opportunity to learn from one another’s journeys and are motivated to try new things, presenters have found that this has helped them to see and organize their personal journeys in a new way, and staff are grateful to deepen our own understanding of brain injury. Collectively, we all look forward to Monday mornings a bit more! For more information, visit [biama.org](http://biama.org).

## MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted our annual “Sports Concussions: Facts, Fallacies and New Frontiers” education program virtually. Youth sports and school personnel watched recorded educational sessions including: “Concussion Facts and Fallacies,” “Research Updates,” “Side-line Dos and Don’ts” and “Let’s Get Schooled on Concussion.” A panel of experts held four virtual “Concussion Conversations” to answer questions by participants.

This program also offers every school in Missouri access to the Get Schooled on Concussions website, which provides resources to support any student in return-to-learn activities.



The annual Survivor and Family Education series was also held virtually. Survivors and family members attended sessions on making and keeping relationships after brain injury, understanding types of doctors and brain injury specialists, navigating the workforce, and assistive technology. For more information about BIA-MO programs, visit [www.biamo.org](http://www.biamo.org).

## MAINE

The Brain Injury of America – Maine Chapter (BIAA-ME) published the fifth edition of its Maine Brain Injury and Stroke Resource Directory in both print and online formats and is in the process of distributing the directory across the state. In January, BIAA-ME established a new statewide virtual brain injury support group for Maine brain injury survivors and caregivers.

BIAA-ME continues to focus on increasing awareness and resources around the intersection of brain injury and substance use disorder (SUD) with a TBI Partnership Grant through the Administration for Community Living. Recent accomplishments through the grant include multiple sessions on the topic at the 11th annual “Defining Moments in Brain Injury” conference; providing education and resources for Maine SUD organizations; and efforts to expand and improve the membership of Maine’s Acquired Brain Injury Advisory Council. In addition, through a contract with the Maine Department of Health & Human Services, BIAA-ME continues to expand access to core brain injury resources and supports for Maine brain injury survivors and families.

*(continued on page 26)*

## PENNSYLVANIA

The Brain Injury Association of Pennsylvania (BIAPA), in collaboration with the Pennsylvania Department of Health, has implemented the Brain Injury Ambassador Program. The focus is on reaching out to individuals with brain injury, families, and caregivers coming through inpatient rehabilitation hospitals throughout Pennsylvania. The program's goal is to let families know that there is hope and help available after brain injury and to provide them with resources.

Currently, there are 11 volunteer Brain Injury Ambassadors. They are all individuals with lived experience, either as persons with brain injury or as caregivers. This puts them in a unique position to relate to families who are new to the world of brain injury – they've been there!

Ambassadors were extensively trained to serve in this role. They completed BIAA's Brain Injury Fundamentals Training and Certificate program for non-licensed direct care staff and individual caregivers. They also completed BIAPA's customized trainings on privacy issues, effective communication with active listening, and the use of scripts when interacting with families. We meet as a team on a monthly basis to provide ongoing training, share experiences, and identify ways to refine the program. To learn more, visit [biapa.org](http://biapa.org).

## RHODE ISLAND

The Brain Injury Association of Rhode Island (BIARI) finished 2020 with a virtual auction. The event allowed BIARI to reach a larger audience than usual and will be incorporated into the yearly fundraising event calendar. BIARI staff are excited to host more events, including a casino night and trivia tournament, in 2021.



Plans are underway for the 20th Annual Statewide Brain Injury Educational Conference. BIARI will offer sessions on a variety of topics throughout the

year, rather than during a one-day event, to appeal to a wider audience. While we all miss the opportunity to meet in person, pivoting to a virtual format for the 2020 conference taught us that there are some advantages to online learning. BIARI also discovered the advantages of virtual connection through online support groups. While online will never fully replace in-person support groups, we have found that the format fills a need for those survivors unable to travel. The Board and staff at BIARI looks forward to more positive opportunities in 2021! Learn more about BIARI at [biari.org](http://biari.org).

## VIRGINIA

The Brain Injury Association of Virginia (BIAV) accomplished many projects and events at the end of 2020. In November, we completed a year-long branding and marketing project with Capital One, which focused on creating new materials and messaging for the Information & Referral program. Using the new brochure, pamphlet, social media ads, and website pages, we hope to increase public awareness about how to access critical brain injury services and supports. The final result earned BIAV the Excellence in Collaboration Award presented by BIAA at its annual Affiliate Leadership Conference.

In recognition of November as Caregivers Month, we hosted a virtual Caregiver Forum; caregivers from across Virginia attended educational sessions, learned more about self-care and wellness, and connected with each other. We also held our first virtual Making Headway conference, which included two days of networking, informative presentations, and social activities that brought together persons with brain injury, caregivers, and professionals. We wrapped up 2020 with a final staff retreat led by The Spark Mill, a Richmond-based consulting firm. During the retreat, we explored ways in which our staff can better communicate internally and externally, use each of our strengths and skillsets to support our mission, and how we can continue to connect with each other even with so many in-person limitations. While 2020 challenged us all in unexpected ways, we are proud of the work we continue to do every day and look forward to a new year. To learn more about BIAV, please visit [biav.net](http://biav.net).

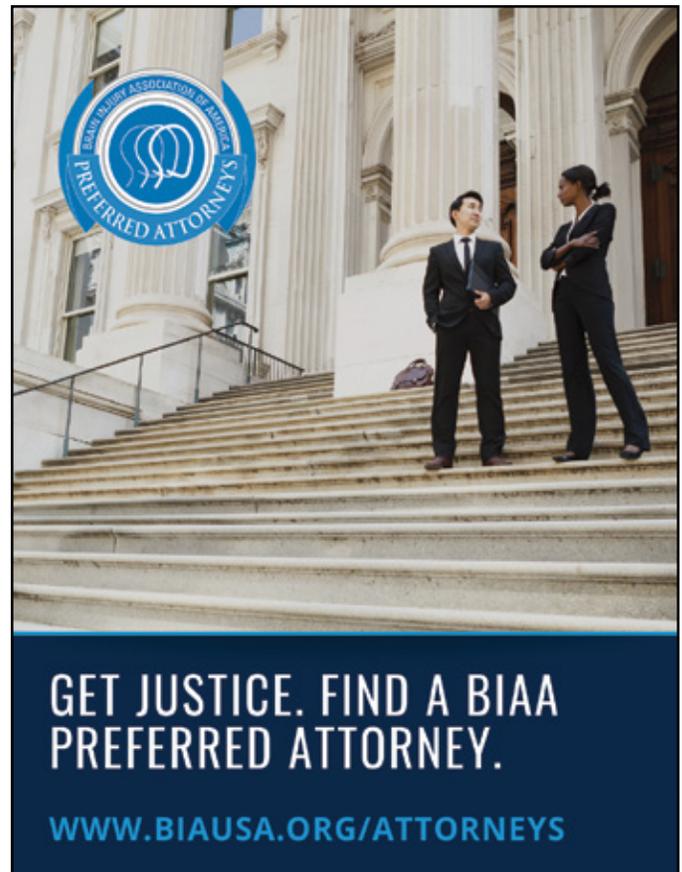
## VERMONT

The Brain Injury Association of Vermont (BIAVT) has launched our new website [biavt.org](http://biavt.org)! While we're still making daily adjustments, we are grateful for its new functionality and expanded resource directory!

We started 2021 by offering many free webinars, and we are continuing to book several great webinars throughout the spring with amazing speakers including Dr. Kim Gorgens. Please visit [biavt.org/events](http://biavt.org/events) for details on all our offerings.

If you are interested in being a speaker for one of our webinars this year, please reach out to [dani@biavt.org](mailto:dani@biavt.org). As always, our helpline is open Monday through Friday, 9 a.m. to 4 p.m. (ET) for information and referrals. ●

For information about all BIAA's state affiliates and to locate resources in your state, visit [biausa.org/find-bia](http://biausa.org/find-bia).



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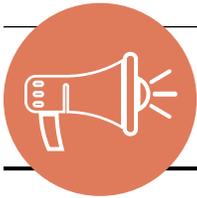
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# NEWS & NOTES

## TeachAids and BIAA Announce the CrashCourse Concussion Story Wall

By Piya Sorcar, Ph.D., Founder & CEO, TeachAids

CrashCourse by TeachAids is proud to partner with the Brain Injury Association of America (BIAA), which for 40 years has provided valuable help and insight for those affected by brain injury. It is with great pleasure that together we announce the launch of the CrashCourse Concussion Story Wall, in which more than 700 people affected by concussions share their personal experiences. The product was launched March 1, in conjunction with Brain Injury Awareness Month, and can be found at [ConcussionStoryWall.org](http://ConcussionStoryWall.org).

“It is incredible that CrashCourse by TeachAids and the Brain Injury Association of America have joined together to kick-off Brain Injury Awareness Month with the launch of the Concussion Story Wall!” exclaims Alison Tetrick, gravel racing champion. “Having experienced a challenging brain injury, I’m certain that this powerful resource will make all the difference.”

The more than 4,000 personal video narratives recounted in the Concussion Story Wall give clarity and hope to those who are affected and their loved ones. “The Concussion Story Wall will be a great

help to those managing various aspects and stages of a concussion. This is especially relevant to my sport of soccer – at all levels ability and all ages. I am proud to be part of this effort!” echoes Jordan Morris of the Seattle Sounders professional soccer team.



Concussions can happen to anyone at most any time – a chance fall, whiplash from a car accident, an event in military service in training or combat, and even recreational activities. The severity of concussions and the symptoms that are manifested vary greatly, as does the time of recovery. What better way for one to understand this than to hear from others? This is especially relevant to parents, teachers, and friends of those who have experienced concussion, also known as a mild traumatic brain injury (mTBI). “The Concussion Story Wall will help those impacted better understand how to manage such challenges. I especially appreciate the interactive nature of the database, which allows users to find video narratives that resonate with their personal experiences,” states Nneka Ogwumike of the Los Angeles Sparks professional basketball team.





The CrashCourse Concussion Story Wall is available to anyone free of charge. Its interactivity allows a viewer to select stories from many parameters, such as age, gender, cause, symptom, helpful hints, and more. In addition, a separate section allows one to access several of the world’s top medical experts addressing the latest scientific information in their related specialty. For example, John Leddy, M.D, State University of New York at Buffalo, describes the role and importance of exercise in rehabilitation. “Understanding the symptoms of concussions and how best to address them during rehabilitation is critical to recovery,” shares Dr. Leddy. “The



Concussion Story Wall will be a powerful tool to understand the complexities of head injuries and help communicate best practices.”

Carlijn Schoutens, olympic bronze medalist in speed skating, summarizes, “What strikes me as most inspiring are the multitude of diverse video narratives on the Concussion Story Wall. Having been through a challenging head injury, it’s empowering to see hundreds of similar and yet vastly different stories. Together we are a united voice providing hope to all others!” ●

## Have you or your loved one had a brain injury?

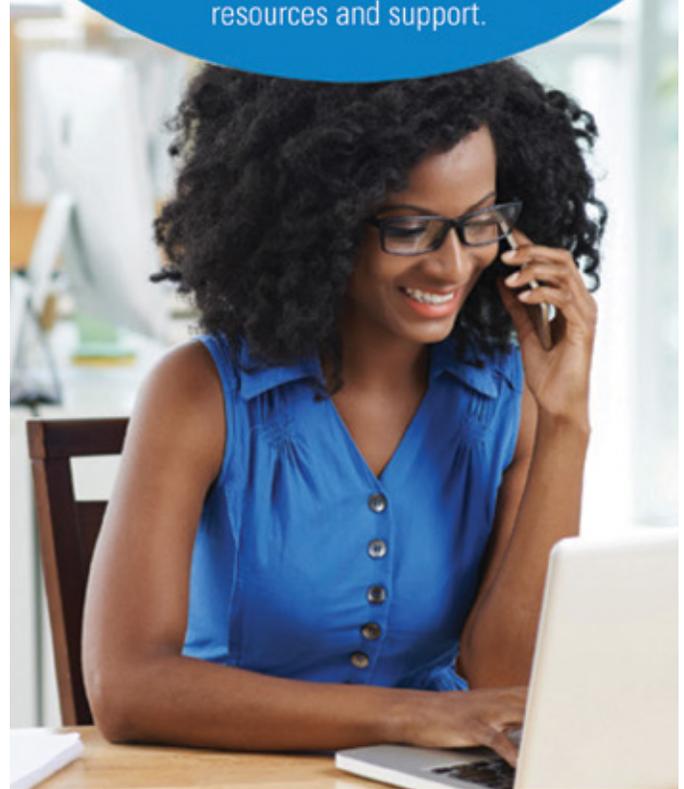
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For general information about brain injury, visit [www.biausa.org](http://www.biausa.org)

(continued from page 20)

## Lance and Laura Trexler: Investing in the Future of Brain Injury Research

funds are used appropriately,” Lance shared. The couple also expressed that they were impressed by BIAA’s track record in advocacy informed by science.

Lance believes that an important part of professional development is being introduced to other perspectives. In an effort to provide mentoring opportunities to grant recipients, he leveraged his involvement with the American Congress of Rehabilitation Medicine (ACRM), where he has served as chair of the Brain Injury Interdisciplinary Special Interest Group. As a result, Dana Lengel, the recipient of a grant funded by the Trexlers, will attend the ACRM conference this fall free of charge, further enhancing her career development opportunities. “Lance had some important mentors along the way and he, in turn, has been a great mentor to others,” says Laura. “We believe you have to take good care of each other in order to take care of others.”

The commitment made by the Trexlers goes well beyond their giving of time and energy, notes BIAA President and CEO Susan Connors. “We appreciate their many years of volunteer service both to the BIA of Indiana and BIAA. Now, they are making this generous annual gift to ensure the future of brain injury research. We are so grateful for their generosity and leadership.”

For more information about the Brain Injury Research Fund or becoming a Research Champion, please contact Robbie Baker at (703) 761-0750 ext. 648 or rbaker@biausa.org. You can also download our research brochure at [biausa.org/supportresearch](http://biausa.org/supportresearch).

## UPCOMING WEBINARS

### Carolyn Rocchio Caregivers Webinar – Understanding and Managing Spasticity after Brain Injury

April 15, 3 p.m. ET/12 p.m. PT

*Laura Wiggs, PT, NCS, CBIS*

### David Strauss Clinical Webinar – Use of Applied Behavior Analysis in Brain Injury Treatment: Training, Ethics and Goals, and Considerations for Success

May 5, 2021, 3 p.m. ET/12 p.m. PT

*Anneka Hofschneider, M.A., BCBA, CBIS and Chris H. Persel, M.A., CCM, CBIS, CPHM*

### Business of Brain Injury Webinar – Conveying a Compelling Value Proposition for Payers

May 19, 2021, 3 p.m. ET/12 p.m. PT

*Effie Carlson, Chief Growth Officer, Healthcents*

### Carolyn Rocchio Caregivers Webinar – Recreation and Social Opportunities After Brain Injury

June 16, 2021, 3 p.m. ET/12 p.m. PT

*Joanne Finegan, MSA, CTRS, FDRT*

To register, please visit [shop.biausa.org/livewebinars](http://shop.biausa.org/livewebinars).

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For more information on how to become part of the Brain Injury Association of America Corporate Partners Program, please visit the sponsorship and advertising page at [www.biausa.org](http://www.biausa.org) or contact Carrie Mosher at 703-761-0750, ext. 640 or [cmosher@biausa.org](mailto:cmosher@biausa.org).

