

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 15, Issue 2

THE CHALLENGE!



Health Challenges
After Brain Injury

JULY 2021

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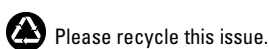


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FROM MY DESK



The Brain Injury Association of America (BIAA) is pleased to partner with several companies and organizations in addressing the health challenges associated with brain injury. This issue of *THE Challenge!* covers neuroendocrine (or hormone) issues, gastrointestinal problems, balance challenges, and injury-related fatigue. Please visit our website or sign up for our new monthly resource e-newsletters for information about other effects of brain injury, including spasticity and pseudobulbar affect (uncontrolled laughing and crying), at biausa.org/signmeup. *THE Challenge!* readers can also learn about the long-term medical complications associated with brain injury on BIAA's YouTube channel.

As we've learned over the last year, COVID-19 has left many with persistent neurological symptoms. As such, BIAA joined the American Academy of Physical Medicine and Rehabilitation and more than 20 other organizations in calling on Congress and the Biden Administration to create a national plan to address Post-Acute Sequelae of SARS-CoV-2 infection, also known as Long COVID. To learn more, read the Advocacy Update on page 24 of this issue.

I'd like to take this opportunity to congratulate Anne McDonnell, MPA, OTR/L, CBIS, on her 20th anniversary as the Brain Injury Association of Virginia's Executive Director. BIAA's affiliates have been delivering a remarkable number of very high quality programs over the last 18 months, especially given COVID-19. Please be sure to read the State Affiliate News section in this issue of *THE Challenge!*

On that note, we are all delighted that the pandemic seems to be lifting. For now, however, I want to remind readers that wearing a mask is NOT a sign of weakness. It is a sign of common sense. If you've sustained a brain injury, your immune system may be compromised. Until everyone in the country has been fully vaccinated, there's no reason to chance it. Wear a mask!

Have a safe and happy summer!

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

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

Brain Injury, Hormone Issues, and the Endocrine System:



with Dr. Tamara Wexler

By Dianna Fahel, Director of Marketing & Communications, Brain Injury Association of America, and Tamara L. Wexler, M.D., Ph.D., Clinical Associate Professor, NYU School of Medicine/Rusk Rehabilitation

Tamara L. Wexler, M.D., Ph.D., is an endocrinologist specializing in neuroendocrinology and reproductive endocrinology. We spoke with her about the pituitary system, the endocrine system, and common hormonal issues that might occur after brain injury. Here's what she had to say:

What is the pituitary system and how does it work?

The pituitary is a gland that sits in your brain, right behind the top of your nose – if you place one finger at the top of your nose and the other just behind your temple, the pituitary can be found approximately where your fingers would intersect.

The hormones most relevant in the chronic period after traumatic brain injury (TBI), defined as three months or more after the injury, come from the anterior pituitary. The anterior pituitary secretes a number of hormones that stimulate production of other hormones from other organs, known as “end organs,” as follows:

- Adrenocorticotropin hormone (ACTH) leads to the production of **cortisol**, or “stress hormone,” from the adrenal glands.
- Thyroid stimulating hormone (TSH) leads to the production of **thyroid hormone** from the thyroid gland.
- Luteinizing hormone (LH) and follicle-stimulating hormone (FSH) lead to the production of **estrogen or testosterone** and are also involved in ovulation and spermatogenesis.
- Growth Hormone (GH) leads to the production of **IGF-1** from the liver.
- The pituitary also makes **prolactin**, which is involved with lactation.

Working together with the hypothalamus and end organs, the pituitary keeps these hormonal systems in balance, via elegant feedback loops. The pituitary senses if levels of end-organ hormones are too low or too high,

and alters secretion of its hormones accordingly. For example, if thyroid hormone is too low, the pituitary senses that and sends out more of the signal (the thyroid stimulating hormone, or TSH) to the thyroid gland to let it know to make more thyroid hormone; if the thyroid hormone is too high, the pituitary senses that and secretes less TSH. The pituitary, this master regulator, functions in this way a bit like the thermostat in your house.

How can brain injury affect the endocrine system?

We know that there is a higher rate of pituitary deficiencies after certain types of brain injuries, such as TBIs. The reason that a TBI can lead to a pituitary hormone deficiency is not entirely clear; it may be related to damage caused to the pituitary itself or to the blood vessels or nerves that feed the pituitary, or it could be the result of inflammatory changes that may occur after an injury. It is important to consider whether pituitary dysfunction has occurred. If left untreated, pituitary deficiencies can have negative effects on physical, cognitive, and emotional health.

How common are endocrine issues after brain injury? Do they occur immediately after injury or can they appear later?

We know that there is a higher rate of pituitary deficiencies after concussion. As for the exact rate, that depends on what population was investigated in any given study. Chronic anterior pituitary deficiencies have been reported in 15-60% of adults after a TBI, and up to 42% of children and adolescents. The rates are even higher when measured in the first months after an injury. It's important to note that these rates come from studies, and reflect the specific population being studied. If a clinical trial reports that 35% of adults receiving inpatient rehabilitation 6 months after a severe TBI, for example, that may only apply to adults who are also undergoing inpatient rehabilitation after a severe TBI.

The question of timing is such an interesting one! Pituitary deficiencies can arise over time. Patients can recover, or they may develop new deficiencies in the months and year(s) after an injury. I focus here on the

(continued on page 6)



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“chronic” period, at least three months after injury. While there may be a high rate of hormone deficiencies in the first weeks and months after an injury, it’s not clear what they reflect, other than cortisol (often referred to as the “stress hormone”). It’s recommended, therefore, that only testing and replacement of the cortisol axis be considered in the acute period.

How are brain injury-related hormone issues diagnosed?

When I’m deciding whether I should conduct an evaluation, I base my decision on history and symptoms. The diagnosis itself is straightforward – there are clear guidelines as to what constitutes a deficiency in any of the pituitary hormones. Many of the hormonal systems can be evaluated with a simple blood draw, frequently in the morning.

Evaluation of some of the systems may require a stimulation test, in which something is given to stimulate hormone release and the body’s response is measured. For example, the diagnosis of growth hormone deficiency often requires stimulating growth hormone and measuring the levels of growth hormone over time. The replacement of deficient hormones must proceed in a specific order: first, cortisol (“stress hormone”) if someone has adrenal insufficiency; then, thyroid hormone; then estrogen or testosterone if needed; then, growth hormone. If someone has adrenal insufficiency, for example, it must be corrected before continuing with testing of the other hormones.

What symptoms or warning signs should caregivers look for in their loved ones? How would endocrine issues present?

Given how many people have suffered a concussion, there have been studies investigating whether biomarkers, imaging results, or aspects of the injury itself might predict which people should undergo testing for pituitary dysfunction, but, thus far, none have consistently yielded a clinically useful predictor. The best indicator appears to be symptoms.

This can be tricky, since symptoms from pituitary dysfunction can be broad and nonspecific, and overlap with symptoms from other aspects of a brain injury.

Symptoms might include persistent menstrual cycle irregularity or sexual dysfunction, difficulties with confusion or cognitive slowing, mood changes such as anxiety or depression, or changes in weight or energy. In children and adolescents, symptoms may be different, with school performance and behavior affected.

If someone continues to suffer from persistent symptoms more than three months after a brain injury, it is worth considering whether a pituitary dysfunction might be contributing. Not every individual with fatigue, brain fog, or other symptoms will have pituitary dysfunction; however, if a hormone deficiency does exist, replacing the hormone should help improve or reverse symptoms that stem from that deficiency.

What questions should you ask your doctor if you think you're experiencing endocrine issues?

Despite increased understanding of many health effects of brain injury, there is a lack of widespread awareness of the increased risk of pituitary deficiencies. If you started having some of the symptoms noted above after sustaining a brain injury, and if they have persisted beyond at least three months after the injury, you may want to approach your doctor to discuss this by saying something like the following: “I’ve read that there is an increased rate of pituitary deficiency after brain injury. Some of my symptoms sound like symptoms of pituitary hormone dysfunction, and I’m interested in an evaluation to see if a hormone deficiency is contributing to my symptoms. Is that something that you might do, or could you refer me to a neuroendocrinologist who could do so?” Your doctor may also have other explanations for some of your symptoms, but it’s always appropriate to raise the question.

In terms of the evaluation itself, it is important to see a doctor who is able to interpret the results and manage any identified deficiencies. This person may be an endocrinologist, though the area of post-TBI pituitary dysfunction encompasses many specialties including neurology, psychiatry, internal medicine, psychology, physical therapy, and others. Any doctor you are seeing will likely be able to discuss this with you.

For personalized support or resources, contact BIAA’s National Brain Injury Information Center at 1-800-444-6443 or email us at info@biausa.org.

The Vestibular System: Finding Your Balance

By Shanti M. Pinto, M.D., Katie L. Sewell, PT, DPT, NCS, CBIS, and Kelly M. Crawford, M.D., Carolinas Rehabilitation

Have you ever heard of the vestibular system? Up to 50% of people with a history of traumatic brain injury (TBI) experience vestibular impairments. Individuals with these impairments may feel lightheaded, dizzy, and off-balance. Vertigo, defined as a feeling of the room spinning, is often used to describe these complaints. Persistent impairments to the vestibular system are associated with increased psychologic distress and lower rate of return to work. It's important to recognize vestibular impairments after a brain injury and seek appropriate treatment to maximize function and quality of life.

The sensory, vision, and vestibular systems are all important for maintaining balance. Each of these systems can be affected by a brain injury.

As shown in Figure 1, the ability to balance the body during everyday activities relies on information from the sensory, vision, and vestibular systems. Often, the symptoms of dizziness and imbalance can be related to vestibular system dysfunction following a brain injury. This system is complex, but it can be simplified into three components for the purposes of this article:

1. The sensory organ
2. The nerve that connects the sensory organ to the brain
3. The area of the brain that processes information from the vestibular system

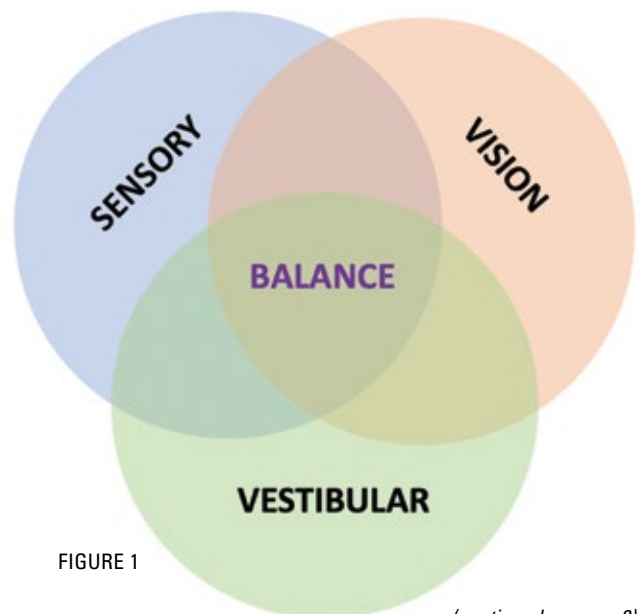


FIGURE 1

(continued on page 8)

The **sensory organ** structures are located in the inner ear and contain different tubes, also called canals, that are filled with fluid and hair cells. Calcium deposits, or “crystals” as they’re often called, move from one end of the tube to the other with the movement of the head. Each sensory organ has three canals – lateral, superior, and posterior semicircular canals – to help the body move in all directions. The calcium deposits shift in the canals when the body moves and stimulate tiny hair cells that carry signals through the **nerve** to **processing centers** in the brain. These brain centers combine this information and coordinate appropriate body responses to allow for proper balance and body orientation with movements.

A brain injury can often cause damage to one or more of the parts that make up the vestibular system. In some cases, the calcium deposits shift into the wrong place and cause the brain to receive inaccurate information about where the body is in space, resulting in vertigo when someone moves. A brain injury may also cause dysfunction of the nerve that connects the sensory apparatus to the brain by direct trauma or swelling in this area. The two nerves, one on each side, work like a seesaw. When the left side turns on (“goes up”), the right turns off (“goes down”). The seesaw relationship

is particularly important when turning the head and trying to keep the eyes focused on an object, such as reading a sign while walking or driving. If one of the nerves is not working, the other side will often become overactive causing imbalance, a feeling of unsteadiness, or dizziness. Finally, a brain injury can cause damage to the areas of the brain that directly process all the information from the other components of the system, which can manifest as continuous dizziness, vertigo, blurred vision, difficulty reading, and poor balance. A physical therapist with specialized training in vestibular impairments can evaluate balance problems and dizziness to develop a treatment plan and help the body move better. A physical therapy evaluation will include tests that involve moving the head to different positions to evaluate symptoms and eye movements, examining the quality of eye movements and the ability to focus on a target with a head movement, and assessing balance during tasks that rely heavily on the vestibular system. Based on the results of these tests, the therapist will design a treatment plan or complete more in-depth testing to determine what part of the vestibular system is impaired. As shown in Figure 2, rehabilitation strategies and treatment are selected based on the location of the dysfunction within the vestibular system.

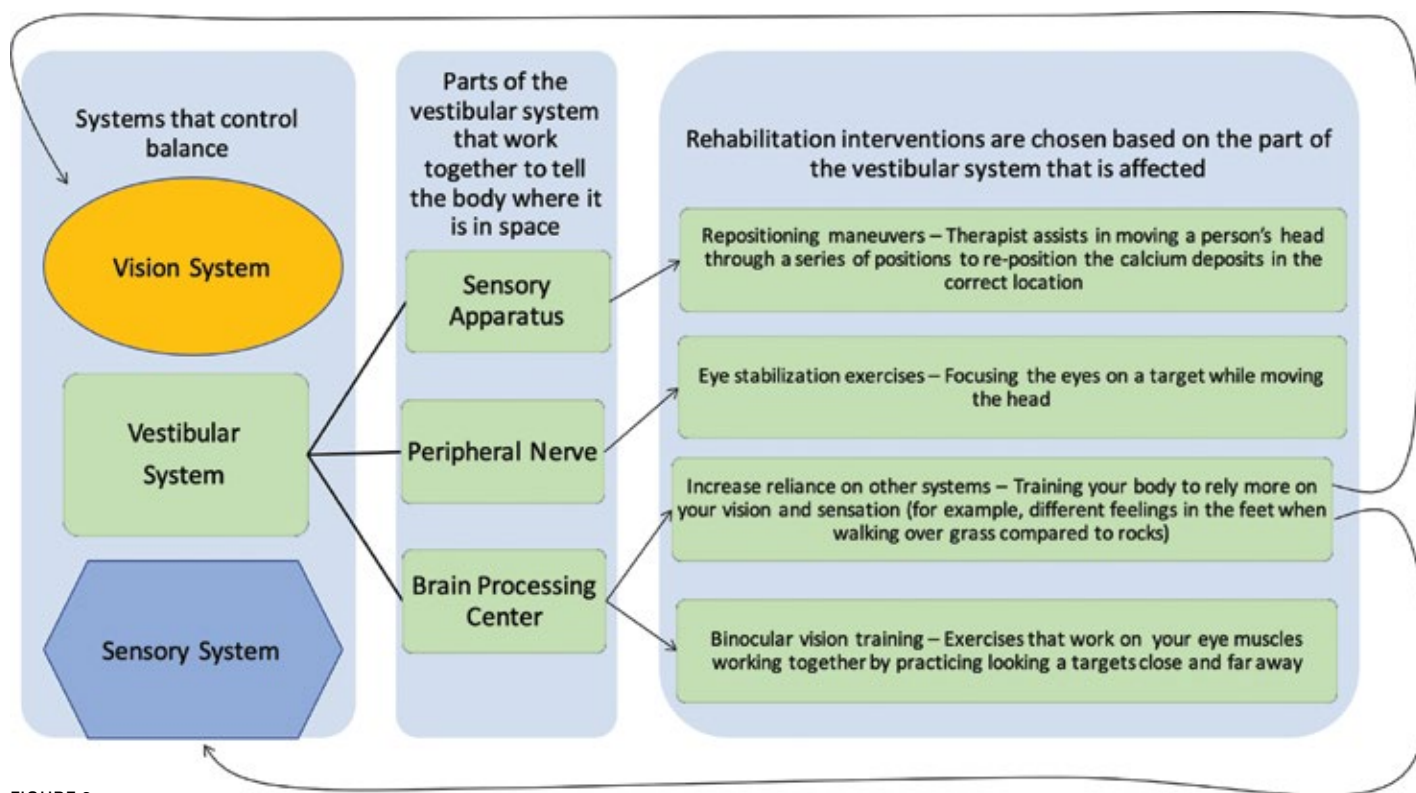
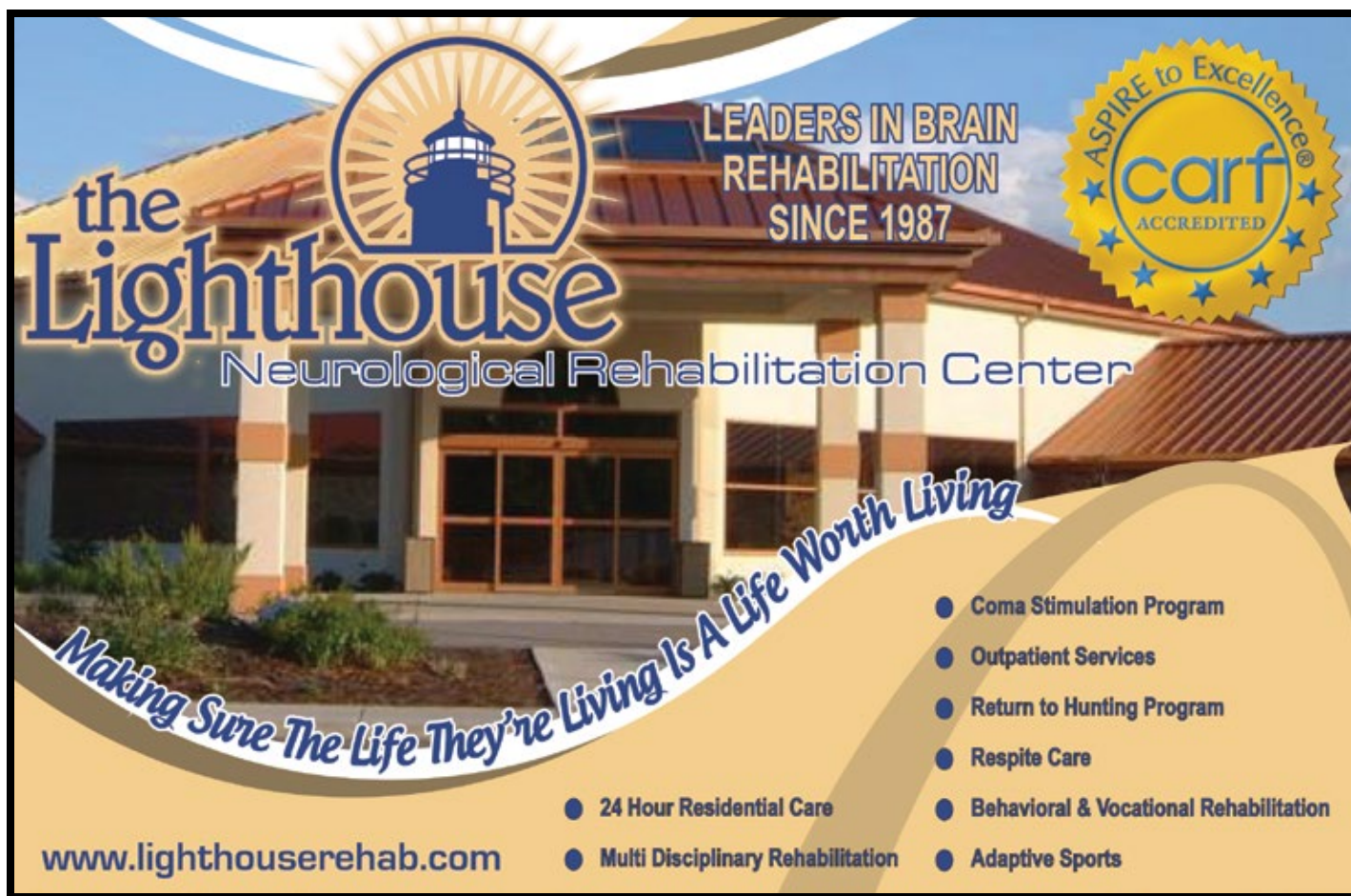


FIGURE 2



Rehabilitation strategies can improve symptoms of vestibular dysfunction. Treatments are chosen based on the part of the system that is not working correctly.

Evaluation by a trained professional is critical to successful treatment and improvement of symptoms. Effective rehabilitation strategies can include repositioning techniques, gaze stabilization exercises, binocular vision training, and up-training of your other balance system. Symptoms of dizziness or vertigo can increase the risk of falling, which is the leading cause of brain injury, so it's important to use strategies to lower the risk. Strategies to prevent falls include:

- Use the assistive device recommended by your therapist or provider
- Remove rugs and other items from the floor
- Use a nightlight to help see in the dark

Medications are sometimes used for management of vestibular dysfunction. Typically, medications are only

used if symptoms do not improve with rehabilitation or, in severe cases, where a person cannot tolerate rehabilitation exercises. Options should be discussed with a physician. A person may also be referred to an ear, nose, and throat (ENT) doctor, also known as otolaryngologist, if symptoms do not improve with therapy or if there is hearing loss. An ENT doctor can do specialized tests to look for structural damage to the ear canal.

Feeling dizzy or being off-balance are common symptoms after brain injury, and they occur due to damage to the vestibular system. Specialized physical therapists can evaluate the cause of these symptoms and start rehabilitation treatments. Medications can also be used if the symptoms do not improve. If you have difficulties with balance or dizziness after brain injury, talk to your provider about an evaluation and treatment options.

References are available at biausa.org/balanceissues. •

The Link Between Gastrointestinal Issues and Brain Injury



By Sheryl Katta-Charles, M.D., Medical Director, Brain Injury Rehabilitation, Rehabilitation Hospital of Indiana

Needless to say, food is important for our physical health. But that's not all of it. Our culture revolves around food. Matters relating to eating affect how we live, how we socialize, and how we look. In many ways, the relationship between food and psychological health is intertwined. Just as eating food affects socialization, so too does the output or elimination of food. After a moderate-to-severe brain injury, individuals may experience gastrointestinal (GI) issues. Brain injuries affect the GI tract in various ways:

Changes in Appetite

Physical and psychological issues can lead to loss of or increase in appetite. Physical issues include changes to the sense of smell or sensation of the tongue and mouth. The olfactory nerve sends smell signals from the nose to the brain, and a brain injury can cause damage to the thin nerve filaments inside this nerve. We rely on our sense of smell to judge food; so, decreased or total loss of smell may make food unappetizing. Psychological issues such as lack of motivation can also lead to loss of appetite. Depression can result in either decreased or increased appetite. Some individuals may experience an increase in appetite after a brain injury due to medications, decreased activity, and other factors. Lastly, neuro-hormonal changes are a rare cause of increased appetite.

Dysphagia

Dysphagia, plainly put, is a problem with eating. Dysphagia can occur for reasons related to the mouth, pharynx, or the food pipe. Brain injuries usually affect the oral and pharyngeal phases of eating and can cause weakness of the mouth, leading to problems controlling food with the tongue. The trigeminal nerve provides general sensation to the mouth and tongue as well as

strength to the chewing muscles. Damage to this nerve can cause a painful sensation in the face and mouth. The pain can be worse when food touches the mouth.

The facial nerve makes the salivary glands produce saliva. An injury to this nerve can decrease salivation. Without saliva, it is difficult to chew and swallow dry foods. The pharynx is the area in the back of the mouth where swallowing occurs. If the muscles back there are weak, they allow food and water to go down the windpipe. This can be dangerous as food in the windpipe can lead to choking or pneumonia. A feeding tube may decrease the risk of choking or pneumonia.

Nausea and Vomiting

The cerebellum, inner ear, eyes, and neck muscles work together to provide equilibrium. Damage to any of these parts can result in dizziness and nausea or vomiting. Physical therapy may restore equilibrium and decrease nausea. Rarely, severe brain injury can lead to gastroparesis or paralysis of the stomach. In gastroparesis, the stomach does a poor job emptying. This can result in acid reflux, nausea, and vomiting. In such a case, avoiding large meals and the use of certain medications can be helpful.



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



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Constipation and Diarrhea

Physical activity helps the GI tract move. When mobility has been affected by a brain injury, constipation can be one result. Others experience diarrhea, which can be caused by medications, certain types of food, or surgeries to the GI tract. Getting fed through a feeding tube also leads to loose stools.

Incontinence

People with poor awareness of their bodily functions can experience incontinence. Loose stools can be difficult to control and mobility issues may interfere with reaching the toilet in time, resulting in incontinence. Durable medical equipment may make it easier to get to the bathroom. It may also be helpful to control the timing of medications, food, and bathroom breaks.

Nutritional Deficiencies

Changes to diet may result in deficiencies of essential vitamins and minerals. Tube feeds may not contain all the essential vitamins and minerals. Those who are on tube feeds for many years may become deficient in zinc and other minerals. Another common deficiency is vitamin D, which is most easily produced by our bodies using light from the sun. Some people do not get enough

sun exposure and end up with vitamin D deficiency. Taking supplements may be helpful, but taking too much can also result in toxicity. Checking your levels and speaking with a medical provider about the right dosage is important.

Gut-Brain Axis

Researchers are working on the gut-brain axis, which is the connection between the brain and the bacteria in our gut. Probiotics are thought to nourish healthy bacteria. They are usually not harmful in non-hospitalized individuals. If you're interested in taking probiotics, talk to your doctor.

These are all common reasons for various gastrointestinal changes after brain injury. This information is meant to empower you to understand nutrition and elimination better – and to make life easier. Be sure to discuss your questions and concerns with a medical provider.

If you need personalized support or resources, contact BIAA's National Brain Injury Information Center at 1-800-444-6443.

Fatigue After Brain Injury

By Katherine Dumsa, OTR/L, CBIS, and
Angela Spears, MA, CCC-SLP, DPNS, CBIS,
Rainbow Rehabilitation Centers



Fatigue is a part of life that is experienced by everyone. Whether it is from a busy day at work, a demanding workout, or after paying attention to a long lecture, the term “I’m tired” is exceedingly common.

Fatigue and Traumatic Brain Injuries

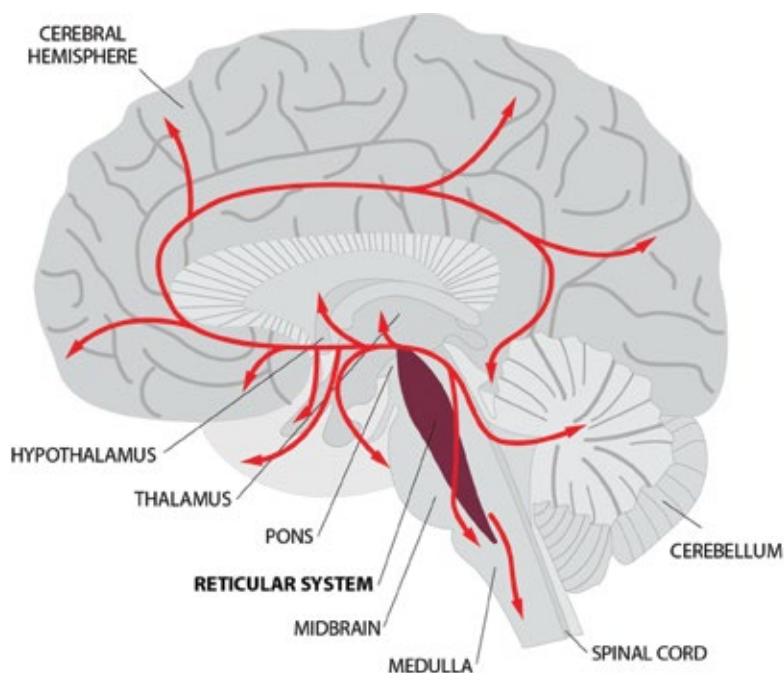
For individuals with brain injuries, fatigue (sometimes referred to as cognitive fatigue, mental fatigue, or neurofatigue), is one of the most common and debilitating symptoms experienced during the recovery process. It can become a significant barrier to one’s ability to participate in the activities they want and need to do in daily life. It is reported that as many as 98% of people who have experienced a traumatic brain injury have some form of fatigue. Many report that fatigue is their most challenging symptom after brain injury. Reasons for the fatigue are not well understood but may include endocrine abnormalities, the need for the brain to work harder to compensate for brain injury deficits (in other words, inefficiency), or changes to brain structures.

Assessment Tools to Determine Fatigue Levels

Fatigue can be difficult to identify because it is not always reported by the patient or obvious to others. Clinicians use various self-report assessment tools to gain further information on a patient’s fatigue

levels and the impact it has on their overall daily functioning. Two of the scales specifically designed for individual patients with brain injuries include the Barrow Neurological Institute Fatigue Scale (BNI) and the Cause of Fatigue Questionnaire (COF). Clinicians must also evaluate physical and mental changes, which can lead to depression and other psychiatric conditions following brain injury. The changes can commonly present as overwhelming fatigue.

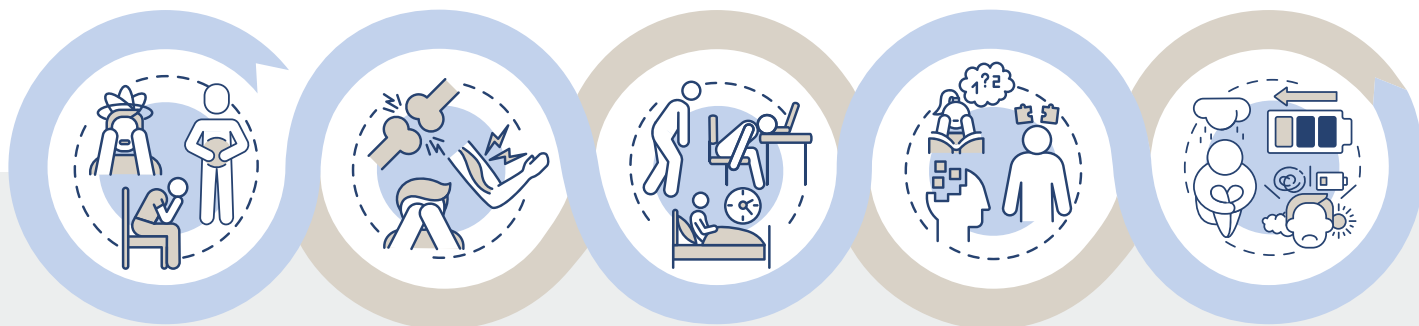
THE ASCENDING RETICULAR ACTIVATING SYSTEM



Symptoms

Generally, those who have sustained brain injuries have described fatigue as a sense of mental or physical tiredness, exhaustion, lack of energy, and/or low vitality. Physical observations of fatigue include yawning, an appearance of confusion or “brain fog,” or easily losing attention and concentration. In more severe cases, it may present as forgetfulness, irritability, slurred speech, or dizziness. Emotions can become raw at this level of fatigue, affecting mood, motivation, and interaction with one’s social network. To manage fatigue effectively, individuals must learn to identify the symptoms of fatigue and how to modify activities that may trigger fatigue. Managing fatigue effectively will help decrease stress levels and improve overall performance for both work and home activities. Some fatigue-inducing activities include:

- Working at a computer
- Watching television excessively
- Having a stimulating sensory environment
- Concentrating on paperwork
- Reading for long periods of time
- Physically demanding tasks
- Cognitively demanding tasks
- Emotionally draining tasks



Symptoms of fatigue can include:

PHYSICAL

- › A pale or greyish pallor
- › Glazed eyes
- › Headaches
- › Tension in muscles
- › Shortness of breath
- › Slower movement and speech
- › Decreased coordination
- › Difficulty staying awake

COGNITIVE

- › Increased forgetfulness, distractibility
- › Decreased ability to follow directions
- › Making an increased number of mistakes
- › Decreased awareness of surroundings
- › Increased response time or lack of response

SOCIAL/EMOTIONAL

- › Decreased ability to communicate effectively
- › Decreased ability to engage in social activities
- › Irritability, restlessness, emotional lability
- › Increased negative thoughts
- › Withdrawal, short answers, dull tone of voice
- › Lack of motivation and interest
- › Difficulty engaging in activities of daily living

Fatigue Is Not Laziness

In today’s multi-media society, we take in, absorb, and process large amounts of information every day. It can be difficult for family members or peers to understand the limitations caused by fatigue following a brain injury. Unfortunately, it can be mistaken for laziness or an unwillingness to participate in therapies and daily activities. It is important to understand that lacking the mental energy needed to complete tasks does not equate to lacking the desire to complete those tasks. Many individuals struggling with fatigue have motivation but lack the energy to keep up with daily demands.

(continued on page 14)

WHEN YOU ARE HEALTHY



In the morning your battery is full.



In the afternoon energy is used for mental activities, but you still have plenty of energy left.



In the evening a substantial part of your energy is used.



At night your battery is recharged again.

AFTER A BRAIN INJURY



In the morning your battery is partly filled. This is your maximum attainable level.



In the afternoon after a few mental activities, your battery is almost empty.



In the evening, or sometimes even before, your battery is empty.



At night your battery tries to recharge, but it's not strong and cannot be fully recharged.

Lack of sleep has a negative effect on our cognition, mood, energy levels, and appetite. The American Academy of Neurology reports that as many as 40% to 65% of people with mild traumatic brain injury complain of insomnia, so maintaining a sleep hygiene program is essential to recovery and to managing fatigue.

- **Practicing energy conservation** – Pacing yourself each day, or prioritizing daily tasks to avoid becoming over-tired, can help with balancing out a busy schedule. Complete tasks that require the most mental effort earlier in the day with planned rest breaks in the afternoon or evening.
- **Organizing daily activities** – Utilize a checklist or planner to set a to-do list. Break up complex projects into manageable tasks. When completing these tasks, minimize environmental stimulation as much as possible.
- **Improving health and wellness** – Increased overall health and wellness has been described as “energizing,” and research suggests that it can improve mood. Aim to exercise three to five times per week for a minimum of 30 minutes per session. Maintain a well-balanced diet rich in protein, fiber, and carbohydrates to help the brain and body stay fully energized.
- **Keeping a fatigue diary** – This kind of diary can assist in monitoring changes and energy levels before and after daily activities. This tracking of fatigue can be used with your treatment team to help mitigate what may be increasing neurofatigue. Assessment and treatment of fatigue continues to be a challenge for clinicians and researchers. While there is no cure for fatigue, there are many ways to manage and overcome the symptom. Awareness and an open mind towards coping strategies will lessen the negative effects of fatigue and allow for meaningful participation in life.

Coping Strategies Used to Ease Symptoms

When managing fatigue, it is important to identify and treat physical factors that may be contributing to the fatigue. Recognizing early signs of fatigue and working with the patient so they understand how to respond to these is beneficial. By learning to recognize these triggers, one can learn coping strategies to successfully meet daily demands, ultimately increasing quality of life. These strategies include:

- **Having a healthy sleep routine** – This can be done by setting a sleep schedule of when to go to bed and when to wake, regardless of the day of the week. Establishing a strict routine using an alarm clock allows the brain proper rest. When rest is needed, aim for a “power nap” of 30 minutes maximum to avoid feeling over tired for the remainder of the day.

This article originally appeared in the Summer 2018 issue of Rainbow Visions Magazine available at rainbowrehab.com.

For a complete list of references, please visit biausa.org/neurofatigue.

HAS A TRAUMATIC BRAIN INJURY CHANGED WHO YOU ARE?



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

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

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

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

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

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

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



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Brain Injury Advocates and Survivors Do More for Brain Injury

By Stephanie Cohen, M.S., Development Manager, Brain Injury Association of America

In honor of Brain Injury Awareness Month, hosted March 2021, the Brain Injury Association of America (BIAA) launched the Do More fundraising campaign. Twenty-one individuals joined BIAA to do more for people living with brain injury. Survivors, family members, friends and professionals set up personalized fundraising pages and together raised more than \$25,000! In celebration of this amazing accomplishment, we want you to meet some of our volunteer fundraisers:



Joe Ferrara

Fundraiser

"I wanted to support BIAA because of all they have done for me and how helpful they have been. I appreciate this organization so much and my TBI has made it even more important. I'm doing the best I can to bring more awareness and funds to this serious issue. Raising money is the BEST thing I can do."



Bre Ashely

Fundraiser

"I started this campaign to help support the research and more advocacy for TBI's. My vision is a better world for all of us and health and justice equality for all. I've turned my concussion into art and have felt so much more alive!"

Laurie Rippon

Fundraiser

"I support BIAA because of their support for me and those across the country living with brain injury. My experience with them has been one of mutual respect and collaboration. I can tell my voice is heard, which is so critical for those who are often dismissed. As just one of millions of others whose lives have been deeply affected by brain injury, I feel that BIAA has our back. I know my fundraising supports their efforts to raise awareness and their commitment to research, education, and outreach."





Mary Turek Schanuel

Fundraiser

"I enjoyed raising money for such a wonderful and important cause. BIAA has improved my life after my brain injury accident in 2017 by the resources it offers. The website was key for me when I first started out on this difficult and challenging journey."

Joanne Finnegan

Fundraiser

"I held the fundraiser because it is a good way to reach out to my network to let them know about BIAA and all of its great work. I also wanted to recognize the 2 most influential people in my 35+ year career in brain injury, Ross Rieder and Dr. David Strauss, co-founders of ReMed. I was thrilled to see the response and support especially from so many current and former staff at ReMed."



Thank You!

Thanks to the hard work of our volunteers and nearly 200 donors, BIAA is able to fund scientific research to better understand the lifetime effects of brain injury, answer the call from thousands of families seeking help from its National Brain Injury Information Center, ensure that trained specialists are available to provide care nationwide, and advocate for state and federal resources to address the needs of the brain injury community. To create your own personal fundraising page or to support the campaign, visit biausa.org/domore.



Paige Melton Ivie

Fundraiser



David Harrington

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Hunter Schulz

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Not pictured: David Anderson, Tammy Andrews, Robbie Baker, Diana Baldovino, Kris Bartik, Encased Commic LLC, Katherine Kimes, PCOM ANST, University of Iowa NSSLA Chapter, and Emily Watkins.



ADVOCACY UPDATE

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

Brain Injury Awareness Day Goes Virtual

The Congressional Brain Injury Task Force, chaired by Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.) hosted a virtual Awareness Day briefing March 3. Nearly 700 people tuned into the event, “The Impact of COVID-19 on Persons with Brain Injury,” which was moderated by Brain Injury Association of America National Medical Director Brent Masel, M.D. The panelists included:

- Matt Breiding, Ph.D., Traumatic Brain Injury Team Lead, Division of Injury Prevention, Centers for Disease Control and Prevention
- Michael J. Hall, Ph.D., Neuropsychologist/Licensed Psychologist, Iowa City Veterans Affairs Health Care System
- Jennifer Braun, Brain Injury Manager, Bureau of Special Health Care Needs, Missouri Department of Health and Senior Services
- Eric Washington, Individual Living with a Brain Injury

BIAA sincerely thanks the speakers for their outstanding presentations. Please visit biausa.org/awarenessday21 for a recording of the briefing.

This year, advocates met with congressional representatives and their staff members in virtual meetings. As in years past, BIAA supported these efforts with legislative issue briefs that urge legislators to:

- Increase Access to Patient-Centered Rehabilitation
- Bolster Brain Injury Research
- Allocate More Resources to the Federal TBI Program
- Join the Congressional Brain Injury Task Force

The Task Force was established in 2001 at BIAA’s urging with assistance and collaboration of the National Association of State Head Injury Administrators. BIAA is grateful to Rep. Pascrell, Jr. (D-N.J.) and his current and previous co-chairs for their dedicated support of

the brain injury community. To download the legislative issue briefs and share them with your elected officials, visit biausa.org/2021issuebriefs.

Pascrell, Bacon Urge Colleagues to Support TBI Funding

Congressional Brain Injury Task Force co-chairs were joined by 53 colleagues in a letter to the House Subcommittee on Labor, Health and Human Services, Education and Related Agencies requesting funding increases for several programs authorized by the TBI Act, and for the National Institute on Disability, Independent Living, and Rehabilitation Research TBI Model Systems, administered by the Administration for Community Living. The Members’ requests include: \$5 million in funding for the National Concussion Surveillance System, \$6.7 million for the Centers for Disease Control and Prevention to continue TBI programming, and an increase of \$12 million for TBI-related state grants.

In a separate letter to the Subcommittee on Defense, Reps. Pascrell and Bacon led 56 House colleagues requesting increased funding for the Department of Defense in FY 2022 to identify and care for wounded warriors with TBI and psychological health issues and to improve research in these areas.

Legislation to Improve Trauma Training for Law Enforcement is Reintroduced

Reps. Bill Pascrell, Jr. (D-N.J.), John Rutherford (R-Fla.), Don Bacon (R-Neb.), and Val Demings (D-Fla.) reintroduced their TBI and PTSD Law Enforcement Training Act on May 4, 2021. The legislation would implement several measures to better train law enforcement for interactions with individuals who have sustained a TBI or PTSD.

Specifically, the TBI and PTSD Law Enforcement Training Act would direct the Department of Justice to solicit best practices and develop crisis intervention

training tools for law enforcement and first responders who interact with individuals displaying symptoms of TBI or PTSD. The law would authorize an additional \$4 million per fiscal year for the Justice and Mental Health Collaboration Program to fund grants to develop and implement this training. It would also require a CDC study of law enforcement and first responders who may have suffered a TBI.

In announcing the legislation BIAA President/CEO Susan Connors noted, “Individuals with brain injury may have symptoms that make it difficult for them to follow directions or communicate clearly. Too often, these individuals are mistaken for being drunk or purposefully aggressive, which leads to misunderstandings with law enforcement. It is imperative that first responders throughout the country receive specialized training to help them understand the complexities involved with brain injury.”

Senators Seek to Extend Spousal Impoverishment Protections for HCBS Participants

Democratic senators introduced S. 1099 to permanently authorize spousal impoverishment protections for people eligible for Medicaid Home and Community-Based Services (HCBS). Senators sponsoring the measure include Bob Casey, Jr. (D-Pa.), Tina Smith (D-Minn.), Kirsten Gillibrand (D-N.Y.), Chris Van Hollen (D-Md.), Richard Blumenthal (D-Conn.), Jeanne Shaheen (D-N.H.), Amy Klobuchar (D-Minn.), Debbie Stabenow (D-Mich.), Sherrod Brown (D-Ohio), Catherine Cortez Masto (D-Nev.), and Tammy Duckworth (D-Ill.) A related bill was previously introduced in the House, H.R. 1717. The purpose is to allow the spouse of the person receiving Medicaid to retain a modest amount of income and assets, which are currently only temporarily authorized for HCBS recipients through 2023.

BIAA, Others Call for National Plan on Long COVID

BIAA joined the American Academy of Physical Medicine and Rehabilitation (AAPM&R) and other organization in calling on The White House and Congress to ensure all patients who experience post-acute sequelae of SARS-CoV-2 infection, also known as “Long COVID,” are able to access the care they need. Specifically, lawmakers are urged to establish a federal commission that can

develop a comprehensive national plan to defeat the Long COVID crisis. AAPM&R believes the plan should include (1) recommendations on resources to build the necessary infrastructure; (2) equitable access to care for all patients; and (3) continued funding for research that advances the nation’s understanding of Long COVID.

BIAA Joins Call to Eliminate Disability Bias

BIAA joined with ten other health and disability organizations in a Letter to the Editor of Health Affairs urging the Biden Administration, clinicians, insurers, and pharmacy benefit managers everywhere to stop making health care and insurance coverage decisions based on quality-adjusted life-year (QALY) calculations. In other words, stop making false assumptions of a lower quality of life enjoyed by people with disabilities and older adults.

BIAA Supports Assistive Technology Legislation

BIAA urged lawmakers to co-sponsor the Assistive Technology and Devices for Americans Study Act (Triple A Study Act, S. 1089 and H.R. 2461), which would expand knowledge of AT devices and lay the groundwork for improvements in care and policy solutions to support people with AT needs. BIAA urged lawmakers to allocate \$50 million in the Fiscal Year 2022 Senate Labor, Health and Human Services, and Education bill for the Assistive Technology Act Programs, which allow individuals with disabilities to access the assistive technology services and devices needed to live, work, and attend school in their communities.

BIAA Urges Research to Prevent Injury and Death from Firearms

In a letter to House Appropriations Committee Chairwoman DeLauro and Ranking Member Granger and House Subcommittee on Labor, Health and Human Services, Education and Related Agencies, BIAA and the Brain Injury Associations of Kentucky, Kansas and Greater Kansas City, Louisiana, Massachusetts, Michigan, and New Hampshire plus nearly 200 more advocacy organizations urged lawmakers to allocate \$50 million in funding split evenly between the Centers for Disease Control and Prevention and National Institutes of Health to conduct public health research into firearm morbidity and mortality prevention. ●



STATE AFFILIATE NEWS

DELAWARE

The Brain Injury Association of Delaware (BIADE) has launched its new website, biade.org! The new website is modern, user-friendly, and will enable us to better serve the Delaware community through improved communication and resources. In addition to our new website launch, we created a webinar series called “Educate Delaware 2021: An Educational Webinar Series for Delaware’s Brain Injury Community” in June. For more information, visit biade.org/events.

INDIANA

The Brain Injury Association of Indiana (BIAI) has had a busy few months. BIAI led individuals all over our state in getting involved and participating in the BIAA national “More Than My Brain Injury” campaign. Our participants made signs promoting brain injury awareness, held weekly Zoom chats to distribute information, and shared their own experiences with audiences near and far. Look for the #MoreThanMyBrainInjury hashtag on social media to see what participants have been up to. BIAI held virtual events on neuroplasticity and recovery as well as its second art therapy experiential collaboration with IU Neuroscience Art Therapy Program. To learn more about these events or to join our new membership program, visit biaindiana.org/become-a-member.

KANSAS

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS-GKC) presented an in-person run/walk on Memorial Day following current COVID-19 guidelines. A virtual option was also available for those who could not participate in person. The event has been a Memorial Day tradition for 34 years! This year, we honored Terri Kern who received a life-threatening brain injury when she was hit by a car in 2008. Confronting the challenges her accident presented to her family, Terri and her husband shared their years-long journey in their book, “Moving Mountains: Discovering Joy through Suffering.” To learn more about BIAKS-GKC and other events, visit biaks.org.

LOUISIANA

The Brain Injury Association of Louisiana (BIALA) shared the #MoreThanMyBrainInjury campaign with rehabilitation hospitals, post-acute residential living centers, and many other colleagues to help promote brain injury awareness statewide. We asked individuals around the state to submit videos about their personal journeys, and these videos were used throughout the month to raise awareness. BIALA also raised awareness through the Unmasking Brain Injury program, sponsored by TASS Brain Injury Rehabilitation Center. Through the program, BIALA staff members visited post-acute residential facilities and helped individuals with brain injury paint 32 new masks to add to the traveling art exhibit. To learn more about BIALA, visit biala.org.



Brain injury survivors pose with their newly painted masks as part of the Unmasking Brain Injury art exhibit.

MAINE

Through an Administration for Community Living (ACL) TBI Partnership Grant, the Brain Injury Association of America – Maine (BIAA-ME) continues to focus on increasing awareness and resources around the intersection of brain injury and substance use disorder (SUD). Recent accomplishments include a statewide brain injury needs assessment, continued education and resources for Maine SUD organizations, and efforts to expand and improve the membership of Maine's Acquired Brain Injury Advisory Council to include greater numbers of brain injury survivors, family members, and advocates.

BIAA-ME continues to expand access to core brain injury resources and supports for Maine brain injury survivors and families through a contract with the Maine Department of Health & Human Services, including a recent four-part webinar series on caregiving after brain injury and a collaboration to establish a statewide virtual support group for Maine brain injury caregivers. To learn more, visit biausa.org/maine.

MASSACHUSETTS

The Brain Injury Association of Massachusetts (BIA-MA) celebrated Brain Injury Awareness Month by holding a virtual conference at the end of March. Keynote speakers Pat and Tammy McLeod, chaplains at Harvard University, spoke about their son's severe brain injury sustained while playing football. Their story reveals many of the physical, emotional, and relational challenges of living with an ambiguous loss – the experience of both having and not having someone the way you once had them. All conference attendees received a copy of the speakers' book, "Hit Hard."

The conference also featured twenty-one sessions on topics such as the neurocognitive effects of COVID-19, healing through artistic expression, opioid use disorders and brain injury, and relationships after ABI. Participants enjoyed more than 31 virtual exhibitors and four poster presentations. To learn more about BIA-MA programs, visit biama.org.



BIA-MA staff pose for a photo at the end of the virtual conference.

MICHIGAN

The Brain Injury Association of Michigan (BIAMI) recently celebrated its 40th anniversary. The Association held a virtual celebration on Zoom with more than 100 attendees and eight sponsors. The event raised more than \$27,000. Our latest initiative, BIAMI Educates, is also in full swing. Through the initiative, we hold monthly educational events on topics such as staying well, heart health, civil rights, and understanding brain injury.

BIAMI formed an exciting partnership with Disability Rights Michigan (DRM), an independent, private, nonprofit, nonpartisan protection and advocacy organization mandated by state law to advocate for people with disabilities, including individuals and families touched by traumatic brain injury. BIAMI will receive additional resources from DRM to enhance its advocacy services to individuals with brain injury. For more information about BIAMI, visit biami.org.

(continued on page 28)

NORTH CAROLINA

The Brain Injury Association of North Carolina (BIANC) has been busy this year converting our training programs, conferences, CBIS reviews, camp, and support groups to virtual formats. In the past year, BIANC staff have provided 110 training programs reaching 11,059 individuals, and we have supported 165 community exhibits or virtual support meetings attended by 8,141 survivors, families, and professionals. Professionals interested in information about virtual review sessions for the Certified Brain Injury Specialist certification exam should email bianc@bianc.net or susan.fewell@bianc.net.

For more information about our virtual events, visit bianc.net. You can also follow us on Facebook at facebook.com/BIANorthCarolina to stay up-to-date on our various survivor resources, recorded interviews, policy briefings, and tips for caregivers!

RHODE ISLAND

So far in 2021, the Brain Injury Association of Rhode Island (BIARI) had a membership drive, celebrated Brain Injury Awareness Month, and planned upcoming events. After a positive virtual conference last year, BIARI decided that the 2021 Educational Conference would remain virtual and would be presented as a series rather than a one-day event. The first session, "Ethics and Evidence: Hard Hats and Hard Choices" took place in April to the largest participation in the history of the conference. Five other sessions will take place from May through October.

The second "Prove You Are a Brainiac" trivia tournament proved to be another popular virtual event. Dozens of teams battled for the coveted Brainiac Trophy, bragging rights, and gift cards. The event offered an opportunity to stay connected with local supporters and helped BIARI establish new relationships. BIARI outreach, while still challenging, has included virtual speaking engagements with local civic organizations. To learn more about BIARI, visit biari.org.

PENNSYLVANIA

The Brain Injury Association of Pennsylvania (BIAPA) embraced the #MoreThanMyBrainInjury awareness campaign. We built our statewide virtual support group meeting in March around this topic and asked our members and friends how they define themselves or how they might re-define themselves. We incorporated their responses into a graphic that we shared on social media. The topic was so popular that we continued the incredible conversation in the months since.

Due to COVID-19 restrictions, BIAPA pivoted its annual conference to a monthly webinar series in 2020. We're very excited to announce that we scheduled an in-person event for 2021! The conference, "Celebrating Connections and Collaborations in Brain Injury Rehabilitation," will take place October 24-26, 2021 at the Lancaster Marriott. Safety precautions are in place, and we're adding space to allow for social distancing. The conference is designed for professionals, survivors, family members, caregivers and volunteers. Some of the features include: 15 in-person CEU opportunities, seven bonus on-demand CEUs available post conference, and experts presenting on ethics, headaches, sleep, opioids, supports, and more. We're also holding a pre-conference review course for those applying to become Certified Brain Injury Specialists and a Brain Injury Fundamentals course. We're so looking forward to connecting with our community in person! To learn more, visit biapa.org.



Attendees at the BIA-PA Virtual Support Group create a More Than My Brain Injury virtual art project.

SOUTH CAROLINA

The Brain Injury Association of South Carolina (BIASC) staff are all working remotely and are adjusting well. We hosted our first ever virtual Brain Injury Fundamentals training, held over two days. Trainers Meghan Trowbridge of the University of South Carolina School of Medicine Center for Disability Resources and Kay Brooks of Thrive Upstate presented the program to 18 participants who learned more about brain injury.

BIASC started a Young Adult Brain Injury Support Group for individuals in South Carolina. We have also been working closely with our state legislators to raise awareness of brain injury and secure funding in the state budget. The statewide Life with Brain Injury Conference will be held July 29-30 via Zoom. Sheldon Herring, Ph.D., will be a speaker this year. Dr. Herring is Chairman of BIAA's Academy of Certified Brain Injury Specialists Board of Governors. To learn more, visit biaofsc.org.



The State of South Carolina Governor's Proclamation announces March as Brain Injury Awareness Month.

VIRGINIA

The Brain Injury Association of Virginia (BIAV) put brain injury awareness, education, and support on center-stage. We started 2021 with a busy General Assembly that led to \$1.2 million in new funding being allocated for community based brain injury services – a huge win for Virginia! Between January and April, we hosted four webinars on a variety of topics like light sensitivity after brain injury, the intersection between substance use and brain injury, and decision-making capacity. We also launched a new six-part webinar series focusing on wellness and creative arts.

During Brain Injury Awareness Month, we invited the community to join us as Brain Ambassadors to help educate the public, change common misconceptions about brain injury, and support those with lived experiences. At the end of the month, we collaborated with another brain injury program to host our first Virtual Brain Injury Awareness Rally. More than 120 people joined the rally, including multiple delegates and state senators, to share personal stories and discuss why being an ambassador is important.

To better support people with brain injuries across Virginia, we launched our Support Network. This

program includes support groups, peer communities, and events aiming to reduce social isolation. We hosted two game nights and a trivia night for anyone. We expect this new initiative to continue to grow and offer unique ways for the brain injury community to connect. To learn more about us and our programs, please visit biav.net.

VERMONT

The Brain Injury Association of Vermont (BIAVT) is busy planning for its annual fundraising event! This year's 19th Annual Walk & Roll will be held Saturday August 21, 2021. To learn more about how you can become involved, please visit biavt.org/walkandroll.



Keep an eye on our website for information about virtual trainings! We host educational events and webinars throughout the year. If you are interested in being a speaker for one of our webinars, please reach out to dani@biavt.org. As always, our helpline is open Monday through Friday, 9 a.m. to 4 p.m. ET for information and referrals.



UPCOMING WEBINARS

Robert Shordone Memorial mTBI/Concussion Webinar – Post-concussion Care: Elevating the Patient-centered Focus

July 21, 2021, 3 p.m. ET/12 p.m. PT

Jessica Schwartz PT, DPT, CSCS

Carolyn Rocchio Caregivers Webinar – Brain Injury, Aging, and Planning for the Future

July 28, 2021, 3 p.m. ET/12 p.m. PT

Christine Weaver, MAS, OTR/L, CLCP, CBIS, C/NDT

Business of Brain Injury Webinar – Developing a Post-COVID Rehabilitation Program

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

Abby Bogaards, MHA, Gail McGaughy, PT, C/NDT, CLT, CBIS, and Tammy Miller, COTA/L, MHS, CBIST, CCM

David Strauss Memorial Clinical Webinar – Clinical Assessment and Management of Spasticity Following Brain Injury

August 18, 2021, 3 p.m. ET/12 p.m. PT

Cindy B. Ivanhoe, M.D.

Mitchell Rosenthal Memorial Research Webinar – Traumatic Brain Injury and the Opioid Epidemic: A Perfect Storm

September 21, 2021, 3 p.m. ET/12 p.m. PT

Rachel Sayko Adams, Ph.D., MPH.

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

NEWS & NOTES



Calling All Volunteers! Connect With BIAA

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



BIAA Welcomes Two New Firms to Preferred Attorneys Program

BIAA's Preferred Attorneys program recognizes attorneys who have demonstrated their knowledge of the physical, cognitive, emotional, and financial tolls a brain injury can inflict. This year, we welcome Berman & Simmons Trial Attorneys, a personal injury firm based in Lewiston, Maine, and Fillmore Spencer LLC, a firm that serves personal injury clients in Utah, to the program. BIAA's Preferred Attorneys have demonstrated expertise at handling brain injury cases. Visit biausa.org/preferredattorneys to find a Preferred Attorney near you.



Free Webinar: Understanding and Managing Spasticity After Brain Injury

Do you have questions about spasticity and how it can impact individuals with brain injury? In our latest Caregivers Webinar, Laura Wiggs, PT, NCS, CBIS, covers the importance of physical therapy interventions and medical considerations for spasticity. Visit shop.biausa.org/spasticity to download the webinar. ●

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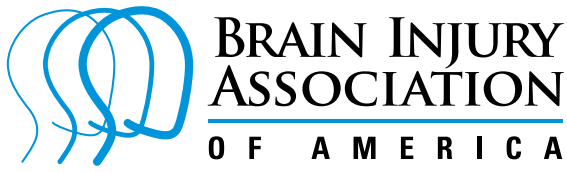
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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and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

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

