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RELATIONSHIPS after brain injury



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FROM MY **DESK**

This message begins with a great big thank you to all of the organizations and people who support the Brain Injury Association of America (BIAA)! While the pandemic continued to test us, 2021 was one of the strongest years in our history thanks to a generous bequest from Mark Davis. Please be sure to read about his legacy in this issue of *THE Challenge*!

We are just a few weeks into the new year, and BIAA has already produced an impressive array of accomplishments. In January, we hosted two webinars: "Pseudobulbar Affect" for clinicians and "How to Fight for What You Need" for survivors and families. We also produced the two-day Brain Injury Business Practices College virtual conference for nonclinical staff of rehabilitation facilities. In February, BIAA presented a half-day virtual symposium, "COVID-19: Long Term Neurological Impact and Nuances," in collaboration with Albert Einstein College of Medicine-Montefiore Medical Center.

March is Brain Injury Awareness Month. Again this year, BIAA will honor all those affected by brain injury – whether traumatic or non-traumatic – with our #MoreThanMyBrainInjury campaign. We are again teaming up with the National Association of State Head Injury Administrators to assist the Congressional Brain Injury Task Force in holding a virtual briefing March 16. Please visit biausa.org for awareness month materials and more details on the briefing. Our hard-working affiliates have lots of events planned for March, too, so be sure to check out their news in this issue.

BIAA was proud to serve as a reviewer for the newly released "Traumatic Brain Injury: A Roadmap for Accelerating Progress" written by the National Academies of Science, Engineering, and Medicine under contract to the U.S. Department of Defense.



The publication presents the current landscape of research and identifies gaps and opportunities to accelerate improvement. The report calls for a transformation of attitudes, understanding, investments, and care systems for TBI. Copies are available free download when you search TBI at nationalacademies.org.

Last fall, BIAA said goodbye to long-time employees Marianna Abashian, Christine Chen, and Dianna Fahel. We miss these talented women very much, but now we are pleased to welcome Maya Horowitz, director of marketing and communications; Laura Ksycewski, education program coordinator; and Sara Fowdy, director of certification, training, and testing.

BIAA is off to a good start in 2022; let's hope the weather warms up some time before spring!

Susan H Cumo

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

Should I Stay or Should I Go?

Healthy vs. Unhealthy Relationships

By Erin Sesemann, Ph.D., LMFT, CBIS, and Kayla Reeve, M.A., LMFTA

Pe have many different types of relationships: romantic, parent-child, sibling, friendship, and work relationships. Knowing if your relationship is healthy or unhealthy can be a challenge. While there are signs that make it easy to know if you are in a healthy relationship, such as open communication, it is harder to know if you are in an unhealthy relationship. Many feel confused about whether their relationship is really that bad. The purpose of this article is to help you learn the red flags or signs of unhealthy relationships and give you some ideas about how to end them.

The Four C's of Healthy Relationships

Consider the four C's – **communication, caring, conflict resolution,** and **cultural differences** – when looking for red flags. The things you say (verbal communication) and the way you say them (non-verbal communication) both matter when communicating. The first two communication red flags to look for are lying and expressing criticism toward you or the relationship. If your loved ones make frequent comments that blame you for their feelings or attack you with harsh words, this is a sign that your relationship is unhealthy. Non-verbal communication that is harmful to relationships includes intimidating posture, eye rolling, and hostile facial expressions (e.g., showing boredom or aggression). Paying attention to communication is very important during **conflict resolution**. When people begin to talk to each other in ways that are critical, defensive, disrespectful, mocking, or completely shut down, communication becomes destructive and should be considered a red flag. Respect is the foundation for communication in healthy relationships, and people in healthy relationships will take responsibility for their feelings and actions during conflict. Caring feelings are also notable in conversations when people in healthy relationships are talking with each other.

Cultural differences shape communication, conflict resolution, and how to show care within relationships. Culture includes how people experience the world through, for example, their race, ethnicity, socioeconomic status, sexual orientation, nationality, or religion. Culture also includes how these experiences help form a person's beliefs, values, and worldviews. Navigating cultural differences is destructive when a person's behavior becomes judgmental, attacking, or rejecting. If you experience prejudice, discrimination, or pressure to change

your culture within a relationship, this is considered a red flag. It is a sign of a healthy relationship when people invest their time and energy into learning about each other's cultures. Cultural differences can enrich the relationship when people remain open, curious, and nonjudgmental. It's important to remember that abuse within a relationship is a critical red flag that should never be overlooked.

Abusive Relationships

Abusive in relationships can be psychological, emotional, or physical. It is abusive to coerce, control, or maintain power over people in relationships. Abuse includes emotional and physical violence such as hitting, slapping, insulting, demeaning, or exerting sexual pressure. Control can also be abusive. Some examples of control within a relationship include managing the finances in the household without discussion, refusing to provide money for necessary expenses, or pressuring a loved one to use alcohol or drugs. Isolation often happens in violent and controlling relationships. If

your loved one prevents or discourages you from spending time with friends, family, or peers, this may be a red flag. Getting help and support is very important when ending an abusive relationship. Flip to the end of this article for resources that help with ending a relationship when

> you are concerned about your safety.

Ending Unhealthy Relationships

Taking a close look at your relationships is hard. The four steps below can help you get started.

Step One: Examine the Relationship

Unhealthy relationships are not always dangerous, but staying in an unhealthy relationship can lead you to dismiss red flags that might be detrimental. So, how do you know when it's time to end a relationship? Consider what is keeping you in the relationship and what is making you think about ending it. Try to envision your life without the person or relationship and how that change might impact you. Ask yourself if you are willing to work with your loved one to address any red flags in the relationships as this will take effort from both partners. If you do not believe change can occur within your relationship or if you need assistance in making a decision, consider speaking with a professional counselor to help provide an unbiased perspective.

Step Two: Find Support

Building a support system is the next important step when deciding to end a relationship. A support system could include family, friends, or neighbors who you trust. Professional counseling can be an additional source of support when making



a decision about your relationship. Contact the Brain Injury Association of America's National Brain Injury Information Center at 1-800-444-6443 to help you learn about community resources in your area.

Step Three: Have Self-compassion

You may blame yourself or feel ashamed, guilty, or hopeless about the issues in your relationship. Forgiving yourself for your actions can help you move forward and end an unhealthy relationship. Accepting how you feel without judgment is helpful as you begin the healing process. You may need to practice self-care and work toward having compassion to help you cope. Self-care can include activities that calm your senses (e.g., soothing smells or sounds), ground yourself in the present moment (e.g., practicing mindfulness, meditation, yoga), increase your emotional awareness (e.g., journaling, drawing, art), or distract yourself from the problem (e.g., puzzle, TV, music).



Step Four: Improve Communication and Set Boundaries

Utilizing clear communication and setting firm boundaries are essential tools when ending a relationship. It is important to leave no doubt about what you will or will not do when ending a relationship. Staying firm in your intentions to end the relationship might be difficult if the other person tries to convince you to stay. Remember, focusing on how we say something as well as what we are saying is important! See the table below for examples.



| Effective Communication | Ineffective Communication |
|--|--|
| "I feel worthless when we are doing chores, and you tell me I can't do anything right." | "You make me feel worthless." |
| "I feel unheard." | "You're not listening." |
| "I feel unappreciated and unimportant when you use your phone at dinner time." | "You're always on your phone. You must care more about talking to other people." |

You can also try the responses below to help uphold your boundaries:

- "I remember things differently."
- "If you continue to speak to me this way, I can no longer continue this conversation."
- "I am not open to further discussion. I have made my decision and I no longer want to be in this relationship."

Ending Relationships When There is a Safety Risk

It is important to gauge if your safety is at risk when ending a relationship. It may be smart to meet in a public setting or to avoid ending the relationship in person. Consider making a safety plan, which consists of creating a personalized plan that prioritizes your safety after leaving a relationship. This



may include having an emergency bag of important items such as birth certificates, social security cards, medications, medical records, insurance documentation, cash, clothes, etc. If you feel your safety is at risk, please review the resources below.

- Battered Women's Justice Project, 1-800-903-0111 www.bwjp.org
- Legal Momentum, 1-212-925-6635 www.legalmomentum.org
- National Domestic Violence Hotline: 800-799-SAFE (7233) or text "START" to 88788
- National Resource Center on Domestic Violence: 1-800-537-2238 | www.nrcdv.org
- National Runway Safeline: 1-800-RUNAWAY or 1-800-786-2929 | www.1800runaway.org

For references and other resources, visit biausa.org/unhealthyrelationships.

MY UNCONVENTIONAL CAREGIVING JOURNEY

By Rachel Michelberg

M rise to the challenge or overcome my ambivalence about taking care of my husband. When confronted with the reality of becoming his caregiver after his small plane crashed, I had to grapple with the fact that my life, too, was being utterly altered. David was 45 years old and had suffered a traumatic brain injury. I was 44, and I couldn't picture spending the rest of my life as a caregiver to a man who was seizure-prone, incontinent, irrational, and susceptible to angry outbursts. My decision not to devote the rest of my life to his care horrified his

family and many of our friends, all of whom assumed I would shoulder that responsibility. It was the ethical thing to do. Isn't that what I'd promised? In sickness and in health, right?

Most of us don't sign up to be unpaid caregivers – our change in identity and role just happens, sometimes slowly, sometimes like a thunderbolt. There is a disease (e.g., Alzheimer's, dementia, cancer or stroke) or an accident (e.g., a car or motorcycle crash, a fall or a severe sports injury) that, in an instant, changes a life forever – changes many lives forever. In my family's case, it was a plane crash.

Most people don't survive plane crashes, but David did. We'd been married ten years when the small plane in which he was flying crash-landed into a vineyard on the central coast of California. David sustained severe spine, pancreatic, and head injuries. His spine healed, as did his pancreas, but the damage to the frontal lobe of Rachel, left, David, and their two children enjoy a day in the snow before David's accident.

his brain was so devastating that he would never regain normal functioning. In the best-case scenario, David would have the mental capacity of a seven-year-old.

Our marriage had been on shaky ground at the time of the accident. We were in counseling. I'd been struggling with a strong attraction to another man, but I was determined to make my marriage work. Then David fell out of the sky, and our rocky relationship became an impossible one. In an instant, I became his caregiver, our family's sole decision-maker, and a single parent to our six and seven-year-old children.

In the months following the crash, David remained hospitalized, suffering seizures and undergoing multiple surgeries. I was in survival mode, melting down on a

(continued on page 8)

(continued from page 7)

regular basis while endeavoring to preserve some sense of normalcy for our children. My health deteriorated: an old eating disorder recurred and a serious abdominal condition resulted in my own hospitalization. With the help of caring therapists, social workers, and my "village" of loving friends and family, I slowly came to accept the realization that I was not equipped to bring David home and take on the role of full-time caregiver.

For years afterward, I struggled with the guilt and shame of that decision. But it was my truth, a clear understanding of my capabilities.

Though I decided not to care for David at home, I was determined to ensure that he receive the best care available. When his physical condition stabilized, I had him moved to a residential facility that specialized in brain injury half an hour away. Every day I worried about David's happiness and his quality of life. Was he bored? Was he lonely? Was he aware of the enormous losses he had suffered? Once his overall health stabilized, I worried that he was frustrated sexually, though I knew I could no longer satisfy that need.

My therapist encouraged me to focus on what I could do, rather than on what I couldn't. That sage advice gave me permission to focus on possibilities for David, rather than my own deficiencies. I made the commitment to bring the kids to visit their father at least once a week. We took David to restaurants, tried horseback riding as a family, and made an event out of each Target or Best Buy shopping excursion. The residential facility provided drivers to bring David to the kids' school events, dance and theater performances, and to our home where he could attend birthday parties or simply hang out with us. It didn't matter what we did. With his substantial cognitive impairment, David was no longer able to be a father in any conventional sense of the word, but I could provide an environment that enabled some kind of relationship between David and his children.

I did what I could and continued to face pressure from David's extended family to bring him home. I continued to resist that pressure. Am I proud of that decision? No. I wish I'd been the kind of person who could rise to the challenge and overcome my resistance to the all-consuming role that had been suddenly thrust upon me. I am in awe of those who can take on caregiving like that, but I just wasn't capable. And the truth is that I didn't want to. I wanted more for myself than just being David's caregiver. I had a choice to make, and I made it.

My family's situation was unique. We were fortunate that, due to a large financial settlement, we had options. So many do not. No one plans – emotionally or financially – for a trauma so severe and debilitating that familial roles are altered in an instant.

I wrote my story to give voice to those who find themselves in similarly devastating circumstances and are doubting their capacity to fulfill that role. I want to give caregivers permission to question the expectations heaped on them and to stay true to their understanding of their capabilities and desires. Because if your own health suffers and you are incapacitated, too, no one wins.

Rachel Michelberg grew up in the San Francisco Bay Area and still enjoys living there with her husband, Richard, and their two dogs, Nala and Beenie. She earned her Bachelor of Music degree in vocal performance from San Jose State University and has performed leading roles in musicals and opera. When Rachel isn't working with one of her twenty voice and piano students, she loves gardening, hiking, baking sourdough bread, and making her own bone broth. "CRASH: How I Became a Reluctant Caregiver" is Rachel's first book. Learn more at https://rachelmichelbergauthor.com.



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Friendship Is a Sheltering Tree

By Laurie Rippon, M.Ed. Advocate & Writer, A Brain Injury Life

o you feel that something is missing from your life that used to be there before? My first "before" and "after" was big: brain injury. But now there's a second: the pandemic. Both came with loss, with something missing that I had to accept, work around, and learn to live with in the best way I could.

Somehow, getting used to the first made the second one harder. Being alone because of brain injury was like retreating from the world, but the social isolation of COVID-19 felt like the world retreating from me. One on top of the other left me struggling, my cognitive and behavioral deficits creeping back. I was unable to be productive and I wanted to sleep all day. I longed for human contact and wondered what happened to my friends, but I never thought of calling them.

For a long time, I denied the friendships I'd lost because I always kept busy and ignored how sad solitude can be. After a while, I realized how much I needed to be part of the world, how the social isolation was hurting me, and that what really mattered was keeping friends.

So, I've been working to reach out, open up, advocate, and even accept help in order to find my way back to life. As you can imagine, it's not easy. I get scared, but try to reason with my fears. I get depressed, but go take a nap, and, when I'm really lonely (or really excited), the best thing I can do is turn up the music and dance!

The funny thing is that my life seems to be a dance, too; from having expectations to sustaining a TBI, from being struck down to climbing up, from feeling fearless to crashing, rebuilding, and so on. I know my experience is not unique – we've all been navigating this pandemic in our own ways. Read on for strategies to help you stay connected with loved ones as you try to find your new normal yet again.

How Do You Avoid Getting Stuck in Social Isolation?

Focus on Others, Not Yourself



CONNECT. My most important tip is to reach out – don't wait for someone to reach out to you. Keep a list on your fridge of everyone you might call and set up a regular call with a friend. Add to your calendar as a "repeat" event and set your alarm so you don't forget. To reduce stress in conversations, I avoid politics and COVID-19 complaints (unless they're personal).



SHARE. Sending funny photos, videos, or pet pictures are all fair game when you're communicating with friends. Check out the newspaper for cultural events like museum tours, concerts, fashion shows, and invite a friend to come along if you feel safe.



CREATE. Try some group activities. Some examples include making a story circle, where each person takes a turn adding a twist or surprise, or picking a play and letting each person act a part. Do you like cooking? Consider cooking for two or more, having an outdoor picnic, delivering a meal to someone's front door, or dining with a few friends virtually.



DISCOVER. Keep an eye out for activities where you can meet people like art openings, outdoor movies, exercise classes, or neighborhood tours. Use these as reasons to get moving, relax your mind, or strengthen your body with a friend. Other fun things to try include online chair yoga, tai chi, meditation, exercise, or dance. Getting outside helps minimize your risk of infection, so try exploring a neighborhood together, taking a stroll, or jogging in the park.



GIVE BACK. Help is always needed. Find a cause you care about, make contact with the organizer of an upcoming event or initiative, and ask how you can help.



DO. The best medicine for isolation is being active in the company of others, physically or virtually. In this COVID-19 world, we need each other more than ever – even if we think we have the answers and can go it alone.

So do your friends a big favor: keep an eye on them and offer help when they need it. And you'll be doing yourself an even bigger favor by thinking of them first. You'll learn that you are capable of more than you realized, have grown stronger and more generous than you were, and have become a better friend. Your trust of them, and theirs of you, will grow as will your hope for the future – because friendship really is a sheltering tree.

— "Friendship is a sheltering tree" is a line from the poem "Youth and Age" by Samuel Taylor Coleridge.

BIAA Awards Third Annual Research Grants Through Brain Injury Research Fund



By Stephani Kelly, Director of Education Programs, Brain Injury Association of America

The Brain Injury Association of America (BIAA) announced the winners of its 2021 Brain Injury Research Fund competition. Michael Williams, Ph.D., University of Houston, and Khalil Mallah, Ph.D., Medical University of South Carolina, are awarded seed grants of \$25,000 each. Naomi Gaggi, CUNY School of Medicine, and Hannah Mitchell, East Tennessee State University, are awarded dissertation grants of \$5,000 and \$3,675, respectively.

The Brain Injury Research Fund offers financial support to studies contributing to our understanding of brain injury as a chronic disease. "This third year of BIAA Research Awards was again marked by many deserving applications from highly talented researchers, both young investigators and seasoned scholars. They are proposing diverse, creative approaches to the challenge of 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 have had the privilege to support. As BIAA's Research Fund grows, we will be able to fund more applications."

BIAA established its research grant program in 2019. Through the Brain Injury Research Fund, BIAA offers two types of funding: Dissertation Grants, funded between \$3,000 to \$5,000, and Seed Grants, funded up to \$25,000. Thanks to the generosity of donors of all kinds, BIAA can fund more investigators who are working to increase our understanding of brain injury as a chronic condition.

"BIAA has a 40-year history of advocating on behalf of the brain injury community and fighting for funding to support research," offered Susan Connors, BIAA's president and chief executive officer. "We're thrilled to advance research through our own awards and hope to grow the Brain Injury Research Fund with continued support from the public." BIAA would like to extend a special thank you to 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 Kreiger 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 2022 awards this spring.

FUNDED PROJECTS

Complement Mediated Cognitive Decline and Neuroinflammation Chronically Post Repetitive Brain Injury



Seed Grant of \$25,000

Grantee: Khalil Mallah, Ph.D., Medical University of South Carolina

Mentor: Stephen Tomlinson, Ph.D.

Project Summary: Traumatic brain injury (TBI) is a change in brain function due to a blow to the head. TBI can result in harmful consequences years after initial

insult which include cognitive deficits with symptoms like those seen in Alzheimer's disease. The changes that occur in the brain after TBI which are responsible for these deficits are not well understood. In this proposed work, I hypothesize that the complement system (a major part of the neuroimmune response after injury) is a major contributor to this phenomenon and inhibiting this system would prevent such deficits seen years after TBI.

Using Mobile Technologies for Research Engaging Persons with Traumatic Brain Injury and Chronic Pain



Seed Grant of \$24,977.70

Grantee: Michael W. Williams, Ph.D., University of Houston

Mentor: Angelle M. Sander, Ph.D.

Project Summary: Chronic pain is common among people with traumatic brain injury (TBI). Typical clinic-based evaluations of pain may not fully capture patients' experiences. This pilot

study will evaluate the utility and benefit of new mobile technologies to assess pain and related person factors in their natural environment, which may enhance pain assessments and treatment monitoring post TBI. Trait mindfulness (dispositional nonjudgmental, presentmoment awareness) will also be assessed as a potential intervention target in a future intervention study using mobile technologies to monitor treatment responses.

Neurocognitive Effects of Transcranial Photobiomodulation in Chronic TBI



Seed Grant of \$5,000

Grantee: Naomi Gaggi, CUNY School of Medicine

Mentor: Junghoon J. Kim, Ph.D.

Project Summary: This project will investigate the cognitive efficacy and underlying hemodynamic effects of a single treatment of transcranial photobiomodulation (tPBM) on

prefrontal cortex in adults with chronic moderate-severe traumatic brain injury (cmsTBI). We predict that tPBM will improve local cerebral blood flow, network-level functional connectivity, and executive function in our participants. The findings and insights gained from this work will ultimately lead to the identification of novel therapeutic targets for neurodegeneration and cognitive decline that are prevalent in chronic TBI patients.

The Implications, Magnitude, and Development of TBI for Individuals Undergoing Treatment for OUD



Dissertation Grant of \$3,675 supported by Dr. Lance and Laura Trexler

Grantee: Hannah Mitchell, East Tennessee State University

Mentor: Meredith K. Ginley, Ph.D.

Project Summary: Despite the high rate of prescribing opioids for pain management following a traumatic brain injury (TBI)

and the epidemic of opioid use disorder (OUD) in the U.S., little research has analyzed the impact of TBI on OUD treatment. The present study will explore the impact of TBI on OUD treatment outcomes. The chronological trajectory between TBI and opioid initiation and behavioral health correlates of TBI among patients with OUD will also be evaluated. These findings may provide meaningful insight into patients' prognosis and opportunities to tailor treatment appropriately.

Brain Injury Research Fund Honor Roll

Our thanks to the following Research Champions for their generous support of brain injury research:

Dr. Barry Aron Chaikin, Sherman, Cammarata and Siegel, P.C. Dr. Julieen Crane Mary and David Gerhart Dr. Juliet Haarbauer-Krupa Jennifer and Eric Kirk Stephanie Rivard Lane Dr. & Mrs. Brent and Ann Masel Michael's Mission in memory of Michael Leo Seguin Janis Moskowitz Dr. Linda Redmann John Rivard Ira Sherman, Esq. Dr. Lance and Laura Trexler Angela Caveness Weisskopf

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.

Intimate Relationships After Brain Injury

Excerpted from BIAA's Moderate to Severe Brain Injury: A Practical Guide for Families

Sustaining a moderate to severe brain injury is a life-changing, sometimes devastating, event for an individual who is injured and for his or her family. For many, brain injury can profoundly affect a marriage or relationship. A spouse who was once head of household may now become dependent. The partner you once knew might experience fundamental personality and behavioral changes. The individual may appear immature, aggressive, unappreciative, and self-centered.

It may seem as if the partner who said "I do" has vanished or presents only a glimpse of the person they used to be. The attraction or connection between partners may have changed. It is natural for partners to feel loss and grieve for the former version of their loved one with brain injury as well as to grieve for all the plans that might have been. Intimacy, sexual attraction, and emotional expression between a couple may be gone. When so many aspects of the relationship have changed, it is common for the spouse without a brain injury to experience "stranger syndrome" – the feeling of being married to a stranger.

Sex and Intimacy

Changes in sexual behavior are a common consequence of brain injury and can present many problems. Your loved one may be unable to perform for physical reasons. Damage to vital control areas of the brain often result in impaired emotional responses, touch, inability to benefit from feedback, and physical impairment. Caregivers may no longer be attracted to their spouses. Discovering how important sex is to you may help you decide what to do next. Such decisions for spouses vary from person to person and are likely to change over time.

What you can do:

• Discuss your concerns with a doctor or counselor as well as your partner's physiatrist and neuropsychologist for options that may help restore physical performance and enhance physical pleasure.

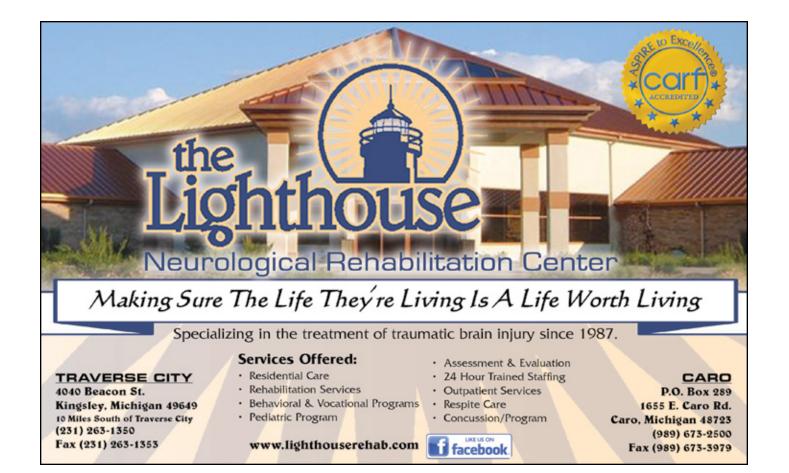


- Couples reestablishing intimacy may want to seek guidance from a licensed family and marriage counselor who is familiar with brain injury.
- Learn ways to communicate with your spouse.
- Gain a realistic view of your spouse's strengths and weaknesses from a brain injury professional.
- Get support for yourself. Remember, brain injury affects the whole family.

Sexual Disinhibition

Sexual disinhibition is particularly apparent when the injury affects the frontal lobes of the brain. A variety of inappropriate behaviors with sexual overtones are possible, such as fantasizing, flirtatiousness, impulsiveness, lewd verbal responses, disrobing or masturbating in public, attempts to hug and kiss, and unwarranted flirtatious advances. Behaviors condoned before injury may intensify after injury, and it may be difficult for your loved one to understand how things have changed.

Frontal lobe injuries can "turn off the filter" in a person's brain. Persons with sexual disinhibition often need cues from other people to avoid social gaffes. It is important to remember that inappropriate sexual behavior is a type of behavior to manage just as any other unwanted behavior might be. Ask your physiatrist or neuropsychologist for



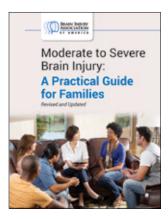
specific suggestions. It is hard for others to understand that brain injury can affect self-monitoring skills. Families and friends may be more tolerant of this type of behavior than they were pre-injury because they are moreaware of the causes of such behavior. At the same time, your loved one may be less aware of subtle nuances, have lower ability to benefit from feedback, and may repeat mistakes. Keep in mind that brain injury often results in undesirable changes that require intervention and ongoing management. The behavior is not willful.

Sexuality is an area that is often difficult for families to discuss within and outside the family circle. However, the family needs to communicate about inappropriate behaviors of any kind and about problems related to inappropriate sexual behavior in particular. Learning how to help your loved one monitor sexually inappropriate behavior will save you from embarrassing or unsafe situations.

What you can do:

• Try to become more comfortable with the subject of sexuality and have frank discussions about it with the whole family.

- Make sure all family members learn behavior modification/redirection techniques to ensure consistency.
- Assure your loved one that sexual feelings are appropriate and establish ground rules to protect the rights and privacy of others.
- Identify issues of consent. Is the individual competent to consent? Is the individual vulnerable to others? Are others at an increased risk of unwanted sexual advances from the person with the brain injury? Discuss these issues with your medical team.



This is an excerpt from BIAA's Moderate to Severe Brain Injury: A Practical Guide for Families, Revised and Updated © 2021. The Guide helps readers understand brain injury, find rehabilitation and community services, and learn about the support options available. If you love someone living with a brain injury, you need this book. Get your copy at shop.biausa.org/practicalguide.

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BIAA Celebrates the Life and Legacy of Mark Davis

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

In 2021, BIAA received a gift of \$1.3 million from the estate of Mark W. Davis. This contribution is the largest planned gift in BIAA's forty-year history. Thanks to Mark's extraordinary philanthropy, BIAA will be able to advance a number of critically important projects, increasing service to the brain injury community for years to come. For those who knew Mark best, this gift is consistent with who he was – a person who was always thinking about others and how to better the world.



Mark Davis prepares a meal for others.

Mark had lifelong passions for food, wine, art, the mountains, life on the water, and helping people. Friends and family knew him to be reliable, trustworthy, genuine, outspoken, and generous while not looking for anything in return. "Mark was one of my favorite people," says Mark's niece, Abby Reid. "He loved helping people to love food. Everything he had me try was always spot on, whether it was anchovies when I was five or escargot when I was older."

Abby and her brother, Curtis Reid, believe that some of their first lessons about the importance of helping others came because of Mark's generosity. "Every birthday or holiday gift from Mark was a gift to help someone else out," says Curtis, "I would open the cards to find he had sponsored a family in Africa in my name or bought a cow, a goat, or horse for someone in need." A renowned chef who got his start at New York City's famed Carlyle Restaurant, Mark spent many years teaching at the New England Culinary Institute in Burlington, Vermont. He loved his students, and the feeling was mutual. If Mark knew a student was unable to go home for the holidays, he extended an invitation to his own gathering. If a student had trouble affording a textbook or other class resource. Mark made sure it was available at no cost.

YOU ALWAYS FELT THE LOVE IN THE ROOM WHEN YOU WERE WITH HIM. **J**

"We couldn't get enough of him, his knowledge, and his willingness to share it," shared one former student. "Mark opened my eyes and palette to wine for the very first time," another student shared. Mark's lessons went well beyond food and wine as yet another student noted, "His teaching on customer service stuck with me across multiple careers and business ventures."



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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A Legacy With Lasting Benefit

Thanks to careful estate planning, Mark Davis was able to make gift that will affect BIAA's long-term ability to provide more services and supports, extend educational programming, and reach more survivors at the time of their injury. Bequests provide the resources for BIAA to invest in new lines of services and meet the ever-evolving needs of the brain injury community. For more information about how you can include BIAA in your will or estate plan and be recognized as a member of the Futures Fund Legacy Society, contact Robbie Baker, Vice President & Chief Development Officer at (703) 761-0750, ext. 648 or rbaker@biausa.org.



Surgery for a brain tumor followed by a brain injury ended his teaching career. Mark lost his sense of smell and, with that, his ability to continue to work as a professional chef. During his recovery, he became familiar with BIAA's work and was grateful for not only the services and supports, but also the investment made in brain injury research. After a lifetime of supporting others through his giving, Mark realized he was now the person who needed help.

He filled his time involving himself in his family business, Davis Publications, which specializes in arts education materials. Mark volunteered for a local hospice and the Vermont Association for the Blind, where he met his friend Walter. Understanding that Walter needed day-to day assistance managing his home, Mark stepped in to help as a surrogate partner.

"Family and friends were so important to Mark," explained Curtis. "You always felt the love in the room when you were with him." Mark's legacy of kindness and generosity extends to the entire brain injury community. "Mark was extremely grateful to BIAA," shared Curtis. "Helping others was really important to him, which is something he directly experienced after his injury."



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

The Brain Injury Association of America (BIAA) and brain injury advocates across the nation have our work cut out for us as the second half of the 117th Congress begins. In addition to funding for brain injury programs and services, a big challenge for BIAA is to ensure that people who sustain brain injuries have access to the rehabilitation therapies they need to recover as much function as possible while also ensuring there are adequate home and community-based services and supports available for the long term.

Appropriations

On March 9, the U.S. House of Representatives approved an historic, bipartisan bill to fund the federal government for the current fiscal year, which ends September 30, 2022. Of interest to brain injury advocates are programs operated by agencies within the U.S. Department of Health and Human Services (HHS).

The Administration on Community Living (ACL) TBI State Grant Program, which helps states improve access to services and supports for individuals with TBI throughout the lifespan received \$15.321 million, an increase of \$4 million from FY21.

Congress allocated \$8.75 million for TBI programs within the Centers for Disease Control and Prevention, including a \$2 million set-aside for a national concussion surveillance first authorized by the TBI Reauthorization Act of 2018. Congress included funds to increase annual grants awarded to TBI Model Systems centers, and specifically allocated a \$100,000 increase for the TBI Model Systems National Data and Statistical Center.

For the military, the Omnibus bill allocated \$60 million for peer-reviewed brain injury and neurological disease prevention research and \$170 million for peer-reviewed TBI and psychological health research within the Defense Health Program.

Policymakers noted the increasing prevalence of deployment-related TBIs and the continued need to provide adequate long-term specialty care for Veterans who sustain severe TBIs. In the Report accompanying the Omnibus legislation, appropriators direct the VA to (1) ensure an adequate number of long-term residential care facilities tailored to care for Veterans with severe TBIs are available and (2) consider entering into agreements to provide long-term specialty care for Veterans suffering from severe TBIs where VA-provided direct care is not available.

BIAA is delighted with the results of the Fiscal Year 2022 funding allocations. We are grateful to the members of the Congressional Brain Injury Task Force, especially co-chairs Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.) for their leadership.

Build Back Better Act

The House of Representatives passed the Build Back Better Act by a very narrow margin in November 2021. The bill provides \$2.15 trillion to fund a broad array of education, labor, child care, health care, taxes, immigration, and environmental programs. BIAA is most interested in the part of the bill dealing with Medicaid Home- and Community-Based Services (HCBS). The bill allocates \$400 billion to address challenges in the HCBS workforce, which has led to severe staff shortages that brought about crucial gaps in service availability, lengthy waiting lists, service line closures, and additional obstacles to achieving a high quality of life for workers and people with disabilities alike. Since the Senate failed to pass the Build Back Better Act before the end of 2021, advocates are now lobbying policymakers to incorporate HCBS provisions into other bills being considered by Congress.

Access to Inpatient Rehabilitation Therapy Act

The Centers for Medicare and Medicaid Services (CMS) uses an intensity of therapy requirement to determine, in part, which Medicare beneficiaries qualify for treatment in an inpatient rehabilitation facility (IRF). The so-called "Three-Hour Rule" requires a patient to participate in, and benefit from, at least three hours of rehabilitation therapy per day, five days per week (or 15 hours per week if documented appropriately). Since 2010, CMS has only allowed physical therapy, occupational therapy, speech therapy, and orthotics/ prosthetics to count under the rule. BIAA believes other therapies – such as recreational therapy, psychological services, neuropsychological services, and respiratory therapy - should count as part of an intensive rehabilitation program, even if they are delivered after admission. The proposal has several champions in the House and the Senate, so bills are likely to be introduced soon.

Stabilizing Medicare Access to Rehabilitation and Therapy Act

The Stabilizing Medicare Access to Rehabilitation and Therapy (SMART) Act, H.R. 5536, seeks to improve access to treatment by reducing the impact of the payment cut imposed by the 2022 Physicians Fee Schedule for services furnished under Medicare Part B by physical therapy assistants (PTAs) and occupational therapy assistants (OTAs). The SMART Act would (1) temporarily suspend the payment cut for all PTAs and OTAs until January 1, 2023; (2) permanently eliminate the cut for therapy assistants who work in rural and underserved areas; and (3) amend Medicare so that the rules for supervision of therapy assistants are the same regardless of setting of care. The SMART Act was introduced by Rep. Bobby Rush (D-III.) in October 2021 and was referred to the Energy and Commerce Committee and the Ways and Means Committee in the House. No companion bill has been introduced in the Senate yet.

Improving Seniors' Timely Access to Care Act

The Improving Seniors' Timely Access to Care Act House (S. 3018/ H.R. 3173) has 11 cosponsors in the Senate, 250 cosponsors in the House, and more than 450 endorsing organizations. In short, the legislation would push back against the ever-increasing efforts by Medicare Advantage (MA) plans to limit access to care through prior authorization mechanisms. Specifically, the bill would streamline the prior authorization process, ensure requests are reviewed by qualified medical personnel, and protect beneficiaries from disruptions in care as they transition between MA plans. Overall, the legislation would increase the transparency around prior authorization requirements and their use.

Join Us Virtually for Brain Injury Awareness Day on Capitol Hill



Please visit BIAA's website to learn more about the plans for our virtual Brain Injury Awareness Day March 16. A briefing, sponsored by Congressional Brain Injury Task Force Co-Chairs Bill Pascrell, Jr. (D-NJ) and Don Bacon (R-Neb), is expected to take place in the afternoon. Visit biausa.org for event details along with advocacy fact sheets to use in virtual or local district meetings with your senators and representatives!

STATE AFFILIATE NEWS

Indiana

The Brain Injury Association of Indiana (BIAI) has had a wonderful few months, full of new collaborations, initiatives, and plans for 2022 and beyond. BIAI hosted two educational online events in the last quarter of 2021. In August, BIAI and Love Your Brain Yoga presented on their evidence-based brain injury yoga program, which is held nationally and in two locations in Indiana. In November, BIAI partnered with IU Health Physiatrist Dr. Ruth Stanton for a livestreamed presentation, "COVID-19: Effects on Long Haulers and those with History of Brain Injury." Dr. Stanton spoke about local services, resources, and supports for those with COVID-19 and brain injury. To learn more about this topic or services available in Indiana, contact us at biassociationofindiana@gmail.com.

BIAI is excited to announce its partnership with the Sons of the American Legion, a patriotic service organization made up of men whose fathers served in the Armed Forces. Together, BIAI and the Sons of the American Legion are working to raise awareness of brain injury and provide support and information to those in need. BIAI would like to thank Right Hemisphere Designs (RHD) for their recent generous donation. Created by two dedicated and passionate brain injury professionals, RHD creates and sells beautiful jewelry, stationary, apparel, tumblers, glassware, and more, donating 100% of profits from all sales to non-profit organizations like BIAI. Visit righthemispheredesigns.com to see their merchandise. On behalf of all of us at BIAI. thank you RHD!

Be on the lookout for some exciting FUNdraising events, educational opportunities, and more from BIAI in 2022!



BIAI staff and volunteers host an information table to raise awareness of brain injury in Indiana.



BIAI hosts a brain injury education session through its Sons of the American Legion partnership.

Maine

In early 2022, the Brain Injury Association of America – Maine Chapter (BIAA-ME) published the sixth edition of its Maine Brain Injury and Stroke Resource Directory in both print and digital formats. BIAA-ME is in the process of distributing the directory across the state. To download a digital copy, visit biausa.org/maine.

The State of Maine's Office of Aging and Disability Services (OADS) recently received a five-year TBI Partnership Grant through the Administration for Community Living. Through this grant, OADS is partnering with BIAA-ME to strengthen systems and services of support for Maine's underserved brain injury populations. BIAA-ME is also collaborating with Speaking Up For Us – Maine (SUFU) to provide outreach and education around brain injury and self-advocacy through a two-part virtual presentation series.

Michigan

The Brain Injury Association of Michigan (BIAMI) is proud to have been selected by the State of Michigan as one of several key strategic partners in its Covid Vaccination for Underserved Populations Program. Working with the Michigan Department of Health and Human Services and other community partners, BIAMI will be rolling out a three-phased approach designed to:

- foster an understanding of existing and perceived barriers and establish an Outreach Advisory Committee;
- create/enhance relationships with community health care providers to help connect people to vaccinations; and
- educate and inform our community about the importance and safety of the vaccine, help individuals schedule their vaccine appointment(s), and arrange for transportation to get them to and from the appointment.

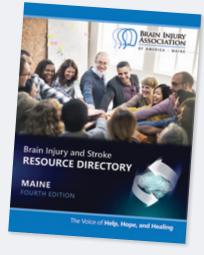
BIAMI will also seek to reach out to other constituency groups whose members may have likely sustained a brain injury but may not have an official diagnosis. These groups include veterans, and survivors of domestic violence and sexual assault, and BIAMI will collaborate with veterans service organizations and domestic violence programs to reach them. To learn more, visit biami.org.

New Hampshire

In December, the Brain Injury Association of New Hampshire (BIANH) and St. Joseph Hospital launched a pilot program to identify brain injury in patients with Substance Use Disorder (SUD). The program launched with a training led by Deepak Vatti, M.D., chief of emergency medicine at St. Joseph Hospital. "It is important for us to be able to identify patients with brain injury early on because they need a different treatment plan than traditional SUD patients," says Dr. Vatti. "The sooner we can identify these patients, the sooner we can get them the help they need to speed their recovery process."

Using the screening tool developed by Dr. John Corrigan, director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation, Dr. Vatti's training focused on educating providers, nonproviders, case managers, and social workers about the process for identifying brain injury in their patients. The pilot program, funded by Foundation for Healthy Communities, will run for 22 months. St. Joseph Hospital will work with a neuro-resource facilitator to help direct patients to appropriate resources. This program is a step toward ensuring that individuals from New Hampshire receive the treatment and support they need. To learn more, visit bianh.org.

(continued on page 28)



Rhode Island

In 2021, the Brain Injury Association of Rhode Island (BIARI) created a new part-time position at the organization called the Brain Injury Navigator. This staff member will be able to better assist the brain injury community by supporting survivors, families, and caregivers through ongoing communication and referral to available resources as they "navigate" the system. Through the program, BIARI will promote quality of care and cost-effective outcomes to assist survivors in bettering their wellness and functional ability. The Brain Injury Navigator works with hospitals, primary care physicians, rehabilitation professionals, in-patient rehabilitation units, community-based service providers, neurologists, neuropsychologists, emergency departments, insurance case managers, and discharge planners. We hope this program will expand opportunities to address service gaps in the system and allow BIARI to reach more survivors and families. In working closely and collaboratively with health professionals on behalf of the client, the Navigator aims to help survivors have better outcomes.

Colleen McCarthy has taken on this exciting addition to the BIARI staff. McCarthy, a social worker by training, was previously employed as vice president of programs and services at Sargent Rehabilitation Center. McCarthy also serves as vice president of BIARI's Board of Directors. Many thanks to the Brain Injury Association staff who provided input to McCarthy as she was identifying best practices for her new position.



Colleen McCarthy will work with survivors, families, and health care professionals as BIARI's new Brain Injury Navigator.

South Carolina

The Brain Injury Association of South Carolina (BIASC) was proud to continue its work on the Brain Injury Safety Net (BISN), a program focused on youth with concussions. BISN was made possible by a three-year grant, which ended in December, from the BlueCross BlueShield of South Carolina Foundation. One goal of the program was to create a state-specific resource, the SC REAP Manual, which is a color-coded resource to help adults provide support to a young person with brain injury in the typical 28-day recovery period after concussion.

The program's other major goal was to provide education to professionals and communities. BIASC hosted presentations and trainings on concussion best practices and created the "Get Schooled on Concussions – Teacher Acute Concussion Tool" resource. During the three-year grant period, the BISN program provided more than 5,074 professionals with concussion education and information through



61 conferences and training opportunities – a more than 256% increase from the number of professionals we had hoped to reach! We also distributed 8,409 SC REAP Manuals to professionals and caregivers over the grant period. Funding through the state will allow this program to continue through the end of 2022. Visit braininjurysafetynetsc.com to learn more. Vermont

The Brain Injury Association of Vermont (BIAVT) held Vermont's 33rd annual Brain Injury Conference in October, hosted by Stacia Bissel and Dr. Michael Hall. There were more than two hundred attendees at the virtual conference, which included an online silent auction and virtual exhibitor hall. We are especially excited to be planning for 2022 as we'll be hosting our first in-person event since 2020! This June, we will host our immensely popular annual "Walk-and-Roll" fundraiser.



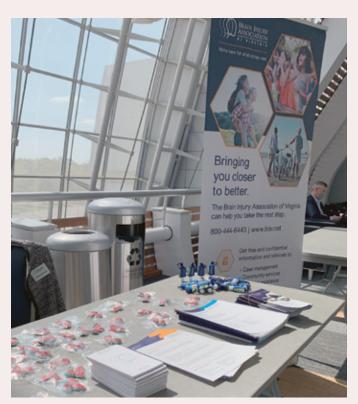
For information on past conferences, upcoming events, and how you can support BIAVT, contact us at support@biavt.org. You can also visit our website at biavt.org or follow us on social media to stay up-to-date. Find us on Facebook and Instagram at @biavermont on Facebook and Instagram or @BrainInjuryVT on Twitter. As always, our helpline is open Monday through Friday, 9 a.m. to 4 p.m. (ET) for information and referrals.

Virginia

In November, the Brain Injury Association of Virginia (BIAV) was able to host its 21st annual Making Headway Conference in person in Roanoke! Our keynote address, "Look Closer, My Brain Injury is Invisible" was presented by Stacia G. Bissell, M.Ed. Bissell shared her TBI story and discussed challenges and insights gained, both personally and professionally, throughout her TBI journey. Other sessions included: "Coping with Anxiety and Depression after Brain Injury," "Utilizing Creative Arts Processes," and "Making the Invisible Visible: Virginia's Domestic Violence and Traumatic Brain Injury 'Screen and Intervene' Project."



The "Screen and Intervene" project session was presented by Maria Altonen, rape prevention and education director and violence prevention coordinator at the Virginia Department of Health (VDH), and Amy Smith, OTD, clinical liaison at BIAV. This session explored how BIAV and VDH's partnership worked with brain injury and domestic violence service providers to pilot a program fostering community collaborations, introducing screening tools, and collecting critical data to shine a light on this hidden epidemic. The project summary for year one showed that 75% of clients



The BIAV table is ready for the 21st annual Making Headway Conference.

reported being hit in the head, choked, or strangled, and 51% of their brain injuries were due to an assault or fight. More than 60% of clients who were hit in the head, choked, or strangled reported problems in their daily life as a result of their injuries. In year two, we have extended our partnership to more areas of the state and to more organizations. To learn more about BIAV and its programs, please visit biav.net.

NEWS & NOTES

BIAA WELCOMES NEW OFFICERS AND DIRECTORS

The Brain Injury Association of America (BIAA) announced the election of new directors and officers for the term beginning January 1, 2022. Shana De Caro, J.D., partner in the New York-based firm of De Caro & Kaplen, LLP, will continue as the Association's chairwoman and Page Melton Ivie, owner and manager of The Source Group, LLC, will continue as the vicechair. The secretary will be Eleanor Perfetto, Ph.D., M.S., recently retired executive vice president of the National Health Council. Nicole Godaire, chief executive officer of the Brain Injury Association of Massachusetts, will serve as BIAA's treasurer.

New directors include Kevin Bingham, ACAS, CSPA, MAAA, chief results officer of Subsidiary Initiatives at Chesapeake Employers' Insurance Company and president and CEO of the company's corporate venture capital subsidiary iCubed Ventures, LLP; Chris Brisbee, president of the property casualty division of USI Northwest; and Owen Perlman, M.D., founding partner of Associates in Physical Medicine & Rehabilitation, P.C. Learn more about BIAA's new volunteer leaders at biausa.org/board.

RAISE AWARENESS THIS MARCH

BIAA is entering the second year of its wildly popular, survivor-focused More Than My Brain Injury awareness campaign. The three-year initiative aims to destigmatize brain injury and empower survivors to share their lived experiences with others. Join us



for one of our virtual events during Brain Injury Awareness Month this March, get involved on social media, or contact a local BIAA State Affiliate for information about in-person events in your state. For posters, public services announcements, at-home activities, and other resources, visit biausa.org/raiseawareness.

DO YOU WANT TO DO MORE FOR BRAIN INJURY?

With your help, BIAA can do more for people living with brain injury. This is an opportunity for everyone who wants to get involved: survivors, family, friends, relatives, co-workers – any member of your community. Fundraising is simple and easy, so step up and sign up! Visit biausa.org/domore or email development@biausa.org to get started.

UPCOMING WEBINARS

Mitchell Rosenthal Research Webinar – Self-Advocacy after Brain Injury: An Evidencebased Model of Empowerment March 31, 2022, 3 p.m. ET/12 p.m. PT *Lenore Hawley, MSSW, LCSW, CBIST*

Robert Sbordone Concussion/mTBI Webinar – Concussion Symptoms: Thinking Beyond Headaches April 6, 2022, 3 p.m. ET/12 p.m. PT *Lori Boyajian-O'Neill, D.O.*

Mitchell Rosenthal Research Webinar – Life after TBI in a Remote World: How mHealth Technology Can Support Individuals with TBI in their Community May 19, 2022, 3 p.m. ET/12 p.m. PT Shannon Juengst, Ph.D., CRC and Amanda Rabinowitz, Ph.D.

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

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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 biausa.org/corporate or contact Carrie Mosher at 703-761-0750, ext. 640 or cmosher@biausa.org.













