# THE EXAMPLE 14, Issue 1















#### **FEBRUARY 2020**

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

For more information regarding advertising in *THE Challenge!*, please visit biausa.org.

#### **Association Staff & Volunteers:**

Marianna Abashian

Sarah Augustoski

**Greg Ayotte** 

Robbie Baker

Christine Chen

Stephanie Cohen

Amy C. Colberg

Susan H. Connors

Tiffany Epley

Dianna Fahel

Holly Kisly

Carrie Mosher

Mary S. Reitter

Rula Tareq

Postmaster: Send address changes to: THE Challenge! 1608 Spring Hill Rd., Ste. 110

Vienna, VA 22182

Copyright © 2020 BIAA

All rights reserved.

No part of this publication may be reproduced in whole or in part without written permission from the Brain Injury Association of America. Email requests to publications@biausa.org.

Publication designed by Eye to Eye Design Studio, LLC eyetoeyedesignstudio@gmail.com



Please recycle this issue.

#### TABLE OF CONTENTS

- 4> From Patient to Advocate: The Story of Ten Years at Brain Injury Awareness Day
- 7 > Only Silent Tears
- 9 > Brain Injury Survivor Defies the Odds and Embraces Advocacy
- 10> Mother Raises Awareness About Bed Safety
- 12> True or False? Seven Common Myths About Brain injury

- 14> BIAA Awards Inaugural Grants
  Through its Brain injury
  Research Fund
- 16 Honor Roll of Donors
- 20 Advocacy Update: Special Edition
- 24 BIAA Welcomes New Officers and Directors
- 26 > State Affiliate News
- 30 > Upcoming Webinars



#### FROM MY DESK



pring has sprung in Washington, D.C. Purple crocuses and yellow daffodils are beginning to poke through the ground, promising warmer weather and basketball madness ahead.

The Brain Injury Association of America (BIAA) is ready to celebrate Brain Injury Awareness Month beginning March 1. Our theme for this year's campaign is #ChangeYourMind. Please visit our website at biausa.org/ChangeYourMind to download posters, social media graphics, and other materials to help raise awareness.



BIAA will again co-host Brain Injury Awareness Day on Capitol Hill March 4. We are grateful to Congressional Brain Injury Task Force co-chairs Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.) for

sponsoring the day-long event. This issue of *THE Challenge!* includes a special edition of our Advocacy Update, giving readers an overview of BIAA's legislative goals for 2020. The goals are also available as one-page handouts on our website at biausa.org/2020briefs. We encourage advocates to schedule visits in district offices and provide legislators with copies of these issue briefs throughout Brain Injury Awareness Month.

This issue of *THE Challenge!* also includes articles written by my friends Carol Bray and Angela Tucker. I am grateful to both of these women – and the many others who contribute articles to BIAA's magazine and website – for sharing the wisdom they've gained through lived experience. Brain injury is tough. The injury takes its toll on the individual and his or her family. It also impacts friends, neighbors, and the broader community. If BIAA can make lives easier in any way, we are honored to do so. We know that those who meet the adversity head-on make the best advocates.

Speaking of great advocates, I want to take this opportunity to recognize and thank our state affiliates. Please take a few minutes to read their submissions at the back of this magazine. Their state-by-state accomplishments are remarkable.

Last but not least, I am thrilled to welcome Robert S. Baker, III (Robbie) as BIAA's new Vice President/Chief Development Officer. Robbie comes to BIAA after more than 20 years working on behalf of adults and children living with chronic health conditions at organizations like the National Multiple Sclerosis Society, the Make-A-Wish Foundation, and the Leukemia & Lymphoma Society. Robbie will focus on individual and corporate philanthropy, including the establishment of a planned giving program at BIAA.

**Happy Spring!** 

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

Susun H Cumoz



## THE STORY OF TEN YEARS AT BRAIN INJURY AWARENESS DAY

By Angela Leigh Tucker, Member, Brain Injury Association of America Advisory Council

ight months after surviving a life-changing car crash and at a time when people were unsure if I would ever be able to walk again, I made it all the way to the steps of Capitol Hill in Washington, D.C. for the 2009 Brain Injury Awareness Day. Last year marked the tenth time I attended Awareness Day and in honor of that, I want to examine the impact this event has made on my healing journey.

Writing this was an exercise in concentration and to help fill in my gaps in memory. I reviewed old photos that were stored in my iPhone and sifted through old travel timelines and documents I created called "Lessons Learned," a habit I developed over my years in public relations. Fifteen years ago, I had no way of knowing that this skill would later become a helpful tool in my recovery from brain injury that would aid me in being able to remember past events and look forward to future planning.

While reviewing these old notes, here are some important lessons I learned during my adventures:

- Establish a Capitol Hill "buddy" or travel companion who will make sure you don't get lost or lose track of time.
- Print out the names of people who you schedule meetings with, including time and location of appointments.
- Pack snacks and remember to bring cellphone charger.
- Date and make personal notes on the back of each business card you collect to help remember each person.

- Print extra copies of Capitol Hill and D.C. maps for those who may need them.
- Practice mindful alcohol consumption during the Congressional Brain Injury Task Force Awareness Day Reception.
- Don't wear the shoes with the gold buckle because they are very uncomfortable! And don't wear the gold blouse again; it reveals too much cleavage!

My dear friend Karen Keating from the Brain Injury Association of North Carolina introduced me and my father to this important national event, which has since become one of the highlights of my year. I cannot recall many of the details from my first trip. I was still wearing a hard neck-collar to protect a healing C1 vertebrae, so my friend, Claire, helped me get dressed in my business suit to meet with my North Carolina representatives. Claire lives and works in the D.C. area and ever since that first trip has continued to generously open her home to me so that I may attend each year. Brain Injury Awareness Day occasionally falls on my birthday, and Claire has definitely served me a slice of birthday cake more than once.

In 2009, I was safely guided by Karen, who booked all the appointments for me. I vaguely recall being led to a chair in an office where I would simply answer questions. I have no way of knowing how my answers may have influenced change. I don't remember whether I felt self-conscious about the neck brace or about the fact that I needed someone to lead me everywhere. Regardless of this, I felt like an expert in that moment and that had a profound and lasting effect on me. That initial energy is why I continue to advocate today.

So many "versions" of me have visited D.C., and somewhere along the way I experienced a shift from arriving as a patient to showing up as an advocate. But that shift did not happen overnight and was not without a lot of bumps along the way. Prior to the accident, I travelled often for my job and was a skilled navigator. After the accident, as a TBI survivor, I learned traveling would be challenging. I believe it was during my 2011 trip to D.C. that I left all of my important travel documents in a folder at home. I didn't realize this until I reached Penn Station in midtown Manhattan and had no choice but to return to my apartment on the Upper West Side. The pressure to get there and back in time was enormous.

I always plan for big trips like this for weeks in advance in order to feel safe. My bag was packed, and I had prepared a folder with my travel itineraries, D.C. maps, and train ticket. I remembered my bag, but the folder was still sitting on my dining room table. Maybe other survivors can relate? In order to prevent this scenario in the future, I developed a strategy that I still use today. I leave all important travel documents on the floor in front of my front door (no more table) so I literally cannot walk out of the house without them.

While some years have been a little stressful, others have brought new friends and great connections. In 2013, I met a survivor from Pennsylvania in a most unexpected way: while I was standing in a bathroom line in the Rayburn Building. I guess I was eavesdropping on the two beautiful women in front of me, because I interrupted during a break in their conversation.

"Excuse me," I said. I have never been a shy person and I had not yet re-developed my brain's filter, "Are you survivors?"

The brunette standing closest to me nodded. I smiled and arrogantly responded, "Wow! We make brain injury look good!" She introduced herself as Angie Ficco. Angie invited me to attend her state's annual conference two months later, and we have remained close friends ever since. One of my favorite parts about attending this event is being able to meet incredible people who travel from across the nation to share their stories of survival.

As I gained experience and continued cognitive remediation therapy, I began to help others living with brain injury attend this event. I introduced Brain Injury Awareness Day to members of a New York City TBI support group I attended. With the news and enthusiasm I shared, the NY delegation attended the event each year and grew from one or two people to a formidable force of ten eager advocates! It's exhilarating to be part of this purpose-driven troop on Capitol Hill.

I always organize a celebration dinner at a casual Mexican restaurant nearby called Tortilla Coast as a nice way to finish the day. While noshing on tacos and laughing over margaritas, it isn't long before many of us are faced with a condition called neuro-fatigue. I experience it as an overwhelming exhaustion unlike

(continued on page 6)



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









#### NeuroRehab Outpatient Therapies

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

#### Supported Living Services

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

#### Life & Health Management Services

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

#### **Vocational Services**

- Supported Employment
- . Brain Injury Clubhouse
- NeuroVocational Evaluations
- BeechTree Enterpirses



Main Number: 215-750-4001 Admissions: 800-782-3299 | 215-750-4245 Program Development: 215-750-4299 Website: BNRadmissions@woods.org

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

#### (continued from page 5)

any other. I will yawn, slur my words, and become unable to focus my eyes. My husband often recognizes it's happening before I do. The only remedy I have discovered is immediate sleep. For this reason and to combat crashing during appointments, I try to carve out a short nap or break somewhere during the day full of action.

Brain Injury Awareness Day provides an opportunity for people to learn about research, prevention, rehabilitation, and community services within the world of brain injury. It is also an opportunity to meet with political leaders who are potential advocates within our community. Hundreds of survivors, families, friends, and professionals attend to raise awareness of the many ways brain injury visibly and invisibly impacts members of our community and society in general. During the event, there is an Awareness Fair that is designed to bring people together so that federal and national organizations can network among state peers and leaders.

I recognize all the growth that has transpired during my transition from patient to advocate, and I will

continue to encourage my members of Congress to join the Congressional Brain Injury Task Force. Due to brain injury, my life and millions of other lives are forever changed. Because there will always be new discoveries, treatments, and services, I will continue to attend Brain Injury Awareness Day. There will always be wonderful new friends to meet who are traveling their own healing journey. While no two recoveries will ever look the same, there is something tremendously therapeutic about not traveling the path of healing alone.

Author's Note: We can all "Be the Voice of Brain Injury" — we don't have to travel to D.C. to have our voices heard! I invite you to consider what you can do to help. Visit house.gov to find your representatives, call their offices, and set up appointments locally to talk about what we all know so well: our injuries and our circumstances. By telling our stories, we become advocates. Remember, we can make a local phone call, send an email, or write a letter. These actions can make as much of an impact as meetings do in D.C.



By Carol P. Bray

n the 2012 publication of *THE Challenge!*, I chronicled my husband Bill's life in a story called "No More Ants at Our Picnic!" after he suffered an anoxic brain injury I wrote about the difficulties we had navigating hospital and insurance systems, dealing with the invasion of our personal space while he needed home care, and his journey to recovery.

One year later, I wrote "How To Avoid (or lessen) the Silent Scream," an article about my job as Bill's caregiver and how I managed to take care of myself while taking care of him – an important reminder for all caregivers. I am writing again with a final story.

Following years of inpatient and outpatient therapy, Bill

regained almost all his abilities; he still had difficulty with balance, for which he had to use a walker. Over the next 10 years, Bill had numerous hospital admissions for various medical problems indirectly associated with his brain injury. Each time, he had to go to rehab to regain his walking. Bill and I spent 372 days in hospitals. I was always with him, and we formed a special bond during these occasions. Each time Bill was hospitalized, he worked hard to improve his condition so that he could return home. He was always successful, which is why his death on March 14, 2019 was devastating! He died the day before our 44th wedding anniversary.

Bill's brain injury was not the primary cause of his death, but it was a significant factor as the problems he had with his kidneys, lungs, and heart were linked to his limited mobility issues.

At the time of his death, Bill was in the ICU of a local hospital where he had been transferred from the rehabilitation hospital after a medical episode.

Upon his arrival, he was immediately intubated and placed in intensive care. In the weeks before his rehab

admission, Bill's overall condition had deteriorated. His eating, drinking, walking, and strength were poor, and his cognition was not good. We had home health care aides as well as occupational and physical therapists in our home. When he did not progress and his doctors could not diagnose his problems, he began rehabilitation.

After five days in the ICU, Bill was taken off the ventilator. While still critical, he continued to improve and was

I felt relieved that Bill was safe and

free from needing assistance every

day. I realized I had all this time and

freedom that I had not had in years.

However, when I finally had the time

and space I had so often desired,

I realized I didn't really want it.

doing well the day he died. The possibility of his death in the hospital was never discussed, so to say his death was a shock is an understatement. We knew his recovery would be long and difficult, but death was unexpected. I had promised I would take him home that day and had made arrangements to do so. I was sad that I broke that promise. He had never

failed to get home before, and I did not think this time would be different. Yet, there I was – a survivor, a widow, and no longer a caregiver.

Bill's death brought feelings that both surprised and saddened me. I was not as upset as I thought I should have been. Perhaps this was because I believed Bill's death was a conscious choice he made as he was tired of the fight he had fought for so many years. The limitations he experienced due to his medical issues were numerous. I think he was tired of the struggle and

knew his road to recovery would be long and difficult.

(continued on page 8)



Research Study

# Are you caring for a family member with an acquired brain injury (ABI)?

If so, you may be eligible to participate in the Positive Coping for Family Caregiver of Persons with Acquired Brain Injury research study.

To be eligible to participate, you must:

- be a family caregiver of an individual with an ABI, and have been looking after them for at least one year
- are between 22 to 75 years old
- · English speaking

Participation in this research study involves completing an anonymous, one-time IRB-approved online survey (i19-01400). Approximately 20 minutes. To access the survey, visit https://bit.ly/37LPH9X.

#### To find out more information, please contact

Sonya Kim, PhD, CRC
Research Assistant Professor (Principal Investigator)
NYU Grossman School of Medicine
212-263-4849 | sonya.kim@nyulangone.org

(continued from page 7)

I also think he wanted me to be free from his daily care, to enjoy life, and to do things I could not do with him.

I felt relieved that Bill was safe and free from needing assistance every day. I realized I had all this time and freedom that I had not had in years. However, when I finally had the time and space I had so often desired, I realized I didn't really want it. I hated being alone and still do, especially at night, watching our favorite TV shows and doing things by myself. For the first few weeks, I could not read obituaries in the newspapers and did not like going places alone. I worried about my own health and the fact that there would be no one with me should I have a problem. Fortunately, these feelings have subsided. I have family and friends living nearby who help fill the void and help me feel safe. I wonder if my feelings are similar to those of other caregivers. I believe they are normal, but difficult to talk about.

There are no more "Ants at Our Picnic" or "Silent Screams" only silent tears. I miss my husband, his humor, and his many kindnesses to myself and others. We did everything together. At times, being a caregiver was a burden, a great responsibility, and sometimes drained my energy and spoiled my joy; it also brought

me great happiness because I was caring for someone I loved. While I was always the one who received the accolades for my dedication and service, Bill was the one who should have been given the praise and glory. He was one of a kind. He never once complained, yet he was the one who lost the most.

In 2009, Bill's life was changed forever. In 2019, so was mine!

I am reminded of the song "The Dance" by Garth Brooks:

Looking back on the memory of the dance we shared beneath the stars above
For a moment the world was right
How could I have known you'd ever say goodbye
And now I'm glad I didn't know
The way it all would go
Our lives are better left to chance
I could have missed the pain
But I'd have had to miss the dance.

Bill was a Vietnam veteran, United States Air Force. He was buried, with full military honors, at Arlington National Cemetery February 5, 2020.



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

Photo credit: Ben Wiese

ylan Flynn, brain injury survivor and advocate, has always had a love of music. In fact, his two favorite things are music and his dog. When Dylan was a freshman in high school, he purchased his first bass guitar. Just as he was planning to start a band with his friends, he was in a terrible car accident and was in a coma for 12 days. Initially, doctors told his family he wouldn't survive and that he would spend the rest of his life in a nursing home. Defying the odds, Dylan walked out of rehab 10 weeks later and was able to return to school for his sophomore year.

As a result of his brain injury, Dylan has epilepsy, memory difficulties, anxiety, and depression. Despite these symptoms, he eventually earned his GED and sought to do something meaningful with his time. At the recommendation of a friend, he started a campaign called "Pass the Bass" as a way to use his love of music to increase awareness of brain injury. Through Pass the Bass, Dylan attends music concerts and asks the performing band to play one song with his bass guitar. He is often invited on stage to tell his story.

While Dylan's life may not have gone as planned, he enjoys being part of the music scene. "I'd wanted to make a living as a musician. Although I am unfortunately not taking part in the actual music at these shows, music is still a very big part of my life thanks to this campaign. I love watching my bass be played and have had the honor of watching some of my favorite bassists [play]

with mine," he explains. Nearly 50 musicians from bands like Flogging Molly and Pennywise have "passed the bass" so far.

One of Dylan's goals through his campaign is to fundraise for the Brain Injury Association of America (BIAA). As a survivor, he believes he's in the "ideal position to spread awareness and raise money to help individuals struggling with brain injury." He decided to design Pass the Bass t-shirts, which he sells at each concert he attends. The money he raises from t-shirt sales is donated to BIAA.



Dylan created the Pass the Bass campaign to raise money for brain injury services. Follow him on Facebook at @PassTheBassDylan.

Although Dylan's brain injury prevented him from doing exactly what he'd wanted to do with his life, he still found a way to merge his passion with his daily living and says that other survivors should try to do the same. To support Dylan in his efforts to raise awareness of brain injury and get your own Pass the Bass t-shirt, visit shop.biausa.org/passthebass.

# MOTHER RAISES AWARENESS ABOUT BED SAFETY

By Mariellen Jacobs, Founder, Rail Against the Danger

nyone who has sustained a traumatic brain injury (TBI) knows that life changes in the blink of an eye. In 2015, my son Clark's life almost ended after a terrible accident at his fraternity house. Of all the campus dangers I thought I knew about when I sent him to college, it turned out to be something that wasn't even on my "helicopter mom" radar that almost took his life.

I'll never forget gazing up at the seven foot high lofted bed in Clark's new room and thinking out loud whether he should have a safety rail. I also remember the laughter from Clark, his dad, and his big sister, Kelsey, as they exclaimed, "He's not going to roll out of bed!" Remembering that he had just spent a year on the top bunk at his residence hall, I relented.

Four months later, Clark rolled over in his sleep one night, plunging to the hard floor where he landed on the back of his head. He doesn't remember falling - just coming to while vomiting into a trash can. After vomiting a dozen more times, he had a massive headache and was unable to turn his head. Clark decided then that it was time to call us. We took him to the emergency room. where a CT scan confirmed our fear that he had fractured his skull. During the hours that followed, he developed a brain bleed that required emergency surgery. As the surgeon spoke to us in the waiting room, the words we heard were surreal, "Your son's brain is hemorrhaging. If we don't operate, he will die. Even if we do, he may not make it."



Clark Jacobs and his mom, Mariellen, share information about safety rails at an educational event.

Thankfully, Clark did survive brain surgery. The next 72 hours were spent on pins and needles in the ICU with our son on a ventilator, barely conscious. Within hours of surgery, we were told that Clark had suffered a hemorrhagic stroke in his cerebellum, the part of the brain that controls motor movement, balance, and speech. In the days that followed, we were transferred from the ICU to Shepherd Center, a renowned rehab hospital in Atlanta. He spent the first two and a half months in a near-comatose state. As the days and weeks stretched on with no improvement, we began to wonder if our son was ever coming back to us. Would he ever walk again or entertain us with his trademark sarcasm? The thought of him waking and returning to college seemed a far-off dream.

As I sat by his bed day after day, I found myself wondering how often this type of freak accident happens. My internet research showed that bunk and loft bed accidents weren't really rare at all, with 71,000 children aged 4-21 reporting to the emergency room every year with severe bed-related injuries. It made me wonder how many

parents were just like we were, making residence hall decisions without any idea of the potential dangers. The thought of another family going through this nightmare convinced me that someone had to do something. That is how "Rail Against the Danger" (RAD) was born.

I began a grassroots campaign in the state of Georgia to change perception and policy regarding safety rail usage in the college setting. As sturdy safety rails cost about \$40, it's this mom's opinion that any bed that is six or more feet off the ground should have a rail on the bed, provided by the institution. Safety rails are instrumental in preventing the unthinkable. Students should also note that thick mattress pads might affect a rail's efficacy, so be sure to measure and ask for a taller rail if needed.

When I think back to the day that changed our lives forever, I am always struck by the fact that a \$40 safety rail would have prevented all of it. Clark will have challenges for the rest of his life from his brain injury and stroke. I encourage everyone to ask questions about bunk and loft bed safety at their universities.

If the tragedy our family experienced helps prevent one family from experiencing the same thing, maybe we will all sleep a little better.

For more information about RAD and safety rails, visit railagainstthedanger.org.

Mariellen Jacobs is a mother and safety activist. She works as a brain injury peer support liaison at Shepherd Center in Atlanta, Georgia where her son rehabilitated for 18 months following his accident.

Editor's Note: Dylan Hernandez, a student at San Diego State University, died from a brain hemorrhage sustained from a loft bed fall at the end of 2019, after this article was written. His death could have been prevented with a taller rail. Education is vital, so please help BIAA and RAD raise awareness.





By Kellie Pokrifka, Member, Brain Injury Association of America Advisory Council

here is so much misinformation regarding brain injury floating around on the internet. Research in this field is progressing every day, and we frequently disprove old theories. It can be difficult to keep up with the latest research, so let's take a few minutes to dispel some of the most common myths regarding brain injury.



#### Myth: You can always see brain injury on CT and MRI scans.

CT and MRI scans are looking for brain bleeds, skull fractures, and other acute trauma. Not all brain injuries, and especially not concussions, will appear on these scans. A clear CT or MRI does not eliminate the possibility that you have a brain injury.



#### Myth: Two years after brain injury, no further recovery can be made.

Many people assert that recovery from brain injury is only possible within the first year or two. We now know that is incorrect. Following the first nine months of recovery, time is no longer an indicator of recovery. What matters after this point is finding the proper therapies for your symptoms. Doing the right activities 50 years post-injury has the same chance of recovery as receiving proper treatment nine months out. Improvements in your recovery are always possible.



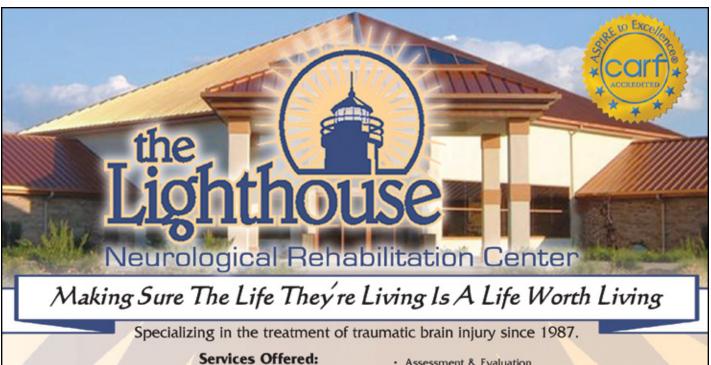
#### Myth: Concussions are not serious.

Concussion is a form of mild traumatic brain injury (TBI). "Getting your bell rung" or "seeing stars" are never things to ignore - they are signs of brain injury. Concussions are described as "mild" brain injury because they not usually life-threatening, but this does not mean they are not serious. While many people will fully recover after two weeks, a percentage of patients will have lifelong symptoms following a concussion.



#### Myth: Individuals with brain injury don't think about suicide.

Unfortunately, suicide is not an uncommon occurrence after brain injury. Nearly one in five brain injury survivors admit to suicidal ideation, plans, or attempts in the five-year period following injury. In the general population, that statistic goes down to one in 25. Extreme life changes and organic changes in the brain after TBI can increase the chances of suicide. Because of this increased risk, it is important for medical teams and loved ones to address this subject. Being open and



#### TRAVERSE CITY 4040 Beacon St.

Kingsley, Michigan 49649 10 Miles South of Traverse City (231) 263-1350

Fax (231) 263-1353

- · Residential Care
- · Rehabilitation Services
- Behavioral & Vocational Programs
- · Pediatric Program

www.lighthouserehab.com

- Assessment & Evaluation
- 24 Hour Trained Staffing
- **Outpatient Services**
- Respite Care
- Concussion/Program



P.O. Box 289 1655 E. Caro Rd.

Caro, Michigan 48723 (989) 673-2500

Fax (989) 673-3979

honest about this tough conversation can save a life and help connect your loved one with proper resources. If you need help, you can call the suicide hotline at 1-800-273-8255.



#### Myth: Only athletes get concussions.

Concussions are not only a problem for athletes; concussions, like other TBIs, can happen anywhere, at any time, and to anyone. TBI is a common result of motor vehicle accidents, falls (particularly in elderly and child populations), military action or blast exposure, intimate partner violence, abuse, gunshot wounds, and other physical trauma.



#### Myth: If someone has sustained a concussion, you should wake them up every hour for the next day.

There is no need to keep someone awake for 24 hours after a concussion. Sleep is critical for brain injury recovery. If the person has been cleared by a professional for brain bleeds and acute trauma, restful sleep is safe and is crucial for recovery.



#### Myth: You should not be exposed to any stimulation that may trigger symptoms until you are completely recovered.

It used to be common practice to protect patients with brain injury by placing them in silent, dark rooms for weeks or months until symptoms subsided. However, the "rest and wait" approach is no longer an appropriate recovery plan and can actually worsen symptoms. Many experts even suggest light, controlled exercise within 72 hours of sustaining a concussion. As always, consult your doctor before making any changes to your recovery plan.

References available at biausa.org/sevenmyths.



# BIAA AWARDS INAUGURAL GRANTS THROUGH ITS BRAIN INJURY RESEARCH FUND

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

he Brain Injury Association of America (BIAA) announced the winners of its 2019 Brain Injury Research Fund competition. Orion Furmanski, Ph.D., Uniformed Services University, and Raj Kumar, Ph.D., Icahn School of Medicine at Mount Sinai, were awarded seed grants of \$25,000 each; Katherine Giordano, University of Arizona College of Medicine, and Marie Hanscom, University of Maryland-Baltimore, were granted dissertation awards of \$5,000 each.

The Brain Injury Research Fund offers support to studies contributing to our understanding of brain injury as a chronic disease. John D. Corrigan, Ph.D., BIAA's research committee chair noted, "The board of directors is pleased to advance the science of brain injury through these seed grants and dissertation awards. We thank the research committee members

who helped shape the program and evaluate the applications. We look forward to the 2020 competition." BIAA established its research grant program in 2019 with a generous bequest from the estate of Linda Redmann and an allocation from the Association's reserves. Through the Brain Injury Research Fund, BIAA offers two types of funding: Dissertation Awards, funded between \$3,000 to \$5,000, and Seed Grants, funded up to \$25,000. The Association will accept Letters of Interest (LOIs) for the 2021 awards this spring.

We welcome and encourage donations from the public to help grow the fund and support research toward finding cures for brain injury," offered Susan H. Connors, BIAA's president and chief executive officer. "We are particularly interested in donor-advised endowments. To make your donation, visit biausa.org/researchfund.

#### **FUNDED PROJECTS**



Orion Furmanski, Ph.D., Grantee

#### **Meningeal and Trigeminal Contributions to Post-TBI Pain**

Seed Grant of \$25,000

**Grantee:** Orion Furmanski, Ph.D., Department of Anatomy, Physiology, and Genetics,

Uniformed Services University

Mentor: David Mears, Ph.D.

**Project Summary:** Posttraumatic headache (PTH) is characterized by increased headache frequency and/or severity following a traumatic brain injury (TBI). Current treatments for headache often fail to provide adequate relief for PTH. Improving treatment for PTH has been hindered by lack of knowledge on how TBI alters the nervous system to cause chronic headaches. We propose preclinical experiments to examine TBI effects on nerves of the dura mater, the protective jacket between the brain and skull. We hypothesize that dura mater injury promotes inflammation and abnormal pain processing that contribute to PTH.



Raj Kumar, Ph.D., Grantee

#### The Epidemiology of Comorbidities and Associations with **Functional Outcome among Adults with TBI**

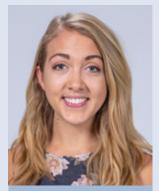
Seed Grant of \$24.893

Grantee: Raj Kumar, Ph.D., Rehabilitation and Human Performance,

Icahn School of Medicine at Mount Sinai

Mentor: Kristen Dams-O'Connor, Ph.D.

**Project Summary:** As rates of traumatic brain injuries (TBI) increase and the population ages, there is an unprecedented urgency to understand the burden and implications of health morbidity on TBI recovery. Prior TBI studies are limited by incomplete disease characterization and under-representation of older adults, necessitating use of populationbased data. Existing indices focus on predicting acute mortality (not function) and exclude diseases associated with TBI. We propose: 1) to use an administrative dataset to characterize disease prevalence, and 2) to create a functionally-relevant comorbidity index.



Katherine Giordano, Grantee

#### **Precision Identification and Targeting of Rod Microglia in Diffuse Brain-injured Cortex**

Dissertation Award of \$5,000

Grantee: Katherine Giordano, Child Health, University of Arizona College of Medicine

Mentor: Jonathan Lifshitz, Ph.D

**Project Summary:** Neurological insults, such as traumatic brain injury, trigger inflammation signaling that go on to activate microglial cells. In this proposal, we investigate lesser-known microglia subtype, the rod microglia, to determine cell surface markers and gene expression unique to their occurrence after diffuse traumatic brain injury. These rod microglia markers could serve as biomarkers in the diagnosis and prognosis of injury and recovery from neurological injury.



Marie Hanscom, Grantee

#### Impact of Intestinal Inflammation on Long-Term Neurological **Outcomes Following TBI in Mice**

Dissertation Award of \$5,000

**Grantee:** Marie Hanscom, STAR-ORC, University of Maryland-Baltimore

Mentor: Terez Shea-Donohue, Ph.D.

**Project Summary:** Traumatic brain injury (TBI) causes peripheral organ dysfunction including gastrointestinal dysfunction. Increased gut leakiness is associated with greater risk of comorbidities in trauma patients. TBI patients surviving longer than 1-year postinjury are more likely to die of sepsis and digestive conditions. Infection with an intestinal pathogen in mice worsened TBI lesion volume. This study examines the effect of intestinal inflammation following TBI on long-term TBI-associated brain injury, inflammation and cognitive dysfunction and the role of the brain-gut axis in TBI disease progression.



## HONOR ROLL OF DONORS

November 1, 2019 - December 31, 2019

#### **HONORS**

In honor of Lisa Bukkhegyi Mr. Joel Dube

In honor of Bethany Cantin

Mr. Robert Gebelein Ms. Alice Ruckert

In honor of Jessica Cantrell

Ms. Tracey Rabelow

In honor of Arnold and Wanda Coldiron

Mr. Michael Coldiron

In honor of Linda Corcoran

Ms. Kelly A. Balboni

In honor of Katrina Paige Heiser

Mrs. Dianne Heiser

In honor of The Bill Hood Family

Mr. & Mrs. Rod and Marie Harley

In honor of Diane Kempf Jones

Dr. C. Ruth Kempf

In honor of Christian Keith

Ms. Sharon Keith

In honor of Kesera

Mrs. Leticia Jones

In honor of Kiarina Londono

Mr. Jonathan Landono

In honor of Outpatient TBI and Young Stroke Team

Dr. Sheldon Herring

In honor of David and Geraldine Pincus

Ms. Wendy Pincus

In honor of Ella Rodriguez

Mr. Ken Clark

In honor of Ed Roland

Ms. Lynn Roland

#### In honor of Ira Sherman

Mr. & Mrs. Steven and Charla Lerman Dr. John Williams

In honor of the Stewart-Varelas Family

Ms. Aubra Fletcher

In honor of Rvan Stoller

Ms. Andrea Smith

In honor of Stanley Travis

Mr. Paul Owens

In honor of Stan Travis III

Dr. & Mrs. Stanley and Louise Travis

In honor of Amy Tridgell

Mr. Glenn Tridgell

In honor of David Ulrey

Mr. Prescott Ulrey

In honor of Lee Westgae

Mr. Dennis Goulet

In honor of Sam Workman IV

Mr. & Mrs. Samuel and Kim Workman

In honor of Amanda Zyroll

Mr. Corey Dolan

#### **MEMORIES**

In memory of Butch Alterman

Mrs. Maureen Alterman

In memory of Dennis Bender  $\,$ 

Mrs. Carolyn Keeve

In memory of Andre Bertin

Ms. Barbara Zeins

In memory of Rich Betancourt

Ms. Angela Leigh Tucker

In memory of Clara M. Burton

Ms. Barbara Clay and Ms. Stacie Clay

#### In memory of Jessica Marie Cantrell

Ms. Merina Cameron

Ms. Nancy McFarland

Mr. & Mrs. Rudy and

Beth Steinmetz and Family

Dr. William Todd

Ms. Katherine Moore and

Bridgitte Tsobgny

Bridgitte I sobgny

Mr. & Mrs. Brent and Gay Turner

#### In memory of Christopher Conklin

Mr. & Mrs. Brian and Heather Walker

In memory of David

Mrs. Brenda Brenner

In memory of Barbara J. Eggart

Mr. Steven Eggart

In memory of Michael Fecile

Mr. & Mrs. Ed and Kathleen Nawrocki

In memory of Dr. Irving Feigenbaum

Mrs. Shirley Feigenbaum

In memory of Jared Harlan Feigenbaum

Mr. & Mrs. John and Sharon Bitzer
Ms. Caroline Damask

Mrs. Shirley Feigenbaum

In memory of Marilyn Marie Gage

Ms. Finnuala McLaughlin

Mr. & Mrs. David and Lindsey Peters
Ms. Mary Ellen Sanders

Ms. Martha Wilson

In memory of Gina Frezza's Father

Mr. & Mrs. Anthony and Cynthia Rivelli

In memory of Daniel Goodner

Mr. Theodore Giovanis

In memory of Keith Michael Gratkowski

Dr. Holly Gratkowski

In memory of Kimmie Greendahl

Ms. Diane Swenson

#### In memory of Harry Jacob Hanna

Ms. Jodi Gitt Ms. Emily Smith Ms. Suzanne Suskind

#### In memory of Pat Hartman

Dr. Bonnie Nakasuji

#### In memory of Melanie Hayhow

Mr. Peter Hayhow

#### In memory of Dennis Houseman

**Attorney Howard Sobel** 

#### In memory of Jess James Howarth

Mr. Nathan Kluth

#### In memory of Zach Ivie

Ms. Linda Weber

#### In memory of Carolyn Joyce "Karol" Lalonde

Ms. Cynthia Duke Ms. Karen Whitson

#### In memory of John R. Lentes, Jr.

Ms. Amy Coombs

#### In memory of Michael "Mic" Maner

Mr. & Mrs. T. A. III and Susan Miller

#### In memory of Sydney Marcus

Mr. Glenn Marcus

#### In memory of Gertie Maziroff

Mrs. Pauline Davis

#### In memory of Dennis Migdal

Mrs. Maureen Alterman Mr. & Mrs. Mark and Marlene McCartin

#### In memory of Timothy W. Mikullitz

Mrs. Cheryl Mikullitz

#### In memory of Jessika Niley

Mrs. Sara Hines

#### In memory of Mr. Harold O'Leary

Danielle Whalen Memorial Foundation

#### In memory of Brain Pengra

Ms. Stephanie McFarland

#### In memory of Jorge Prado

Ms. Rebecca Fennessy International Code Council Mr. Robert Ouaranta Mr. Jeff Rainwater

#### In memory of Karen A. Reitter

Mr. Frank Reitter Ms. Mary S. Reitter Mrs. Sheila Sferrella

#### In memory of M. Bernice Reitter

Mr. Frank Reitter Ms. Mary S. Reitter

#### In memory of Timothy Rocchio

Mrs. Carolyn Rocchio

#### In memory of James and Arlene Sima

Mr. & Mrs. David and Audrey Bahde

#### In memory of Richard Siniscalchi

Ms. Susan Munguia

#### In memory of Joseph Michael Toennis

Ms. Karen Toennis Ms. Eve Zacharakos

#### In memory of Wally Walsh

Mrs. Donna Walsh

#### In memory of Ray Wright

Ms. Suzanne Wright

#### **SUPPORT**

#### In support of Bowling for **Brain Injury - Maine**

Ms. Kathleen Albert Ms. Heidi Alpern

Ms. Karin Anderson

Ms. Meridyth Astrosky

Ms. Joan Ayers

Ms. Vicky Bell

Ms. Andrea Bouchard

Brain Injury Association of New Hampshire

Mr. Alan Brigham

Mr. & Mrs. Anthony and Patricia Brissette

Mr. Richard Brown

Miss Bethany Bryan

Ms. Lynda Bryan

Mrs. Cynthia Buzzell

Mr. James Canty

Ms. Mary Carter

Ms. Darlene Chase

Ms. Jeanine Chesley

Mr. Tobie Colgan

Creative Works

Mr. & Mrs. Glen and Catherine Davis

Mr. Gary Dawbin

Ms. Rachael Dean

Ms. Elaine DeMay

Ms. Jane Driscoll

Ms. Pam Emery

Ms. Tonya Emery

Ms. Terry Fletcher

Mr. Fred Fridman

Ms. Aimee Gaffney

Ms. Sarah Gaffney

Mr. Leland Glynn

Mrs. Sharon Hartl

Heikkinen, Farina and Bracy Families

Mr. Matthew Hickey

Mr. Philip Ingle

**Innovative Prosthetic Solutions** 

**I&D** Orton Transportation, Inc

Ms. Carol Jordan

Ms. Judy Katzel

Ms. Linda Kilch

Mr. Howard Kunin

Ms. Denise Leathers

Ms. Jayne Ludwig

**Taylor Ludwig** 

Ms. Kathleen Mahoney

Ms. Christina Monagle

Ms. Linda Morey

Ms. Donna Patterson

Ms. Alice Pearce

Mr. Glen Pelligrinelli

Mr. Brian Phelps

Mr. Guy Pilote

Ms. Brittney Poulin

Mr. & Mrs. Jesse and Ruth Quirion

Ms. Donna Rauschke

Ms. Julia Reger

Ms. Maricel Romero

Ms. Terry Roy

Ms. Kellie Selberg

Mr. & Mrs. Michael and Sara Shapiro

Ms. Linda Shapleigh

Ms. Lisa Siciliano

Ms. Katherine Soverel

Ms. Erin St. Pierre

Mr. & Mrs. Dave and Debbie Jordan Stankowicz

Ms. Carole Starr

Ms. Donna Stetson

Ms. Allison Stevens

Mr. Robert Straznitskas

Mrs. Melanie Tassinari

Ms. Charleen Taylor

Mr. Steven Wade

(continued on page 18)

Ms. Christine Webber Ms. Sarah West Ms. Jennifer Will Mr. Andrew Wood

#### **FACEBOOK FUNDRAISERS**

The Brain Injury Association of America (BIAA) is grateful for the individuals listed below who held fundraisers benefitting BIAA through Facebook. A complete list of donors to these fundraisers will be included in BIAA's *Annual Report*.

#### **Birthday Fundraisers**

Ms. Connie Gortney Allen
Ms. Stefanie Alyce
Ms. Sierra Arnott
Ms. Shasmin Asbury
Mr. Harold Aydelott
Ms. Audrey Bahde
Ms. Debbie Beach

Ms. Lisa Detweiler Bockenstedt

Ms. Vicki Boyle

Mr. William Busch

Mr. Dale Cash

Mr. Fonzy Con

Ms. Lauren Coonan

Ms. Krista Dickson

Ms. Caitlin Elizabeth Dietz

Ms. Jesse Duke

Ms. Kerri Elizabeth

Ms. Emily Falcon

Ms. Melissa Hartrum Fisher

Ms. Jocelyn Frago

Ms. Jessica Freitag

Ms. Stacey Fruth

Mr. Antonio Giannico

Mr. Bruce A. Gomez

Cadíz Cokie Gomez

Ms. Tina Simonson Hannan

Mr. Joshua Hansmann

Ms. Stacey Hasting

Ms. Holly Overstreet Hogan

Ms. Marcia White Howard

Mr. Arty Kojoyian

Mr. Cody Laahs

Mr. John Lierman

Mr. Ron McDaniel

Ms. Mayra McGowan

Ms. Jeannette McHugh

Ms. Tiffanie Nicole Morgan

Ms. Sarah Morris

Ms. Cambridge Kaufman Mudd Ms. Kayti Patton

Ms. Elana Barrish Riback Ms. Justine Rilev

Ms. Blanca Dinora Robles

Ms. Kiara Rubino

Ms. Lindsay Rust

Corri Sandwick

Ms. Lisa MacIntyre Schafer

Ms. Alanna Schumacher

Mr. Henry Seekins

Ms. Cecilia Speranzella

Ms. Alexus J. Starks

**Bobin Thomas** 

**Jesse Torres** 

Ms. Julie Whitt

#### **General Fundraisers**

Mr. Travis Flateau Ms. Meridian Kerner-Kubat

Ms. John Lombardi

Ms. Cheyenne M-j Simpson Mr. Barry Weary

#### **Giving Tuesday Fundraisers**

Harold Aydelott

Ms. Vicki Boyle

Ms. Kathy Costa

Ms. Shana De Caro

Mr. Christopher Ewalt Ms. Caitlin Gill

Ms. Holly Gratkowski

Ms. Heidi Hoffmann

Mr. Matthew Jessen

Mr. Steven Joseph

Ms. Ariel Kasheri

Ms. Morgan Keough

Ms. Gretchen Kling

Mr. Drew McKinney

M I M

Ms. Leecy Momano

Mr. Sam Mosberg

Mr. Jason and Jenny Ornelas

Ms. Megan Plank

Ms. Michele Scarlet Ridenour

Mr. Jordan Aaron Ritsema

Ms. Elysia Severson

Ms. Dianna Taylor

Ma Mia Vaga

Ms. Mia Vega

#### **GENERAL DONATIONS**

Ms. Elizabeth Ackerson and Mr. Alan Mcllhenny Mr. Michael Adam Dr. & Mrs. Guillermo and Enid Arbona

Ms. Jolanta Baranowski

Mrs. Erica Bender

Ms. Lori Bennett

Mr. Bruce Berrol

Dr. Anthony Beshara

Dr. Jennifer Bogner

Mr. & Mrs. Francis and Penn Branin

Mr. & Mrs. Doug and Heidi Brewer

Ms. Suzanne Caffrey-Yoscary

Mr. Jonathan Cantrell

Mrs. Mary Carson

Ms. Virginia Catlin

Ms. Christina Cesco-Cancian

Ms. Sandra Cesco-Cancian

Ms. Amy Chester

Mr. & Mrs. William and Rita Joan Clark

Ms. Erin Connors

Dr. John Corrigan

Dr. Julieen Crane

Ms. Sandra Crawley

Ms. Amanda Crumbly

Mr. & Mrs. Chris and Brenda Cutler

Mr. Mark Dabney

De Caro Kaplen

Ms. Linda Dean

Dr. Ramon Diaz-Arrastia

The Dallas Foundation

Ms. Lynne Dintiman

Mr. Richard Dumas

Ms. Tracy Dumas

Mr. Michael Dumbroski

Mr. & Mrs. Steve and Marsha Dunaway

Ms. Stephanie Duncan-Peters

Ms. Marisa Eligio

Mrs. Christine Everitt

Mr. & Mrs. Phillip Feliciano

Ms. Joanne Finegan

Ms. Sophie Flood

Mr. Stephen Philip Gianni

Ms. Jennifer Gilbert

Dr. Mel Glenn

Ms. Laura Goldberg

Mr. & Mrs. Scott and Shari Goldstein

Mrs. Kay Graber

Mr. Ronald Great

Mr. Joseph Greenberg

Ms. Barbara Guidos

Mr. Craig Hahn

Mr. Kenneth Handwerger

Ms. Sandra Hassenplug

Dr. Jessica Hodson

Mr. & Mrs. Michael and Karen Hrabowski Ms. Lauren Hughes Mrs. Brittany Hutchens Mr. Lloyd Hutchins Mr. Steven Israel Mr. Ryan Kele Kim S. Storey & Douglas I. Katz Fund Ms. Hendrika Vande Kemp Mr. & Mrs. John and Barbara Klang Ms. Julie Krupa Mr. Tom Kurosaki Ms. Judi Lachenmyer Mr. Jihoon Lee Mr. Craig Leres Mr. Eduardo Lopez

Ms. Pamela Lotre Ms. Cynthia Lunt Jaye Lyn Ms. Mary Lou Mallinson Dr. Brent Masel Mr. Joseph Matuscak

Mr. David McGlone Ms. Kate McIlhenny

Dr. Michelle Mead Mr. William Meier

Mr. Carlos Moreno

Ms. Jennifer Morris

Ms. Tamara Moser MSU Rodeo Club

Dr. Drew Nagele Naomi Chapter #25 OES

Mr. & Mrs. James and Martha Nield

Mr. & Mrs. Herbert and Donna Nurick

Ms. Elizabeth Olson

Pennsylvania State Employees Campaign Mr. & Mrs. Robert and Martha Page

Ms. Karen Park

Kamish Patel

Mr. Brian Pengra

Mr. Nathan Penner

Ms. Natasha Perkins

Mr. Joseph Radford Jr.

Ms. Elizabeth Ramsey

Mr. Kenny Ray

Rehabilitation Psychology, Inc.

Mr. & Mrs. Dennie and Lois Rewis

Mr. & Mrs. John and Carol Richards

Ms. Brenda Rohena

Ms. Elizabeth Rouse

Mr. & Mrs. Allen and Ellen Rubin

Dr. Debra Russell

Mr. David Scherr

Mr. & Mrs. Paul and Judith Schwartz Ms. Ann Sexton

Mrs. Jackie Shaw

Mr. Ira Sherman & Ms. Maryjo Meier

Ms. Sofia Skavdahl

Ms. Christy Smith

Ms. Barbara Snelling

Ms. Katherine Soverel

Ms. Janis Spivack Ms. Sandra Sussman

Ms. Karen Swan

Ms. Erika Swyler

Mr. & Mrs. John and Maureen Szostak

Dr. & Mrs. Thomas and Andrea Tatlock

Mr. & Mrs. Allen and Ann Siegrist Taylor

Ms. Jessica Ticzon

Mr. Philip Vanaria

Ms. Vieve Veith

Mr. & Mrs. Mike and Linda Verzal

Ms. Angela Weisskopf

Mr. & Mrs. David and Cindy Whitehouse

Dr. John Whyte

Mr. Gary Wildman

Ms. Hallee Winnie

Mr. & Mrs. Benji and Gwen Wolken

Mr. Steven Yuhas

Mr. H. J. Zoffer THANK YOU!

### **Make a Lasting Impact**



As you think about the difference we make in the lives of the people we serve, please consider making a planned gift to BIAA.

You will join a special group of people who want to ensure that the quality education, advocacy, and awareness programming we provide lives on.

Your planned gift will have meaning and impact for generations to come. If you have already named BIAA in your will or other estate plans, please contact Stephanie Cohen at 703-761-0750 or via email at scohen@biausa.org.

Visit biausa.org/support to learn more.



Each year, the Brain Injury Association of America (BIAA) releases legislative issue briefs detailing the critical public policy issues of importance to individuals with brain injury. Advocates are encouraged to use these issue briefs when working with national, state, and local government officials to educate them on topics ranging from access to care, research, TBI Act appropriations, and information about the Congressional Brain Injury Task Force. Keep reading for the content from this year's issue briefs or download them as individual handouts on our website at biausa.org/2020briefs.

#### BOLSTÉR RESEARCH FOR TRAUMATIC BRAIN INJURY

#### FULLY FUND THE TBI MODEL SYSTEMS OF CARE

The TBI Model Systems are a collection of 16 research centers located across the United States that conduct disability and rehabilitation research under grants administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) of the Administration for Community Living. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury across the lifespan. They are a key source of evidence-based medicine and serve as a "proving ground" for future researchers. TBI Model Systems sites work closely with the Department of Veterans Affairs on research to improve the treatment of Veterans with brain injuries.

- Increase funding in FY2021 for NIDILRR's TBI Model Systems of Care program so as to add one new Collaborative Research Project.
- Over the next five years, the Congressional Brain Injury Task Force requests increased funding by \$15 million to expand the TBI Model Systems program:
  - Increase the number of multicenter TBI Model
     Systems Collaborative Research projects from one to three, each with an annual budget of \$1 million;

- ► Increase the number of competitively funded centers from 16 to 18 while increasing the per-center support by \$200,000; and
- Increase funding for the National Data and Statistical Center by \$100,000 annually to allow all participants to be followed over their lifetime.
- Provide "line-item" status to the TBI Model Systems within the broader NIDILRR budget.

## INCREASE ACCESS TO CARE FOR INDIVIDUALS WITH BRAIN INJURY

#### ENSURE PATIENT-CENTERED ACCESS TO REHABILITATION

Individuals with brain injury rely on Medicare and Medicaid to access the rehabilitative services and devices needed to regain health, function, and independence. When an individual sustains a brain injury, emergency medical treatment and hospital-based acute surgical care is only the first step in recovery. Post-acute medical rehabilitation of sufficient scope, duration, and intensity delivered in inpatient rehabilitation facilities (IRFs), residential or transitional treatment programs, and community-based outpatient clinics is vital.

Patients often face barriers to access to rehabilitative services and devices due to coverage restrictions.



954-767-6500 Fort Lauderdale 888-459-0529 Toll Free

#### WWW.MONTEROLAW.COM

## MONTERO Law Center

More Than 30 Years Serving Brain Injury Survivors

#### ACCIDENTS

Construction • Auto • Maritime Aviation • Railroad • Slips & Falls

INADEQUATE SECURITY WORKERS COMPENSATION IMMIGRATION CRIMINAL DEFENSE

Many private insurers place limits on services or steer patients away from the most appropriate settings of care to cut costs. If trends continue, some Medicare beneficiaries will find it harder to access rehabilitation. The Medicare Payment Advisory Commission (MedPAC) reports Medicare Advantage participants have one-third the access to IRFs compared to traditional Medicare beneficiaries. Utilization management tools like prior authorization, restrictive or proprietary admission guidelines, and onerous regulatory requirements significantly limit access to care for individuals with brain injury. Key steps to increase access to care include the following:

- Ensure that efforts to unify Medicare's Post-Acute Care payment system do not negatively impact access for people with brain injury and other complex conditions.
- Oppose efforts to restrict access to rehabilitation therapy services in all settings of care.
- Revise the "three-hour rule" to expand access to all appropriate skilled therapies (Access to Inpatient Rehabilitation Therapy Act)

- Reform the use of prior authorization in Medicare Advantage (Improving Seniors' Timely Access to Care Act), and reject the use of prior authorization for IRF care in traditional Medicare.
- Reform managed care plans in Medicare, Medicaid, and private insurance to ensure appropriate access to rehabilitation and habilitation services and devices.
- Maintain rehabilitation's status as the standard of care for people with brain injury to achieve maximum recovery, full function, return to work and other life roles, and independent living.

#### **IMPROVE AWARENESS AND UNDERSTANDING OF BRAIN INJURY**

#### TAKE A STAND TO PROTECT STUDENT ATHLETES FROM CONCUSSION

The CDC estimates as many as 3.8 million concussions related to sports and recreation occur each year. A concussion is a mild traumatic brain injury (mTBI). Middle and high school students sustain mTBIs while

(continued on page 22)

participating in athletics, but many schools do not have the resources to adequately diagnose and treat these injuries. Too often, student athletes return to the field before their brains heal. A repeat concussion can slow recovery and increase the likelihood of having long-term challenges. Repeat concussions can result in second impact syndrome, which can lead to permanent brain damage and even death.

In addition to funding important work at the CDC and introducing legislation to protect student athletes, Congress should:

- Support the Concussion Awareness and Education Act sponsored by Rep. Joyce Beatty (D-Ohio) to implement recommendations of the Institute of Medicine in its report, "Sports-Related Concussions in Youth: Improving the Science, Changing the Culture."
- Appropriate \$5 million for the CDC to take to scale the National Concussion Surveillance System, which would provide nationally representative incidence estimates of all TBI, sports- and recreation-related TBI, and TBIrelated disability as well as the ability to monitor trends over time, including at the state level. Authorization for funding was included in the Reauthorization of the Traumatic Brain Injury Act of 2018.

#### **COORDINATE FEDERAL RESOURCES**

#### SUPPORT FEDERAL TBI PROGRAMS

The Department of Health and Human Services (HHS) Administration for Community Living (ACL) funds programs impacting individuals with brain injury and families, including Aging and Disability Resource Centers; Assistive Technology; Federal TBI Program; Independent Living Centers; Lifespan Respite Care; and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

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

#### INCREASE TBI ACT FUNDING

In October 2015, the TBI State Grant program was transferred to the ACL Administration on Disabilities' Independent Living Administration, and the Protection & Advocacy (P&A) Grant Program was moved to the ACL Administration on Intellectual and Developmental

Disabilities. Currently only 24 states receive TBI State grants, and all the P&A grants are severely under-funded.

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

#### **FUND CDC TBI PROGRAM**

The TBI Act of 1996, as amended, authorizes funding for the CDC for data collection, prevention, public education, and research.

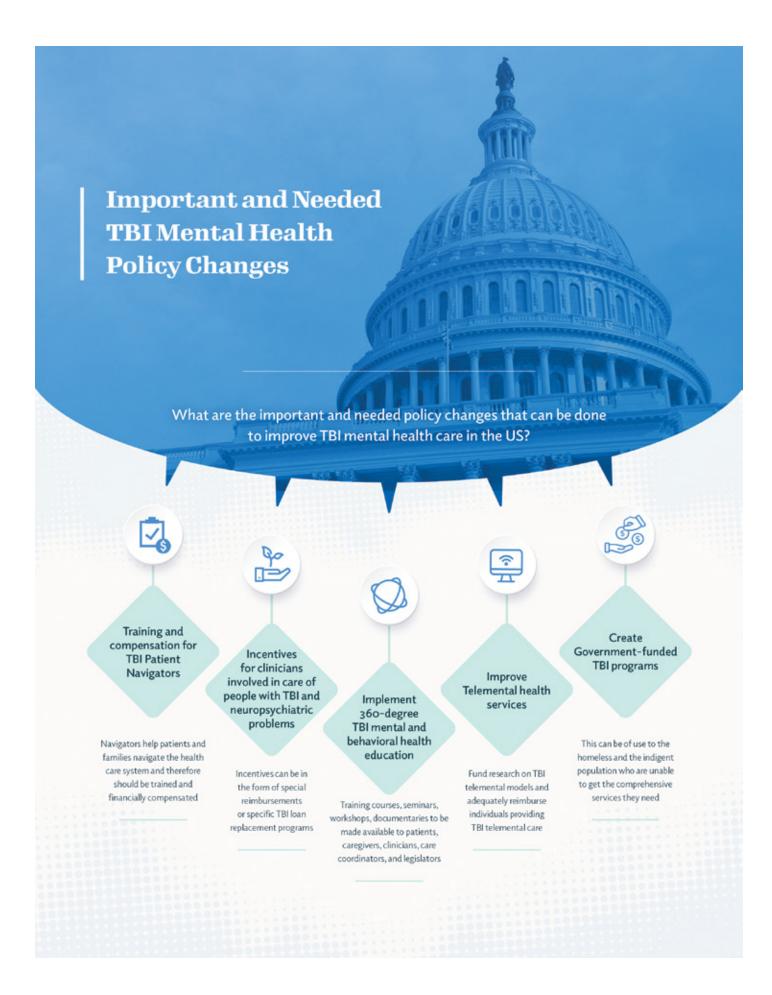
- Support CDC in its mandate to review the scientific evidence related to brain injury management in children and identify opportunities for research;
- Support TBI national surveillance; and
- Appropriate \$10 million to fund CDC's TBI programs.

#### SUPPORT BRAIN INJURY EDUCATION **FOR FIRST RESPONDERS**

#### TRAIN FIRST RESPONDERS ON TBI AND PTSD

First responders should be trained on TBI, acquired brain injury (ABI), and post-traumatic stress disorder (PTSD). Individuals with TBI, ABI, or PTSD may have symptoms from their injuries that make it difficult for them to understand and follow directions or communicate clearly with first responders.

- Support the Traumatic Brain Injury and Post-Traumatic Stress Disorder Law Enforcement Training Act sponsored by Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.), which would direct the Attorney General to develop crisis intervention training tools for use by law enforcement officers and first responders related to interacting with persons with TBI, ABI, PTSD.
- Require that the training be made available as part of the Police Mental Health Collaboration Toolkit, which is a no-cost online training tool that provides resources for law enforcement agencies partnering with mental health providers to effectively respond to calls for service, improve outcomes for people with mental illness, and advance public safety.
- 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.



## BIAA WELCOMES NEW OFFICERS AND DIRECTORS

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

BIAA's board of directors elected a new slate of officers and four new directors as volunteer leaders at the national level.



HAROLD GINSBURG is the new chairman of the board. He is the managing principal of Southern Asset Service Corporation, a real estate consulting and brokerage firm specializing in corporate real estate based in Dallas, Texas. Harold has more than

30 years of experience in the commercial real estate industry. He serves as a director of Pegasus Bank of Dallas and has previously served on the boards of directors of Lone Star Bank, Reunion Bancshares, Inc., Allied Bank of Dallas, American Bank of Denison, American Bank of Sherman, and North America Bank Shares. He holds a bachelor's degree from the University of Texas at Austin. He is the husband of a person with a traumatic brain injury.



MAUREEN CUNNINGHAM, CFRE, is the new secretary of the board. She is employed as the executive director of the Brain Injury Association of Missouri. Her 23 years of non-profit experience with health and social service organizations includes

the Alzheimer's Association, Easter Seals, Lutheran Ministries, Catholic Charities, and Talking Tapes/ Textbooks on Tape. She is knowledgeable in the areas of fundraising, program implementation, administration, financial management, public relations, public education, and volunteer management.



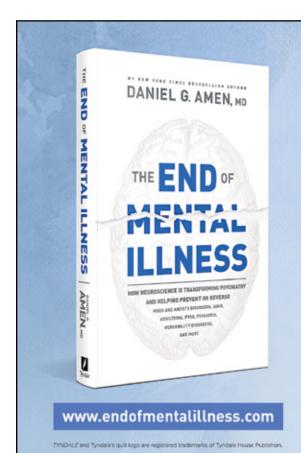
SHANA DE CARO, J.D., is vice chairperson of the board. She is a partner in the New York personal injury law firm of De Caro and Kaplen, LLP. She is a graduate of The George Washington University and Benjamin Cardozo School of Law. Shana is past Chair of the

Traumatic Brain Injury Litigation Group of the American Association for Justice and is the Secretary and a Trustee of the Civil Justice Foundation board of trustees. She is a Fellow of the Litigation Counsel of America, Trial Lawyer Honorary Society, and the Melvin Belli Society. She is an advisory board member to the Acquired Brain Injury Program at The George Washington University and serves on the board of the New York State Academy of Trial Lawyers. She has published in numerous professional journals and is a sought-after speaker at professional conferences. She has been named one of the top 100 trial lawyers in New York and was elected an Elite Lawyer.



KENT HAYDEN is BIAA's new treasurer. He joined Pate Rehabilitation in 1991 and has served as president and chief executive officer since 2002. He is responsible for day-to-day administration of the company, overseeing multiple facilities in the

Dallas/Fort Worth area. Prior to joining Pate, Kent worked as a liability insurance adjuster for seven years, gaining valuable finance experience. He earned a bachelor's degree in Business Administration from Texas State University – San Marcos in 1986. Kent is a strong advocate for brain injury rehabilitation at both the state and national level. In 2016, he was elected as Chairman of the BIAA Business and Professional Council.



#### The end of mental illness begins with A REVOLUTION IN BRAIN HEALTH

The stigma of "mental illness" prevents many from getting the help they need. But there is new hope for those dealing with anxiety, depression, ADHD, and other so-called mental illnesses.

Based on his brain-imaging work, Dr. Daniel Amen has learned that most psychiatric illnesses are not mental health issues at all. Rather, they are brain health issues that steal your mind. This one idea changes everything: Get your brain right and your mind will follow.

Learn how to improve the health of your brain, minimizing or reversing conditions that may be preventing you from living a full and emotionally healthy life.





DAVID HARRINGTON, MBA, **OTR/L, CBIST**, is a new director. He has worked in the field of post-acute brain injury rehabilitation since 1993 with positions including therapist. clinical case manager, quality manager, and director of operations. He is currently

the president and chief operating officer at Centre for Neuro Skills. David studied Occupational Therapy at San Jose State University prior to obtaining his master's degree in Business Administration at California State University in Bakersfield. He is also a Certified Brain Injury Specialist and Trainer (CBIST), to augment his current role in neurological rehabilitation and to provide opportunities to educate others about the complexities of acquired brain injury. David is an adjunct instructor at the School of Business at California State University Bakersfield where he teaches operations management, business ethics, business data analysis, organizational behavior, and diversity management. His professional interests include heightening awareness of acquired brain injury, improving the efficacy and quality of brain injury rehabilitation, and facilitating better business practice in health care.



**ELEANOR PERFETTO, PH.D.,** 

**M.S.**, another new director, is executive vice president of the National Health Council (NHC), a united voice for the more than 160 million people in the U.S. with chronic diseases and disabilities and their family caregivers.

Eleanor holds a part-time faculty appointment at the University of Maryland School of Pharmacy. Her research and policy work focus on patient engagement in health care. She was previously employed in government affairs by Pfizer Inc. She formerly served as a member of the CMS MedPAC, an expert panelist for National Quality Forum, a member of the Health Industry Council Board of Advisors, and as past president and board member for the Drug Information Association Board. Eleanor holds bachelor's and master's degrees in pharmacy from the University of Rhode Island, and a doctorate from the University of North Carolina at Chapel Hill School of Public Health. She served in the U.S. Public Health Service at the Agency for Health Care Policy & Research and began her government career in the Indian Health Service. She has contributed book chapters, authored

(continued on page 30)



## STATE AFFILIATE NEWS

#### **GEORGIA**

The Brain Injury Association of Georgia (BIAG) had a full 2019 with support from our community statewide. The Association's annual casino night brought many BIAG community members who helped raise funds for the camp and other activities. Augusta and Savannah support groups held Walk for Brain Injury events, donating proceeds to BIAG. Two organizations honored BIAG as their designated charity last year: Restore Health Group, specializing in neurobehavioral treatment and supported living services, and Atlanta Whipz of Atlanta, a club that hosted a family and community car show. Thank you for believing in our mission to provide hope, help, and support to Georgians!

BIAG welcomed 2020 with new branding on Brain Injury Georgia (BIG) events: Think BIG: Conferences, Dream BIG: Walk, Roll, Run, Bet BIG: Casino Night, and Live BIG: Camp BIAG. BIAG also welcomed new Board Chair Bamidele Adeyemo, M.D., WellStar Atlanta Medical Center, and Board Secretary Marti Hanson, MSP, CCC, SLP, CBIS, NeuroRestorative. Jane Jackson, BIAG's director, successfully completed the Person Centered and Option Counseling certification. This certification supports our efforts as partners of the Georgia Aging and Disability Resource Center and Brain and Spinal Injury Trust Fund and allows us perform as designated service providers for individuals with brain injury statewide. For more information about BIAG, visit braininjurygeorgia.org.



BIAG Director Jane Jackson (middle) and BIAG Board Chair Bamidele Adeyemo, M.D., attend Bet BIG.



Atlanta Whipz car show attendees pose with their trophies.



Emily Poole, Restore Health Group, with BIAG Director Jane Jackson.

#### **KANSAS**

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS-GKC) was honored to sponsor an advocacy day at the Kansas State Capitol in Topeka Feb. 5. Kansas legislators received a piece of pie and learned about brain injury and legislative issues that impact survivors and their families.

Later in February, BIAKS-GKC held a family-friendly fundraising golf event at Topgolf. The event featured three hours of golf play, competitive games, raffles, and a lunch buffet. Novice and experienced golfers enjoyed the afternoon, and a golf pro was on hand to offer suggestions.

#### **MAINE**

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its fifth Bowling for Brain Injury<sup>SM</sup> event Dec. 1 at Spare Time Portland. More than 100 bowlers participated, and the event raised \$10,000 to support BIAA-ME programming. The Chapter also published the fourth edition of the Maine Brain Injury and Stroke Resource Directory in both print and online format and is in the process of distributing the directory across the state.

During Brain Injury Awareness Month, BIAA-ME will hold its fifth annual BIAA-ME Brain Injury Resource Fair in Augusta March 2. The event will feature exhibitors from across the state representing services, resources, and opportunities for Maine brain injury survivors, family members, caregivers, and professionals.



The RiverRidge Unbowlievables team celebrates being the top fundraiser with nearly \$900 in donations at the fifth annual Bowling for Brain Injury<sup>SM</sup>!

#### **KENTUCKY**

The Brain Injury Association of America – Kentucky Chapter (BIAA-KY) is proud to be the newest chapter of an organization whose mission it is to advance awareness, research, treatment, education and to improve the quality of life for all people affected by brain injury. Diane Gutierrez leads the BIAA-KY team with her extensive clinical experience and passion for advocacy. BIAA-KY was busy in 2019, welcoming new advisory board members, forming committee teams, and planning community outreach events. Additionally, BIAA-KY has been focused on moving forward with TJ's Bill, which would require children under 12 years old to wear bicycle helmets. We welcome you to follow our new chapter as we develop this organization. The entire BIAA-KY team looks forward to growing strong together in the years to come!

#### **MASSACHUSETTS**

Over the last 30 years, the Brain Injury Association of Massachusetts (BIA-MA) has worked tirelessly within state legislators' offices to advocate for brain injury services as well as raise awareness of general safety concerns for citizens of the Commonwealth. This fall marked a huge win for the state of Massachusetts: Gov. Charlie Baker signed the anti-distracted driving bill Nov. 15 after 15 years of advocacy! Massachusetts became the last state in New England, and 16th in the country, to require hands-free devices behind the wheel. We are certain this law will save lives and applaud the efforts of everyone involved.

Additionally, in recent months BIA-MA has partnered with the Massachusetts Rehabilitation Commission and New Start Brain Injury Community Center, a Worcester County-based brain injury clubhouse program, on a three-year grant from the Administration for Community Living. The grant provides an opportunity to build connections between providers in both brain injury and substance use disorders (SUD) to address the needs of individuals managing sobriety and brain injury as they are discharged from SUD programs and entering brain injury service programs. Grant partners hosted an eight-day training for 40 agency staff on the intersection between the two conditions. We very much look forward to improving awareness, education, and support for individuals living with co-occurring brain injury and SUD.

(continued on page 28)

#### **MICHIGAN**

The Brain Injury Association of Michigan (BIAMI) launched Think aHEAD, a yearlong statewide campaign encouraging children and teens to wear helmets while participating in recreational sports in which helmet use is not regulated. The aim of the Think aHEAD campaign is to increase helmet usage, prevent brain injuries, and save lives. The initiative will work to break down the misguided perception that it is "not cool" to wear a helmet while participating in recreational activities in which helmet use is elective, such as skiing, snowboarding, biking, roller skating, horseback riding, and skateboarding.



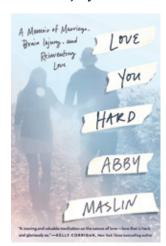
To kick off the campaign, BIAMI is partnering with 34 ski resorts across the state to incentivize children of all ages to wear helmets while skiing or snowboarding. Those spotted wearing helmets by ski patrol at the participating resorts are rewarded with a coupon for a free hot chocolate. Those without helmets will be given a coupon for a 20% discount on a ski or snowboarding helmet at one of more than 25 participating retailers located across the state. During warmer seasons, BIAMI will enlist police officers, firefighters, and others from across the state to award those wearing helmets during warm-weather recreational sports such as bicycling, skateboarding, roller skating, and rollerblading.

#### **NEW HAMPSHIRE**

The first six months of the year can be a busy but productive time for the Brain Injury Association of New Hampshire (BIANH)! The state legislature is now in session, and we're working to amend the state concussion law to strengthen the focus on returning to the classroom after concussion. Case Management services continue to expand throughout the state; BIANH has added three more independent service coordinators to its staff to help oversee Choices for Independence (CFI), Acquired Brain Disorder (ABD) and Developmental Disabilities (DD) services to residents in the state.

The Vertical Challenge winter event was held in January at the pristine Bretton Woods Resort in the White Mountains of New Hampshire. The event was a great success with funds raised going toward supporting veterans. In May, the 37th annual Brain Injury and

Stroke Conference will be held at the Grappone Conference Center in Concord. Abby Maslin, author of "Love You Hard: A Memoir of Marriage, Brain Injury and Reinventing Love," will be the keynote speaker. Shortly after the conference, BIANH will enjoy its 34th annual Walkby-the-Sea & Picnic at the Hampton Beach State Park June 7. For more information, visit bianh.org.



#### **MISSOURI**

The Brain Injury Association of Missouri (BIA-MO) hosted its annual Sports Concussions: Facts, Fallacies, and New Frontiers educational programs from Feb. 6 through Feb. 20 across Missouri. Youth sports and school personnel attended presentations to learn about concussion facts and fallacies, school support for students with concussion, and how to identify concussion care for youth. These programs were presented by local and national concussion experts.

BIA-MO held its annual Survivor and Family Seminars in Springfield and Kansas City in March and April of last year. Survivors and family members discussed

suggestions on how to adjust to life with brain injury and shared personal stories to support each other. Seminar attendees participated in sessions about understanding types of brain injury specialists, making and keeping relationships, navigating the workforce, and assistive technology. The same seminar topics will be offered in St. Louis in October.

Survivors of brain injury will enjoy a week of fun, independence, and adventure at the BIA-MO Donald Danforth Jr. Wilderness Camp, which will be held June 21-26. For more information, visit biamo.org.

#### **VERMONT**

The Brain Injury Association of Vermont (BIAVT) is currently working on new programs, offering public offsite or private on-site trainings as well as webinars and even an online support group! BIAVT has been hard at work updating its new website and offering a searchable resource database for anyone looking for services provided by professionals in the state of Vermont.



#### -FOR-**BRAIN INJURY**

Plans have begun for the 18th annual Walk and Roll for Brain Injury, taking place in Montpelier May 9. Lastly, we're looking for feedback and committee members for various projects and advisory boards. For more information on all these exciting events, visit biavt.org or email support@biavt.org.

#### **VIRGINIA**

The Brain Injury Association of Virginia (BIAV) had a busy yet exciting end to 2019. BIAV kicked off the quarter with its very first young professional meetup where locals who work in brain injury professions came together to network, have a few drinks, and enjoy each other's company. Our Annual Caregiver Forum and Making Headway Conference happened just before Thanksgiving and hosted persons with brain injury, caregivers, and professionals for a weekend focusing on Assistive Technology. Immediately following the conference, we launched our first Giving Tuesday social media campaign and raised a record-breaking \$4,000!

Amongst the event and campaign madness, we also welcomed a new staff member who now manages our development and operations programs. As the year came to a close, our staff gathered for a holiday celebration and to say a bittersweet goodbye to one of our employees of 25 years, who is now embarking on a new chapter: retirement! As we reflect on all the challenges, successes, and memories we have from 2019, we are so grateful to all who have shown their support for BIAV. For more information about our upcoming events and programs, visit biav.net.



#### **BIAA WELCOMES NEW OFFICERS AND DIRECTORS**

journal articles, and served as a peer reviewer. She has also presented at many national and international conferences and scientific meetings. As a caregiver for a spouse who suffered from dementia due to chronic traumatic encephalopathy, she is a recognized advocate for people with head-trauma-related dementia and their families by the Alzheimer's Association New York City Chapter and the Concussion Legacy Foundation.



NICOLE M. GODAIRE, CBIS, is a new director on the BIAA board. She is employed as chief executive officer of the Brain Injury Association of Massachusetts (BIA-MA) and has been with BIA-MA since 2005. Nicole's passion is advocating for the brain injury

community and improving access to more programs and services for individuals with brain injury and caregivers in the Commonwealth of Massachusetts, Nicole's relationships within the provider community have made it possible for BIA-MA to increase brain injury awareness and close gaps in services across the state.



**PAGE MELTON IVIE.** the final new director, is owner and manager of The Source Group LLC, a firm specializing in research, government affairs and corporate intelligence. A former director of public affairs for the National **Governors Association** 

and press secretary to Maryland Gov. William Donald Schaefer and Virginia Lt. Gov. Donald S. Beyer Jr., Page started her career as a reporter and editor for United Press International in Virginia and Maryland. She commits her spare time to advocating for, and raising money for, nonprofits that matter to her family. She is active in advocating for supports and services in the brain injury community. Page is a former gubernatorial appointee to the Commonwealth Neurotrauma Initiative Advisory Board in Virginia. She is a graduate of the University of Virginia.

#### **UPCOMING WEBINARS**

#### Mitchell Rosenthal Memorial Research Webinar -**Functional Outcome Trajectories Following Inpatient Rehabilitation for TBI**

March 25, 2020, 3 p.m. ET/12 p.m. PT Kristen Dams-O'Connor, Ph.D., Icahn School of Medicine at Mount Sinai

#### **Business of Brain Injury Webinar – Contracting and Payor Relations**

April 2, 2020, 3 p.m. ET/12 p.m. PT Ken Diashyn, Centre for Neuro Skills, and Corey Morrison, MBA, On With Life

#### **David Strauss Memorial Clinical Lecture – Recreation Therapy Following Brain Injury**

April 16, 2020, 2019, 3 p.m. ET/12 p.m. PT Marlene Rivera, CTRS, CBIS, ReMed

#### Mitchell Rosenthal Memorial Research Webinar -**Symptom Attribution in Service Members with** mTBI and PTSD

May 13, 2020, 3 p.m. ET/12 p.m. PT Douglas Cooper, Ph.D., ABPP-CN, and Capt. Morgan Hardy, M.D., MPH

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

#### **ADVERTISER INDEX**

Advertiser and Website	Page
Beechwood Rehabilitation Services BeechwoodNeuroRehab.org	6
Hope Network Neuro Rehabilitationhopenetworkrehab.org	11
The Lighthouse Neurological Rehabilitation Center lighthouserehab.com	13
Montero Law Centermonterolaw.com	21
NYUhttps://bit.ly/37LPH9X	8
Rainbow Rehabilitation Centersrainbowrehab.com	31
Special Treespecialtree.com	29
Tyndale Publishersendofmentalillness.com	25



## Brain and Spinal Cord Injury Rehabilitation Programs for People of all Ages







## There's no better place to heal!

With multiple residential programs, five treatment centers, a NeuroRehab Campus® and three vocational centers, Rainbow Rehabilitation Centers offers services that span nearly every aspect of brain injury rehabilitation and spinal cord injury rehabilitation. From hospital discharge to community re-entry, Rainbow Rehabilitation Centers has programs to treat each client with optimal care at every stage of their rehabilitation. There's no better place to heal!







To schedule a tour or to speak with an Admissions team member, call 800.968.6644















1608 Spring Hill Rd., Suite 110 Vienna, VA 22182



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.













