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THE CHALLENGE!

NAVIGATING THE SYSTEM

BRAIN INJURY ASSOCIATION OF AMERICA

JUNE 2019

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.

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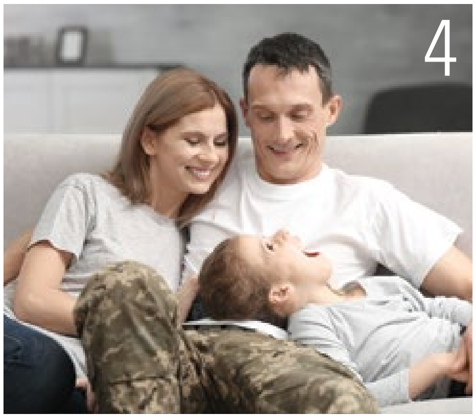
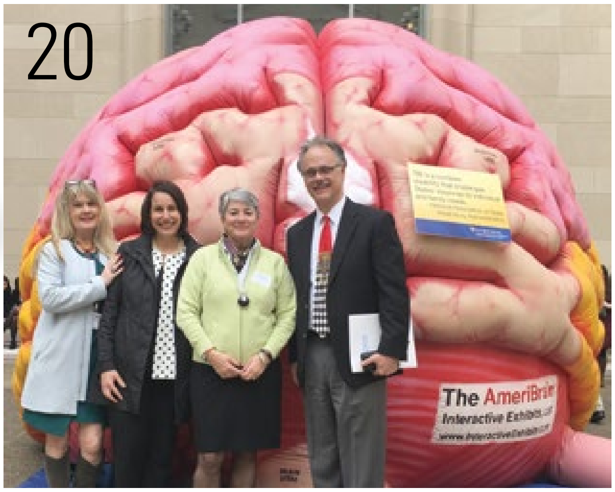




FROM MY **DESK**

Readers of *THE Challenge!* know the consequences of brain injury, the need for a broad array of healthcare and disability services, and the anger and frustration individuals and family members experience while trying to navigate various federal programs and state agencies. Obtaining needed services can be stressful and anxiety-provoking. The effort can leave you feeling a lack of control and lowered self-esteem. Fortunately, the Brain Injury Association of America's National Brain Injury Information Center and the information, resource facilitation, and case management services offered by our chartered state affiliates can help.

In addition to our wonderful state affiliate leaders and staff, there are two other groups of people who work hard to meet the needs of individuals with brain injury and their families. We call them "advocrats" because they work inside state and federal bureaucracies to bring about change.

The National Association of State Head Injury Administrators (NASHIA) is made up of professionals who are responsible for administering state government brain injury policies, funding, and services. This includes programs like Medicaid, aging and disability services, special education, vocational rehabilitation, behavioral health, injury and violence prevention, and long-term services and supports. NASHIA is celebrating its 30th anniversary this September in Kansas City, Missouri, where the organization was founded by Susan Vaughn and other advocrats.

Many federal employees of the Centers for Disease Control and Prevention, National Institutes for Health, and Administration for Community Living (ACL) are also advocrats. As Challenge readers know, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) administers the TBI Model Systems research program. A. Cate Miller, Ph.D., like her predecessor Ruth Brannon, Ph.D., has dedicated years to advancing health and function research in the brain injury field. At Awareness Day on Capitol Hill in March, Dr. Miller delivered a fantastic explanation of the ways NIDILRR has added to the body of knowledge in brain injury. With permission, we have printed Dr. Miller's speech as the lead article in this issue of *THE Challenge!*

Of course, I am also grateful to the other authors who contributed to this publication on Navigating the System. I hope you will find the articles informative and inspirational. As always, the BIAA staff are pleased to recognize and thank the many generous donors who make all our programs and services possible. If you have not already done so, please consider hosting a Facebook fundraiser, designating BIAA when you shop on Amazon Smile, or simply donate online at biausa.org.

Enjoy your summer!

Susan H Connors

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

P.S. Please be sure to read the News & Notes announcement on page 29. It describes the honorary doctorate degree presented to Mark J. Ashley, Sc.D., from the State University of New York (SUNY) at Geneseo. Dr. Ashley is the chief executive officer of Centre for Neuro Skills and a member of BIAA's board of directors. Congratulations, Mark, on this well-deserved honor!

Each year, the Congressional Brain Injury Task Force selects a theme for the Brain Injury Awareness Day congressional briefing on Capitol Hill. This year's theme was "Living Well with Brain Injury." While all the panelists were wonderful, we reached out to Dr. Cate Miller from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) for a copy of her remarks as they were especially poignant.

– Dianna Fahel, Editor-in-Chief

LIVING WELL WITH BRAIN INJURY:

Remarks made by A. Cate Miller, Ph.D., at Brain Injury Awareness Day on Capitol Hill, March 13, 2019

What does it mean to "live well with brain injury?"

The Rehabilitation Act of 1973 avows that (and I'm sure that some of you can quote this by heart), "disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society." This is what it means to "live well with disability." This is what it means to "live well with TBI." This declaration is the guiding light for the work of the agency I represent – the National Institute on Disability, Independent Living, and Rehabilitation Research or NIDILRR.

What is NIDILRR?

NIDILRR is an office within the Department of Health and Human Services' Administration for Community Living. NIDILRR has been in existence for 40 years, and is the federal government's principal funder of disability and rehabilitation research. NIDILRR funds the Traumatic Brain Injury Model System Centers (TBIMS) program, which includes the largest longitudinal database for TBI in the world. NIDILRR's research programs are aimed at improving outcomes of people with disabilities in three areas: (1) health and function, (2) employment, and the ultimate outcome area, (3) community living and participation.

What is NIDILRR doing to help persons who have experienced brain injury and their families to live well with brain injury?

Let’s look at how NIDILRR Research is making a difference by considering Steve. Steve is a college student who is seriously injured when the car in which he is travelling is struck by another car driven by an intoxicated driver.

HEALTH AND FUNCTION

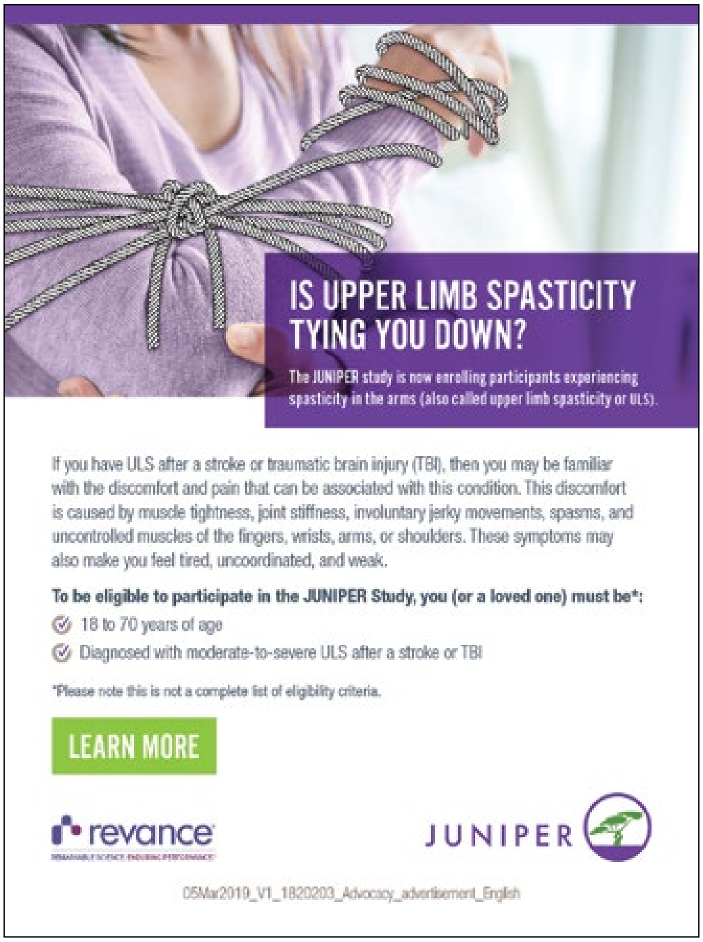
Clinical Guidelines: Steve’s care providers are immeasurably benefiting from clinical practice guidelines widely disseminated to the medical community in 2018. These guidelines for the diagnosis and treatment of severe TBI – disorders of consciousness – were created through a collaboration between the American Academy of Neurology, the American Congress of Rehabilitation Medicine and NIDILRR.[1]

Diagnosis: While still unable to speak for himself, Steve’s level of consciousness is assessed with a state of the art measure developed with NIDILRR funding, the Coma Recovery Scale-Revised.[2]

Early Treatment: During Steve’s inpatient rehabilitation, he receives the medication, Amantadine. NIDILRR-funded research proved that Amantadine speeds recovery of functionally meaningful behaviors such as consistent responses to commands, intelligible speech, and reliable yes-or-no communication.

Measures: As he recovers, Steve’s health care providers use specialized tools to assess his pain, agitation, attention, neurobehavioral functioning, degree of disability, and safety risk. These tools are critical to ensuring Steve’s progress is steady and continuous. The results of some of these tests are used to guide his clinical care, and some will be used to further research because Steve’s family has agreed to participation in TBIMS research. Each of these tools was developed with NIDILRR funding by national leaders in TBI.

Successful Health and Wellness Interventions: As his rehabilitation progresses, Steve has the benefit of receiving treatments proven to be successful through NIDILRR funding. Examples of these successful treatments for co-occurring conditions include interventions to: improve memory, improve survivor resilience and adjustment, improve emotion regulation, decrease chronic irritability and aggression, and decrease substance misuse to name a few. A NIDILRR-funded brief intervention clinical trial proved that for persons with TBI who drank excessively prior to their injury, the intervention cut the rate of return to alcohol use in half when compared to alcohol use education only (32% vs. 63%).[3]



Family/Caregiver Support: As time passes and Steve is discharged to his parents’ home, his parents seek assistance in learning how to cope in the face of ongoing caregiving challenges. Providers encourage them to enroll in a TBIMS proven telehealth intervention that provides individualized education and mentored problem-solving training.

Future Health Concerns and Benefits: When returning to clinic for follow-up care, Steve’s healthcare providers speak with him about a plan for maximizing his health and wellness. They share NIDILRR-funded research showing that 59% of persons who experienced a

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moderate or severe TBI are either obese (23%) or overweight (36%) following acute rehabilitation.[4] It is well known that obesity is associated with poor health outcomes.

Steve's healthcare team is aware of TBIMS research showing that moderate to severe TBI is a chronic health condition. At five years after injury some 26% of adults who receive inpatient rehabilitation in the United States (U.S.), continue to improve; 22% maintain their rehabilitation gains; but the majority (52%) have either declined from the recovery they had attained following the injury (30%) or died (22%).[5] They are aware that the TBIMS and the CDC are calling for the development of a disease management approach to extend lives and improve quality of life, just as is done for persons with diabetes, Alzheimer's Disease, or Multiple Sclerosis, to name a few. It's time to do this for persons with TBI.

EDUCATION AND EMPLOYMENT

As Steve makes progress in his recovery, he wants to explore employment options. Co-funded NIDILRR-CDC research shows that the prevalence of unemployment for individuals with moderate/severe TBI in the U.S. is 60.4 percent at 2-years after injury; and for those who are employed, 35% are employed part-time.[6]

Successful Employment Interventions: Steve learns about an innovative demonstration project funded by NIDILRR, called "Project Career."[7] It is an interprofessional demonstration designed to support the academic and career success of college students who have sustained TBI. The program merges the use of cognitive support technology and vocational rehabilitation practices to improve academic and employment outcomes. Early results show that of 41 students who have graduated from the program to date, 66% are employed full-time, 15% are employed part-time; and 17%, although not employed, are pursuing further education on a full-time basis. Through TBIMS research, Steve also learns about the potential benefit of resource facilitation for promoting access to his state's vocational rehabilitation services.

COMMUNITY LIVING AND PARTICIPATION

Successful Community Participation Interventions: Perhaps what Steve misses most since his injury is being out and about with his family and friends. Steve reads about the improvements in well-being and life satisfaction for those with TBI who take part in a NIDILRR-funded structured volunteer activity program. So as he continues to work toward employment, Steve decides to volunteer as an assistant little league coach. With so much change in their relationship since Steve's injury, Steve and his girlfriend are very appreciative of the opportunity to enroll in the TBIMS Therapeutic Couples Intervention.[8] The program includes educational, skill building and psychological components and is proven to improve the quality of couples' relationships after one partner has experienced a TBI.

Measures: Over time, Steve's care team of clinicians and researchers, use measures developed with NIDILRR funding to track his progress, including measures of community participation.

Important Needs are the focus of New Research: While Steve continues to make improvements in most areas, he still feels as if his independence is limited. For example, his parents and his girlfriend drive for him. NIDILRR is currently funding a multi-site research project to look at "Return to Driving after Moderate-Severe TBI," which will provide valuable information to inform Steve's decisions regarding returning to driving.

KNOWLEDGE TRANSLATION

Throughout his recovery, Steve and his family benefit from the suite of resources that are available through NIDILRR's Model Systems Knowledge Translation Center. In fact, Steve offers some of his time to provide consumer input and to review newly drafted materials. There are numerous evidence-based factsheets and infocomics on issues that survivors have underscored are important to them. For example, Steve will be able to read "TBI and Sleep," "Memory and Moderate to Severe TBI," "Couple's Relationships after TBI," "TBI and Headaches," "Driving after TBI," "Depression after TBI," and "Alcohol Use after TBI," to name a few. The "Alcohol Use after TBI" factsheet was accessed over 77,000 times in 2018 alone and 350,000 times in the last 4 years. Videos addressing some of these topics are also available on the website. Both Steve and the TBI field have come a long way, and there is so much more to do.

Thank you for your support of NIDILRR as we seek to help people live well with TBI!

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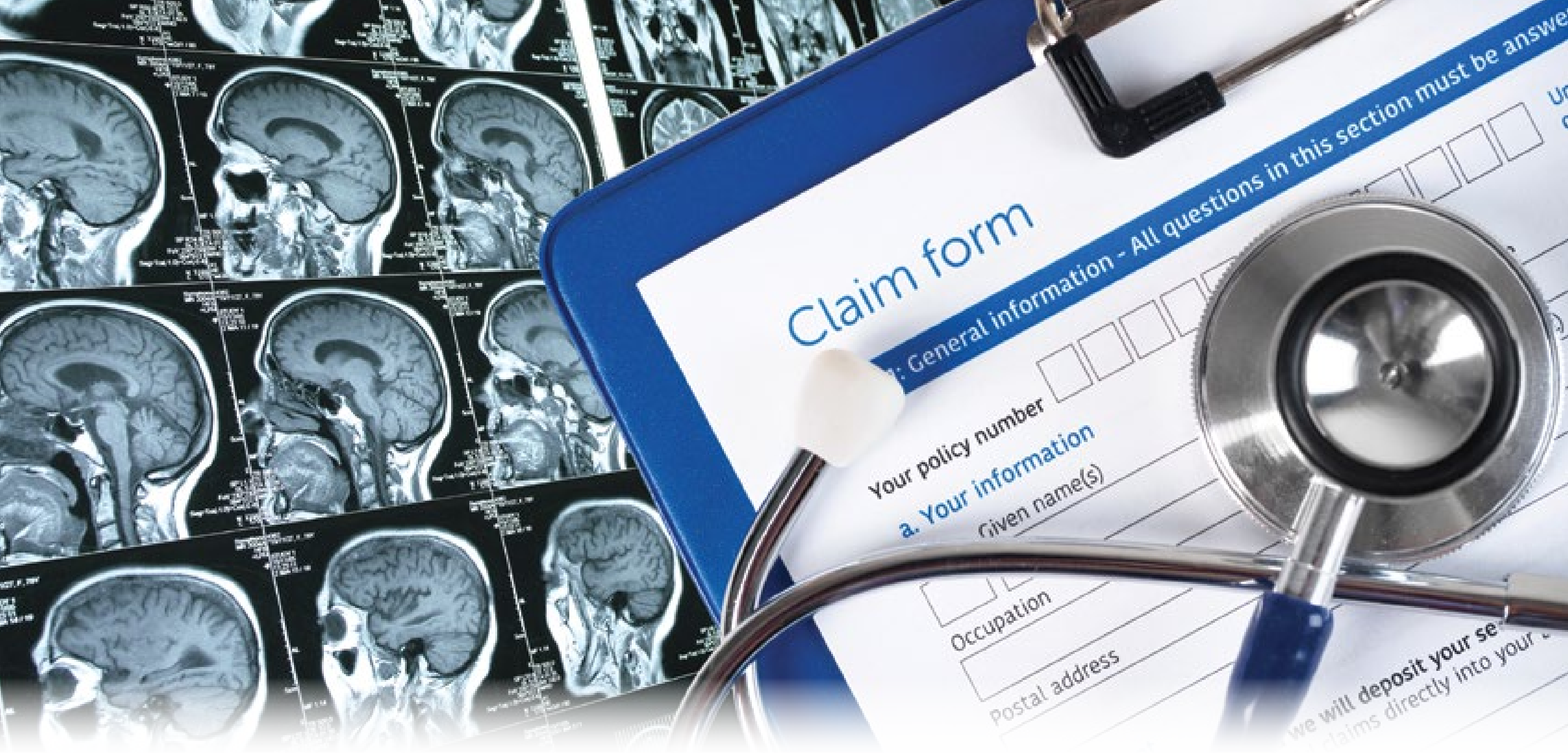

ADVOCATING FOR YOUR LOVED ONE'S HEALTH

By Carrie Mosher, Sales Manager, Brain Injury Association of America

> "Appealing would be a waste of your time." These were the words my brother's neurologist used when my family asked if we should fight the denial of a test he needed. "There is no point in fighting the insurance company," he continued, "you can't win. So don't even bother."

As my mom, dad, brother, and I gathered our things and left the doctor's office, I had a different idea. If my brother could secure the test, there was a chance his health – and his life – would significantly improve. Even if I lost the appeal, and I most likely would, wouldn't it be a worthwhile thing to do? As we drove home that afternoon ten years ago, I said to my family, "We should fight this. That neurologist is wrong. I can't think of a better use of our time."

My brother, Greg, was diagnosed with epilepsy in the first years of his life. He has experienced nearly every type of seizure there is and has been prescribed all types of anti-seizure medication. No medication controlled his seizures completely and many of them came with horrible side effects. In his late teens, Greg was outside on the street hitting baseballs with some friends when a seizure struck without warning. He fell backward and slammed his head onto the pavement, causing him to sustain a severe traumatic brain injury.

Greg had always been a medical mystery. He tried holistic treatments, followed various diets, and traveled to many doctors. None of these resulted in seizure freedom. Unexpectedly, a new opportunity opened up – Greg learned that he might be a candidate for brain surgery. If the area of his brain producing seizures could be located, it might be possible to have it removed. This would put an end to the seizures he had been dealing with for decades.

As you can imagine, before a person has brain surgery, many tests need to be completed. One of them was a Magnetoencephalography (MEG) scan, used to produce a magnetic source image (MSI) to pinpoint the source of seizures. It was one of the last tests he needed, and our family was devastated after hearing of the insurance denial.

I found an ally in Patti Quint, B.S. (R.T.), clinical coordinator at the MEG Lab at Scripps Green Hospital in La Jolla, California, where Greg was to have his scan. Patti gave me the tools to push forward. She mentioned she would help me contact the state of California Department of Insurance requesting an independent medical review (IMR). I needed to submit a letter describing the need and Greg's medical history. Patti would also submit information about the long-term costs of epilepsy versus a successful neurosurgery, the American Academy of Neurology's recent policy, Medicare coverage policies, and relevant medical journal articles.

I began creating a spreadsheet of all combinations of medicines Greg had taken over the past 30 years. Organizing it was overwhelming. My family and I became investigators, searching the internet for any relevant information that could back up our case. Once Patti submitted to the state, we waited. We were told it could take months – and it did. Not surprisingly, the follow up with the state of California was a nightmare. Phone calls went unreturned. When I could get through, I was sent from one person to the next.

Even if no one ever got back to me, I knew the effort was worth my time. My brother is one of my best friends. Just when I had accepted I might never get an answer, my phone rang. Patti was calling to let me know Greg's MEG test had been approved by the state. The insurance would have to pay for it! After doing a celebratory dance in my living room, I picked up the phone again. I called the neurologist and let him know I had appealed to the state and won, making sure to mention that the fight was time very well spent.

Greg's MEG test revealed that he was not a good candidate for brain surgery because his seizures had several points of origin in his brain. Despite this disappointing discovery, I learned a very important lesson – that one can fight the system and prevail, and that the effort to receive better care is always worth it. ●

How to Choose a Lawyer and What to Expect from the Legal Process

By Ira Sherman, Esq., Managing Partner,
Chaikin, Sherman, Cammarata & Siegel, P.C.

Clients with brain injury present a unique constellation of symptoms; no two people are alike. Some may have problems with memory and concentration, some have lost their sense of taste, and some have difficulty with word recall, just to name a few. Wrongdoers and their insurance companies often fail to understand the devastating impact of these injuries. It is essential to hire competent counsel to help persons with brain injury navigate through the claims process and court system. This article discusses how to choose a lawyer and what to expect during the different stages of a case involving brain injury.

Choosing an Attorney

Choose an attorney with experience in brain injury to help you navigate the complex legal system and ensure proper compensation. Experienced attorneys should be brought into the process as soon as possible so they can help deal with insurance companies and gather evidence before it becomes unavailable. Consulting attorney rating services, friends and family, and the Brain Injury Association of America's Preferred Attorneys program will help you find highly qualified attorneys with experience resolving cases involving brain injury.

Once candidates are identified, set up meetings with selected attorneys and a close friend or family member. The close friend or family member should be prepared to take notes as it is common for individuals with brain injury to have difficulty remembering meeting details.

The Early Stages of the Case

A brain injury can be life-altering for a person and his or her family. No one is appropriately prepared for the impact on everyday activities and the strain on relationships that can result from a brain injury. Individuals with brain injury frequently do not recognize changes in concentration, thinking, and mood caused by the injury. Therefore, if you are injured, you

Ten Questions to ask While Meeting with a Lawyer:

1. **What is your prior experience in cases in which your client sustained a brain injury?**
2. **Are you recognized or rated by any lawyer rating services or surveys?**

   Note: Local magazines' "Top Lawyer" surveys, nationally known surveys such as "Superlawyers," and Martindale Hubbell "AV" ratings are some specific rating services and surveys to inquire about.
3. **What prominent positions have you, or other lawyers in the firm who you might be working with, held with national or local brain injury organizations?**
4. **Have you held prominent positions in local bar associations that demonstrate that you are respected in your field?**
5. **Are you and your firm recognized as Preferred Attorneys by the Brain Injury Association of America?**
6. **Are attorneys in your firm Board Certified by any Trial Specialty Boards and will they be working on the case?**
7. **How many lawyers are in the firm, and who will be working with you on your case?**
8. **Are your cases exclusively those that involve a personal injury, and do you exclusively represent the injured parties?**
9. **How does your attorney's fee work?**
10. **Can you explain the retainer agreement to me?**

    Note: Retainer agreements discuss the terms of a lawyer and the client's professional relationship.

should seek medical attention as soon as possible. Not only does this begin the treatment process and the long road to recovery, but it also documents the injury through medical records, which will eventually be available for the insurance company and for a jury, if necessary, to evaluate the nature, extent, and duration of your injury.

Follow-up medical care must also be sought. This can include appointments with physicians such as neurologists, trauma surgeons, neuropsychologists, physiatrists, and other medical professionals such as physical therapists, occupational therapists, and speech language pathologists. Family members may also want to seek the services of social workers and psychologists. The follow-up care is necessary treatment and further documents the nature, extent, and duration of the injury.

What other actions can you take?

- Report the incident to first responders.
- Gather information including contact and driver's license information from all those involved (including witnesses), photographs of the incident scene, the vehicles involved (if any), and any visible injuries.
- Work with law enforcement; make sure to get officers' badge numbers and contact information.
- Create an organization system for medical bills, photographs, and other documents that may be useful to you or your attorney.
- Check your insurance policy to determine the amount of your available insurance coverage.
- Create a journal; a written account of the effects of brain injury can be a great tool to show the impact of an incident on persons with brain injury and their family members.

  Tip: In motor vehicle accidents, you may be required to promptly report the accident to your insurance company, but you should avoid talking to any representative of anyone who caused or contributed to your injury, including representatives of another person's insurance company. An experienced attorney can handle communication with insurance companies on your behalf.

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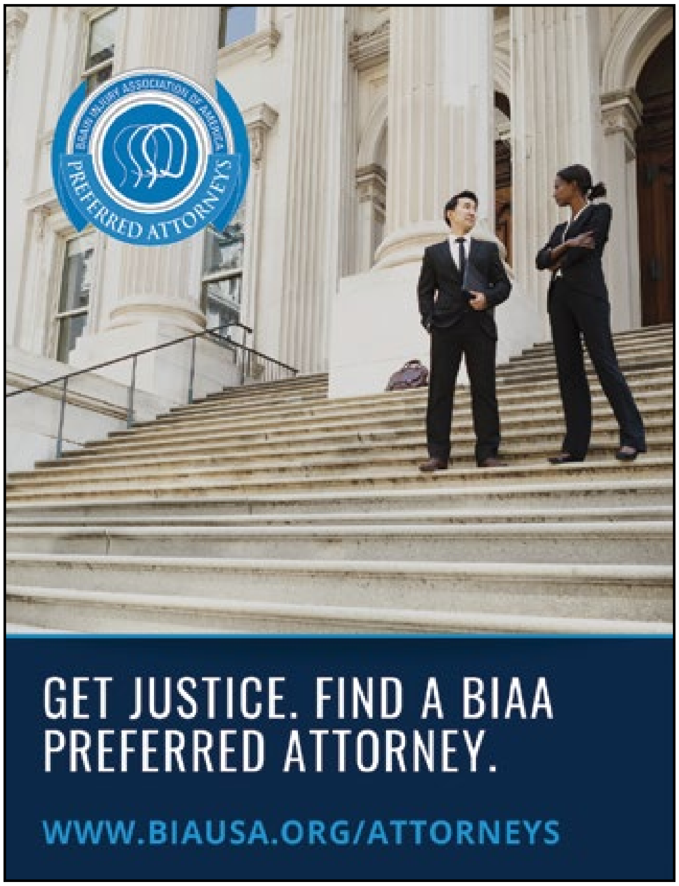
The Lawsuit

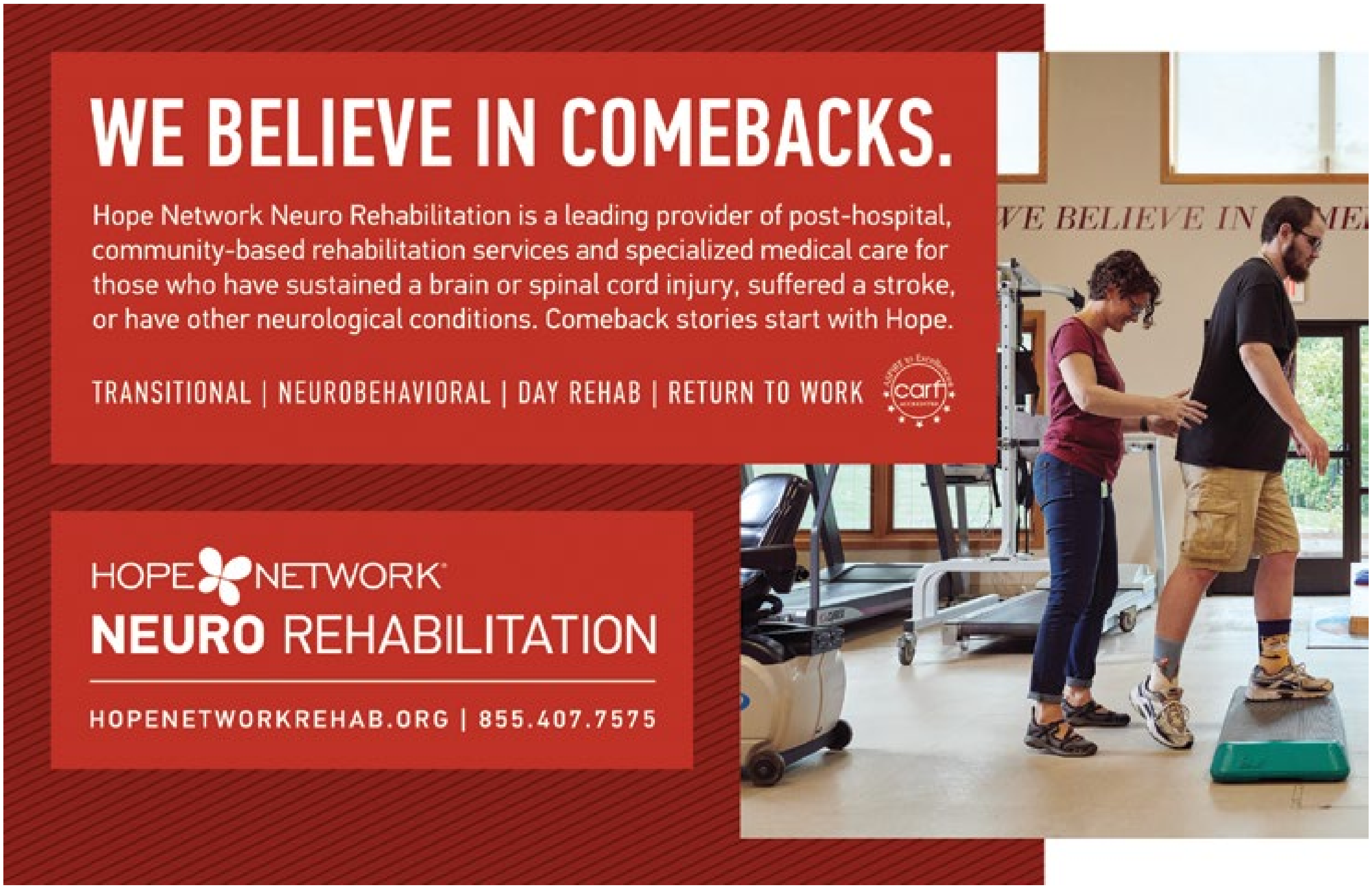
Attorneys attempt to resolve every claim without filing a lawsuit. Because brain injury is often complex and has multi-faceted effects on a person's life, insurance companies lack the ability to properly evaluate the claim. It is often better for clients to go forward with their claims by filing lawsuits because they, their doctors, and their family and friends are often the best at explaining the nature, extent, and duration of the injury.

A lawsuit begins when the victim's attorney files a "complaint" with the court that sets out the allegations against the wrongdoer. The victim is the plaintiff in the court case. The plaintiff's attorney serves the complaint on the alleged wrongdoer, who is the defendant in the court case. The defendant is required to answer the allegations by admitting or denying them and can also assert other defenses. As the plaintiff and the defendant learn more information concerning the facts of the claim, they may engage in settlement negotiations.

The next stage in litigation is the discovery process. Discovery is a process in which the parties in the lawsuit are able to conduct factfinding to better understand the issues and evidence in the case. Discovery can include the following:



- Interrogatories, which are written questions one side asks of the other. Questions concern topics like the circumstances of the incident, the nature of the injuries, past medical issues, and how the plaintiff performed in his or her job and at school, both before and after the incident.
- Requests for the Production of Documents, which ask the other party to provide documents related to the claim. These requests include things like medical records, school records, proof of income (if there is a lost wage claim), and photographs of the scene of the incident.
- Both fact witnesses and expert witnesses are identified. Fact witnesses are people who have personal knowledge of the circumstances of the case. Expert witnesses are people recognized by the court as authorities on specific topics with knowledge beyond that accessible to the average person. Oftentimes, expert witnesses will prepare written reports detailing their expertise and their expert opinions about the facts of the case. Treating physicians are often identified as expert witnesses.
- Depositions, which allow each party to question the other party and potential witnesses who must answer under oath. Depositions afford attorneys an opportunity to analyze the credibility and likability of witnesses.



- In a case where a plaintiff sustained a brain injury, the defendant's lawyer will often request that the plaintiff be examined by a doctor of the defense attorney's choice. The plaintiff may need to appear for the examination.

Settlement or Trial

After the discovery process, it is very likely there will be settlement negotiations. Often the parties will agree to submit the case to mediation, which is a settlement conference where the parties will meet and attempt to resolve their differences. If settlement discussions are not successful, the parties and their lawyers will thoroughly prepare for trial. Choosing an experienced trial lawyer who has a good track record and excellent reputation will provide you with the confidence to say no to an unfair settlement offer and proceed to trial. The legal process can be time-consuming, and it will require effort. It can at times be frustrating, especially for individuals with brain injury. However, hiring the right lawyer is the first and most important step to ensure you will be able to navigate the process successfully.

We hope no one ever needs to hire a personal injury attorney for a brain injury-related claim. Nevertheless, if you have a brain injury, we hope this article provides helpful guidance on what to look for when choosing your lawyer and what to expect as you attempt to resolve your claim.

Ira Sherman is the Managing Partner of Chaikin, Sherman, Cammarata & Siegel, P.C., a Washington, D.C., law firm that is widely recognized as one of the area's leading advocates for individuals who were injured due to the carelessness of others. Mr. Sherman is licensed to practice law in the District of Columbia, Maryland and New York. He is an active member of the American Association for Justice and a member of their Traumatic Brain Injury Litigation Group. He is a former president of the Trial Lawyers' Association of Metropolitan Washington, D.C. and a member of the Board of Directors of the Brain Injury Association of America. Mr. Sherman was included in the list of Washington, D.C. Super Lawyers every year since 2011, was named to the "Top Lawyers" in Washington, DC in the 2018 edition of Washingtonian magazine's "Top Lawyers" list, and has consistently received an "AV Preeminent" rating, the highest possible rating awarded by the Martindale-Hubbell Directory of Attorneys. ●

BIAA Welcomes Congressman Don Bacon as CBITF Co-chair

By Amy Colberg, M.Ed., Director of Government Affairs, Brain Injury Association of America

The Brain Injury Association of America (BIAA) is pleased to welcome Rep. Don Bacon (R-Neb.) as the new co-chair of the Congressional Brain Injury Task Force (CBITF). Rep. Bill Pascrell (D-N.J.) named Congressman Bacon as co-chair in April. The CBITF hosts Brain Injury Awareness Day on Capitol Hill, advocates for increased funding for TBI programs and research, and introduces legislation pertaining to brain injury, including reauthorization of the TBI Act.

Rep. Bacon grew up on a farm in Illinois, earned a bachelor's degree in political science from Northern Illinois University in 1984, and joined the U.S. Air Force one year later. He served nearly 30 years, retiring as a Brigadier General, and earned two masters degrees from the University of Phoenix and the National War College.

During his Air Force career, Rep. Bacon specialized in electronic warfare, intelligence, reconnaissance, and public affairs. He is a highly decorated aviator, having flown most of his career on the EC-130H Compass Call. His career included two assignments as Wing Commander in Germany and Nebraska, Group command in Arizona, Squadron command in Arizona, and Expeditionary Squadron command in Iraq. Rep. Bacon is a combat veteran who has served four deployments in the Middle East, most notably in 2007 and 2008 during Operation IRAQI FREEDOM.

His military decorations include the Air Force Distinguished Service Medal, two Bronze Stars, two Legion of Merit awards, and five Meritorious Service Medals. He was named Europe's top Air Force Wing Commander and was a three-time distinguished graduate of the Air Command and Staff College, Navigator-Electronic Warfare School, and Officer Intelligence School.

Following his retirement from the Air Force in 2014, Rep. Bacon served as the Military Advisor to Rep. Jeff Fortenberry (R-Neb.) and was assistant professor at Bellevue University, teaching Undergraduate Leadership and American Vision and Values. Rep. Bacon was elected to represent Nebraska's Second Congressional District in November 2016. BIAA appreciates Rep. Bacon's leadership in Congress for the 5.3 individuals living with a disability as a result of a brain injury. ●

Raising Awareness One Helmet at a Time

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

For more than 20 years, Gary Chiaverotti has been involved with the brain injury community in a variety of ways: first as a caregiver seeking information, then as a volunteer fundraiser, and most recently as a member of both the Brain Injury Association of America (BIAA) Board of Directors and the Virginia Brain Injury Council. As a retired Naval Surface Warfare Officer, Gary holds a special interest in providing support and help to military families. He is also committed to raising awareness of brain injury through education and believes strongly that prevention works.

Gary first became aware of BIAA in 1995 after his wife, Lynn, was in a car accident while living overseas. She sustained a traumatic brain injury (TBI) and was in a coma for three weeks. After two months in intensive care, Lynn continued extensive physical therapy until she could be transported back to the United States. Lynn was unable to recover from her injuries and passed away in September 1996.

The following year, Gary created the Lynn Fund in partnership with BIAA to help people obtain essential information and resources after brain injury. His aim was "to assist BIAA in realizing a number of its strategic goals, specifically partnering with BIAA in efforts to educate and raise public awareness about brain injury and helping to strengthen BIAA's capacity at the national and state levels." He held golf tournaments in multiple states in order to fund his efforts.

Gary Chiaverotti and family at a golf tournament held in partnership with the Brain Injury Association of Ohio in 2002.

A student at W.T. Cooke Elementary School shows off her new Lynn Fund helmet

Initially, the Lynn Fund was specifically dedicated to military families because of the lack of resources Gary had while he was oversees and initially dealing with Lynn's injury. As the fund grew and Gary became more involved in the community, he updated its goals. One day, Gary noticed that many of the children in his neighborhood did not wear bicycle helmets, so he and his second wife, Debbie, designed a helmet they thought kids would want to wear. From 2000 to 2018, the Lynn Fund distributed more than 26,000 helmets at countless community events.

"Gary Chiaverotti's commitment to the brain injury community has been extraordinary. Over the last 20 years, Gary has educated thousands of children throughout the Ohio Valley about the importance of keeping their brains safe. We are grateful to him for his efforts," said Susan H. Connors, BIAA president and CEO. Gary has continued to work with BIAA because he believes so strongly in this cause and in the organization. "Everyone knows someone who has sustained a TBI, from 'minor' concussions to major brain damage. Not only can we prevent many TBIs, we must advocate for those who have sustained them. The BIAA is the premier, nationally federated organization doing both." To support BIAA, visit www.biausa.org. ●

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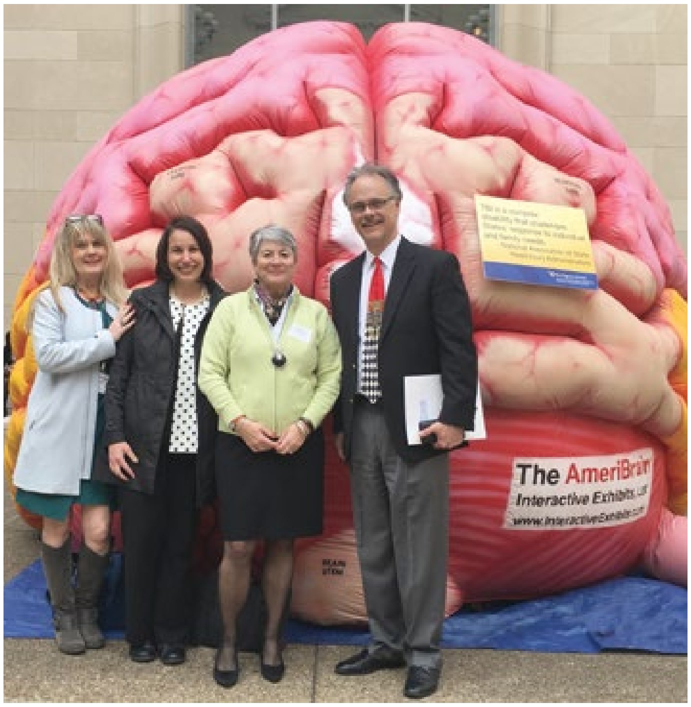
ADVOCACY **UPDATE**

By Amy Colberg, M.Ed., Director of Government Affairs, Brain Injury Association of America

Brain Injury Awareness Day on Capitol Hill

The Congressional Brain Injury Task Force, chaired by Rep. Bill Pascrell, Jr. (D-N.J.), hosted a successful Brain Injury Awareness Day March 13. As in years past, there was an awareness fair, a briefing focusing on Living Well with Brain Injury, and a reception to celebrate Brain Injury Awareness Month. The highlight of the day was the blow up brain from the West Virginia University, which was on display in the Rayburn courtyard. Brain Injury Association of America (BIAA) chartered state affiliates, individuals with brain injury, caregivers, professionals, and advocates participated in meetings with their elected officials urging Congress to increase funding for brain injury programs. BIAA thanks Rep. Pascrell for another productive advocacy day!



Karen Keating from BIA of North Carolina, Robin Abramowitz from BIA of Kansas and Greater Kansas City, Susan Connors from BIAA, and Tom Constand from BIA of Michigan visit the West Virginia University brain installation.

BIAA Director of Consumer Services Greg Ayotte mans the BIAA table.

BIAA Submits Testimony to House and Senate Appropriators for TBI Programs

BIAA submitted testimony to the House Appropriations Subcommittee on Labor, Health and Human Services (HHS), Education and Related Agencies this spring calling for increased fiscal year 2020 funding for TBI Act-related programs and the TBI Model Systems, administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Specifically, BIAA requested $19 million total for Administration for Community Living's (ACL) TBI State Implementation Grant program, $6 million total for ACL's Protection and Advocacy (P&A) Grant Program, and $5 million additional funding for the Center for Disease Control (CDC) and Prevention Injury Center to establish and oversee a National Concussion Surveillance System. BIAA also recommended $15 million for the

NIDILRR TBI Model Systems, administered by ACL, to expand the number of centers and research projects and requested that appropriators oppose the president's recommendation to move the program to NIH.

House Appropriators Increase Funding for TBI State Partnership Program

The House Appropriations Committee marked up the Labor, HHS, Education,and Related Agencies spending bill for fiscal year 2020 in May. The bill includes an additional $1 million for a total of $12.321 million for the ACL's TBI Program. The additional funding is appropriated to the P&A and state grant programs combined. The president's budget called for a $2 million cut for the program. The committee recommended level funding for NIDILRR, which funds the TBI Model Systems, whereas the president recommended that the research program be reduced by $19 million. The committee also recommended a $1 million increase for the Assistive Technology Act program and $5 million (level funding) for the ACL falls prevention program for older adults. The president's budget eliminated funding for the ACL falls prevention program.

The bill proposes level funding of $700 million for the CDC Injury Center. An additional $2 million is allocated to the Injury Control Research Centers for a total of $11 million and an additional $1 million is proposed for the elderly falls prevention program. The bill proposes a $14 million increase to the Substance Abuse and Mental Health Services Administration (SAMHSA) for opioid prevention and treatment, including new behavioral health programs.

The Appropriations Subcommittee recommended $300,000 to establish a Disabled Veterans Program within the Department of Labor. The purpose is to address the high unemployment and low labor force participation rate of veterans with service-connected and non-service-connected disabilities.

House Passes Bill Protecting Preexisting Conditions

The House of Representatives passed the Protecting Americans with Preexisting Conditions Act of 2019, H.R. 986, in early May. The purpose of the bill is to correct the Administration's efforts to abolish the Affordable Care Act (ACA) by nullifying the U.S. Department of the Treasury and the U.S. Department of Health and Human Services guidance, "State Relief and Empowerment Waivers," published Oct. 24, 2018. The guidance pertains to Section 1332 waivers, known as State Innovation Waivers or State Relief and Empowerment Waivers, which allow states to forego certain requirements of the ACA in order to implement experimental plans for health care coverage as long as the resulting coverage meets certain statutory criteria. For example, the guidance (1) redefines acceptable coverage under such waivers to include short-term, limited-duration insurance and association health plans; (2) allows the comprehensiveness and affordability of coverage under such waivers to be assessed based on projected availability, rather than enrollment; and (3) allows the level of coverage to be assessed based on the effects over the entire course of the waiver, rather than per year.

Senators Introduce Bill on Fitness Facilities Accessibility for People with Disabilities

To coincide with the 41st anniversary of the end of the historic protests of the disability community in San Francisco and Washington, D.C., resulting in implementation of Section 504 of the Rehabilitation Act, Sens. Tammy Duckworth (D-Ill.), Bob Casey (D-Pa.), and Richard Blumenthal (D-Conn.) introduced legislation to make fitness facilities across America more accessible for persons with disabilities. The Exercise and Fitness for All Act would establish new federal guidelines to help ensure people with disabilities have the same opportunity to use fitness facilities as their able-bodied peers, and it would allow small businesses to use the Disabled Access Tax Credit to help cover the purchase of accessible exercise equipment.

According to the CDC, adults living with a disability experience far higher rates of obesity and chronic disease than those without a disability. The CDC also

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found that the inaccessibility of many fitness facilities creates barriers for those with a disability to exercise due to the lack of accessible space and equipment.

Section 504 of the Rehabilitation Act was signed into law in 1973, but the former U.S. Department of Health, Education, and Welfare failed to implement the new rules until the protests occurred in 1977.

ACL Revises Organizational Chart

ACL published an updated Statement of Organization, Functions, and Delegations of Authority in the Federal Register in May. Programs administered by ACL are organized under the Administration on Aging, the Administration on Disabilities, and NIDILRR. ACL also administers the Center for Regional Operations to serve as the liaison, advocate, and representative for the agency regionally across the U.S. for all ACL's programs areas. Programs under the Administration on Disabilities have been reorganized within these offices:

- Office of the Commissioner on Disabilities
- Office of Intellectual and Developmental Disability Programs
- President's Committee for People with Intellectual Disabilities
- Office of Independent Living Programs
- Office of Disability Innovation

The TBI program (P&A and state grant programs) is located in the Office of Disability Innovation. In addition to the P&A TBI grant program, the Office will administer the P&A programs authorized by the Developmental Disabilities (DD) Act, Section 292 of the Help America Voter Act, and Section 5 of the Assistive Technology Act. The office is also responsible for the coordination, oversight, management, and evaluation of the Projects of National Significance program authorized by the DD Act. The Office ensures the dissemination of grantee results in coordination with the Office of Intellectual and Developmental Disability Programs, the Office of Independent Living Programs, and the Office of the Commissioner on Disabilities. The Office coordinates information sharing and other activities related to national program trends and studies and reviews and analyzes other federal programs providing services applicable to persons with disabilities for the purpose of integrating and coordinating program efforts.

Grassroots Brain Injury Advocates Take Action!

This year, members of Congress will be working in district at least one week per month. Brain injury advocates should take advantage of this opportunity and meet with elected officials in their district offices. Here are the dates Congress will be at home working in district for the rest of the year:

JULY 1-5, 29-31
AUGUST 1-31
SEPTEMBER 2-6
OCTOBER 1-11
NOVEMBER 4-8, 25-29

This schedule provides advocates with more opportunities to educate elected officials. You can invite your representatives to walk for brain injury, tour your facility or clubhouse, and join the Congressional Brain Injury Task Force. Visit www.biausa.org to download BIAA's legislative issue briefs and use them when you meet with your elected officials.

To better connect with your representatives and senators, follow them on Facebook and Twitter. Connecting on social media can help you learn more about your members of congress, alert you to events in your district, and increase awareness of brain injury.

BIAA and the Commissioner on Disability Hold Meeting on Brain Injury

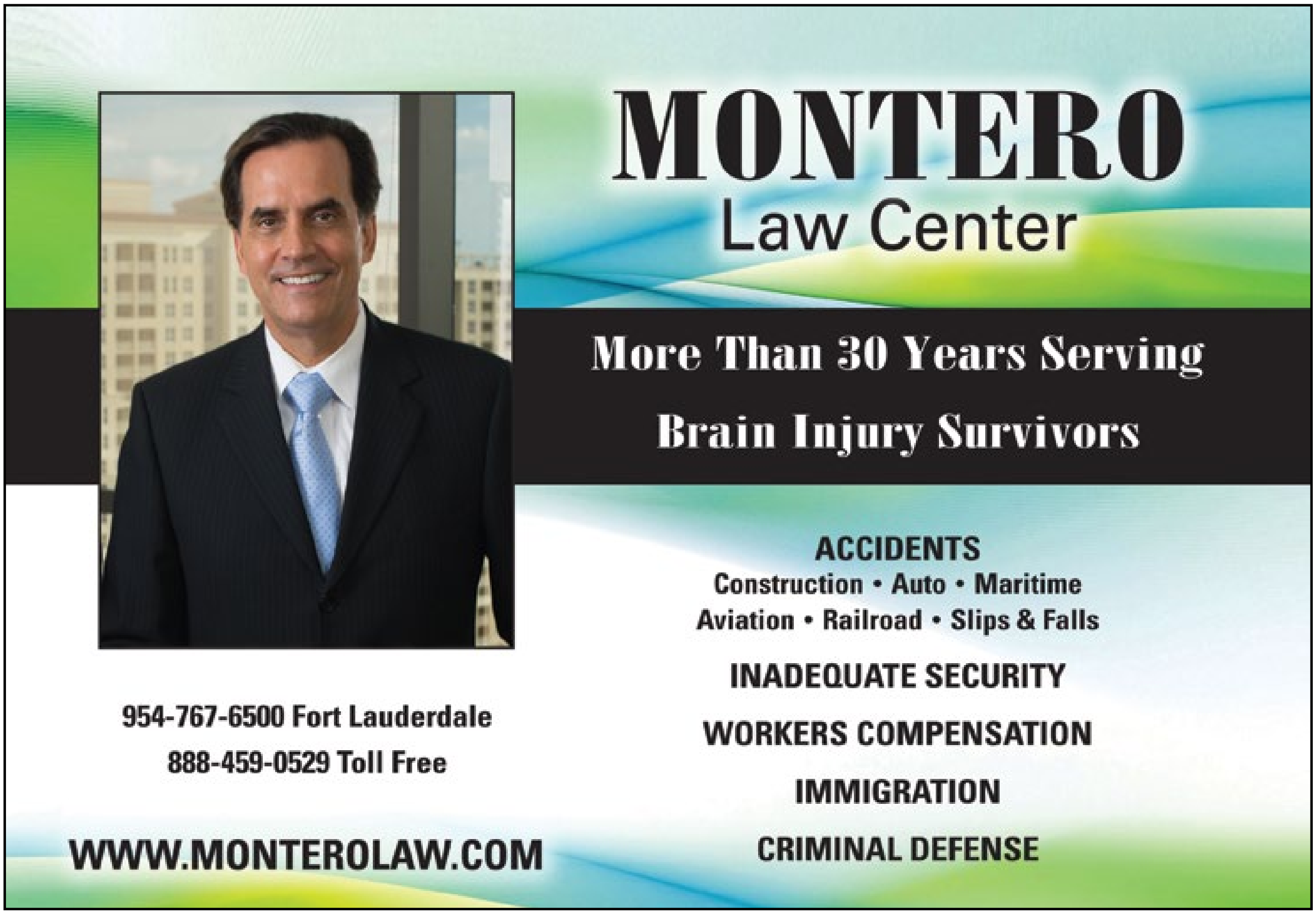
ACL hosted a TBI Stakeholder Day March 12. The event was an opportunity for members of the brain injury community to come to Washington, D.C., to hear about and discuss important issues related to TBI with other brain injury survivors, family members, support networks, and state and federal representatives.


Drew Nagele, Psy.D., CBIST, CESP


Julie Hocker, Commissioner of the Administration on Disabilities at ACL

During the meeting, BIAA Director of Government Affairs Amy Colberg met with Commissioner Julie Hocker and Drew Nagele, Psy.D., from the Brain Injury Association of Pennsylvania.. Dr. Nagele shared the work that Pennsylvania has been able to accomplish with a TBI Act grant. The grant project addresses the under-identification of brain injury, juvenile justice and brain injury, a school-based reintegration program after brain injury called BrainSTEPS, and the opioid epidemic.

●



STATE AFFILIATE NEWS

DELAWARE

The Brain Injury Association of Delaware (BIAD) has been extremely busy the past few months. Kristy Handley, M.S., was named executive director in February. She brings more than 20 years of healthcare and marketing experience to the organization along with a passion for advocating to ensure that all individuals with brain injury experience the quality of life they deserve.

BIAD Executive Director Kristy Handley, bottom right, meets with Sen. Nicole Poor (D-Del.) during Brain Injury Awareness Month.

For Brain Injury Awareness Month in March, BIAD held its annual Brain Injury Conference. More than 20 speakers provided information to 300 survivors, caregivers, and healthcare professionals. Brain Injury Awareness Month was also officially recognized on the state Senate floor, and members of BIAD and the State Council for Persons with Disabilities were present to accept the honor.

BIAD has been actively meeting with state senators and representatives this spring to advocate for additional research, coordination of services, increased funding support for concussion research and data collection, and support for the Brain Injury Task Force. The group also advocated against proposed budget cuts to disability funding. These meetings have yielded positive feedback and cooperation.

LOUISIANA

The Brain Injury Association of Louisiana (BIALA) hosted its 12th annual conference during Brain Injury Awareness Month in March. Professionals came together to hear from speakers from around the country and had the opportunity network with other professionals. Topics included cognitive deficits, multi-modal learning, neuroplasticity, vocational rehabilitation, and behavioral changes, among others. Survivors participated in Survivor Saturday, where they engaged in hands-on activities and workshops including yoga, music therapy, and recreational opportunities.

The Northwest Louisiana Brain and Spinal Cord Injury Support Group hosts the first Connections Circle event.

Individuals living with brain injury enjoy Survivor Saturday at BIALA's annual conference.

BIALA launched its new program, Connections Circle, April 9 during the Northwest Louisiana Brain and Spinal Cord Injury support group meeting in Shreveport. Connections Circle brings individuals living with brain injuries together for social enrichment events, such as art therapy and story sharing, to increase their support systems. For more information, visit www.biala.org.

KANSAS

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS) kicked off Brain Injury Awareness Month with its third annual Pie Rally and Legislative Day at the Capitol Rotunda in Topeka March 19. All 165 legislators received empty pie tins with invitations to the Pie Rally, where they could exchange their tins for a piece of pie and learn about brain injury. Survivors and family members also visited representatives to share their stories on living with a brain injury. Kansas State Rep. Jarrod Ousley recognized March as Brain Injury Awareness Month during a Point of Privilege Motion on the House Floor, and BIAKS received a signed proclamation by Governor Laura Kelly that day.

BIAKS Executive Director Robin Abramowitz (left), BIAKS Past-President Terrie Price, and award co-sponsor Erin Butterworth, HCA Menorah Medical Center, present Dr. Brent Masel with the Gary Berger Memorial Lecture Award.

The month culminated with the 11th annual professional conference, “Beyond Rehab: Succeeding at Life,” attended by 160 guests. Conference highlights included keynote presentations by Michelle C. Reynolds, Ph.D., associate professor, University of Missouri-Kansas City (UMKC) School of Medicine, and Brent Masel, M.D., executive vice-president for medical affairs, Centre for Neuro Skills. BIAKS presented Dr. Masel with the Gary Berger Memorial Lecture Award, created in memory of Dr. Berger, to honor professionals exhibiting compassionate and dedicated care of individuals with brain injury.

Rep. Jarrod Ousley, center, presents BIAKS with a gubernatorial proclamation recognizing March as Brain Injury Awareness Month.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its fourth annual Maine Brain Injury Resource Fair March 28. The event was held at the Augusta Armory and had nearly 50 exhibitors from across the state representing services, resources, and opportunities for Maine brain injury survivors, family members, caregivers, and professionals. Nearly 250 people attended the fair, including 70 survivors and more than 50 family members and caregivers.

BIAA-ME's 10th annual conference, “Defining Moments in Brain Injury,” will be held Oct. 9 at the University of Southern Maine's Abromson Center in Portland.

Barbara Howard chats with attendees at the 2019 Maine Brain Injury Resource Fair. *Photo credit: Sarah Gaffney*

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MASSACHUSETTS

As part of Brain Injury Awareness Month, Nicole Godaire, CEO, Brain Injury Association of Massachusetts (BIA-MA) and Kelly Buttiglieri, BIAMA's public policy manager, visited Washington D.C. They attended the Administration for Community Living's TBI Stakeholder Day and took part in Brain Injury Awareness Day on Capitol Hill. They visited the Massachusetts congressional delegation to discuss both the federal and state legislative goals. Tim Shotmeyer, TBI survivor, joined BIA-MA and met with Rep. Bill Pascrell, Jr., as Tim is originally from New Jersey and is a family friend of Rep. Pascrell.

BIA-MA CEO Nicole Godaire, left, and Tim Shotmeyer, BIAA CEO Susan H. Connors, and other advocates meet with Rep. Bill Pascrell, Jr., during Brain Injury Awareness Day.

MISSOURI

During Brain Injury Awareness Month, the Brain Injury Association of Missouri (BIA-MO) shared a Brain Injury "Fact of the Day," sponsored by the Missouri AgrAbility Project, on social media. The facts focused on prevention, causes, and effects of brain injury throughout rural Missouri and were very popular with followers.

BIA-MO hosted the Donald Danforth Jr. Wilderness Camp for survivors of brain injury in May 26-31. Attendees enjoyed a week of fun, independence, and adventure with swimming, ziplining, dancing, arts and crafts, a talent show, and more. In June, BIA-MO held Bowling for Brain Injury events in St. Louis, Springfield, and Kansas City. For more information about BIA-MO's events, visit www.biamo.org.

An attendee enjoys the activities at the Donald Danforth Jr. Wilderness Camp.

RHODE ISLAND

The Brain Injury Association of Rhode Island (BIARI) had a busy March! While the Rhode Island State House dome shone blue in honor of brain injury March 11-17, staff members were advocating for the brain injury community throughout the state. BIARI Communications Manager David Lima participated in a neuro-advocacy forum panel and encouraged advocates in attendance to share their stories with legislators. Later in the week, staff and volunteers visited the Rhode Island State House to set up information tables and meet members of the general assembly. BIARI also participated in Brain Week fairs at the University of Rhode Island and Brown University.

BIARI staff and volunteers advocate at the Rhode Island State House.

BIARI held the 18th Statewide Brain Injury Education Conference, “Mood, Memory, Modality” March 29. More than 120 professionals, exhibitors, and individuals affected by brain injury attended the conference. Speakers addressed topics such as managing memory problems, legal matters, concussion diagnosis and management, cortical integrative therapy, and cognitive decline after brain injury.

A new fundraiser, Bowling for Brains, launched in May. Participants had fun bowling in support of an important cause, and BIARI presented awards to top fundraisers. BIARI is looking forward to its fifth Hidden Treasure Gala, which will feature tastings created by Rhode Island’s leading chefs this September. Visit www.biari.org for more information.

SOUTH CAROLINA

Brain Injury Awareness Month in South Carolina was exciting! During the week of its commission meeting, the SC Department of Disabilities and Special Needs allowed the Brain Injury Association of South Carolina (BIASC) to exhibit its Unmasking Brain Injury displays. The Capital City Club Young Professionals Group also hosted Cocktails that Care. Atop one of Columbia’s tallest buildings, this beautiful fundraiser brought together BIASC members and potential new sponsors and members. Executive Director Joyce Davis shared the impact of BIASC with attendees. Finally, the 11th annual Upstate Run & Roll 5K/1 Mile Walk was a perfect ending for March! BIASC welcomed nearly 250 registrants of all ages. Special guests included Bill and Stacy Halstead, who ran in memory of their 8-year-old son Tripp; Tyrone Johnson, a former Spartanburg Police Officer and TBI survivor; and Dede Norungolo, TBI survivor and former BIASC board member.

BIASC will also host its annual Life with Brain Injury conference July 26 in Columbia. For more information, visit www.biaofsc.com.

Participants at the Upstate Run & Roll show their support for BIASC.

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TENNESSEE

The Brain Injury Association of Tennessee (BIATN) held its 30th annual TBI Survivor and Caregiver Event at the beautiful Nelson Andrew Leadership Lodge in Nashville March 29. Attendees arrived to the music of keynote speaker Martha Summa-Chadwick as she performed on the grand piano in the entrance lobby. They perused the exhibitor tables as they nibbled on breakfast pastries and fruit and made their way into the main meeting room. Beginning with the presentation, "Dance of the Neural Tango," the day focused on improving the quality of life for everyone present. Next was a participatory session on Tai Chi, followed by an attorney leading a lively discussion on rights and responsibilities during a police encounter. The day concluded with a moving panel presentation where a survivor, caregiver, and service provider shared their stories and answered questions from the audience.

This was a day dedicated to survivors and families. The conference committee worked to create a festive atmosphere that included exhibitors, door prizes, and lunch. The agenda was compressed so as to be mindful of fatigue issues and allow registrants to travel to Nashville and back home in one day. Securing a sufficient number of sponsors allowed all 90 attendees to attend at no charge. The glowing evaluations from this year's event made all the planning and work worthwhile.

VIRGINIA

The Brain Injury Association of Virginia (BIAV) celebrated Brain Injury Awareness Day January 30 at the Virginia State Capitol. More than 50 members of the brain injury community joined together to advocate to increase brain injury funding for hospital and community-based supports and services.

BIAV's Annual Making Headway Conference kicked off its 18th year in a new location in March: Portsmouth, Virginia. The majority of attendees were new to the event, giving BIAV a great opportunity to connect with new people and increase its awareness efforts. Abby Maslin, writer and wife of a TBI survivor, gave a heartfelt keynote address about her experience dealing with her husband's injury. Conference attendees expressed that the sense of community was the best part of the day.

BIAV participated in eight Brain Injury Awareness Month events throughout March, including three BIAV exhibitions, three BIAV-led trainings, and an interview with Abby Maslin, in Washington, D.C. For more information about upcoming events and programs, visit www.biav.net.

Conference keynote speaker Abby Maslin shares her experience with other attendees.

NEWS & NOTES

Dr. Mark Ashley Receives Honorary Doctorate from SUNY Geneseo

Mark Ashley, Sc.D., BIAA Board Member and CEO of Centre for Neuro Skills (CNS), was awarded an honorary Doctorate of Science degree (Sc.D.) by his alma mater, State University of New York (SUNY) at Geneseo. This esteemed honor recognizes Dr. Ashley's unprecedented contributions to the field of brain injury rehabilitation. His career began in the halls of SUNY at Geneseo, where he completed his undergraduate education in just three years. His innovative leadership and attention to detail in the implementation of services would later lead him to establish CNS, which has operated industry-leading, post-acute brain injury rehabilitation programs in California and Texas since 1980.

Dr. Ashley went on to earn a Master's degree in speech pathology and a Doctorate of Science degree from Southern Illinois University. His work has been published in numerous professional and research publications, and he has written several books. He is also a licensed Speech and Language Pathologist in California and Texas and is a Certified Case Manager.

In response to this recognition, Dr. Ashley addressed the graduating class of 2019, stating, "The best advice I ever received was to read outside my discipline. This has enabled us to open clinical doors once thought unopenable for people with acquired brain injury, and will continue to facilitate the discovery of new and better treatment approaches for them and their families."

Denise Battles, SUNY at Geneseo President, commented, "Dr. Ashley's remarkable contributions to the field of TBI treatment and rehabilitation embody the values of excellence and service to others exemplified by a Geneseo education. We are proud that his chosen life's work promotes the health and well-being of others, and we are very pleased to pay tribute to him with an honorary Doctor of Science degree."

Mark Ashley, Sc.D, left, with SUNY Geneseo President Denise A. Battles and commencement speaker Jeri Muoio, accepts his award.

The Brain Injury Association of America congratulates Dr. Ashley and is thrilled to share in this momentous occasion with him. ●

UPCOMING **WEBINARS**

Carolyn Rocchio Caregivers Webinar – How to Use Apps and Strategies in the Real World

July 11, 2019, 3 p.m. ET/12 p.m. PT

Michelle Wild, Coastline Community College ABI Program

Robert Sbordone Memorial mTBI/Concussion Lecture – The Challenge of Brain Injury in Older Adults

August 8, 2019, 3 p.m. ET/12 p.m. PT

Matthew Peters, M.D., Johns Hopkins, Department of Psychiatry and Behavioral Sciences

Carolyn Rocchio Caregivers Webinar – Employment and Accommodation After Brain Injury

September 12, 2019, 3 p.m. ET/12 p.m. PT

Melanie Whetzel, M.A., CBIS, Job Accommodation Network

Robert Sbordone Memorial mTBI/Concussion Lecture – Status of State Concussion Legislation in the U.S.

October 10, 2019, 3 p.m. ET/12 p.m. PT

Susan Vaughn, Director of Public Policy, National Association of State Head Injury Administrators

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

Brain Injury Association of America

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BRAIN INJURY RESEARCH FUND

The Brain Injury Association of America is pleased to announce the launch of its Brain Injury Research Program toward finding cures for brain injury.

Two funding opportunities will be available: Dissertation awards funded up to $5,000 and seed grants funded up to $25,000.

Visit **biausa.org/research** for more information.

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

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