BRAIN INJURY ASSOCIATION OF AMERICA | Volume 13, Issue 1

THE CHALLENGE!

Women and Brain Injury

BRAIN INJURY ASSOCIATION OF AMERICA

MARCH 2019

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TABLE OF **CONTENTS**


14


24


25


28


30

FROM MY **DESK**

In March, the Brain Injury Association of America leads the nation in celebrating Brain Injury Awareness Month and in advocating for the 3.5 million individuals and families who experience brain injury each year.

2019 marks the second year in our three-year awareness campaign to #ChangeYourMind about brain injury. Our campaign features a toolkit with instructions on how to participate and includes links to these free materials from www.biausa.org/changeyourmind:

- Campaign stamp
- Posters/Flyers in vertical and horizontal format
- Fact sheet
- Templates for a press release, newsletter, letter to the editor
- Sample gubernatorial or mayoral proclamation
- Social media messages
- Legislative issue briefs

Brain injury survivors, caregivers, and professionals are encouraged to use the #ChangeYourMind campaign materials to educate others, empower one another, and advocate for public policies that increase access to care and to community-based services and supports for everyone. Using the issue briefs, you can advocate during Awareness Day on Capitol Hill in Washington, D.C., March 13 or in meetings with your representatives when they return home for district work periods.

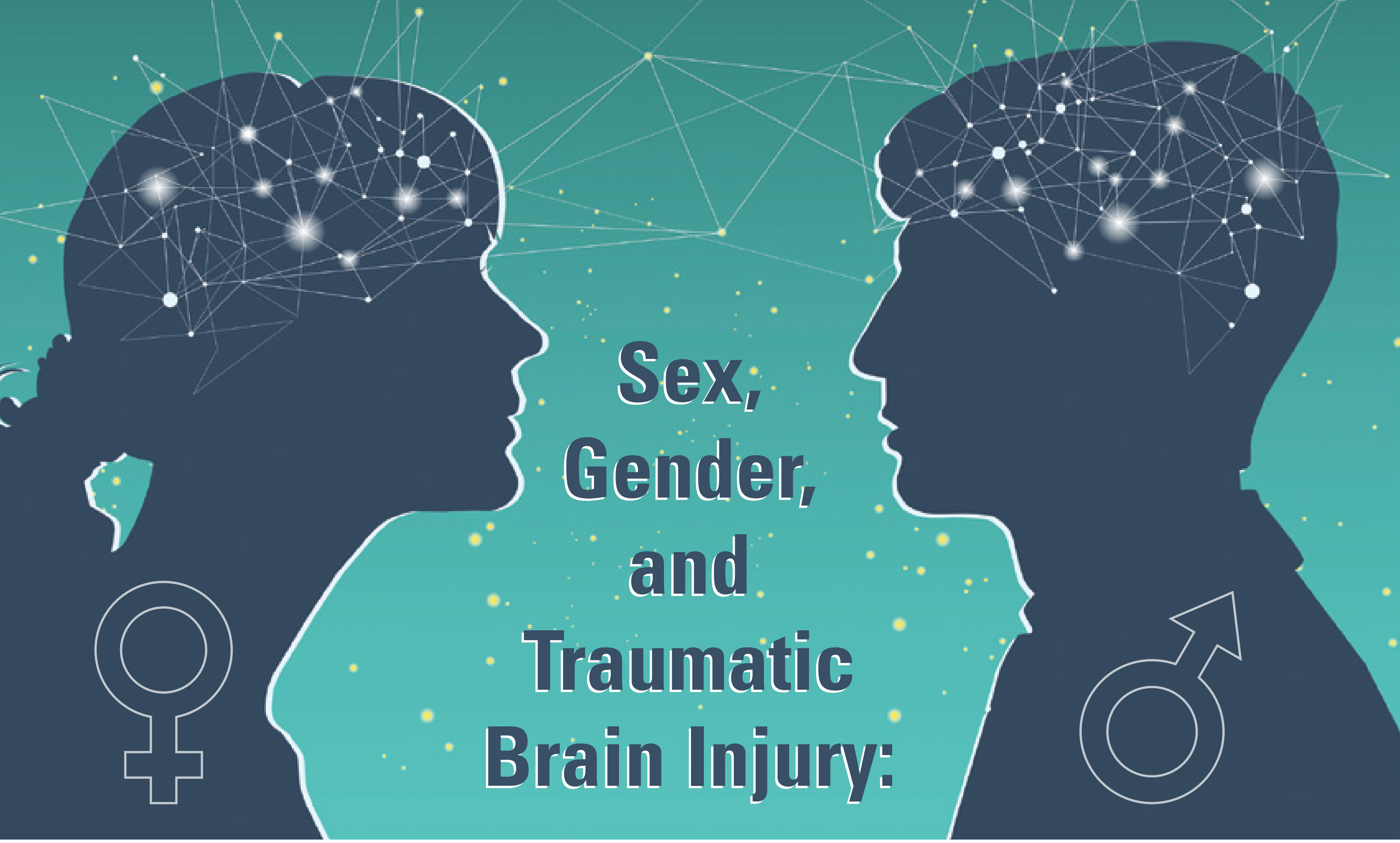
I am grateful to individuals, family members, clinicians, researchers, and other professionals as they undertake advocacy this month and throughout the year. In this issue of *THE Challenge!,* we shine a spotlight on women's issues in brain injury, including profiles of four women who advocated on both the state and federal levels throughout their careers: Julie Dixon, Joanne Finegan, Cindy Ivanhoe, and Susan Vaughn. Thank you for all you've done!

As always, I salute the staff and volunteers of state brain injury associations across the country – their blood, sweat, and tears make the world a better place for all of us. Please be sure to read the state news in this issue.

Happy St. Patrick's Day!

Susan H Connors

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



Sex, Gender, and Traumatic Brain Injury: Implications for Better Science and Practice

By Tatyana Mollayeva, M.D., Ph.D.,[1,3] and Angela Colantonio, Ph.D.[1-3]

The impact of traumatic brain injury (TBI) can be far-reaching and affects more than the health and wellbeing of those with brain injury and persons close to them. Great strides have been made in exploring the many facets of brain injury – medical, personal, and environmental factors that impact risk of injury, cause of injury, and its course of recovery. However, one topic in particular remains largely unexplored, despite its crucial role as a determinant of injury vulnerability, post-injury experience, and extent of recovery. The topic in question is that of the effect of sex and gender, which is now being highly recognized for its importance to good science and practice.

WHAT ROLE DO SEX AND GENDER PLAY IN BRAIN INJURY?

Sex refers to biological differences between men and women, including genetic specificities that distinguish them with respect to hormonal levels and rates of metabolism, and anatomy (e.g., skull thickness, brain size, etc.). In the context of TBI, these differences between men and women can affect differences in susceptibility to TBI after physical trauma and regeneration among other factors. **Gender** refers to the social and cultural processes that shape the experiences of men and women, before, at the time of, and after their injury. It is, however, difficult to separate the individual effects of sex from those of gender in a person who sustains TBI.

Gender affects health directly in the context of TBI. For example, men more often participate in higher risk behaviors that can cause injury, worsen the effects of

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[3] Acquired Brain Injury Research Lab, Dept. of Occupational Science and Occupational Therapy, University of Toronto, Canada

previous injury, or increase the risk of repetitive injury. The effect of gender on health is also indirect. It creates different home and professional workloads for men and women and impacts the time they can dedicate to health maintenance, recovery after injury, and whether they can easily and openly acknowledge their health issues. Finally, gender impacts the social aspects of health after brain injury. Society's gender-based perceptions fault men and women for their circumstances, possibly misinterpret complaints, or fail to take complaints seriously. In doing so, society creates standards and associated pressures with respect to rate and extent of recovery and return to previous roles.

WHAT SEX AND GENDER DIFFERENCES HAVE BEEN REPORTED IN BRAIN INJURY RESEARCH?

The National Institutes of Health (NIH) and federal funding agencies in Canada and Europe have acknowledged that medicine is dominated by findings on men and that there is insufficient data to inform clinical decision-making that considers the unique experiences and needs of women in all areas of medicine, including brain injury. Some examples of sex and gender differences that have been reported in brain injury research are as follows:

Hospitalizations

- Men have a higher incidence of TBI than women, particularly during young adulthood.
- Hospitalization rates between men and women even out in older adulthood as injury rates become similar.
- Men more often leave hospital after admission against medical advice.
- The highest rates for concussion, or mild TBI, among older adults are among women.
- Girls and women with a concussion-related emergency department visit have a higher reported rate of concurrent neck injury than boys and men. This is true across injury causes, including motor vehicle collisions, assault, and sport-related injuries.

Work-Related Brain Injury

- Most work-related TBI fatalities occur in men; the jobs and workplaces of men are associated with more severe injuries.
- Women are at a greater risk of sustaining work-related TBI due to assault, often in the healthcare, social services, and education sectors.
- Men experience higher rates of work-related TBI in law enforcement and public administration.
- Women are more proactive in seeking medical and rehabilitation services.
- Women report more positive return-to-work outcomes if coming from traditionally "feminine" environments (i.e., healthcare, social care) relative to those in more "masculine" environments.

Sports-Related Brain Injury

- In a study of young adults who sustained sports-related concussions, young women expressed greater intention to report than men.
- Men more often exhibit on-field markers of injury such as amnesia and disorientation.
- Women more frequently report headache, drowsiness, and nausea/vomiting.

Life after Brain Injury

- Being a man is associated with a greater likelihood of aggression after TBI relative to women.
- Women are significantly more likely to die from a head injury than men.
- Women are more likely to die from a head injury by assault.
- Women experiencing intimate partner violence (IPV) are at a high risk of brain injury, with up to 90% of incidents of IPV involving hits to the head or strangulation.

WHAT OTHER RESEARCH STRIDES HAVE BEEN MADE?

In December 2017, the "Understanding TBI in Women" workshop took place. This seminal event was hosted by the NIH, in partnership with the Center for Neuroscience and Regenerative Medicine and the Defense and Veterans Brain Injury Center. The two-day workshop

(continued on page 6)

(continued from page 4)

brought together researchers, persons affected by brain injury, and clinicians to identify knowledge gaps, best practices, and target populations relevant to research on sex differences and women with TBI. These proceedings, which will be published in a scientific journal, highlight epidemiological trends, populations such as sports-related injuries and women affected by intimate partner violence, and findings from animal studies.

Dr. Angela Colantonio is the founding chair of the Girls and Women with Acquired Brain Injury Task Force of the American Congress of Rehabilitation Medicine, the world's largest interdisciplinary research organization with a major focus on rehabilitation after brain injury. This task force would not be possible without the support of Marilyn Spivack, founder of the Brain Injury Association of America, who participated in the initial international workshop on Women and TBI in 2010 and advocated for the task force. Members of the task force are often invited to testify at congressional meetings.

The task force has been meeting since 2011 and is supported by researchers, clinicians, and advocates. One of the products of the task force was a first-of-its-kind special issue in the Archives of Physical Medicine and Rehabilitation entitled, "Sex, Gender and Traumatic Brain Injury," published in 2016. The issue is freely available online.

While there is still much work to be done, we must also be inspired by the progress that has been made. For more information about sex, gender, and brain injury, please visit www.abiresearch.utoronto.ca.

Acknowledgements

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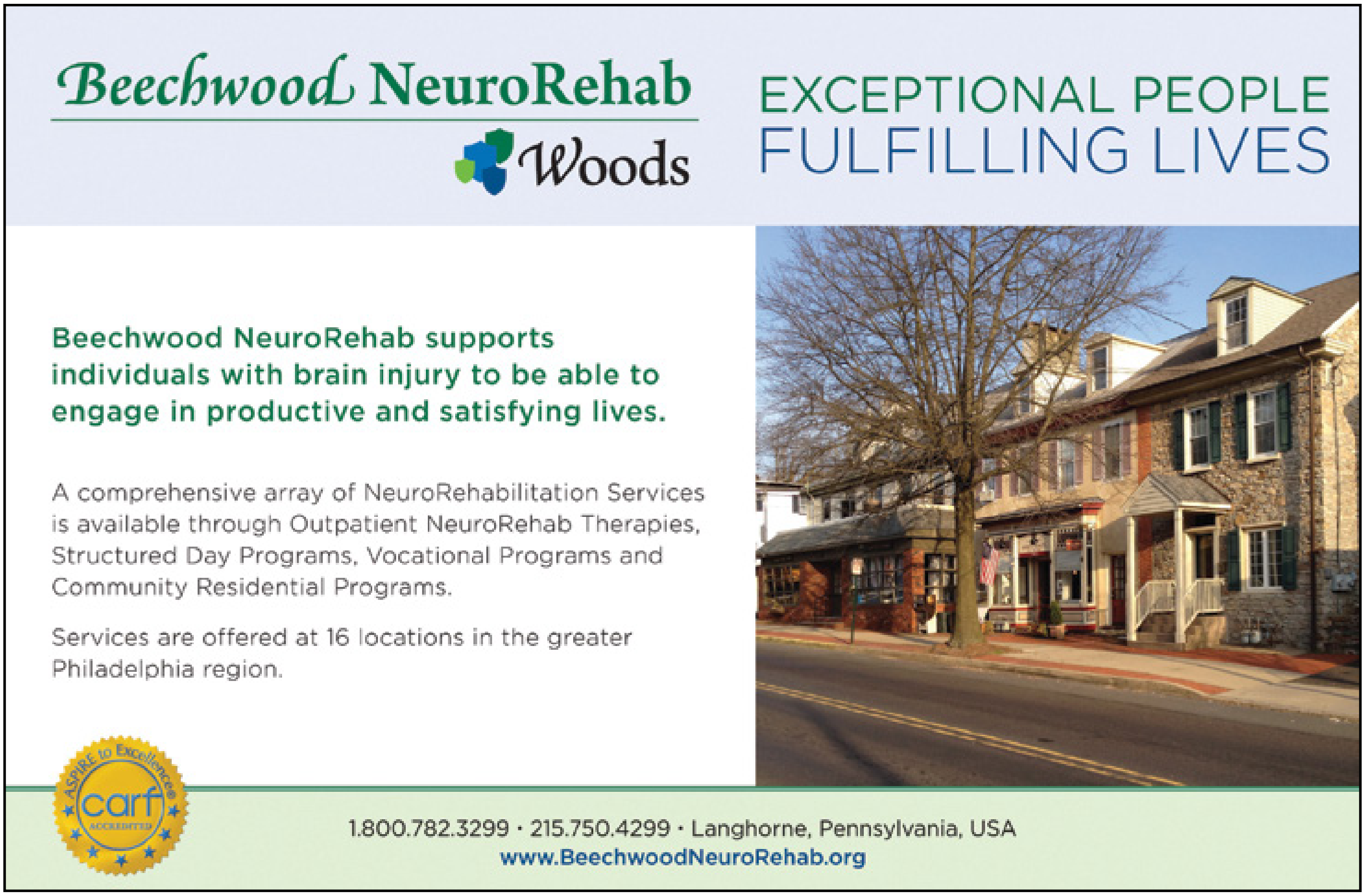
References available at www.biausa.org/sexandgender



Women in Brain Injury: Making an Impact

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

In honor of International Women's Day, March 8, the Brain Injury Association of America (BIAA) is proud to celebrate the accomplishments of women in the field of brain injury. After all, what would an issue on Women and Brain Injury be if we neglected to tell you about some of the incredible women in America who have dedicated their careers to bettering the lives of persons with brain injury? Coming up with a list was hard, as we know countless women who have made an impact, so we decided to limit our list to women who had announced their retirement. Read on to meet some of the women who have had a lasting effect on the brain injury community throughout the years (and why BIAA is especially grateful to them).

Julie Fidler Dixon

In 1994, Julie Fidler Dixon recognized that her master's degree and more than two decades in vocational rehabilitation, substance abuse, and the mental health fields culminated in an awareness of the diverse challenges faced by brain injury survivors. She joined On With Life, an intensive inpatient program in Iowa, and adopted its founding families' example of unrelenting advocacy. In her role as Clinical Director, she successfully convinced Iowa Medicaid to allow qualifying persons with brain injury to access out-of-state programming.

Julie later became president of the Brain Injury Association of Iowa and worked with advocates across the state to develop a Medicaid waiver for individuals with brain injury, creating the state's first program for community-based services. She expanded her focus to include advocacy on a national scale and now serves on the Board of Directors at BIAA.

Julie continued her advocacy after becoming the CEO of On With Life by testifying in legislative hearings and speaking to professional and community groups. After significantly expanding services to include outpatient therapy and campus housing, she helped create Iowa Medicaid's residential neurobehavioral programming. She has also served as a longtime surveyor at the Commission on Accreditation of Rehabilitation Facilities (CARF) and has provided consultation to more than 70 brain injury specialty programs in eight countries!

Looking back on her career, Julie says, "I am most proud of my nickname, Brain Injury B****, which colleagues bestowed, meaning that wherever I am, people know the needs of brain injury survivors will be represented. It's the best possible compliment!"

(continued on page 8)

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Joanne Finegan

Joanne Finegan spent 35 years working in the field of brain injury, 32 of them at ReMed, and 18 of those years as ReMed's CEO and president. The foundation of Joanne's work has focused on continuously educating others on the impact and lifelong effects of brain injury, combining ReMed's real-life rehabilitation model with her background in recreational therapy.

Joanne is a founding member and current president of the Council on Brain Injury (CoBI). She has served as a board member, been chair, and has participated in more than ten International Advisory Committees for CARF. She was also member and chair of the National Council for Therapeutic Recreation Certification. Among her many accomplishments, Joanne was named an American Therapeutic Recreation Association Distinguished Fellow and a Penn State Alumni Association Fellow.

In 2016, Joanne moderated BIAA's congressional briefing, "Women and Traumatic Brain Injury: A Frontier Yet to be Explored" in Washington, D.C. She has written and contributed to numerous articles and has presented at many industry conferences on topics related to brain injury, leadership, and culture over the past 35 years. She has been especially supportive of BIAA's Academy of Certified Brain Injury Specialists (ACBIS), ensuring that her eligible staff understand the value of ACBIS certification in post-acute rehabilitation.

Joanne believes that, in the field of brain injury, the clinical work is the value brought to the individuals served, and she is personally committed to acting in the best interests of those individuals. *Every day. Every individual.*

Cindy Ivanhoe

Dr. Cindy Ivanhoe completed her clinical fellowship in Brain Injury and Stroke Rehabilitation at the Institute for Rehabilitation and Research in the Texas Medical Center (now TIRR Memorial Hermann). She has had a distinguished career in brain injury as a physician, patient advocate, medical director, and professor, proudly teaching students at all levels of medical training and shaping future clinicians in the field of brain injury.

Her clinical experience has spanned the entire spectrum of brain injury, from neurosurgical ICUs and acute rehabilitation to long-term follow up in the community. Her nonprofit, Ivanhoe Foundation, supports endeavors that serve to improve the lives of those with brain injury and other disabilities in the community. Dr. Ivanhoe is most known for pioneering the clinical use of interventions for spasticity including Intrathecal Baclofen therapy, for which she was an investigator on studies leading to its FDA approval.

Dr. Ivanhoe has served on the board of directors of the International Neurotoxin Association and on task forces and committees for the American Academy of Physical Medicine and Rehabilitation. She is recognized by U.S. News and World Report Best Doctors and Best Doctors in Texas and has received awards from the Brain Injury Association, American Congress of Rehabilitation Medicine, and Baylor College of Medicine, among others, for her contributions to advocacy, teaching, and education.

Through teaching in residency programs, treating and interacting with patients, and speaking about brain injury around the world, Dr. Ivanhoe has a history of seeing potential where others have not and a belief that clinicians are only a small part of each patient's journey.

Susan Vaughn

Susan L. Vaughn has a long history of advocacy, beginning locally and moving on to state and national levels to effect policy change for individuals with disabilities including brain injury. Currently, she is the state policy analyst at BIAA and the director of public policy for the National Association of State Head Injury Administrators (NASHIA), of which she is the founder.

Susan believes that advancing public policy is like a three-legged stool: (1) consumers, families, and their associations that educate policymakers about the needs and issues; (2) providers and professionals who specialize in research, treatment, and rehabilitation; and (3) state, federal, and private payers who fund and regulate providers of services. Susan has been involved in the "third leg" as an advocate for state- and public-funded services.

Her interests in public policy began in the 1970s when she worked to develop community services at a time of deinstitutionalization. In 1979, she moved to the state capitol and eventually became assistant to the director of Missouri's Department of Mental Health, serving as the legislative liaison. It was in that capacity that she represented the department on a 1984 Joint Interim Legislative Committee on Head Injury and, subsequently, was the first director of the Missouri Head Injury Advisory Council. During her 17 years as director, the council – in collaboration with the Brain Injury Association – passed a number of bills to address the needs of individuals with brain injury. After nearly 29 years, she retired from the State of Missouri, using these experiences to promote national and federal issues.

Susan writes BIAA's weekly policy e-newsletter, Policy Corner, and collaborates with BIAA staff to disseminate information about state-level advocacy for persons with brain injury. ●

STRANGULATION, DOMESTIC VIOLENCE, AND BRAIN INJURY:

AN INTRODUCTION TO A COMPLEX TOPIC

By Jerrod Brown, Ph.D., Concordia University

Affecting millions of individuals across the United States, intimate partner violence is the physical, sexual, or psychological harm of an individual by a romantic partner (Arroyo, Lundahl, Butters, Vanderloo, & Wood, 2017). Approximately one in four American women are the victims of severe physical violence perpetrated by their intimate partners at some point in their lifetime (Smith et al., 2017). Such intimate partner violence often takes the form of physical attacks including punching, shaking, hitting with an object, assaulting with a weapon, or near suffocation. The consequences of intimate partner violence can range from adverse physiological (e.g., broken bones and traumatic brain injuries) and mental health issues (e.g., post-traumatic stress disorder, depression, and anxiety) to homicide (Pritchard, Reckdenwald, & Nordham, 2017; Strack & Gwinn, 2011).

One particularly common yet destructive form of intimate partner violence is strangulation (Kwako, Glass, Campbell, Melvin, Barr, & Gill, 2011; Messing, Patch, Wilson, Kelen, & Campbell, 2018). Distinctly different than choking, strangulation is the application of pressure to the neck that restricts blood vessels and air passages. This in turn results in asphyxiation, or the restriction of oxygen, where oxygen fails to reach the brain and other parts of the body. It is thought that strangulation symbolizes the perpetrator's control over the victim and demonstrates the perpetrator's ability to kill the victim (Volochinsky, 2012).

There are two types of strangulation: manual and ligature. Manual strangulation is the process of using one's hands or forearm to strangle the victim and may be the most common form of strangulation employed in the context of intimate partner violence. In contrast, ligature strangulation refers to the use of a rope, scarf, belt, or other similar object to strangle the victim (Volochinsky, 2012). Regardless of the type, strangulation may or may not be accompanied by visible symptoms of the injury.

Depending on length of time without oxygen, the victim may experience a loss of consciousness, potentially permanent medical consequences (e.g., strokes, brain injuries), and even death. In fact, victims of intimate partner violence who have experienced strangulation are much more likely to die as a result of intimate partner violence than those victims who do not experience strangulation. Even if the victims initially survive the strangulation, they may eventually die due to other complications. In these cases, victims die in the coming days or weeks after the strangulation as a result of blood clots, arterial complications, respiratory issues, or other reasons.

In the absence of death, brain injuries are often one of the most devastating and long-lasting consequences of strangulation. Victims of intimate partner violence may also experience traumatic brain injuries (TBIs) from blows to the head and other assaults. (Prosser, Grigsby, & Pollock, 2018; Valera & Kucyi, 2017). Caused by open or closed injuries to the head, TBIs can be characterized as short- or long-term brain damage. This could include physical (e.g., loss of consciousness, headaches, and sleep disturbances), sensory (e.g., vision and auditory distortions and sensitivity to light and sound), cognitive (e.g., executive control and memory), and mental health (e.g., depression, anxiety, and mood fluctuations) symptoms. For a review of the injuries resulting from strangulation, please see Figure 1. As a result of these symptoms, individuals suffering from TBI could have difficulty functioning in daily life including performing regular tasks at home, school, or work.

The combination of psychological distress and brain injury can make it difficult to identify the presence of intimate partner violence. Specifically, the victims may have difficulty communicating the transpired events to authorities, physicians, and other professionals in a variety of contexts. For example, this could occur in conversations with police officers during criminal investigations or with mental health care providers during psychological assessments. The causes of communication difficulties may include short- and long-term memory impairments, post-traumatic stress disorder symptoms, or other intimate partner violence sequelae. The practical consequences of these communication difficulties are that intimate partner violence victimization is under-identified. As a result, the individual may be (a) exposed to further intimate partner violence in community settings, (b) viewed as an unreliable source of information in criminal justice and legal settings, and (c) undiagnosed or misdiagnosed in psychiatric settings.

To improve the identification of survivors of intimate partner violence, professionals must adopt advanced methods of screening and assessment (Pritchard, Reckdenwald, Nordham, & Holton, 2018). One consideration should be the manner in which screening and assessments are conducted. Specifically, interactions with clients should be characterized by slow pace, repetition, checks for comprehension, and frequent breaks. Beyond this, professionals should specifically screen for both intimate partner violence victimization and brain injury. This could involve questions about concussions, blackouts, and loss of consciousness. Failure to adopt these suggestions and approaches may result in symptoms being misattributed to other ailments, misdiagnosis, and ultimately inappropriate and ineffective interventions.

A lack of recognition of the links between intimate partner violence, strangulation, and brain injury translates to under-treatment. This is troubling because timely intervention is essential in the minimization of negative short- and long-term outcomes. When untreated, brain injuries can worsen over time and have permanent consequences on the victim's global functioning along with tremendous societal costs. As such, it is essential that the potential brain injuries be evaluated by a physician with referrals to appropriate treatment services as soon as possible.

In instances where professionals lack expertise in brain injury, it may be fruitful to call on the assistance of specialists. Those with expertise can help ensure the client has not only been adequately assessed and diagnosed, but also provide guidance in the development of the course of treatment. This should include a discussion of how to address the client's individualized needs throughout treatment with appropriate services and techniques. Further, professionals with expertise must also assist in the safety planning process. Such plans should clearly identify ways to minimize the risk of intimate partner violence and TBI along with safe places where the victim can receive treatment and recover from injuries (Murray, Lundgren, Olson, & Hunnicutt, 2016).

In light of the serious consequences reviewed in this article, there is an immediate and ongoing need for

(continued on page 12)

(continued from page 11)

increased awareness of intimate partner violence and brain injury. This includes professionals working in law enforcement, forensic, criminal justice, mental health, medical, and social service settings. An essential path forward includes improving the accessibility of these professionals to education and training programs on the areas of intimate partner violence and brain injury, particularly programs that explore the intersectionality of these topics. In addition to broadening awareness, law enforcement agencies and organizations that serve survivors of intimate partner violence should adopt universal screening procedures for identifying brain injury.

> *Any individual identified with potential brain injuries must be strongly encouraged to receive a thorough assessment and any necessary treatment.*

SYMPTOMS OF STRANGULATION

VOICE CHANGES

Hoarseness or even complete loss of voice.

SWALLOWING CHANGES

Difficulty swallowing due to pain.

BREATHING CHANGES

Trouble breathing and hyperventilation

VISION CHANGES

Impaired or loss of vision

BEHAVIORAL CHANGES

Agitation, impulsiveness, concentration difficulties, and post-traumatic stress disorder symptoms

HEARING CHANGES

Impaired or loss of hearing

OTHER CHANGES

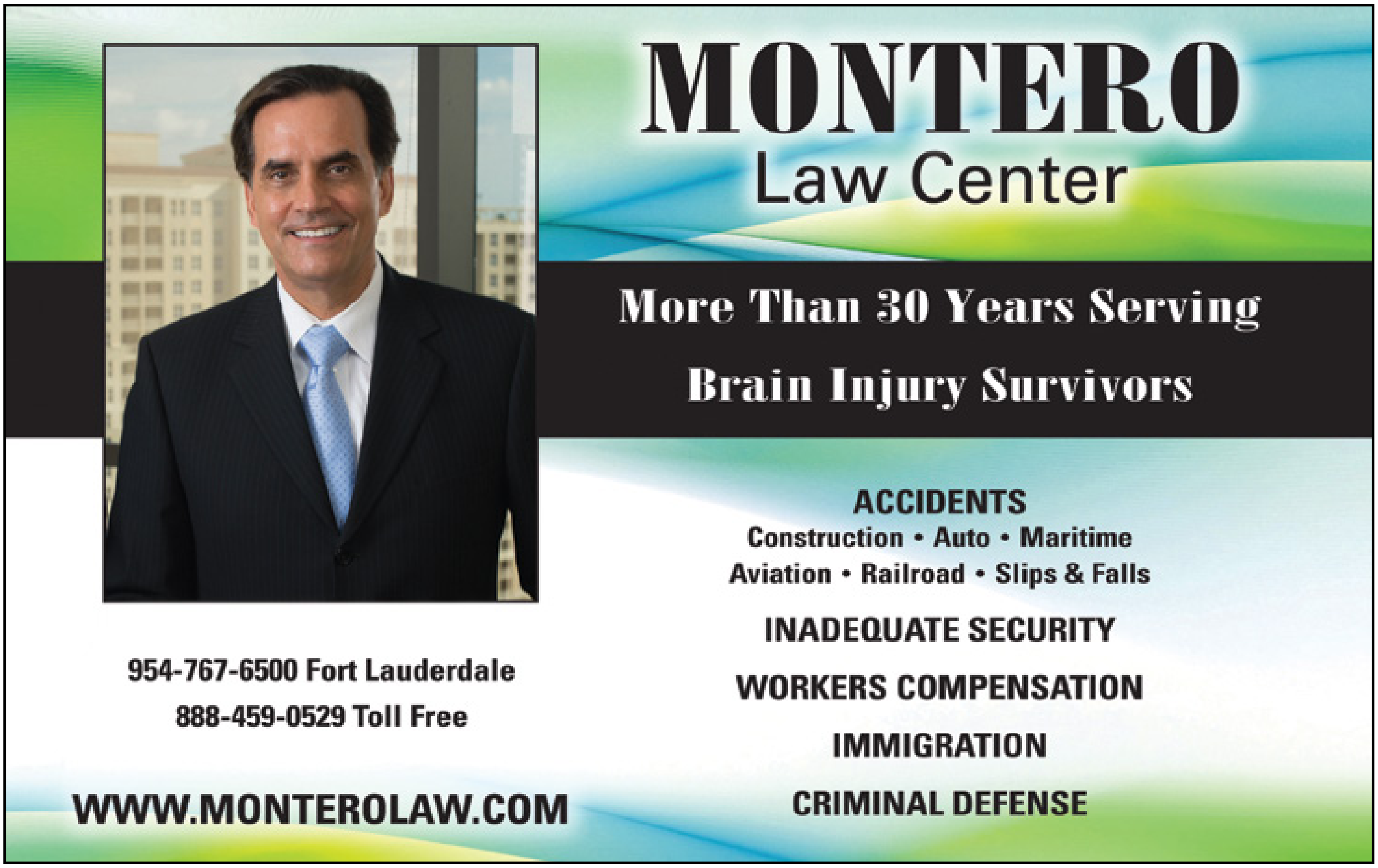
Unconsciousness, headaches, dizziness, memory impairment, coughing, and loss of physical strength.

Figure 1: Categories and Specific Symptoms of Strangulation

Author Biography:

Jerrod Brown, Ph.D., is Assistant Professor, Program Director, and lead developer for the Master of Arts degree in Human Services with an emphasis in Forensic Behavioral Health for Concordia University, St. Paul, Minnesota. Jerrod has also been employed with Pathways Counseling Center in St. Paul, Minnesota, for the past fifteen years. Pathways provides programs and services for individuals affected by mental illness and addictions. Jerrod is also the founder and CEO of the American Institute for the Advancement of Forensic Studies (AIAFS), the editor-in-chief of Forensic Scholars Today (FST), and a Youth Firesetting Prevention and Intervention (YFPI) Mental Health consultant for the Minnesota Department of Health (MDH). Jerrod is certified as a Youth Firesetter Prevention/Intervention Specialist, Thinking for a Change (T4C) Facilitator, Fetal Alcohol Spectrum Disorders (FASD) Trainer, and a Problem Gambling Treatment Provider. Jerrod has completed four separate master's degree programs and holds graduate certificates in Autism Spectrum Disorder (ASD), Other Health Disabilities (OHD), and Traumatic Brain Injuries (TBI). Jerrod has published numerous articles and book chapters, and recently co-authored the book "Forensic Mental Health: A Source Guide for Professionals" (Brown & Weinkauf, 2018) with Erv Weinkauf. Email address: Jerrod01234Brown@live.com

References available at www.biausa.org/domesticviolence



Contributing to a Better Future for Persons with Brain Injury

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

In 2013, Whitney Corby was a 19-year-old biology major and lacrosse athlete already dedicated to a career in the medical field. This all changed when one night while driving to the gym, her car slid on black ice and hit a tree. In addition to a traumatic brain injury (TBI), she suffered a fractured skull, a broken cheekbone, a broken collarbone, and bruised lungs.

She was airlifted to the closest Level 2 trauma center, which was a 15-minute flight from the site of her accident. Whitney was in a coma and does not remember anything that happened during the first few months of her recovery. When she awoke from the coma, she transferred to a rehabilitation center to undergo extensive rehabilitation lasting nearly six months. Working with speech, occupational, and physical therapists, she relearned how to talk, walk, eat, brush her teeth, and perform other routine tasks.

Whitney was eventually able to resume normal life. She re-enrolled in college, this time as a nursing major. Four years after her accident, she earned her degree and now works as a travel nurse for Medical Solutions while also working toward her master's degree in healthcare policy. Whitney hopes her story illustrates that there is hope after brain injury and that there are many resources available for those in need.

> **“I am thrilled to support BIAA, an organization that shares my commitment to creating better futures for people who sustain brain injuries, their family caregivers, and the professionals who treat them. As a TBI survivor, it is my hope that contributions like these can improve the quality of life for people affected by brain injuries.”**
>
> **– Whitney Corby**
> Brain Injury Survivor

Whitney’s TBI completely changed her life, but she wants everyone to know that she should not be treated differently. “I don’t want pity; I am a hard-working individual just like anyone around me. I go to work, come home, make dinner, and take a shower. I do everything anyone can do. I am not what happened to me.”

Because Whitney has been a source of inspiration and strength for others around her, Air Methods – the company that airlifted her after her accident – offered to donate $10,000 on her behalf to the charity of her choice. She chose the Brain Injury Association of America (BIAA) as she wanted to support its mission to advance brain injury awareness, research, treatment, and education.

Whitney explained, “I am thrilled to support BIAA, an organization that shares my commitment to creating better futures for people who sustain brain injuries, their family caregivers, and the professionals who treat them. As a TBI survivor, it is my hope that contributions like these can improve the quality of life for people affected by brain injuries.” ●

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www.biausa.org/support

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(continued on page 18)

(continued from page 17)

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(continued on page 20)

(continued from page 19)

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THANK YOU!

ADVOCACY UPDATE

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

BIAA Announces Legislative Agenda for 2019

As the 116th Congress begins, the Brain Injury Association of America (BIAA) looks toward critical legislative initiatives such as protecting access to health insurance as well as federal resources for individuals with brain injury. BIAA continues working to protect the Patient Protection and Affordable Care Act (ACA) and seeking increased funding for brain injury programs such as the traumatic brain injury (TBI) state grant program, TBI Model Systems of Care, and TBI programs at the Centers for Disease Control and Prevention and Department of Defense.

With many members of Congress retiring last year, rebuilding the Congressional Brain Injury Task Force is a top priority. BIAA has created legislative issue briefs for all of its priorities:

- Coordinate Federal Resources
- Increase Access to Care for Individuals with Brain Injury
- Bolster Research for TBI
- Improve Awareness and Understanding of Brain Injury
- Grow the Congressional Brain Injury Task Force

Visit www.biausa.org to download BIAA's 2019 legislative issue briefs.

BIAA Welcomes the 116th Congress

The 116th Congress, which convened January 3, is off to a historic start. Democrats regained control of the U.S. House of Representatives and elected Rep. Nancy Pelosi (D-Calif.) as Speaker of the House. Speaker Pelosi is the first to return to the post since Rep. Sam Rayburn in 1955. The House is also the most diverse ever, setting new records for both female and minority members. Key chairs are as follows:

- Rep. Nita M. Lowey (D-N.Y.), Chairwoman, House Appropriations Committee
- Rep. Rosa DeLauro (D-Conn.), Chairwoman, House Appropriations Subcommittee Labor-HHS-Education
- Rep. Frank Pallone, Jr. (D-N.J.), Chairman, House Energy and Commerce Committee
- Rep. Richard Neal (D-Mass.), Chairman, Ways and Means Committee
- Rep. Bobby Scott (D-Va.), Chairman, Education and Labor Committee

The House voted on a package of legislative rules, including a "pay as you go" requirement that would allow challenges to legislation that add to the deficit.

Republicans maintained control of the Senate in the midterm elections.

Congressional Brain Injury Task Force Plans Brain Injury Awareness Day

The Congressional Brain Injury Task Force, chaired by Rep. Bill Pascrell, Jr. (D-N.J.), set March 13 as Brain Injury Awareness Day on Capitol Hill. The schedule for the day is:

- **Awareness Fair, Rayburn House Office Building (RHOB) Foyer, 10 a.m. to 2 p.m.**
- **Briefing, RHOB 2043, 2:30-4 p.m.**
- **Reception, RHOB 2043, 5-7 p.m.**

For more information, visit www.biausa.org.

(continued on page 22)

(continued from page 21)

Congress Passes Medicaid Extenders Act of 2019

The House of Representatives and the Senate passed the Medicaid Extenders Act of 2019, H.R. 259, sponsored by Rep. Frank Pallone, Jr. (D-N.J.). The legislation provides three months of funding for the Money Follows the Person (MFP) program. States will have until Sept. 31, 2019, to spend the funds. The legislation also extends Medicaid's home and community-based spousal impoverishment protections until March 31, 2019.

The MFP program helps transition people with brain injury from nursing or institutional facilities to community-based services and supports and helps states re-balance their long-term services and supports systems to offer more community options. Medicaid's spousal impoverishment protections make it possible for an individual who needs nursing home-level of care to qualify for Medicaid while allowing their married spouse to retain a modest amount of income and resources to pay for rent, food, and medication as the spouse with a brain injury receives community-based long-term services and supports. BIAA has been working with the disability community in Washington, D.C., to advocate for this important legislation.

NIDILRR Publishes New Long-Range Plan

The National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR) has published a new Long-Range Plan for 2018-2023. The plan extends NIDILRR's emphasis on the major outcome domains of community living and participation, health and function, and employment. The plan also reinforces the need for investment in three areas that support outcomes across these domains: technology for access and function; disability statistics; and a nationwide network of technical assistance, training, and research centers to support implementation of the Americans with Disabilities Act. You can read the final plan at www.acl.gov.

Legislation to Expand Day Programs for Young People with TBI

Rep. Barbara Lee (D-Calif.) has once again introduced H.R. 320 to expand and enhance existing adult day programs for young people with neurological disease, including brain injury. If passed, the legislation will support and improve access to respite services for family caregivers.

Lawmakers Introduce the Disability Integration Act

The Disability Integration Act of 2019 would affirm the rights of people with disabilities and seniors who need long-term services and supports to live in the community in lieu of institutional services. Rep. James Sensenbrenner (R-Wisc.), along with 55 co-sponsors, introduced H.R. 555, and Sen. Charles Schumer (D-N.Y.) and 24 co-sponsors introduced S. 115 Jan. 15.

Rep. Beatty Re-introduces Concussion Awareness Bill

Similar to past years, Rep. Joyce Beatty (D-Ohio) introduced H.R. 280, the Concussion Awareness and Education Act of 2019. The purposes of the bill are to increase awareness of and knowledge about concussions and to change the culture surrounding concussions among elementary school youth and their parents, coaches, sports officials, educators, trainers, and health care professionals. The legislation establishes a Concussion Research Commission to review the report of the report of the National Academies entitled, “Sports-Related Concussions in Youth: Improving the Science, Changing the Culture,” and recommend corrections or updates to the report.

Legislation Calls for Eliminating the Sunset of the VA Veterans Choice Program

Rep. Richard Hudson (R-N.C.) introduced H.R. 23, the Care Veterans Deserve Act of 2019, to eliminate the sunset date for the Veterans Choice Program administered by the U.S. Department of Veterans Affairs (VA), to expand eligibility for the program, and to extend certain operating hours for VA pharmacies and medical facilities.

The Veterans Choice Program is one of several programs through which a veteran can receive care from a community provider, paid for by VA. For example, if a veteran needs an appointment for a specific type of care and VA cannot provide the care in a timely manner or the nearest VA medical facility is too far away or too difficult to get to, the veteran may be eligible for care through the Veterans Choice Program.

Domestic Violence and Sexual Assault Legislation

Rep. Anthony Brown (D-Md.) and 50 original co-sponsors introduced H.R. 511, the Protecting Domestic Violence and Stalking Victims Act of 2019. The legislation closes fatal loopholes in federal law that allow dangerous dating abusers, stalkers, and those subject to ex parte protective orders to have firearms. Sen. Amy Klobuchar (D-Minn.) introduced similar legislation, S. 120.

Rep. Ken Calvert (R-Calif.) introduced H.R. 505, calling for the U.S. Attorney General to identify and describe best practices for state, local, and tribal law enforcement officers and prosecutors in investigating and prosecuting sexual assault cases involving the victimization of women with disabilities.

Legislators Announce their Transformation to Competitive Employment Bill

Sen. Bob Casey (D-Pa.) and Rep. Bobby Scott (D-Va.) introduced the Transformation to Competitive Employment Act to eliminate the provision known as Section 14(c) in the minimum wage law that allows employers, such as sheltered workshops, to pay workers with disabilities a fraction of the minimum wage. The bills, H.R. 873 and S. 260, also include funding to support states and employment organizations to transform business models to support individuals with disabilities as they transition to competitive, integrated employment and track their outcomes in a six-year phase-out period.

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 2019:

- March 18-22
- April 15-26
- May 27-31
- 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. ●

STATE AFFILIATE NEWS

GEORGIA

The Brain Injury Association of Georgia (BIAG) had a very busy and successful 2018. Highlights included collaborating with the Georgia State University Department of Occupational Therapy to hold Camp BIAG 2018, hosting the "Think BIG" Symposium geared towards professionals and families concerned with health and wellness after brain injury, and having a successful Betting Big on BIAG event to raise awareness and funds to support the association's programs.

In November, the Brain Injury Association of America recognized BIAG with an Excellence Award for Programs and Services for the first virtual support group initiated in Georgia by Kelly Campbell, board member and Cobb Support Group leader. BIAG also welcomed three new board members: Chandni Bhardwaj, MBB, Regulatory Affairs Consultant at Boehringer Ingelheim; Arun Jain, MBA, retired VP of Motion Control at Siemens; and Gregory McAlvin, CTP, Commercial Relationship Officer with Renasant Bank. Together they bring a range of nonprofit and volunteer service.

BIAG receives BIAA's Award of Excellence in Programs and Services.

KANSAS

For six months, the Brain Injury Association of Kansas and Greater Kansas City (BIAKS) was part of the Chiefs' Kingdom! In early summer, the Kansas City Chiefs reached out to BIAKS and invited the organization to be a beneficiary of Chiefs season football ticket sales by helping them promote games. Who knew at that time the Chiefs would be Super Bowl contenders? Not only did BIAKS benefit financially through ticket sales, it had an opportunity to be part of the excitement that grew with each winning game. To cap off this winning season, Chiefs' Offensive Center Mitch Morse named BIAKS as the charity to benefit from the auction of his specialty cleats for the "My Cause, My Cleats" campaign.

Morse's relationship with BIAKS began last spring when he was named as honorary chair for its major fundraising event, Going the Distance for Brain Injury Run. His understanding of brain injury comes from growing up with a younger brother who sustained a TBI as a baby when a babysitter shook him.

The WellStar AMC Rehab Team supports the Atlanta Walk for Brain Injury.

LOUISIANA

The Brain Injury Association of Louisiana (BIALA) completed a strategic planning process in early 2019, resulting in a clear plan to carry out BIALA's mission and increase its capacity to provide service and support for Louisianans facing the consequences of brain injury. In March, BIALA will host its 12th annual conference, "Expanding Possibilities," to bring professionals, survivors, and caregivers together for two days of presentations, workshops, networking, and socializing.

The BIALA Board of Directors gather for a day-long retreat.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) wrapped up 2018 with its fourth annual Bowling for Brain Injury^{SM} event Dec. 2. The event was a great success with more than 80 bowlers raising $11,000!

The team from Creative Work Systems was the top fundraiser with more than $800 in donations!

BIAA-ME published the third edition of its Maine Brain Injury and Stroke Resource Directory, in both print and online formats, and is in the process of distributing the directory across the state. During Brain Injury Awareness Month, BIAA-ME will hold the fourth annual Maine Brain Injury Resource Fair in Augusta March 28. The event features exhibitors from across the state representing services, resources, and opportunities for the brain injury community.

MICHIGAN

The Brain Injury Association of Michigan (BIAMI) brought its Unmasking Brain Injury display to the Michigan State Capitol building last October. The 300-mask display included 12 Unmasking Brain Injury 2.0 project masks, which utilize QR codes linked to videos featuring survivors with their masks telling their brain injury stories. In bringing the masks to the state capital, Michigan's lawmakers were able to see how deeply brain injury affects the lives of their constituents and consider the impact the platforms and policies have on people with brain injury and their families. While many of the masks detail the difficulties survivors face on a daily basis, they also stand as a testament to the amazing level of rehabilitative care available in Michigan, without which many of these stories would have gone untold. As we begin a new year with a new legislature, we will continue to share these stories with our lawmakers to ensure they remember the survivors and their families who reside in their districts.

Visitors explore the Unmasking Brain Injury Display at the Michigan State Capitol.

(continued on page 26)

(continued from page 25)

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual Sports Concussions: Facts, Fallacies and New Frontiers educational programs from Feb. 26 to March 11 across Missouri. Youth sports and school personnel attended seminars and presentations to learn about concussion signs and symptoms, return to life activities, and the continuum of concussion care for youth athletes.


Survivors and families know they are not alone as they learn more about brain injury.

Survivor and Family Seminars are planned in Springfield and Kansas City in March and April. Survivors and family members discuss opportunities and suggestions on adjusting to life with brain injury. Seminar attendees participate in sessions about sensory coping strategies, depression, improving memory, and developing a support system. The same seminar topics will be offered in St. Louis this fall.

Individuals with brain injury can look forward to a week of fun, independence, and adventure at the BIA-MO Donald Danforth Jr. Wilderness Camp May 26-31. Family members will have a week of respite at home to rejuvenate emotionally and physically. For more information, visit www.biamo.org.

NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) ended 2018 with the Caregiver's Conference in November, when caregivers had an opportunity to network and listen to John Broderick, keynote speaker, as he shared a compelling story about his family's journey with mental illness. In addition, eight caregiving workshops were offered throughout the day. Topics included: Reaching for the Positives, I Have Lived Through It, Make the Most of Yourself So You Can Help Others, and more!

Keynote Speaker John Broderick shares a story about his family's journey with mental illness.

Upcoming events at BIANH include the annual Vertical Challenge March 9 at the pristine Bretton Woods Resort in the White Mountains. Proceeds from this event will help support veterans with brain injury. This year, there are two ways to participate: ski and find the letters to solve the anagram or snowshoe and compete with the best poker hand. Either way it is sure to be a fun day for all! In May, the 36th Annual Brain Injury and Stroke Conference will be held at the Grappone Conference Center in Concord. The keynote speaker, Francis R. Sparadeo, Ph.D., will discuss opioids, substance abuse, and brain injury.

NORTH CAROLINA

The Brain Injury Association of North Carolina (BIANC) continues its mission to offer help, hope, and healing and to be a voice for those facing the challenges of brain injury. The BIANC Family Conference will be held April 29 at the NC Aquarium and the BIANC Professional Conference is scheduled for Dec. 6-7 in Asheville.

In 2018, BIANC staff provided more than 140 specialized training sessions, reaching 5,000 individuals including sports clinics for middle school youth and Crisis Intervention Training for law enforcement. A third "Strike Out Concussions" baseball awareness event was held in August, and masks were added this year for the Unmasking Brain Injury project. The popular BIANC camp weekend will take place Oct. 4-6, 2019. Please visit www.bianc.net to learn more.

RHODE ISLAND

This past year has been one of growth for the Brain Injury Association of Rhode Island (BIARI). Once considered the state's best kept secret, the association is happy to report that this has changed. During the past year, BIARI helped more than 13,000 people – including more than 5,620 Rhode Islanders in the last quarter alone! This growth is due to its efforts to increase awareness and understanding of brain injury throughout the state.

In December, BIARI celebrated the holidays with the Jingle Bell Bash. This new event, which proved to be popular with members, was held at the historic Elks Lodge in Newport. The evening included dinner, a silent auction, a raffle, music, and dancing. A special appearance by Frosty the Snow-person delighted the children who attended.

BIARI brought the year to a close at its Annual Meeting. This meeting is always an opportunity to invite board members and supporters to meet each other, review what has happened during the year, and learn about the new initiatives and events planned for the new year. BIARI is excited to welcome three new board members from the local community: Todd Bard, President, Lee Energy Group; Marc Bialek, Director of Membership, Rhode Island Medical Society; and Shelly McCann, Director of Accounting, Collette Vacations.

The BIARI board and staff are looking forward to the challenges that 2019 will bring. In March, BIARI will hold its 18th Annual Statewide Brain Injury Education Conference and turn the State House blue for Brain Injury Awareness Month. Visit www.biari.org to learn more.

SOUTH CAROLINA

The Brain Injury Association of South Carolina (BIASC) partnered with Flourish, an award-winning PR, Marketing, and Events Firm in Greenville. They were quite the movers and shakers for the 8th Annual Shuck-A-Rama, celebrated Jan. 18 in Charleston. Attendees were treated to true Southern hospitality with a live Bluegrass band, silent auction, raw oysters, steamed oysters, chili, and all the fixings. There were more than 200 in attendance. Local celebrity news anchor Emily Gracey served as the emcee, kicking the event off by introducing Shuck-A-Rama Ambassador Emily Yarbrough and Host Committee Member Tate Mikell. Both Emily and Tate experienced brain injury and shared what BIASC meant to them along their journey. At the close of the event, everyone walked away with knowledge and a better understanding of BIASC's mission.

BIASC has received two substantial grants to increase advocacy and education of brain injury statewide. We are excited to welcome Freda King, BIASC's program coordinator, to lead our Advocacy Training for Youth with Brain Injury Project. Learn more at www.biaofsc.com.


Blue Stone Ramblers kick off the 2019 Shuck-A-Rama.

VERMONT

The Brain Injury Association of Vermont (BIAVT) updated its fundraising platform to include events, crowdfunding, and peer-to-peer fundraising. The next event is the Walk & Roll for Brain Injury May 18 in Montpelier. BIAVT has been expanding its social media presence, including a YouTube channel. Videos are in production to share the stories of Vermonters dealing with brain injury. The State TBI Advisory Committee is in the process of revitalization as part of the ACL grant. After surviving two feet of snow in 24 hours, BIAVT is ready for the next challenge!

BRAIN INJURY ADVISORY COUNCIL CORNER

CELEBRATING TEN YEARS OF BIAC

By Amy Zellmer, Brain Injury Association of America Advisory Council member

In 2009, Brain Injury Association of America (BIAA) President and CEO Susan Connors asked long-time volunteers John Richards and Anne Forrest to establish the Brain Injury Advisory Council (BIAC) to provide input to her on issues confronting BIAA. When Sarah D'Orsie, BIAA's former director of government affairs, launched the Self-Advocate Empowerment Program to train and support survivors to lobby Congress, the BIAC were the first participants.

The BIAC consists of a diverse group of brain injury survivors from across the country who have moved beyond the initial stages of recovery and are interested in supporting one another in advocacy and awareness-building efforts. The council comes together once a month to discuss advocacy and awareness at the national level, as well as what its members are doing locally in their states. The group's purpose is to represent the survivor perspective at BIAA, provide BIAA with feedback on policy issues, and advocate both collectively and individually on behalf of survivors in the United States.

BIAA often invites council members to participate in programming or asks for their perspectives on current issues. One of the key activities of BIAC is helping to shape Brain Injury Awareness Day on Capitol Hill. The council helps BIAA identify themes to suggest to the Congressional Brain Injury Task Force and encourages others to get involved and attend the event if able.

Council members are frequently asked to participate as panelists in congressional briefings. In March 2011, Anne Forrest was asked to speak about "The Value of Rehabilitation" and in 2017, Kelly Lang's daughter, Olivia, was asked to speak on the "Faces of Brain Injury: The Invisible Disability Affecting Children and Adults" panel.

Over the last ten years, the council has served as an opportunity for survivors' voices to be heard and to make an impact on legislative policies. Its members celebrate each other's victories and lift each other up in their time of need. With the support of BIAA, the Brain Injury Advisory Council enables survivors to be a larger voice and take their advocacy efforts to the next level.

"The BIAC has meant different things to me over the years. When I've undertaken projects to help others recovering from brain injury, fellow council members have been subject matter experts, advisors, and mentors holding me accountable to my goals. When I've struggled with effects of my own injury, they have been a personal support system, reminding me to be as patient with myself as I am with others. I am grateful for the way BIAC members inspire and motivate one another."
– **Sarah Lefferts**, Virginia, member since 2014

"The Advisory Council enables my learning of what practices are working across the country to reach for a better life post-brain injury. Collaboration is key to winning, especially in brain injury awareness."
– **Paul Bosworth**, Louisiana, member since 2009

"Being on the Brain Injury Advisory Council allows me to collaborate with other survivors on advocacy issues and gives me the opportunity to learn what other areas of the country are doing well. It also allows me to give and receive support from fellow survivors."
– **Kelly Lang,** Virginia, member since 2016

"Being on the council enhances my ability, as a TBI survivor, to positively influence the treatments and legislation surrounding brain injury throughout the United States of America."
– **Cavin Balaster,** Texas, member since 2016

"As a member of the Council, I value the opportunity to connect with other survivors who are leaders in the brain injury community. I appreciate being able to share the survivor perspective with BIAA and federal agencies."
– **Carole Starr**, Maine, member since 2016

"Being on the council has meant feeling valued and connecting with other survivors who feel that nobody should have to go through what we have [. . .] to get the care they need, the coverage, the understanding, the support."
– **Joshua Rouch**, Maryland, member since 2009

"The BIAC has allowed me take my advocacy work further by learning how to lobby for our rights at the Capitol, and working alongside other amazing, passionate advocates."
– **Amy Zellmer**, Minnesota, member since 2015

"It's so meaningful, and the inspiration I get from the other members is tremendous. We have an understanding of each other and have each other's backs."
– **Anne Forrest**, Texas, member since 2009

NEWS & **NOTES**

Brain Injury Voices:
Survivors "Paying it Forward"

By Carole Starr

Brain injury survivors working together can make a difference, and Brain Injury Voices, an award-winning survivor volunteer group in Maine, is proof of that. Survivors Carole Starr and Beverley Bryant founded Brain Injury Voices in 2010 with support from staff at New England Rehabilitation Hospital of Portland. The group began as a way for former patients to "pay it forward" at the hospital. Over the years, the group's reach has expanded into the local, state, and national brain injury community.

Since 2010, the group has volunteered more than 19,000 hours, completed more than 1,900 peer-mentoring sessions, and organized and delivered more than 180 presentations, workshops, and keynotes. Its members have transformed their individual tragedies into a collective force to benefit others, using their personal stories to educate others about brain injury, advocate for brain injury issues, and support other survivors through peer mentoring. In 2014, Brain Injury Voices received the prestigious Hospital Award for Volunteer Excellence (HAVE) from the American Hospital Association. You can view a full list of the group's accomplishments at www.braininjuryvoices.org.

Brain Injury Voices is a powerhouse survivor group whose success comes from its members, leadership, and the support of an organization. This combination is a model that Brain Injury Voices would like to share with other states. If you are a survivor or an organization interested in starting your own group, please contact Carole Starr at braininjuryvoices@maine.rr.com. ●

Brain Injury Voices members raise awareness of brain injury on Capitol Hill.

UPCOMING **WEBINARS**

Business of Brain Injury Webinar – Clubhouse Works! Full Participation in Rehabilitation

April 17, 2019, 3 p.m. EST/12 p.m. PT

Cindi Johnson, M.A., CBIST

Carolyn Rocchio Caregivers Webinar – Barriers, Behaviors, and Addiction Issues After Brain Injury

April 25, 2019, 3 p.m. ET/12 p.m. PT

Rolf Gainer, Ph.D., Principal, Rolf P. Gainer and Associates

David Strauss Memorial Clinical Webinar – Sexuality in Supported Living Programs

May 2, 2019, 3 p.m. ET/12 p.m. PT

Christine Nelson, MBA, M.Ed., MOT, CBIS, CDRS, and Paige Salinas, LCSW, CBIS, Pate Rehabilitation

Robert Sbordone Memorial mTBI/Concussion Lecture – Postconcussive Headache: A Pain in the Brain?

May 21, 2019, 3 p.m. ET/12 p.m. PT

Nathan Zasler, M.D., CEO, Concussion Care Centre of Virginia

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

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

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