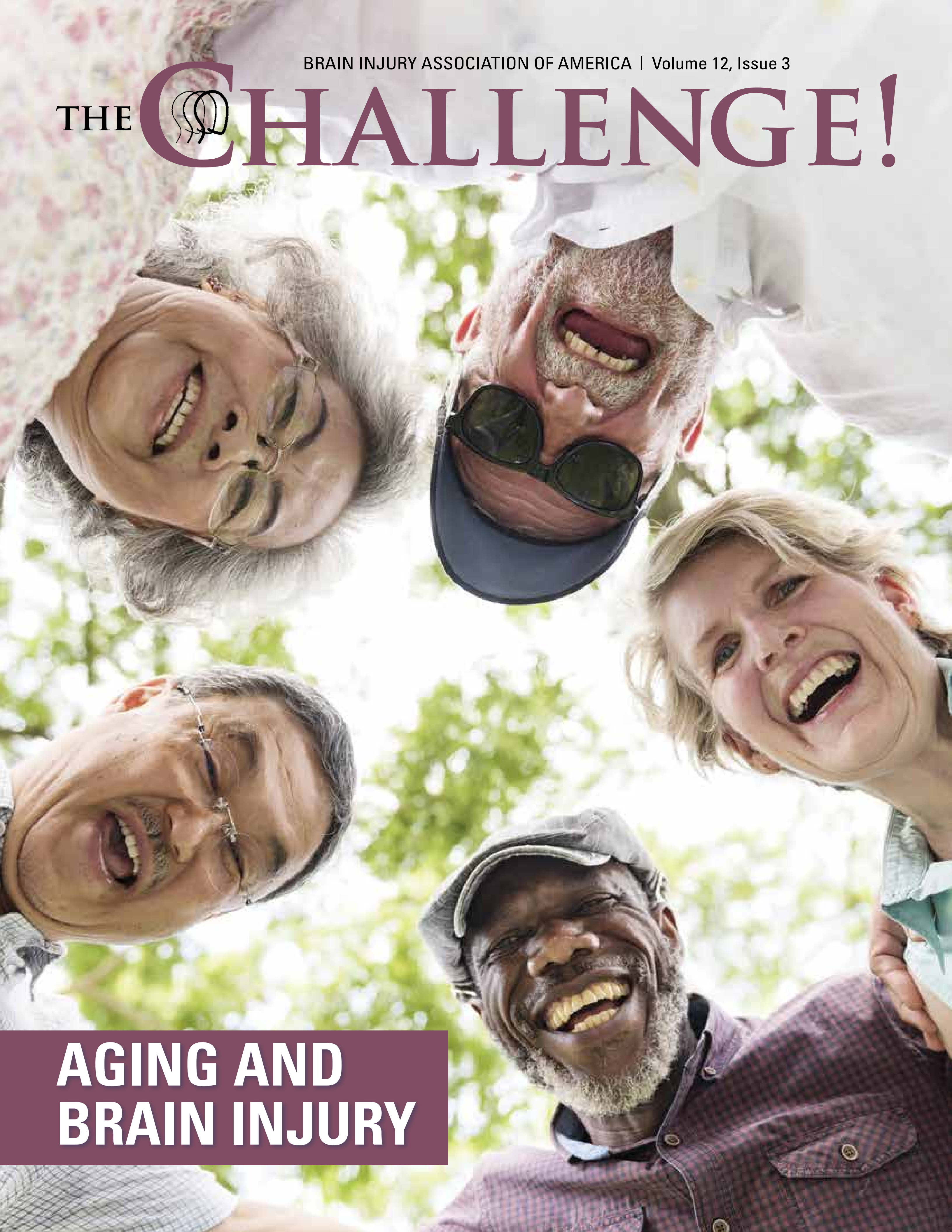
BRAIN INJURY ASSOCIATION OF AMERICA | Volume 12, Issue 3

THE CHALLENGE!



AGING AND BRAIN INJURY

BRAIN INJURY ASSOCIATION OF AMERICA

OCTOBER 2018

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Table of CONTENTS


4


14


12


24

From my **DESK**

BIAA joined with many other health and disability researchers and advocates in celebrating the 40th anniversary of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The agency oversees applied research programs that are important to individuals with brain injury, including the TBI Model Systems of Care.

Long-time NIDILRR employee Ruth Brannon, Ph.D., retired this fall as Director of the Office of Research Sciences. She tirelessly fought for the rights of nearly 40 million Americans who live with disabilities. In the Archives of Physical Medicine and Rehabilitation, Stephanie Kolakowsky-Hayner and Wayne Gordon note that during her career, Ruth elevated the scientific rigor of rehabilitation research, fought for inclusion of people with disabilities in the research process, and increased number and scope of NIDILRR's interagency research collaborations. She also strengthened the training of young investigators and broadened the pool of future researchers to include people with disabilities and those from minority-serving institutions. BIAA is deeply grateful for all that Ruth Brannon contributed to our community.

This summer, BIAA rolled out Brain Injury Fundamentals, a brand new training and certificate program designed specifically for family caregivers and non-licensed direct care staff. Pilot International, a 97-year-old worldwide service organization that is dedicated to brain health and safety, has established a scholarship fund to assist families in taking the training. For more information, visit the homepage of BIAA's website and enter "Pilot Scholarship" in the search box.

BIAA also launched its re-imagined Preferred Attorneys Program to help connect individuals with brain injury and their loved ones with attorneys who have demonstrated their knowledge of the physical, cognitive, emotional, and financial tolls a brain injury can inflict. If you're looking for legal representation for personal injury, financial issues or other matters, visit http://www.biausa.org/preferredattorneys to find a qualified attorney today.

BIAA proudly announces Eisenhower Center as our 2018 Giving Tuesday sponsor! Throughout the month of November, Eisenhower Center will match donations to BIAA of up to $5,000. The company has facilities in Ann Arbor, Michigan, and Jacksonville, Florida, where teams of experts in all aspects of neurorehabilitation are ready to address each person's unique rehabilitation path. BIAA is fortunate to have such a great partner to celebrate Giving Tuesday on November 28, 2018, and throughout the month. Please plan to make a generous donation this year.

As always, we are pleased to report what's happening on Capitol Hill and the accomplishments of our affiliates. We are also glad to share with you insider information about the people who support this great organization. We appreciate everything volunteers do to improve the quality of life for people with brain injury and their families.

Susan H Connors

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

SUCCESSFUL AGING

# of Individuals with Brain Injury

By Paul F. Aravich, Ph.D., Eastern Virginia Medical School, and Anne H. McDonnell, MPA, OTR/L, Brain Injury Association of Virginia

Successful aging is a goal for all creatures great and small. This is true for the lowly mayfly living one day and for the inspiring, if not scrawny, bristlecone pine tree living 4000 years. However, successful aging in people requires more than longevity: it requires the maintenance of physical, cognitive, and social function (Lowry, Vallejo and Studenski, 2012).

Aging is not a disease; it starts at birth and continues across various developmental life stages. But environmental and lifestyle factors play a more important role in successful aging than genetic factors. More research is needed to identify the modifiable environmental and lifestyle factors that are unique to long-term survivors of brain injury. This requires a leap beyond the simple biology to a greater understanding of the biopsychosocial model of successful aging.

The following 10 rules, built upon concepts identified by the Alzheimer's Association, are designed to promote successful aging in persons with brain injury:

Rule 1: Take Care of the Heart

Since brain injury survivors have an already increased risk for Alzheimer's disease, survivors with diabetes, hypertension, or an adverse lipid profile compound that increase their risk for heart disease and stroke. The promotion of successful aging in brain injury survivors requires a focus that goes beyond the brain and includes the early diagnosis and treatment of cardiovascular risk factors.

Rule 2: Exercise the Body

There is little doubt that physical fitness protects against the three leading causes of death in North America: heart disease, cancer, and stroke. It is also clear that moderate exercise promotes respiratory fitness and improves balance, reducing the risks of falls (which are a leading cause of traumatic brain injury). Regular movement also reduces the risk of deep venous thrombus (DVT) formation and premature death from pulmonary thromboembolism. Exercise is not just for rehabilitation – it promotes of successful aging. Consider innovative ways to overcome the limitations of brain injury, such as combining exercise with the virtual reality (Lee et al., 2003) and dance therapy (Pratt, 2004).

Rule 3: Exercise the Brain

There is good evidence that cognitively stimulating activities protect against Alzheimer's disease and other potential complications of aging with a brain injury. Stimulating your brain through intellectual activities like taking a class, learning a new language, and volunteering provides benefits for brain health and can affect how well the brain functions. Strategies building on the principles of music therapy (Kleinstäuber, et al, 2001), art therapy (Rentz, 2002), and theater arts (Noice et al., 2004) are beneficial in exercising the brain.

Rule 4: Feed the Brain

Nutrition is critical to successful aging; it is vital for immunity and essential for cognitive function. Evidence suggests that a Mediterranean diet, rich in whole grain, vegetable, fruit, and olive oil, is beneficial for overall health. A heart healthy diet, which is also a brain healthy diet, should also include regular fish consumption. Fatty fish are rich in various nutrients, including omega-3 fatty acids, which are associated with a reduced risk for Alzheimer's disease (Morris et al., 2003), potential benefits in mood disorders (Freeman, 2000), and the promotion of neuroplasticity.

Rule 5: Promote Mental Health

Mental illnesses, such as depression, bipolar disorder, and schizophrenia, are major risk factors for suicide and increase the risk of a traumatic brain injury (TBI) by 70% (Fann et al., 2002). Even without a pre-injury history, once a TBI occurs, the lifetime risk of depression is increased by 54% (Holsinger et al., 2002). Psychiatric disorders negatively affect successful aging by affecting cognition, emotion, cardiovascular fitness, and general quality of life. Issues of loss and social isolation, combined with the psychological burden of finding adequate housing, education, and transportation, are significant stressors affecting mental health. The importance of early and aggressive mental health interventions, the battle to reduce the stigma against mental illness, and the battle for health insurance parity for mental health coverage are imperatives for the promotion of successful aging.

Rule 6: Avoid Drugs of Abuse

Substance use increases the risk of brain injury and is linked to worse outcomes (Substance Abuse and Mental Health Services Administration, 2010); users are at greater risk of falls, seizures, and certainly damage from use of the substances themselves. Persons with brain injury are more susceptible to developing substance use disorders and they are often prescribed opioids after their injury to manage pain. Nearly 25% of people entering brain injury rehabilitation are there as a result of drugs or alcohol, and approximately half of people receiving substance abuse treatment have at least one brain injury (Brain Injury Association of America, 2018). It is important to recognize that drugs of abuse affect the reward circuitry of the brain, and once this circuit is injured, it is difficult for the chemically dependent person to just say no.

(continued on page 6)

(continued from page 5)

Rule 7: Avoid Social Isolation

It has been said that the human brain is a social brain. Fundamental human emotions like love and happiness depend upon social and physical contact with others. Animal research shows that social isolation causes physical injury to the brain and is associated with cognitive and emotional deficits (Whitaker-Azmitia et al., 2000). Social engagement and enrichment are essential requirements for brain fitness and successful aging in both survivors and caregivers.

Rule 8: Protect the Brain

While the human brain is one of the most miraculous things in the universe, it is also among the most fragile. A brain injury is terrible, but a preventable brain injury is much worse. Protection of the brain goes beyond personal protective equipment and includes regular fall assessments in older people and in people with disabilities (Chang et al., 2004). Protection of the brain also involves letting it sleep; driving skills of sleep-deprived people are similar to those who are intoxicated with alcohol (Arnedt et al., 2001). Sleep deprivation related to lifestyle issues and to various pathologies also impairs impulse control, cognition, mood, attention, abstinence from drugs of abuse, and immune function (Roehrs and Roth, 2004). Data indicate that more sleep disturbances occur in survivors with mild TBI than those with severe TBI (Mahmood et al., 2004). Protect your brain: get some sleep.

Rule 9: Form More Partnerships for Individuals with Brain Injury

Mental health, brain injury, and Alzheimer advocacy groups have overlapping issues regarding lack of services, social isolation, guardianship, end of life issues, stigma, and the need for respite care. It is obvious there should be close partnerships between brain injury, Alzheimer's disease, and mental health professionals. Brain injury can cause behavioral and psychiatric symptoms that are distinct from those associated with mental illnesses, and injury to the prefrontal lobes often impairs the empathy and bonding necessary for psychotherapy; these problems are not unlike the behavioral and psychiatric problems associated with the irreversible dementias.

Rule 10: Look for Greatness in Each Person

The human brain is the last frontier of science. We will know more about parallel universes, colliding galaxies, and black holes long before we understand the universe between our ears. The human brain has nearly as many neurons as there are stars in the Milky Way Galaxy (more than 100 billion). Each neuron makes connections with thousands of other neurons, and these synaptic connections change each time we do something, experience something, or learn something. This continuing, unrelenting reorganization of the brain is called neural plasticity. Another name for neuroplasticity is hope. Every person, with or without a brain injury, has a magnificent and unique brain. There are an infinite number of possible synaptic connections in every brain, injured or not. The organization of the human brain has limitless possibilities. If you look for greatness in people with brain injury, you will see it. If you look for greatness in caregivers, you will see it. If you look for greatness in other professionals, you will see it. Valuing the bonds you have with other people will help you as you age.

About the Authors:

Paul F. Aravich, Ph.D., is a neuroscientist and associate professor in the Department of Pathology and Anatomy and the Glennan Center for Geriatrics and Gerontology at Eastern Virginia Medical School in Norfolk, Va. He has served as Chair of the Virginia Brain Injury Council and as a member of the Governor's Public Guardian and Conservator Advisory Board, the National Alliance for the Mentally Ill of Virginia, the Southeastern Virginia Chapter of the Alzheimer's Association, and the Society for Neuroscience. His research interests include nutrition, exercise, and the brain.

Anne McDonnell, MPA, OTR/L, CBIST, is executive director of the Brain Injury Association of Virginia. She has 30 years of experience in brain injury rehabilitation across a continuum of hospital and community-based settings and holds a clinical faculty position in the School of Occupational Therapy at Virginia Commonwealth University. She is interested in increasing public awareness of brain injury, expanding community-based service options for survivors, and educating of survivors, caregivers, and professionals.

References available at www.biausa.org/successfulaging. ●

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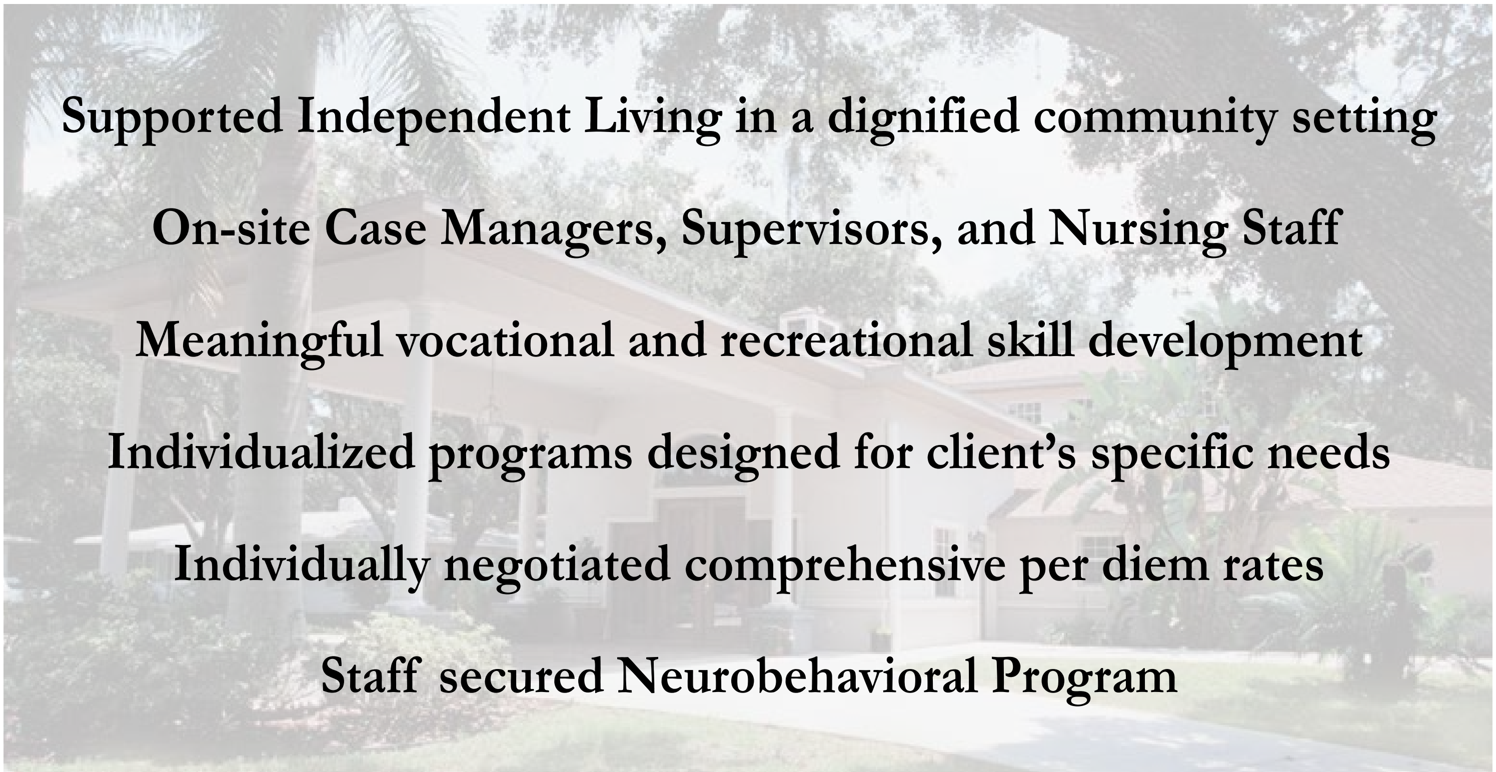

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Sander and Williams
Named as BIAA Award Recipients

Award Winners Recognized for Contributions to Research and Clinical Care

The Brain Injury Association of America (BIAA) announced Angelle M. Sander, Ph.D., as the recipient of the 2018 William Fields Caveness Award and Janet Williams, M.S.W., Ph.D., recipient of the 2018 Sheldon Berrol M.D. Clinical Service Award.

Each year, BIAA presents the William Fields Caveness Award in recognition of an individual who, through research on both a national and international level, has made outstanding contributions to bettering the lives of persons with brain injury.

Dr. Sander is Associate Professor with tenure in the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine and is Director of the Division of Clinical Neuropsychology and Rehabilitation Psychology. She is also Director of TIRR Memorial Hermann's Brain Injury Research Center and Senior Scientist on the TIRR Research Council. She served as Project Director for two NIDILRR-funded Rehabilitation Research and Training Centers on Traumatic Brain Injury and has been the Project Co-Director for the Texas Traumatic Brain Injury Model Systems at TIRR for past three cycles. Dr. Sander said, "I am incredibly honored to be the recipient of the Brain Injury Association of America's William Fields Caveness Award. Throughout my career, I have attempted to conduct research on topics that have practical importance to persons with brain injury and their caregivers. Being able to improve people's lives, in even a small way, is the greatest fulfillment for me as a researcher and clinician. Receiving this award is an honor because it confirms that I am moving on the right path toward making a difference in the lives of the people that I serve."

She has been Principal Investigator (PI) or Co-Investigator on federally funded studies addressing prediction and treatment of cognitive, emotional, and psychosocial problems in persons with TBI, intimacy and sexuality after TBI, impact of TBI on caregivers, and cultural disparities in outcomes following TBI. She co-chairs the TBI Model System Special Interest Group on Caregivers and Families as well as the Cultural Competency Special Interest Group. She has over 80 peer-reviewed publications, numerous book chapters and published abstracts, and multiple consumer-oriented dissemination products, including fact sheets, educational manuals, webcasts, and videos. Dr. Sander also serves as neuropsychologist for the inpatient rehabilitation units at Quentin Mease Community Hospital in Harris Health System and CHI Baylor St. Luke's Medical Center.

The Sheldon Berrol M.D. Clinical Service Award is presented each year to an individual who, through a long service career, has made outstanding contributions to improving the quality of care, professional training, and/or education in the field of brain injury.

Janet Williams, M.S.W., Ph.D., has been the President and CEO of communityworks, inc. and Minds Matter LLC since 1993. Dr. Williams is widely known as an expert in advocacy and independent living. She has designed a service delivery model that gives control back to the person with a brain injury, doing whatever it takes for someone to live in their own home. She has special interests in independent living, families and community-based rehabilitation.

Dr. Williams said, "I worked closely with Dr. Sheldon Berrol in the 1980s when I was the Director of Family and State Services at the National Head Injury Foundation (now the Brain Injury Association of America). His early work as a pioneer in recognizing the rehabilitation needs of people with brain injuries is widely known. He was also one of the first physicians to embrace the independent living movement, supporting the original Rehabilitation Act of 1974. Our early conversations about brain injury and the independent living philosophy has had a profound influence on my career. It is a true honor to receive this award in Dr. Berrol's name."

Dr. Williams is actively involved in local, regional, and national organizations and is devoted to collaborating with others to make sure people with brain injuries are involved in every conversation about their own lives. For more than 35 years, she has lectured extensively to broad audiences and written on a number of specific topics related inclusion for all people with disabilities and family systems.

The awards were presented at the American Congress of Rehabilitation Medicine (ACRM) annual conference Oct. 3, 2018, in Dallas, Texas. ●

An Update from the Administration for Community Living

By Dana Fink, Program Analyst, Independent Living Administration, Administration for Community Living

Four years have passed since stakeholders from across the traumatic brain injury (TBI) community advocated for the move of the TBI State Partnership Program to the Administration for Community Living (ACL). This advocacy recognized that ACL's overall goal, to maximize the independence of all individuals with disabilities, aligns well with lead state agency's efforts to make sure that all individuals who have sustained a TBI have access to the services and supports they need to live independently and fully participate within their community. It has been exciting to get to know the community during this time and to take steps to improve the impact of the program nationwide. ACL is privileged to work with so many knowledgeable and passionate stakeholders toward a future where all individuals who have sustained TBI, their families, and caregivers have access to the services and supports needed to thrive in their communities.

ACL has implemented several initiatives to achieve this, beginning with a new structure for the TBI State Partnership Program (SPP) during the 2018 to 2021 grant cycle, which began in June 2018. The 2018 Funding Opportunity Announcement included two opportunities to apply for the program as either a mentor or a partner lead state agency. Fourteen partner state grantees received funding to focus on establishing or augmenting existing state infrastructure, while 10 grantees serve as mentors are tasked with enhancing the national impact of the program and guiding a series of topic area-focused workgroups to assist partner states as they plan and pursue activities to improve TBI infrastructure.

This new structure funds an additional eleven lead state agencies that did not receive funding during the previous grant period. The program also formed nine workgroups focused on diverse topics including opioid use and mental health concerns in TBI communities, using data to connect people to services, and TBI support in criminal justice populations. Mentors meet with the partners in their workgroups on an ongoing basis throughout the grant period to provide guidance, identify gaps, and develop new initiatives. Mentor state grantees are also working with ACL on a workforce development initiative that aims to identify a common set of professional skills and competencies for providing culturally competent, person-centered services and supports to people with TBIs.

ACL is excited to continue working during the upcoming grant period on several other initiatives explained below.

- ACL is working to draft a Federal TBI Coordination Plan that assesses the landscape of federal TBI-related activities, identifies gaps, and offers strategies for addressing these gaps across federal programs. ACL conducted a series of stakeholder listening forums earlier this year to collect feedback about gaps in services and the lived experience of individuals throughout the TBI community, including TBI survivors, caregivers, and state agency representatives. ACL is currently working with federal interagency partners to incorporate this feedback and determine strategies to address gaps in federal agency coordination.

- The TBI Coordinating Center, the technical assistance center for the TBI State Partnership Program, is beginning to work with states to develop a new data presentation tool called The Community Snapshot. The TBI Coordinating Center held a webinar recently presenting a potential approach using mapping applications to bring together publicly available information with state program data to create intuitive map-based infographics tailored to the activities and goals of a particular state program. Lead state agencies can use these tools to communicate progress, identify gaps in services, and highlight the need for new initiatives. The TBI Coordinating Center seeks additional feedback and encourages stakeholders to contact them via email at TBICC@us.gt.com for more information.

- ACL is excited to announce the formation of the National Center for Advancing Person-Centered Practices and Systems (NCAPPS). NCAPPS will create a central clearinghouse and provide technical assistance to states on implementing person-centered thinking, planning, and practices in their systems. Once this work has launched, ACL will reach out to state agencies.

- The SPP is working with The Traumatic Brain Injury Model Systems National Data and Statistical Center at Craig Hospital in Colorado to determine potential methodology for collecting TBI incidence data including around the intersection of opioid use and abuse and brain injuries.

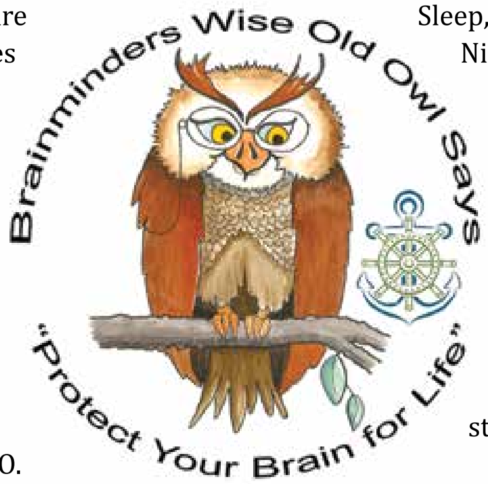
- ACL recently launched a public website for all TBI stakeholders at https://tbi.acl.gov/. Some of the website's content is still being developed and ACL would love to hear from stakeholders about useful content.

Each of these new initiatives relies on ACL's partnership with national partners, TBI state agencies, and other stakeholders across the country. ACL is grateful for all the hard work that you have done, and will continue to do, to ensure the provision of equal opportunity, full participation, and independent living for people with brain injury. ●

Pilot International Offers BrainMinders™ for Older Adults:

A Focus on Brain Health and Safety

Pilot International's signature program, BrainMinders™, is an entertaining educational curriculum covering a broad span of brain health and safety topics. With the theme "Protecting Your Brain for Life," BrainMinders™ includes specialized materials for children, youth, and older adults. The program is provided through Pilot Clubs across the country and overseas.



The older adult presentations are uniquely tailored for audiences that include independently living adults who take care of most of their daily needs or dependent adults who live in nursing homes or other senior care facilities. Informative and fun, they include proven exercises that help build new neural pathways. A favorite component of BrainMinders™ for older adults is the game BRAIN-O, a take-off on the popular game BINGO. Pictures on the BRAIN-O cards include: a Shower Bench, Caution: Wet Floor Sign, Bedroom Slippers, Eyeglasses, Microwave Oven, Lamp, Cat, Keys, Shower, Sticky Notes, Getting Out of Bed, Identification, Sleep, Electrical Cords, Bedspreads, Rugs, Night Lights, Medicine, Walking Cane, Clock, Shopping Cart, Shoes, Closet, and Walker. As each picture on the BRAIN-O card is described aloud, safety tips related to that item are shared with the participants. Of course, no BRAIN-O game is complete without fun prizes! Pilot Club members enjoy providing prize items like peppermints, Kleenex, and sticky notepads.

Individuals or agencies interested in scheduling a BrainMinders™ presentation may contact their local Pilot Club. You can search for a club on the Pilot International website at www.pilotinternational.org.

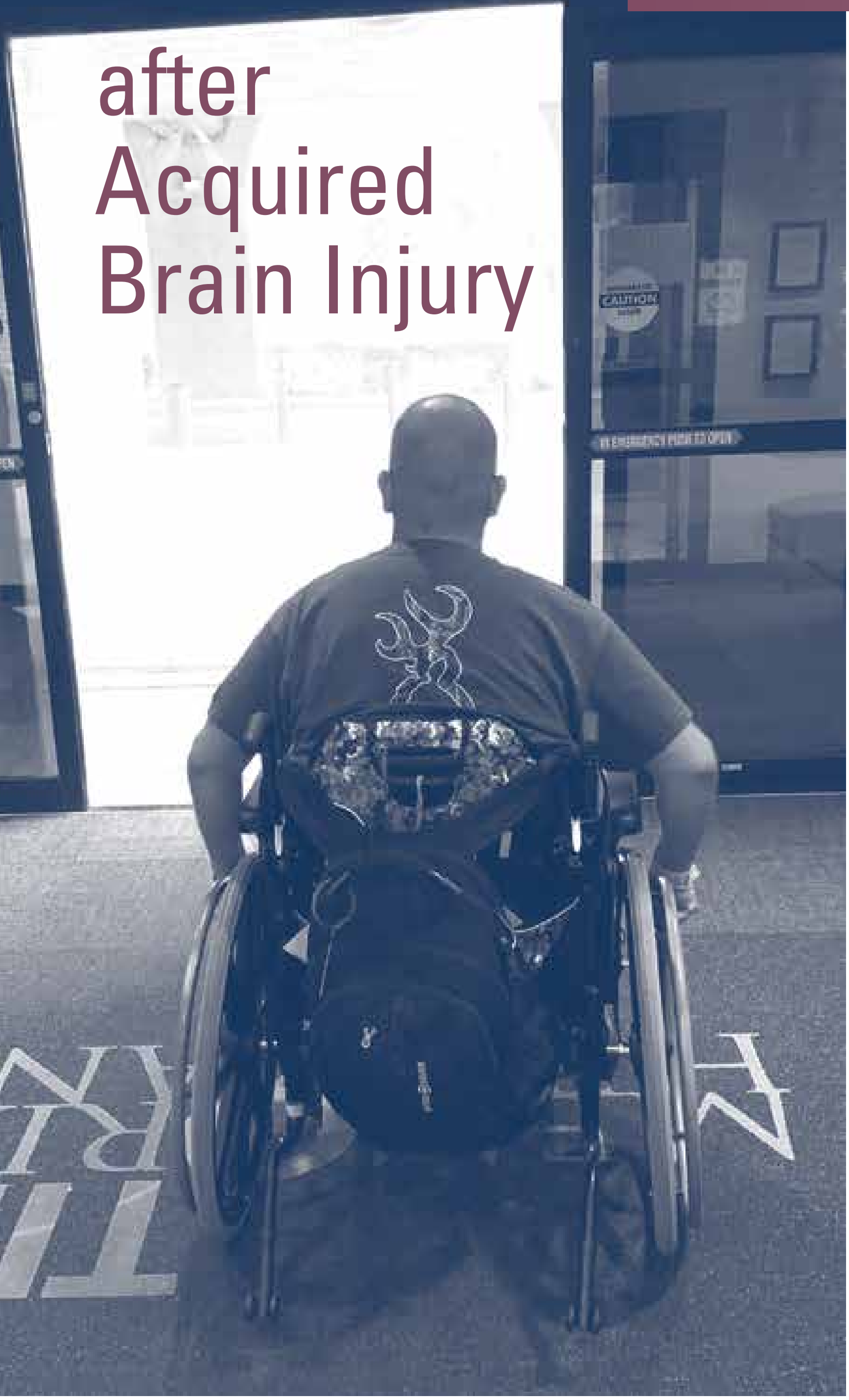
About Pilot International

Pilot International is a community-based volunteer service organization founded in 1921 in Macon, Georgia, on the principles of friendship and service. The name Pilot was inspired by the mighty riverboat pilots of that day who represented leadership and guidance. With more than 7,200 members in almost 300 Pilot clubs, Pilots are across the U.S., the Bahamas, Japan and South Africa. Pilots carry out their mission to "Do More, Care More and Be More" by providing financial and hands-on support for national and local initiatives in keeping with its causes of youth development and leadership, brain safety and fitness, and caring for families in times of need. In addition, there are more than 7,500 school and community based Anchor Club members worldwide. ●

Rebecca and Eddie Find Hope

after Acquired Brain Injury

Rebecca met Eddie in 2009. She was a pre-school teacher and he was a fabricator. They married in 2015 and had their daughter, Emilia, two years later. They loved spending time together as a family – going on road trips, camping, or working on home projects. But everything changed one March day.



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

Eddie was home sick with a stomach bug. While taking a nap, he experienced sudden cardiac arrest (SCA). Rebecca called on a neighbor to help and was able to perform CPR until medics arrived. Rebecca explains, "I won't describe the sights or sounds of seeing the person you love most slowly passing before your eyes. The feeling of doing compressions and crying out for help. I wouldn't wish that on anyone. That night was a blur for weeks, but now that the adrenaline has worn off and I've had time to process that event, I remember everything."

Eddie's heart stopped more than six times that night. The following day, Rebecca learned Eddie had suffered an anoxic brain injury, which is a type of brain injury that occurs when the brain is deprived of oxygen. Eddie's MRI showed significant damage to his occipital and temporal lobes as a result of the lack of oxygen and blood flow to the brain. He was unresponsive most of that day and unable to follow commands, and the treatment team began preparing Rebecca for the worst. Two days after Eddie's SCA, Rebecca was told to pray for a miracle.

Eddie spent nearly two months in the intensive care unit (ICU) under medically induced sedation. Rebecca had to quickly educate herself in order to advocate for her husband and to get him the help he needed. She found out about the Brain Injury Association of America (BIAA) through an online anoxic brain

> “Take support that is being offered, and get educated. Brain injury recovery is a marathon, not a sprint.”

After more than three months in various hospitals, Rebecca finally takes Eddie home.

Eddie holds his daughter, Emilia.

injury support group. BIAA provided her with the resources and support she desperately needed as she was struggling through such a difficult time. Rebecca was scared, but knew she had to keep calm so she could make the best decisions for her husband.

Rebecca spent nearly every day with Eddie, taking copious notes and documenting every aspect of his recovery. She felt it was imperative to be present and to continue learning about brain injury to ensure Eddie’s progress. “I had my moments where I was hopeful, but I’d be lying if I said I didn’t have my moments where I was inconsolable and completely crushed,” Rebecca offered. “I was thankful to have an amazing support system to help lift me up those first few weeks. Support from loved ones, our daughter, medical professionals, and prayer helped me get through the weeks.”

Eddie received inpatient treatment for nearly four months. He is now home, where he is walking, talking, and living life. Despite being cortically blind, Eddie hopes he will regain his vision with time and rehabilitation. Eddie also suffers from short-term memory loss; he doesn’t remember the year leading up to his injury or the day his daughter was born. Challenges remain, but both Rebecca and Eddie continue to take it day by day.

“I’m hoping by sharing our story that other couples will find strength from our journey,” Rebecca explains. “It’s not easy and this isn’t something anyone expects to be thrown into early on in their life. You have to choose each other every day and take the good and the bad. Your loved one is more than likely going to be in an incredibly vulnerable place.”

Rebecca feels grateful for the help and support she has received over the last few months. “As a caregiver, it’s imperative to reach out to organizations such as the BIAA,” Rebecca says. “Take support that is being offered, and get educated. Brain injury recovery is a marathon, not a sprint.”

Rather than accepting gifts for her birthday this year, Rebecca asked friends and family to donate to BIAA. She decided to hold a fundraiser through Facebook because she considers BIAA to be “a wonderful organization that devotes its time and effort to help families affected by brain injury.” ●

To learn more about hosting a Facebook fundraiser for BIAA, visit http://www.facebook.com/braininjuryassociationofamerica

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Ms. Holly Brosius
Mr. & Mrs. Bill and Tara Dugger
Ms. Tonya McLain

In honor of Lee Spivey's Birthday
Ms. Stephanie Jean

In honor of Lulu Winchester
Ms. Ashley Williams

In honor of Lynn Schaefer
Dr. Lyn Weiss

In honor of Maigan Alyssa Simi's Birthday
Mr. Chris Curtis
Vic Rigas
Ms. Christina Rodriguez
Ms. Kate Shonuff

In honor of Marilyn Dohanish's Birthday
Ms. Lori Lamers
Leslie Petiya
Ms. Erin Sheppard-Fitzgerald Benson
Ms. Cheryl Thomas

In honor of Mark Razniewski's Birthday
Mr. Brandon Bachner
Chris Gould
Mr. Maxwell Krause
Ms. Annie Miskella
Ms. Cynthia Raz
Ms. Cari Razniewski
Ms. Rosann Razniewski

In honor of Mary Alice Jenkins
Mr. Timothy Jenkins

In honor of Mervyn Chapman's Birthday
Charley Garrett
Mr. Bill Harris
Mr. Al Ruler

In honor of Rae Pittenger Yingling's Birthday
Ms. Vickie
Mr. Charles Fry
Mr. & Mrs. Richard and Laura Hess
Mr. Brian Hess
Ms. Tina King
Ms. Julie Marshall
Mr. Todd Morrow

In honor of Rick Barrera's Retirement
Mrs. Debbi Bonneau

In honor of Russok Kay's Birthday
Ms. Brittany Ahr
Ms. Rebecca Rutan

In honor of Shane Hayward's Birthday
Mr. Matt Francis
Ms. Loretta Hayward
Ms. Linda Sublette

In honor of Shane Reinhart's Birthday
Ms. Claire Butler
Ms. Jody Erickson
Mr. Justin Jerger

In honor of Shawnee Woolwine's Birthday
Ms. Lynda Eshelman

In honor of Skillet Burch's Birthday
Ms. Valerie Plucinski

In honor of Stacia Bissell
Ms. Katya Bowen

In honor of Steve Wright's Birthday
Ms. Amanda Doughty
Ms. Aimee Gasser
Mr. James Henry
Ms. Krissee Neff
Leslye Randall
Ms. Kathy Randall Wright

In honor of Steven Tswei Davies' Birthday
Mr. Steven Davies
Ms. Brooke Dendiu
Ms. Emily Long
Mr. Tyler Long
Mr. Bradley Olson

In honor of The Dorval Family
Mr. Ryan Waitt

In honor of Trish Shen's Birthday
Bilall Cela
Ms. Anne Chu
Quilma Afan
Sam Garrison
Lanilei Iva
Ms. Kara Jean
Ms. Meghan JG
Mr. Dan Li
Ms. Christine Madsen
Mr. Connor Shapiro
Mr. Marco Shen
Ms. Trish Shen
Ms. Steph White

In honor of Zina Karana
Mr. Kevin Hsu

MEMORIES

In memory of Aileen Drugan
Ms. Laura Hampton

In memory of Douglas Earl Hofeldt
Mr. Jeff Klaumann

In memory of Elizabeth Burkart
Drs. Chris and Gay Winters

In memory of Evelyn Benwire Lamb
Mrs. Carolyn Campbell
Mrs. Barbara Globerman
Ms. Georiga Kalhorn
Ms. Diana Lenik
Ms. Audrey Taylor

In memory of Gloria Stevens
Mr. & Mrs. Bill and Jan Stevens

In memory of Jessica Huse
The Jersey Mamas

In memory of John Gorospe
Ms. Sally Ormston

In memory of John Klossner
Alpha Gamma Rho - Iota
Ms. Lisa Behnke
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In memory of Karen A. Reitter
Ms. Mary S. Reitter

In memory of Leslie Craig Wise
Ms. Maureen Wise

In memory of M. Bernice Reitter
Ms. Mary S. Reitter

In memory of Malorie Hayhow
Mr. Peter Hayhow

In memory of Martha Sharkey Spinelli
Mrs. Mary McNamara
Mr. & Mrs. George and Dorothy Condoleon

In memory of Michael E. Bedard
Ms. Debbie Buitron

In memory of Michael "Mic" Maner
Mr. & Mrs. T. A. and Susan Miller

In memory of Nicholas E. Popovich
Ms. Jan Berger
Ms. Catherine Calvey
Ms. Elizabeth Calvey
Mr. & Mrs. Richard Losey
Mr. & Mrs. Patrick and Eileen McIntyre
Mr. & Mrs. Bryan and Kryl Carpenter
Mr. & Mrs. Pat and Val Edmonds

(continued on page 18)

(continued from page 17)

In memory of Paul M. Tulipano
Ms. Trudi Murphy

In memory of Paul S. Cohen
Ms. Marcia Greenfield
Mrs. Lynn Phillips
Mr. & Mrs. Samuel and Esther Rosenzweig

In memory of Richard Vieira
Mrs. Sharon Garber

In memory of Susan Eileen Losinski
Ms. Rose Mays

In memory of Susan Sidden's Brother
Mrs. Donna Zides

SUPPORT

In support of AGR Dairy Dash
Mr. & Mrs. Steve and Kathy Endres and Family

In support of Bowling for Brain Injury
The Billy Williams Foundation

In support of Bruce Clark
Mr. Neil Clark

In support of Ride for Lou
Ms. Barbara Davis
Mr. Patrick Gibbons
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Mr. & Mrs. David Leonard
Shane O'Connor
Ms. Maura O'Connor
Mr. & Mrs. John and Kathy Scribi
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Ms. Diane Waller
Ms. Robin Waters
Ms. Yevette Waul
Mr. Simon Younger

Thank You!

Advocacy UPDATE

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

Reps. Bill Pascrell, Jr., and Thomas J. Rooney Introduce TBI Legislation

Congressional Brain Injury Task Force Co-chairs Bill Pascrell, Jr., (D-N.J.) and Tom Rooney (R-Fla.) introduced H.R. 6615, Traumatic Brain Injury Reauthorization Act of 2018. The TBI Act of 1996, as amended in 2014, is the only federal legislation specifically addressing the needs of civilians with traumatic brain injury (TBI). Although current law authorizes funding through fiscal year 2019, the lawmakers introduced the legislation to commemorate the retirements of Sen. Orrin Hatch (R-Utah) and Rep. Rooney. The Senator was an original sponsor of the TBI Act, which authorizes funding to the U.S. Department of Health and Human Services (HHS) for the TBI State Partnership Program and the Protection and Advocacy TBI Program, administered by the Administration on Community Living (ACL). The law also authorizes the Center for Disease Control and Prevention (CDC) Injury Center TBI programs addressing prevention, surveillance, and public education as well as research conducted by the National Institutes of Health (NIH). H.R. 6615 will authorize the CDC to conduct a National Concussion Surveillance System. Sens. Hatch and Robert Casey, Jr., (D-Pa.) plan to introduce their bill in the Senate soon. Please contact your members of Congress and ask them to co-sponsor H.R. 6615 today!

WAYS TO ENGAGE WITH YOUR MEMBER OF CONGRESS

- Find your representative online at www.house.gov
- Call your representative through the Capitol Switchboard at 202-224-3121
- Visit your representative's website and send an email
- Follow your representative on Facebook and Twitter

Brain Injury Awareness Day on Capitol Hill 2019

The Congressional Brain Injury Task Force will host Brain Injury Awareness Day on Capitol Hill Wednesday, March 20, 2019. Please join BIAA in Washington, D.C. to advocate for access to care for individuals with brain injury! As in years past, there will be a brain injury awareness fair in the Rayburn House Office Building Foyer followed by a briefing and reception in the Gold Room.

BIAA Joins Friends of ACL

BIAA has joined a new coalition, Friends of ACL. The purpose of the group is to work together to assist the agency in pursuing its mission to help older adults and people with disabilities of all ages live where they choose, with the people they choose, and with the ability to participate fully in their communities. As the voice of brain injury on Capitol Hill, BIAA was invited to join this group. Other members include the Christopher and Dana Reeve Foundation, Amputee Coalition, National Disability Rights Network, National Centers for Independent Living, Association of University Centers on Disabilities, and the National Association of Councils on Developmental Disabilities.

(continued on page 20)

(continued from page 19)

BIAA Presents in SAMHSA Webinar on TBI and Veterans

The Substance Abuse and Mental Health Services Administration (SAMHSA) invited BIAA to present at a webinar that focused on TBI and veterans. The invitation came after a year of advocating to SAMHSA to highlight brain injury in its work. Greg Ayotte, BIAA's director of consumer services, presented with Lisa Brenner, Ph.D., Director, Rocky Mountain Mental Illness Research Education and Clinical Center. The webinar took place August 28, 2018. "Traumatic Brain Injury Among Service Members and Veterans: What Behavioral Health Providers, Families, and Peers Should Know" included an overview of BIAA's National Brain Injury Information Center and the new Brain Injury Fundamentals Program.

BIAA Pushes for Passage of the ABLE Adjustment Act to Benefit Persons with Brain Injury

As the current legislative session winds down, BIAA is working with the Senate Finance Committee members to obtain cosponsors for S. 817, the ABLE Age Adjustment Act. The legislation, which has also been introduced in the House of Representatives as H.R. 1874, would allow more individuals with disabilities to take advantage of an important savings tool by extending eligibility for use to people whose disability occurs before age 46.

Currently, 38 states have implemented ABLE programs, yet data collected by the National Association of State Treasurers shows the number of ABLE accounts being opened is much lower than anticipated. The long-term sustainability, availability, and affordability of some ABLE programs for individuals with disabilities are in doubt without this expansion of eligibility. We urge advocates to contact their members of Congress to support this legislation and ensure its passage prior to this session's end in December.

Senator Casey Introduces the Disability Employment Incentive Act

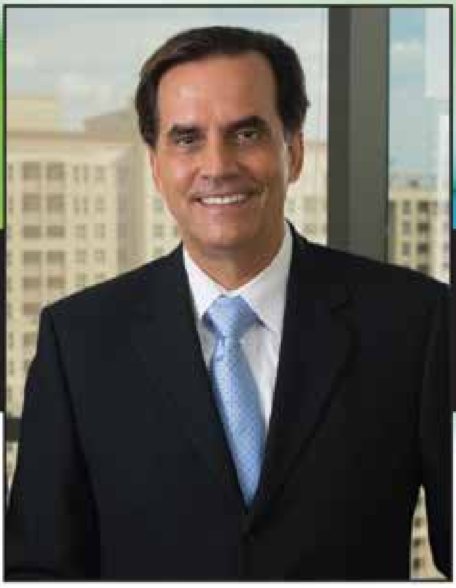
Sen. Casey introduced S. 3260, the Disability Employment Incentive Act (DEIA), July 24. This legislation would increase the Work Opportunity Tax Credit (WOTC), the Disability Access Expenditures Tax Credit, and the Architectural and Transportation Barrier Tax Credit. Among the provisions, the DEIA would increase the tax credit for employers who hire a person with a disability referred to them through a state Vocational Rehabilitation agency, a person who is receiving Supplemental Security Income (SSI) benefits, or a person who is receiving Social Security Disability Insurance (SSDI) benefits. The DEIA also provides a tax credit for any business that retains an employee for a second year of employment.

BIAA Opposes the Administration's Cuts to the Health Care Navigator Program

The Administration announced in July that it would cut funding for the Navigator Program from $36 million to $10 million. The Navigator Program supports nonprofit organizations in helping Americans buy individual health insurance coverage. Last year, the Administration cut advertising and other outreach activities carried out by the program by 40 percent. In response to these recent cuts, BIAA signed a letter to HHS Secretary Alex Azar and Centers for Medicare and Medicaid Services Administrator Seema Verma expressing concern that these cuts would hamper Americans' ability to obtain affordable coverage. The letter urges the administrators to restore funding for outreach and enrollment activities as soon as possible. The organizations also expressed deep concern that alternative health insurance products, including short-term, limited duration plans and association health plans (AHPs), would be promoted alongside comprehensive, Affordable Care Act-compliant plans as well as Medicaid and Medicare. AHPs and short-term plans have a long history of leaving enrollees with medical debt while also denying coverage for even basic medical care.

President Signs Veterans Bill

In June, President Trump signed the VA Mission Act, which combined a number of existing private-care programs, including the Veterans Choice Program, administered by the U.S. Department of Veterans Affairs (VA), and expanded private health care options. The VA Mission Act also expands caregiver assistance to the families of veterans with disabilities. The Choice Program allowed veterans who lived



more than 40 miles from a VA facility or had to wait more than 30 days for an appointment to have access to private care, but the program was time limited and was to run out of funding May 31. VA continued funding until this bill was enacted.

The legislation expands caregiver assistance over two years to veterans of all eras, which was previously was limited to post-9/11 veterans. The Congressional Budget Office has estimated that more than 41,000 caregivers could be added to the program over the next five years at a cost of nearly $7 billion.

President Signs Opioid Bill

The Senate and House leadership reached consensus Sept. 26 on a package of 70 bills that had passed both bodies separately. The President signed this legislation into law Oct. 11. The legislation includes the STOP Act to help stop the shipment of synthetic opioids; extends support for Medicaid patients seeking treatment from 15 to 30 days, covering all substance use disorders; and permanently allows more medical professionals to treat people in recovery to prevent relapse and overdose. The bill also allows the FDA to require prescription opioids to be packaged in set amounts such as a three- or seven-day supply in blister packs and will help spur the development of a non-addictive painkiller.

President Signs Appropriations Bill into Law

The appropriations package passed by Congress Sept. 26 was signed into law Sept. 28. The House of Representatives passed the Conference Report for fiscal year 2019 appropriations for the Departments of Defense, Labor, Health and Human Services, and Education, including a Continuing Resolution (CR). The CR provision temporarily funds remaining government programs until Dec. 7 of this year.

The TBI Act programs were funded at $11,321,000, which is $2 million more than the previous year and above the President's budget request. The bill provides a $2 billion increase to NIH for research. A total of $6.6 billion was appropriated across federal programs to fight the opioid abuse epidemic by supporting prevention, research, and other efforts to end the national crisis.

(continued on page 30)

State Affiliate NEWS

KANSAS

The Brain Injury Association of Kansas (BIAKS) began a volunteer visitor program for brain injury patients and their families in March at the University of Kansas (KU) Medical Center Acute Inpatient Rehabilitation unit. Two trained survivors and one trained spouse have helped BIAKS pilot this program. BIAKS developed the program in response to a suggestion by a KU Traumatic Brain Injury (TBI) Clinic Nurse who had experience with a similar program for stroke survivors. After a series of planning meetings and the training of three volunteers, BIAKS launched the program.
The visits are voluntary and coordinated by KU staff. Trained volunteers introduce themselves, share their experiences, and encourage questions, while BIAKS staff members share materials and contact information. The volunteers also encourage patients and their families to reach out to BIAKS to learn about support groups and community referrals as they adjust to life after brain injury.

"As I look back I would have found it very comforting to speak to someone that had been in the situation my wife and I were in. It is very rewarding to be able to fill that role now. We want to provide them with information but most importantly we want to provide them with the most powerful tool to their recovery: the hope and strength to move forward," explains a volunteer. So far, the team has met with 14 patients and family members. BIAKS plans to conduct a comprehensive evaluation prior to formalizing and expanding the program beyond KU.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) recently wrapped up Year 4 of the TBI State Partnership grant from the Administration for Community Living (ACL). Since the start of the grant, BIAA-ME staff members have assisted more than 700 individuals and families through information and resource facilitation services, provided education for 92% of Maine's hospitals, and conducted outreach at more than 40 brain injury support groups, community organizations, brain injury rehabilitation programs, and events throughout the state.

The ninth annual conference on Defining Moments in Brain Injury took place Oct. 16 in South Portland. Susan H. Connors, BIAA's president and CEO, presented her keynote, "The Brain Injury Association of America – Your National Organization at Work." The conference featured five tracks: clinical/allied health, alternative, survivor, family, and youth concussion management training.

BIAA-ME's fourth annual Bowling for Brain Injury^{SM} event is scheduled for Dec. 2 at Spare Time Portland.

MICHIGAN

Advocacy has been and will always be a cornerstone of the Brain Injury Association of Michigan (BIAMI). As such, BIAMI gathered a number of organizations to form the Michigan Disability Supports Alliance (MiDSA) to fight the ACA repeal and protect Medicaid

▲ MiDSA speakers Barb Valliere and Brett Williams encourage voters with disabilities to exercise their rights at a recent presentation.

last year. All involved were cognizant of the fact work needs to be done at the state level not only to preserve crucial programs like Medicaid, but also to ensure the well-being of Michigan residents living with disabilities.

This year, MiDSA has developed an initiative to educate and encourage those living with disabilities to vote in the upcoming election. MiDSA members hosted presentations across the state, starting in August, to explain why it is important to vote, the voting rights granted to those with disabilities, the responsibility all voters share, and issues regarding accessibility at polling stations. Attendees can also register to vote during these presentations.

MiDSA has grown since last year. Partner organizations include the Michigan Department of Health and Human Services, Disability Rights Coalition, Michigan Developmental Disabilities Council, Epilepsy Foundation of Michigan, Michigan Protection and Advocacy Services, Michigan Disability Networks, and Wayne State Developmental Disability Institute.

MISSOURI

The Brain Injury Association of Missouri (BIA-MO) hosted its annual Donald Danforth Jr. Wilderness Camp May 27 to June 1, 2018. Approximately 70 survivors of brain injury enjoyed a week of fun, independence, and adventure as they ziplined across the lake, played sports, danced, and walked along nature trails. Family members had a week of respite to rejuvenate emotionally and physically. Campers took part in the Walk Float Swim Challenge, an activity allowing family and friends to sponsor laps around the pool or campground that raised nearly $2,000.

Bowling for Brain Injury Missouri℠ was held in Springfield and St. Louis, with 200 bowlers and spectators in attendance. Attendees and organizers raised more than $22,000 to increase awareness of brain injury and provide support for survivors and families in Missouri.

The BIA-MO Annual Statewide Conference took place Oct. 4-6 at the Marriott St. Louis West Hotel. The conference was dedicated to innovative therapeutic strategies, cutting-edge and best practice treatment options, and current research. For more information about other BIA-MO events, visit www.biamo.org.

▲ Bowling for Brain Injury℠ Missouri's top fundraising team, Sargent Strike Club, shows support for BIA-MO.

▲ Campers enjoy the Donald Danforth Jr. Wilderness Camp this summer.

(continued on page 24)

(continued from page 24)

RHODE ISLAND

The Brain Injury Association of Rhode Island (BIARI) and the Dr. Martin Luther King, Jr. Community Center of Newport joined forces in June to distribute free bike helmets to 30 children. Each child was fitted with a bicycle helmet, had his or her bicycle inspected for safety, and was educated about why wearing a helmet is so important. BIARI receives bicycle helmets through donations from the Billy Andrade-Brad Faxon Charities for Children and the Chartercare Foundation. Distributing helmets helps BIARI to further its mission of increasing awareness of brain injury, providing education to prevent brain injury, and enhancing the quality of life for those affected by brain injury.

With some of the biggest names in golf, the CVS Health Charity Classic event celebrated its twentieth year in June as one of the largest charitable events in Rhode Island. BIARI once again stepped up to the tee for the twentieth time and recruited more than 35 volunteers to assist at the event. This year's tournament took place June 25 and featured six PGA golfers, six LPGA Tour golfers, and six PGA Tour Champions. Longtime volunteer and former BIARI board president, Mike Baker, was excited to support BIARI and enjoyed meeting some of the greatest golfers of all time. The CVS Health Charity Classic awards BIARI with an annual donation for its participation, helping the association to continue providing services and support to more than 13,000 Rhode Islanders annually.

Thanks to a generous sponsor, BIARI has initiated a veterans outreach program. The program is currently in development and will be managed by Jeremy Tolleson, a Veteran U.S. Army Medic with a background in social work, occupational therapy, and work with people with special needs. A veterans employment and training counselor with the Rhode Island Department of Labor and Training (DLT) and Intensive Services Coordinator between DLT and the VA Vocational Rehabilitation and Employment Program, Jeremy has extensive experience and a valuable network in the veteran community. We are so glad he has joined the BIARI team.

▲

BIARI Community Relations Manager Robyn Chapman and volunteer Kevin Aldrich show their support at the CVS Health Charity Classic.

◀

Rhode Island and staff of the Dr. Martin Luther King, Jr. Community Center of Newport, R.I. are all smiles!

SOUTH CAROLINA

The Brain Injury Association of South Carolina (BIASC) along with its partner, the South Carolina Brain Injury Leadership Council, held the annual Statewide Life with Brain Injury Conference July 27. There were a variety of sessions ranging from Brain Injury 101 to crafts and Tai Chi. More than 30 exhibitors were present to provide information about their services.

Barbara and Brennen Barber, mother and son from Prosperity, gave the keynote address. The speech, "Not Less – Just Different" centered around the personal experience of an excited parent in the stands as she watched her son play his senior year of football who transformed into a helpless parent as she saw her son go down on the sidelines after a helmet-to-helmet hit. Due to the quick response of the team's athletic trainer from the University of South Carolina, Brennen was airlifted to Palmetto Richland Children's Hospital, where it was discovered that he had a subdural hematoma and was in critical condition. Brennen's recovery and new outlook on life has been an inspiration to others. Prior to the accident, Brennen was diagnosed with Attention Deficit Disorder, which only intensified with his injury. He misses doing many of the things he did prior to his injury but says, "Accomplishments for some people may take me a longer time, but that does not mean that I am less valuable, just different."

▲ BIASC's Executive Director, Joyce Davis, is flanked by keynote speakers Barbara and Brennen Barber at the Statewide Life with Brain Injury Conference.

The conference was a huge success, and BIASC is looking forward to showcasing awareness and education at next year's conference. While the Run For Thought has been held every October, this year's event had been moved to March for Brain Injury Awareness Month 2019. Visit www.biaofsc.com for the new date and location.

VERMONT

The Vermont Department of Disabilities, Aging, and Independent Living (DAIL) was chosen by ACL as one of 24 recipients of a three-year cooperative agreement under a new funding opportunity for ACL's Traumatic Brain Injury (TBI) State Partnership Program. Vermont will receive approximately $150,000 per year for three years (2018-2020). During the three-year period, DAIL, in partnership with the Brain Injury Association of Vermont (BIAVT), the Vermont Department of Corrections, the Vermont Department of Health, and key stakeholders, will

▲ Attendee Hannah Deene Wood has a great time at BIAVT's Walk for Thought.

(continued on page 26)

(continued from page 25)

expand and enhance the infrastructure of the TBI System of Care in the state. The state's objectives for the TBI Partnership Grant include improving the surveillance of TBI; improving care transitions for individuals with TBI and their families/caregivers; improving ease of access to programs and community support services; implementing screening for TBI upon entry into the correctional system; and creating a person-centered culture in the correctional system for underserved individuals with TBI.

▲ The Surviving Well team enjoys the Walk for Thought.

BIAVT's Concussion Task Force is working with two school systems to implement a pilot program to assist schools in working with students with concussions. BIAVT has also been keeping busy with its annual Walk for Thought, which was held in May. The weather cooperated again to make it a delightful event. To learn more about BIAVT's upcoming events, visit www.biavt.org. ●

Brain Injury
ADVISORY COUNCIL CORNER

Member Spotlight: Kelly Lang

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

Kelly Lang was about a mile from home, taking her daughter to rehearsal for The Nutcracker, when she was rear-ended at a stoplight 17 years ago. The car hit two other vehicles before hitting hers, pushing Kelly's car so far forward it ended up suspended on a guardrail.

In the backseat were her daughters, Hannah, 5, and Olivia, 3. Once the car stopped, Kelly was unconscious, but woke up to the sound of Hannah screaming, "Mommy, wake up!" She remembers the EMTs talking to her, but doesn't remember any details other than being repeatedly asked if anyone was seated in the third row. Later, after seeing the vehicle, Kelly understood why they kept repeating the question –no one would have survived there.
First responders transported the Lang family to the local emergency department (ER) about four miles away. Olivia was code blue at the scene, barely breathing and struggling for her life. The local hospital was not equipped for pediatric trauma, so she had to be transferred to the nearest pediatric unit in Fairfax, Virginia.

In her daze, Kelly thought to ask the ER nurse to call a friend to accompany Olivia to the Fairfax hospital. Hannah was physically okay, though she would later suffer from PTSD. Kelly called one of Hannah's school friends to pick her up so she could spend the night with another family at their home.

After a few hours, the ER released a shoeless Kelly to the care of a friend. She was given scrubs to wear home, but Kelly and her friend quickly headed to the Fairfax hospital to be with Olivia. While on the way, Kelly was shocked to look into the mirror and discover that she had two black eyes and a bloody nose with dried blood all over her face. She couldn't believe they had let her leave the ER looking like that! She would have a lot of pain over the next few days.

At the pediatric trauma facility where Olivia was receiving treatment, Kelly found her three-year-old girl intubated and suffering from a traumatic brain injury (TBI). The doctors explained that they would have to perform surgery if the swelling inside her skull didn't go down. Luckily, Olivia's swelling ceased and she did not need the surgery. She had fractured the back of her skull, and they were monitoring three or four bleeds in her brain. She was in a coma for roughly 10 days. Approximately two weeks after the accident, Olivia relocated to a pediatric rehabilitation hospital in Baltimore, Maryland.

After Olivia came home from inpatient rehabilitation, the Lang family started to notice that something was wrong with Kelly. She was very fatigued and her husband often had trouble waking her. She went to her general practitioner who sent her to a neuropsychologist immediately. Kelly was diagnosed with Post Concussion Syndrome (PCS).

(continued on page 28)

(continued from page 27)

In 2002, Kelly attended a support group for parents of kids with TBI, and discovered a community-based organization called Brain Injury Services (BIS), where Olivia was immediately accepted. BIS encouraged Kelly to apply and she joined their speaker's bureau in 2006. The bureau ended up being extremely therapeutic for her, and she remains an active member.

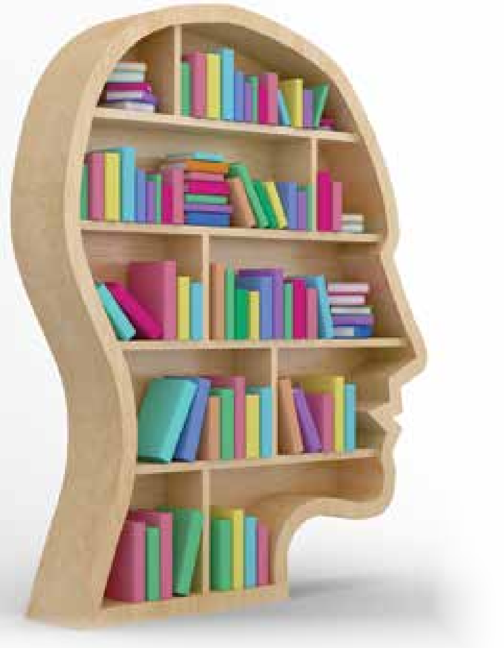
Through BIS, Kelly eventually met Anne Forrest, who connected her with the Brain Injury Association of America (BIAA). In 2006, Olivia was on BIAA's poster to promote Brain Injury Awareness Month. In 2011, Kelly joined BIAA's Brain Injury Advisory Council (BIAC).

Olivia graduated high school in 2017 and now attends a local community college, taking two classes per semester. She was a panel member at Brain Injury Awareness Day in 2017. Together, Kelly and Olivia are actively involved in spreading awareness of brain injury. Kelly stated, "This whole experience has taught me how to advocate and share our story, hoping to help others."

How has the Brain Injury Advisory Council changed your life?

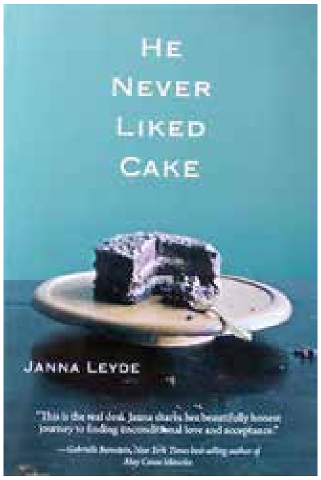
It has given me resources, advocacy opportunities, and learning opportunities. It has put me in touch with a lot of professionals in the brain injury community as well as other advocates.

▲ Kelly and Olivia show off BIAA's brain injury awareness poster, featuring a young Olivia.



The BIAA BOOKSHELF

By Roxane M. Dean, Social Worker, Carolinas HealthCare System



I just finished an extraordinary book, "He Never Liked Cake" by Janna Leyde. I have read many stories about traumatic brain injuries (TBIs), most of which were written by persons with brain injury, their spouses, or their parents. This is the first account I've read by a daughter.

John Leyde was a dynamic individual and a terrific dad. He taught his only child to swim at nine months and to waterski at six years. His wife, Claire, had Janna on a horse before her first birthday! They were an athletic, active, and happy family.

One summer day, 13-year-old Janna was waiting for her dad to pick her up and take her and her friends waterskiing. Then the call came – the call we all dread.

John was a seat-belted passenger in a horrible car accident. The jaws of life extracted him from the scene and he was life-flighted to an intensive care unit (ICU) nearby. John had a significant brain injury with damage to the frontal and occipital lobes, and spent many weeks in the hospital before transferring to a rehabilitation hospital.

It soon became obvious to the family that John had major deficits and was not the man everyone knew before the accident.

The reader feels like a member of the family, experiencing frustration at the runaround Janna's mother gets from the worker's compensation representatives. After the initial injury, treatment, and rehabilitation, the insurance company decided the treatment was complete. They had no concept of brain injury or the impact one inflicts on the individual and/or his or her family. John was not responsible for his injury in any capacity, yet continued brain injury rehabilitation was repeatedly denied.

This story is told through the eyes of a thirteen-year-old girl who searches for the father she adored. Soon after the accident, a dear family friend told Janna, "No matter what happens, this is part of your story. You can always tell it that way – like a story. This will not be your entire life, just one piece."

I thought about his advice. Brain injury is not the whole story, but it becomes a huge part of our stories and often stays with us our whole lives.

"He Never Liked Cake" is Janna's story. For more than 20 years, she struggled with her father's impulsiveness, addiction issues, and lapses in judgement. Again, what makes this book unique is seeing it through the eyes of a teenager and young adult robbed of the father she knew.

I won't tell what the title means; you'll have to read the book! You can get your copy at https://shop.biausa.org. ●

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BRAIN INJURY ASSOCIATION OF AMERICA

CAROLYN ROCCHIO

CAREGIVERS WEBINAR

Managing Stress as a TBI Caregiver: A Mindful Approach

November 8, 2018, 3 p.m. ET/12 p.m. PT

Angelle M. Sander, Ph.D., TIRR Memorial Hermann Brain Injury Research Center

BRAIN INJURY ASSOCIATION OF AMERICA

DAVID STRAUSS

CLINICAL WEBINAR

Disorders of Consciousness Practice Guidelines

November 12, 2018, 3 p.m. ET/12 p.m. PT

Joseph Giacino, Ph.D., Spaulding Rehabilitation Hospital, Douglas Katz, M.D., Boston University School of Medicine, and John Whyte, M.D., Ph.D., Moss Rehabilitation Research Institute

Neuroendocrine Function after Brain Injury

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

Lisa Kreber, Ph.D., CBIST, Centre for Neuro Skills

BRAIN INJURY ASSOCIATION OF AMERICA

ROBERT SBORDONE

CONCUSSION/mTBI WEBINAR

Concussion as a Craniocervical Injury

December 6, 2018, 3 p.m. ET/12 p.m. PT

Kevin Crutchfield, M.D., LifeBridge Health Sports Medicine

To register, please visit

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(continued from page 21)

Advocacy **UPDATE**

President Signs the Sports Medicine Licensure Clarity Act Into Law

The Senate agreed to H.R. 302, the Sports Medicine Licensure Clarity Act, to protect physical therapists and other health care providers who travel across state lines with a sports team. President Trump signed this bill into law Oct. 5. This bill extends the liability insurance coverage of a state-licensed medical professional to another state when the professional provides medical services to an athlete, athletic team, or team staff member pursuant to a written agreement. Prior to providing such services, the medical professional must disclose to the insurer the nature and extent of the services. This extension of coverage does not apply at a health care facility or while a medical professional licensed in the state is transporting the injured individual to a health care facility. In its original form, the coverage was restricted to physicians and athletic trainers. Through advocacy, physical therapists were included. BIAA worked with Congress to support and pass this important bill. ●

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