

THE CHALLENGE!



RESEARCH

SPRING 2018

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Postmaster:
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1608 Spring Hill Rd., Suite 110
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Publication designed by
Eye to Eye Design Studio, LLC
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From my **DESK**



Today my desk is piled high with new and renewed programs and services that will soon be released from the Brain Injury Association of America (BIAA).

Brain Injury Fundamentals is an all-new training and certificate program designed exclusively for non-licensed direct care staff and individual caregivers. The training course, which was developed by BIAA's Academy of Certified Brain Injury Specialists (ACBIS), covers essential topics such as cognition, medical complications, and medication safety and management. The program will launch this summer at existing ACBIS sites, roll out this fall at state affiliate conferences, and eventually be available through online webinars, using an easy, fill-in-the-blanks workbook style of learning.

This fall, family members will be able to demonstrate their know-how by taking the course and earning a certificate attesting to their knowledge. Pilot International, the worldwide service organization that seeks to advance brain safety and health, will offer scholarships for people with financial need who want to take the Fundamentals course. Please watch www.biausa.org for more information.

Pilot is also partnering with BIAA to relaunch Brown Bag It for Brain Injury. Pilot Clubs throughout the United States will host awareness and fundraising events this fall and throughout the year. One hundred percent of the proceeds from Brown Bag It events will benefit BIAA.

In July, BIAA will recruit supporters who are willing to raise money for the National Brain Injury Information Center (NBIIC), the 1-800-444-6443 phone line that connects individual callers to their state brain injury organizations for local information, resources, and support. The NBIIC program costs BIAA \$157,653 per year to operate. That calculates to \$432 per day. So, we need 365 people to host their own online fundraisers this summer. BIAA will have information to assist our supporters in setting up online fundraising pages and raising money through Facebook. Please visit www.biausa.org for more information.



In the meantime, we are pleased to promote the fantastic work of the TBI Model Systems of Care, to share the accomplishments of our chartered state affiliates, and recognize the individual and corporate donors who help make our work possible.

Thank you for your support!

A handwritten signature in black ink that reads "Susan H. Connors".

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

The Rocky Mountain Regional Brain Injury System

The Rocky Mountain Regional Brain Injury System (RMRBIS) is organized around the rehabilitation services of Craig Hospital. The RMRBIS also includes seven trauma centers, three long-term acute care facilities, and an extensive community-based support network that collaboratively provide a comprehensive, multidisciplinary, specialty system of TBI care for Colorado and beyond. The RMRBIS is conducting a research program focusing on the health and function and community living and participation of individuals with moderate to severe TBI. It is conducting a site-specific randomized controlled trial of a group intervention to improve Self-Advocacy for Independent Life (SAIL) after TBI to help people get the services they need. It is leading a collaborative multi-center module study using data from the TBIMS National Database to evaluate various procedures for creating crosswalks between the Functional Independence Measure



(FIM) and the Continuity Assessment Record and Evaluation (CARE) Item Set in order to maintain a longitudinal measure of function in the TBIMS National Database. It is also participating in two other module studies lead by other TBIMS Centers on the topics of driving after TBI and caregiver resilience. It is continuing to enroll individuals into the TBIMS National Database and following the people it has already enrolled. Craig Hospital is also the site for the National Data and Statistical Center for the TBIMS.

Indiana University School of Medicine / Rehabilitation Hospital of Indiana TBI Model System

The Indiana TBI Model System is based on partnerships with Indiana University (IU) School of Medicine, IU Health, St. Vincent Health, the Rehabilitation Hospital of Indiana, the TBI community, and other key stakeholders. The focus of our local research is aimed at improving awareness of one's emotions after TBI in the hopes of decreasing irritability and aggression. Reduced emotion control is a common and often chronic problem after TBI. Although impaired emotion control is a multifaceted problem, one key component identified in the research is alexithymia. Alexithymia is characterized by poor emotional awareness, difficulty describing and differentiating emotions, and problems acknowledging and associating physical sensations with emotions. Post-TBI alexithymia is a frequent problem (30-61%) and has been associated with poor emotional control, anxiety, depression, anger, and aggression. The rationale is that one must



be able to recognize self-emotions before regulation can occur, and disruption of the former (alexithymia) disrupts the latter. Our TBI Model Systems project entails a phase II (efficacy) assessment of an alexithymia intervention via a randomized, wait-list controlled trial with a 3-month follow-up. Results are expected to directly improve clinical care, outcomes, and quality of life for people with TBI and alexithymia.

(continued on page 6)

Spaulding-Harvard TBI Model System

In light of the high incidence of diagnostic error among patients with disorders of consciousness (DoC) (estimated to be 30-40%) and the risk of premature withdrawal of life-sustaining treatment, the Spaulding-Harvard TBI Model System (SH-TBIMS) is testing the validity of an abbreviated version of the Coma Recovery Scale-Revised (CRSR) for use in the intensive care unit, the CRSR For Accelerated Standardized Testing (CRSR-FAST). The CRSR-FAST will provide clinicians with a brief, standardized assessment measure that can accurately determine level of consciousness. The CRSR-FAST will enable longitudinal assessment across the continuum of recovery, bridging the communication divide between the acute care and rehabilitation settings.

The SH-TBIMS is also leading a multi-center study, in concert with the Indiana TBIMS, TIRR TBIMS, Tampa VA Polytrauma Rehabilitation Center (PRC), and Richmond VA PRC, that will develop and test the feasibility of a telephone-based structured caregiver interview, the "Post-Acute Survey on Severe Disability after TBI (PASSD-TBI)." The PASSD-TBI will provide an efficient means of obtaining long-term outcome data on persons with prolonged DoC, identify favorable and unfavorable influences on caregiving activities, and increase knowledge of caregiver burden. If the results of the pilot study are favorable, the PASSD-TBI will be nominated for inclusion in the TBIMS National Database.

Michigan TBI Model System

The Southeastern Michigan TBI System's (SEMTBIS) main area of focus is a study looking at the ability of group therapy to improve resilience and social support in family members and friends of those with TBI. It addresses the well-established problem of burden and social/emotional distress associated with caring for persons with TBI, and the potential effects of family emotional distress on the outcomes of the person with the brain injury. Few injuries have the same impact as brain injury, and it is widely known that family plays a key role in a person's recovery after brain injury. Yet, there is a need for research on family members who have coped well, demonstrating strength and resilience in relation to their loved one's injury. This study will measure baseline resilience and explore associated coping traits. It also includes an intervention that attempts to enhance resilience and social support in family and friends



in a group intervention. SEMTBIS is the lead center for a multicenter project that examines the role of menopause in women with TBI. Women with TBI have been woefully understudied and the proposed module will provide researchers with an opportunity to determine if the experience of menopause is different in women with brain injury as compared to those without.

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Mayo Clinic TBI Model System

Testing an Integrated Medical and Resource Facilitation Intervention (MRFI) after Traumatic Brain Injury: A Community-based Randomized Pragmatic Clinical Trial

Mayo Clinic's TBI Model System Center will collaborate again with the Minnesota Brain Injury Alliance (MN-BIA) to address the ineffective connection of individuals with TBI to specialized medical and community resources after hospital-based care, limited access to TBI experts, and variable knowledge by primary care providers (PCP) about TBI. This trial will test a complex behavioral intervention that includes MRFI group participant access to the direct clinical and therapy services of Mayo's Brain Rehabilitation Clinic using telemedicine. Throughout the 18-month study, remotely provided medical-rehabilitation services will be integrated with the highly developed MN-BIA Resource Facilitation program. Fundamental to MRFI is family and PCP involvement. This integrated and holistic intervention appears essential to address the complex, intertwined, and long-lasting medical and



social problems often faced by individuals with TBI. Analysts from the Minnesota Department of Health and Mayo Clinic's Center for the Science of Health Care Delivery will evaluate MRFI's cost-effectiveness. Other collaborators include Mayo Clinic's Center for Connected Care and Social Media Network. Anticipated long-term results are the development of a sustainable, replicable model that uses technology to integrate medical-rehabilitation with community expertise to improve TBI care and outcomes while advancing TBI knowledge among PCPs and families.

JFK Johnson Rehabilitation Institute

Rehabilitation after a brain injury should improve a person's ability to perform the usual activities of his or her everyday life. At the JFK Johnson TBI Model System, a new measure, the Activity Measure for Post-Acute Care (AM-PAC), is being used to examine basic mobility, everyday thinking skills, and practical daily activities after TBI. During this project, JFK will:

1. Keep track of changes in activity limitations during acute rehabilitation and through the first year of recovery after TBI.
2. Evaluate treatment-induced changes in activity limitations after post-acute rehabilitation.
3. See how well AM-PAC results agree with traditional clinical measures and how closely individuals with TBI responses agree with their family members/caregivers about their abilities and limitations.



As a result of this work, clinicians will have a measure that is easily administered and assesses changes related to important activities of everyday life. Individuals with TBI and their families/caregivers will be provided with meaningful information related to improvements in physical, functional, and cognitive abilities in daily functioning.

New York TBI Model System

The New York TBI Model System (NY-TBIMS) is housed in the Brain Injury Research Center of Mount Sinai (BIRC-MS) in New York City. Since 1987, NY-TBIMS has been committed to improving the health and quality of life of people living with TBI and their families. In addition to its contributions to the national database, which add to the demographic diversity of the TBI Model Systems, its research aims to better understand the short- and long-term consequences of TBI; develop innovative treatments to improve cognitive, emotional, and behavioral function; and to provide education, services, and support to the public. The NY-TBIMS research has greatly advanced scientific understanding of the long-term challenges of living with TBI and the best approaches to leading better lives after injury. The NY-TBIMS is currently testing the effectiveness of an internet-delivered skills training intervention to improve emotional regulation



after TBI. It also leads a study that involves ten TBIMS centers to investigate diverse trajectories of cognitive functioning after TBI. The BIRC-MS also leads the first brain donor program in the United States focused on TBI (the Late Effects of TBI project) and is a CDC-funded Injury Control Research Center focused on preventing TBI and its consequences.

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Rusk Rehabilitation Traumatic Brain Injury Model System

Rusk Rehabilitation TBI Model System will be conducting a research project titled “Living Life with Traumatic Brain Injury (TBI).” The goal is to determine the ways that living with TBI affects the quality of life of people with brain injury and their families. The research team will examine the medical and psychological issues that people with TBI experience many years after injury. The goal is to understand what has helped and what has caused problems when living with TBI for many years.

The study will look at these issues in people from different racial/ethnic and cultural backgrounds to see if there are differences. As part of the project, educational toolkits for persons with TBI, family and/or caregivers, and community medical providers will be created. The project will involve local community organizations to provide education, increase awareness, and improve the lives of individuals living with TBI.

Ohio Regional TBI Model System

The Ohio Regional Traumatic Brain Injury (TBI) Model System is located in the Department of Physical Medicine and Rehabilitation at Ohio State University (OSU). The program operates under the umbrella of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation, which provides a structure for consumer participation via its 30-member Advisory Council. Composed primarily of consumers from multiple states, as well as representatives of the Brain Injury Association of America, the Advisory Council prioritizes needs, reviews funding opportunities, participates in implementation, monitors progress, and evaluates program outcomes. The Advisory Council’s “Envisioning” process was central to the projects proposed in this application.

The Ohio TBIMS will conduct one local research project and has proposed a module project, both addressing NIDILRR’s “Health and Function” priority. Both projects are exploratory and designed to gain new knowledge on TBI as a chronic health condition that can inform the development of protocols for prospective management. The local project seeks to



identify underlying biological processes that may be the source of poor health and reduced function that occurs for 50% of people by five years after their injury and rehabilitation. The module project seeks to identify social determinants of these poor outcomes, including family structure and support, socio-economic status, access to healthcare, use of community-based programs, neighborhood characteristics and state policy. Both projects tap national and international experts from the larger OSU faculty to assist in applying new research methods to a pressing problem in TBI rehabilitation.

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The Moss TBI Model System

The Moss TBIMS conducts a wide variety of studies, including creating new kinds of assessments (e.g., the Moss Attention Rating Scale) and creating new treatment approaches for emotional problems. Its researchers are especially interested in the use of mobile devices, like cell phones, in TBI rehabilitation. In the 2017-2022 cycle, these interests are combined in a study comparing two types of Behavioral Activation therapy. Both types of therapy use text messages to remind people with depression/anxiety and TBI to stay active with meaningful and fun activities. Researchers at Moss aim to create treatments that people with TBI can learn to keep using for themselves, so that they can keep improving after the study ends. Other projects involve training TBI therapists to help people with memory problems and those who need



anger management therapy. In every grant cycle, the Moss TBIMS works closely with its state Brain Injury Association affiliate on workshops and other projects to help people with brain injury and their families.

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North Texas TBI Model System

Being overweight or obese is common among people with TBI and this puts them at greater risk of having diabetes and heart disease. Yet, there are few programs to help people with TBI lose weight. The North Texas TBIMS project delivers a healthy lifestyle program that will help people learn the



skills to eat healthy food and be more physically active. People will complete the program in a group and will also use a smartphone app to help remind them about making healthy eating and activity choices during the day. The program will help people with TBI lose weight, improving their confidence and quality of life.

The Texas TBI Model System of TIRR

The Texas TBI Model System of TIRR is focused on addressing chronic health conditions following TBI. It is conducting one local research project and leading one of the multi-center collaborative projects. The local project targets mental health through a randomized, controlled trial of the effectiveness of use of a mood tracker app for reducing emotional distress. The researchers anticipate that this project will result in a low-cost method for persons with TBI to monitor their emotional health in order to prevent minimal emotional distress from increasing to clinical depression and/or anxiety. The collaborative project assesses health literacy and its impact on physical and mental health. The Texas TBIMS of TIRR will also be investigating the relationship of injury characteristics and cognitive impairment to health literacy. Anticipated results of this project include an understanding of how TBI impacts health literacy and how improving health literacy may positively impact health. The center has planned several dissemination products, including: fact sheets



on self-monitoring of mood and on the impact of TBI on health management; multimedia presentations on use of mood tracking and on improving health literacy; and a podcast for clinicians on providing education and information in a manner that will facilitate understanding and implementation.

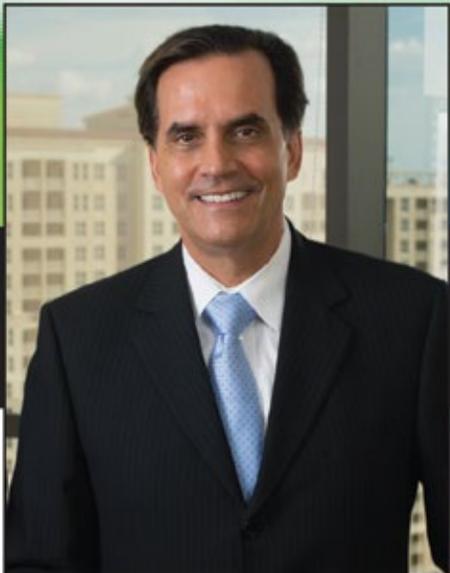
Virginia Commonwealth TBI Model System

Virginia Commonwealth University's (VCU) TBI Model System research program has four main projects. One compares the value of a basic resilience-building treatment with an expanded, patient-centered, resilience treatment. Outcomes include resilience, emotional distress, adjustment, and stress management. The long-term benefits of the intervention will be examined as well. A second project is focused on caregivers. The negative impact of TBI on caregivers is well-known. Focused on caregiver strengths, VCU leads a multi-center study of caregiver resilience. The project looks at caregiver factors related to resilience, including emotional well-being, needs, and burden. Information related to the survivor is also included, such as emotional distress, level of function, resilience, and injury characteristics.



A third major project relates to the National Database. VCU continues to collect data for the National Database and works with other centers to look at TBI outcomes. Dissemination is a fourth project. The center has an active dissemination program in partnership with the Model Systems Knowledge Translation Center. VCU produces many articles, newsletters, and workshops for survivors and professionals.

Other TBIMS include the Northern New Jersey Traumatic Brain Injury System and the University of Washington Traumatic Brain Injury Model System. You can learn more about these centers at <https://mskctc.org/tbi/model-system-centers>.



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Promising Research Promotes Hope Among Veterans with Moderate to Severe TBI

*By Adam S. Hoffberg, MHS, and Lisa A. Brenner, Ph.D., ABPP-Rp,
Rocky Mountain Mental Illness Research Education Clinical Center for Suicide Prevention*

Traumatic Brain Injury and Suicide Risk

Among U.S. military personnel injured during Operation Enduring Freedom and Operation Iraqi Freedom, 10 to 20 percent sustained traumatic brain injuries (TBIs). TBIs are injuries caused by sudden trauma to the brain, such as a person's head being struck by an object or a dramatic change in air pressure following explosions. Although the vast majority of TBIs are classified as mild, more than 40,000 service members have sustained moderate to severe TBIs since 2000 (DVBIC, 2018). While research has shown that veterans with a history of TBI are significantly more likely than other veterans to die by suicide (Brenner et al., 2011), a developing line of research offers promise that hopefulness can be increased among at-risk veterans with living with TBI.

The Original Australian Trial

Before 2011, no studies looked at specific treatments to prevent suicide among adults with TBI (Bahraini et al., 2013). Grahame Simpson, Ph.D., and colleagues from Australia recognized a need to fill this gap and developed and tested a psychotherapeutic

intervention called Window to Hope (WtoH). Based upon previous research suggesting that hopelessness is a strong predictor of who is likely to die by suicide and reducing hopelessness can reduce the risk of suicide, Simpson and colleagues focused on finding ways to increase hope (Beck et al., 1985; Simpson and Tate, 2002). The WtoH treatment is a ten-session program conducted in small groups that incorporates principals from cognitive behavioral and problem-solving therapies. Findings from the initial study demonstrated that it was possible to reduce hopelessness among adults with severe TBI (Simpson et al., 2011).

Adapting the Window to Hope Program for Veterans

Based on the need for treatments for veterans with TBI, Colorado researchers at the Department of Veterans Affairs (VA) Rocky Mountain Mental Illness Research Education & Clinical Center (MIRECC), led by Lisa A. Brenner, Ph.D., collaborated with Dr. Simpson to see if an approach similar to the one he pioneered might be able to reduce hopelessness among those seeking care in the VA.

The first step in this line of work was to adapt Dr. Simpson’s program to apply to U.S. Veterans. The team assembled a stakeholder panel that included experts in TBI and mental health, including those living with TBI. The panel unanimously agreed on a number of changes to the Australian model. Some were simple changes, like inserting the U.S. food pyramid in place of its Australian counterpart, while others were more substantive, such as modifying the manual to include “tactical breathing,” a type of deep breathing that U.S. service members are taught to use, instead of the original breathing exercises designed for use by Australian civilians.

The next step was to test the revised program among U.S. veterans with moderate to severe TBI. The pilot study was carried out with four different groups of veterans. Results suggested that the revised program was indeed feasible to implement within a Veterans Health Administration (VHA) setting as well as acceptable to those seeking care within VHA. Most encouraging were the comments from the veterans enrolled in the study, several of whom reported that the program did indeed help them build hope. In 2014, the group published a report in the journal *Brain Injury* describing this process (Matarazzo et al., 2014).

Second Trial Confirms Positive Impact of Window to Hope

The team then engaged in a randomized clinical trial designed to test the efficacy of the intervention to reduce hopelessness among veterans. Brenner and colleagues randomized 44 veterans, each with moderate to severe TBI and moderate to severe feelings of hopelessness. To evaluate whether the treatment worked, the researchers measured veterans’ feelings of hopelessness, depression, and thoughts of suicide at the beginning, middle, and end of the six-month enrollment period.

Window to Hope



▲ The core Window to Hope therapeutic strategies are represented by each of the four window panes.
Design courtesy of Rachel Warden, Rocky Mountain MIRECC.

Participating in WtoH resulted in a reduction of hopelessness and depressive symptoms among veterans with TBI, and the favorable results were recently published in the *Journal of Head Trauma Rehabilitation* (Brenner et al., 2018). This rare replication of a psychological trial – with a different sample of participants, in a different country, and with different clinicians – increases the likelihood that changes observed among the participants were due to their participation in the intervention. Brenner and Simpson are now exploring strategies to provide and further evaluate this intervention to an even broader audience.

References available at www.biausa.org.

Dancing Well: The Soldier Project

By Diane Schirmer, Brain Injury Association of Kentucky

How many times have you found yourself lost in a song or melody, completely forgetting what you're doing, why your head hurts, and how you were feeling to begin with?

Edwin O. Walker, M.D., psychiatrist at the Veterans Administration Hospital in Fort Knox, Kentucky, always searched for new ways to help his soldiers and their families with their physical and emotional pain. He knew music could dispel his own aches and pains, and he had seen improvements in a patient's mood and memory after learning to play the guitar. He began to wonder if music could help other soldiers and their families, too.

To test his theory, Dr. Walker invited Deborah Denenfeld, a seasoned dancer and dance instructor, to the VA. They asked a specific group of veterans and their loved ones to participate in a dance series. The goal was to identify some veterans whose lives had been impacted by the devastating effects of PTSD and brain injury and to integrate them with volunteer dancers in community dance, a type of group dancing with a caller who announces each dance move. It is always accompanied by live, joyful music.



At the end of the series, the soldiers reported that, not only did they enjoy the dance, but they saw improvements in memory, mood, and overall outlook. They also reported reduced anxiety and physical pain. Additionally, the experience had a profound impact on couples. Everyone reported improved relationships with their loved ones.



Denenfeld then founded Dancing Well: The Soldier Project in Louisville, Kentucky, to bring the healing power of music, dance, and community to veterans and families coping with PTSD and TBI. Deborah had experienced the healing power of community dance herself and wanted to give every person access to the physical, mental, and emotional benefits of dance, regardless of background and ability. Veterans, veteran organizations, and individuals from the wider community provide venues and volunteer as dance partners and photographers. Participating veterans and family members also serve as active members of the program, providing ongoing feedback, outreach, recruitment, fundraising, and vision.

As a provider of brain injury rehabilitation services, I have been rewarded many times in my career; however, becoming involved with this project is special beyond words. My contribution is simply providing a training template to teach others about brain injury. My rewards are endless as this program captures national attention, and I have the pleasure of meeting countless veterans, family members, and dance instructors who can't wait to extend these services in their state. You see, for veterans, isolation is often significant. Yet, Dancing Well, in a very simple, beautiful way, helps them form partnerships through dance and regain their lives.

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Dr. & Mrs. M. M. and Maureen Selim

MEMORIES

In memory of Alice Demichelis
Ms. Elizabeth Rouse

In memory of Andrew Cox
Ms. Terry Cox

In memory of Barbara Kay Patterson
Ms. Wendy Vang

In memory of Bobby Hodges
The Cerritos Family

In memory of Brian James Hom
Alexandria Hom

In memory of Butch Alterman
Mr. Matthew Beckerson

In memory of Carol Danforth
Mrs. Robin Jonas

In memory of Charles
Mrs. Katharine Freeman

In memory of Charles Robert Powers
Ms. Anna Gomez
Mr. Barry Lambergerman
Ms. Christine Poirier
Chairman Alan Tilles
Mrs. Kim Wilkerson

In memory of Clara Mae Burton
Ms. Barbara Clay and Ms. Stacie Clay

In memory of Daniel Paul Staples
Mrs. Barbara Brown
Mr. & Mrs. Gene and Judith Carter
Ms. Mitzi Carvajal
Mr. & Mrs. David and Dorothy Dziejumski

In memory of Darlene Barber Plyter
Mrs. Robyn Gragg
Ms. Sharon Inman
Mrs. Robin Wagner

In memory of Denard Duheart
Mrs. D'Angeliqque Russ

In memory of Dr. Irving Feigenbaum
Mrs. Shirley Feigenbaum

In memory of Erwin Siporin
Ms. Nancy Haller

In memory of Ginger Cockerham
Mr. & Mrs. Clifton and Evelyn Giles

In memory of James Dean Hesser
Mrs. Joy Stilwell

In memory of James R. Day
Mr. Overton Day

In memory of Jan Gravlee
Ms. Pamela Cezayirli
Lawrence, Arendall, Humphries
Dr. Julius Linn
Dr. & Mrs. John McVey
Ms. Alice Schleusner

In memory of Janet Barnett
Ms. Megan Coonts
Ms. Sharon Kelly
Mr. & Mrs. Wayne and Maxine Williams

In memory of Jared Harlan Feigenbaum
Mr. & Mrs. Robert and Roberta Feigenbaum
Mrs. Shirley Feigenbaum

In memory of Jean Halland
Mrs. Valdean Lueck

In memory of Joan Latinski
Mrs. Judith Pitchforth

In memory of Josephine Trudy Tomcho
Mr. John Sandone

In memory of Josiah Hamlin
Miss Leah Hamlin

In memory of Karen A. Reitter
Ms. Mary S. Reitter

In memory of Kevin Wong's Father
Mr. Brett Weisel

In memory of Leslie C. Wise
Ms. Maureen Wise

In memory of Marilyn Simpson
H. Manning Company
Mr. & Mrs. David and Bonnie Huston
Ms. Mary King
Mrs. Jamie Mulvihill
Mr. & Mrs. Gary and Linda Rabideau
Ms. Mary Risley
Ms. Linda Springer
Mr. & Mrs. Michael and Lynda Tinsley
Mr. & Mrs. Patrick and Erlene Tinsley

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

In memory of Martta Alisa Laing-Gustavson
Ms. Diana Gustavson

In memory of Michael E. Bedard
Ms. Debbie Buitron

In memory of Mr. Trevor G. Bosse
Ms. Deborah Large
Ms. Donna Lefevre

In memory of Muriel Clifford
Mr. & Mrs. Thomas and Joan Rodeck

In memory of Patricia Antoneili
Mr. & Mrs. Thomas and Luci Hartmann

In memory of Patricia Ericksen
Ms. Joni Barry

In memory of Paul S. Cohen
Mr. & Mrs. Gary and Nancy Caine
Mr. Penn Caine

(continued on page 20)

Mr. & Mrs. Philip Cohen
Mr. & Mrs. Adam and Amy Beth Forman
Gerry Goldstein
Mrs. Amy Goldstein
Mr. & Mrs. Richard and Alyson Katzman
Mr. & Mrs. Ivan and Lois Kipnis
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Ms. Sandra Bastinelli

In memory of Vinod Dadhich

Ms. Sonia Dadhich

In memory of Wayne Lunak

Ms. Suzanne Lunak

In memory of William Lapay

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Mr. Artem Yaschenko
Mr. John Zagraiek, Jr.
Prof. Jad Ziolkowska
Mr. H. J. Zoffer

BEQUEST

Ms. Linda Redmann

Thank You!



Walking for Brain Injury

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

Over the past several years, the Walk for Brain Injury fundraisers have raised nearly \$150,000 throughout the state of Texas. The money raised through these events provides local resources and support for individuals with brain injury and their family members throughout the state. Nearly 1,500 advocates have supported the walks, including many – like Dr. Christine Johnson – who have taken part in the fundraisers every single year.

Dr. Johnson has been involved with the Brain Injury Association for more than 15 years and has worked in the brain injury field for much longer. She is board-certified in both Physical Medicine and Rehabilitation and in Brain Injury Medicine. Dr. Johnson is the Medical Director for the Centre for Neuro Skills Irving and Fort Worth Locations.

Every year, along with a large group of co-workers, patients, and family members, Dr. Johnson takes part in the Dallas Walk for Brain Injury. She explains, “The patients and families that I have had the opportunity to care for inspire me to do whatever I can to support them and get them the assistance that they need. Walking for Brain Injury is one way to increase awareness, raise money, and demonstrate my commitment to these individuals.”

Based on her years of experience, Dr. Johnson offers this advice about brain injury: “Brain injuries can happen to anyone, at any time. It is not something that one can prepare for. It affects the patient, the family, and all those around them. There are treatment options available, and things will improve over time. Understand that the recovery is ongoing and never give up hope for more improvement.”

Dr. Johnson continues to be part of these fundraising events because she knows how emotionally, financially, and physically devastating a brain injury can be – both for the individual and for caregivers. She enjoys raising money to help decrease those burdens and increase awareness of brain injury.

Interested in hosting a fundraising event for BIAA?

- STEP 1:** Visit www.biausa.org/support
- STEP 2:** Download BIAA’s event guide
- STEP 3:** Promote your event on Social Media
- STEP 4:** Have Fun!

Advocacy UPDATE

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

BIAA Presents Awards to Reps. Bill Pascrell, Jr. and Thomas J. Rooney on Brain Injury Awareness Day



The Brain Injury Association of America (BIAA) honored Reps. Bill Pascrell (D-N.J.) and Tom Rooney (R-Fla.) with awards recognizing their service and dedication to Americans living with brain

injury. Rep. Pascrell founded the Congressional Brain Injury Task Force (CBITF) in 2001. Co-chaired by Rep. Rooney, the CBITF hosts Brain Injury Awareness Day on Capitol Hill, advocates for increases in TBI programs across the federal government by circulating support letters to appropriators, and hosts briefings throughout the year focusing on brain injury. Rep. Rooney will retire at the end of this year. BIAA is grateful for his leadership.

Lawmakers to Introduce TBI Act Reauthorization Legislation



Sens. Orrin Hatch (R-Utah) and Bob Casey, Jr. (D-Pa.) and Reps. Pascrell and Rooney plan to introduce legislation to reauthorize the Traumatic Brain Injury (TBI) Act of 1996, as amended in 2014. Although

current law authorizes funding through fiscal year 2019, the lawmakers are planning to introduce the legislation to commemorate the retirement of Sen. Hatch and Rep. Rooney. Sen. Hatch was an original sponsor of the bill, which authorizes funding to the U.S. Department of Health and Human Services (HHS) for the Federal TBI State Grant and Protection and Advocacy (P&A) programs, administered by the Administration for Community Living (ACL); the Centers for Disease Control and Prevention (CDC) Injury Center TBI programs addressing prevention,

surveillance, and public education; and National Institutes of Health (NIH) research.

Congress Sends FY 2018 Omnibus Spending Bill to President to Sign



The U.S. House of Representatives passed the Omnibus Bill March 23, which the U.S. Senate supported to fund the federal government for the remainder of the 2018 fiscal year, ending Sept. 30.

The president signed the bill, after threatening a veto because it did not contain immigration provisions or fully fund the wall for the southern border.

Overall, the legislation provides an additional \$80 billion for national defense and increased funding to address the opioid epidemic, for homeland security, to promote school safety and mental health, and to make investments to help rebuild America's aging infrastructure and grow jobs. Of interest to brain injury advocates, the bill includes more than \$2 million in additional funding for the Federal TBI Grant Program, administered by ACL – the first increase for the program in many years. The total for the program, \$11.321 million, would fund both the state grant and P&A programs. ACL's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), which awards grants for the TBI Model Systems program, received an additional \$1 million. The spending bill also provides increases for other ACL programs, including a \$750,000 increase for the Lifespan Respite Care Program and a \$30 million increase for the National Family Caregiver Support program, which BIAA supported.

The House approved an extra \$1 billion for the CDC. With regard to the National Center for Injury Prevention and Control, the bill approves funding for the Injury Research Centers (\$9 million), which the

administration proposed to eliminate in the fiscal year 2019 budget, and provides full funding for the nationwide expansion of the National Violent Death Reporting System (NVDRS). The Injury Center's TBI program would receive \$6.75 million and \$2.05 million for the elderly falls prevention program. The NIH would receive a \$140 million increase for a total of \$400 million for Brain Research through Advancing Innovative Neurotechnologies, known as the BRAIN Initiative, and an additional \$500 million for research into opioid addiction, which would be split between the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute on Drug Abuse. In addition, the bill provides \$125 million for TBI research within the Department of Defense (DoD).

CBITF Circulates Dear Colleague Letter for TBI Programs



CBITF Co-chairs Reps. Pascrell and Rooney are circulating a "Dear Colleague" letter asking members of congress to support additional funding for TBI Act programs, which include the CDC and ACL

grant programs, and NIDILRR TBI Model Systems. The co-chairs are also circulating a separate letter for Department of Defense TBI programs.

BIAA Submits Testimony to House and Senate Appropriators for TBI Programs



BIAA submitted testimony to the House Appropriation's Subcommittee on Labor, Health and Human Services, Education and Related Agencies calling for increased fiscal year 2019 funding for

Traumatic Brain Injury (TBI) Act-related programs and the TBI Model Systems. Specifically, BIAA requested \$11 million total for ACL's TBI State Grant program, \$6 million for the P&A program, and \$5 million additional funding for the CDC Injury Center to establish and oversee a national concussion surveillance system. BIAA also recommended \$15 million for the NIDILRR TBI Model Systems to expand the number of centers and research

projects and requested that appropriators oppose the administration's recommendation to move the program to the NIH.

CDC Releases Report to Congress on the Management of TBI in Children



The CDC National Center on Injury Prevention and Control released its "Report to Congress on The Management of TBI in Children." The report details the impact TBI can have on children and

their families. It identifies gaps in care, provides opportunities for action to reduce the gaps, and highlights key policy strategies to add the short- and long-term consequences of TBI. To access the report, visit <https://www.cdc.gov/traumaticbraininjury/pubs/congress-childrentbi.html>

White House Announces New CDC Director



The White House announced that Robert R. Redfield, M.D., will serve as the director of CDC. Dr. Redfield is a clinical scientist and former Army doctor who co-founded the Institute of Human Virology at

the University of Maryland School of Medicine. He has been leading a massive HIV treatment program and a global program funded by the President's Emergency Plan for AIDS Relief. He previously served on former President George W. Bush's HIV/AIDS advisory panel and in various advisory roles at NIH.



BIAA Stops Administration Proposal with the Help of a Survivor and His Family



“Traumatic brain injury is a family injury, and ongoing, high-quality rehabilitation and counseling is essential if TBI survivors are to reach their highest potential after an injury. It is only when these survivors can once again interact with, relate to, and participate in family life that families begin to heal and survivors step out into the larger world.”

By Amy Colberg, M.Ed., Director of Government Affairs, Brain Injury Association of America, and Rosemary Rawlins, Brain Injury Advocate

The President’s FY 2019 Budget proposed to relocate the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) from the Administration for Community Living (ACL) to the National Institutes of Health (NIH). ACL is not a research agency, but it houses the Traumatic Brain Injury (TBI) Model Systems, a group of university and hospital-based institutions that study medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with TBI.

Since the type of research conducted by the Model Systems varies dramatically from the type of research conducted by NIH (which tends to involve basic science laboratory experiments), the Brain Injury Association of America (BIAA) opposed the relocation of the Model Systems to NIH. BIAA met with leaders in both the House and Senate and successfully persuaded each chamber to reject the Administration’s proposal. We are very pleased with this outcome as moving NIDILRR could have been the first step in eliminating the Model Systems program.

Among its many advocacy efforts, BIAA urged its grassroots network to share stories about how the TBI Model Systems affects real families. Rosemary Rawlins, a brain injury advocate whose husband sustained a severe TBI and received rehabilitative care at a TBI Model System, shared her story with Congress. Read Rosemary’s story on the next page.

“As the wife of a man who sustained a severe traumatic brain injury fifteen years ago – my husband was hit by a car driving 50 mph while he rode his bicycle home from an afternoon workout – I know this is a lifelong injury with life-altering repercussions.

I also know that the time my husband and I spent at VCU [Virginia Commonwealth University] Health Center in the care of the TBI Model System Neuropsychology Department helped me understand my post-injury spousal relationship, reduced my stress and my husband’s stress, helped me and my husband understand each other’s challenges, and we learned new strategies to accept the unexpected but permanent realities of our lives.

As participants in the Couple’s Intervention and as a consultant for The Brain Injury Family Intervention, our marriage and our relationship with our teenage children was better understood and navigable at a tumultuous time in our lives. I believe that quality of life for family members and survivors improves through education, counseling, and skill building with supportive professional guidance at the local level.

My husband, formerly an accounting executive in a Fortune 100 firm, took two years to rehabilitate, but he did finally return to work successfully and worked twelve years as a CFO [chief financial officer] before retiring early. His recovery is a testament to what the best treatment can deliver.

I know the importance of determining and implementing resilience-building therapies. I also think it’s crucial to examine caregiver resilience, since caregivers play such a direct role in a TBI survivor’s outcome – and keep in mind that this saves communities money, especially when survivors like my husband return to work, and when caregivers are well enough to continue working and contributing to their communities.

I have served as a consultant for the TBI Model System at VCU with the goal of presenting a personal angle to further inform the clinical perspective, creating a holistic approach. The priorities presented in this program are certainly consistent with the needs of survivors and caregivers, and the potential outcomes of this intervention will positively impact lives by offering tools, strategies, skills, and ways of thinking that lead to a more rewarding life for so many.

I believe strongly that VCU Medical Center is ideally suited to complete this work successfully. Dr. Kreutzer has a strong track record of leadership, along with a demonstrated commitment to individuals and communities affected by TBI. He has added value to the brain injury community over the past thirty years and mentored many qualified professionals to carry on these successes.

VCU has also developed practical, specialized interdisciplinary brain injury programs, published hundreds of peer-reviewed brain injury publications, and emphasized family and relationship building for community-based rehabilitation, while serving persons regardless of ability to pay – and this is where the biggest payback resides.

Traumatic brain injury is a family injury, and ongoing, high-quality rehabilitation and counseling is essential if TBI survivors are to reach their highest potential after an injury. It is only when these survivors can once again interact with, relate to, and participate in family life that families begin to heal and survivors step out into the larger world.

Please keep all of this in mind when you are making decisions that directly impact TBI survivors and their families. TBI can happen to anyone, anytime, and chances are, you will know someone who will have to navigate these tough waters alone.”



State Affiliate NEWS

GEORGIA

The Brain Injury Association of Georgia (BIAG) has been busy educating the public about brain injury. Staff attended the Atlanta Science Festival, which drew more than 10,000 attendees of all ages, to share information about brain injury. Visitors at BIAG's booth learned about the various areas of the brain and were even able to touch a real sheep brain! BIAG also had speaking engagements and informational tables set up at the Emory Rehabilitation Center, LeasePlan USA, the Macon Vision Program, and WellStar Kennestone Hospital to teach professionals about brain injury. BIAG is busy planning for Camp BIAG, an overnight camp experience designed specifically for adults with brain injury, which will be happening in the fall. For more information, visit braininjurygeorgia.org.



▲ BIAG presents Emory Center staff with a cake to celebrate their dedication to their patients.



▲ Curious student touches a real sheep's brain at the Atlanta Science Festival BIAG booth.

KANSAS

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS) had an exciting March in honor of Brain Injury Awareness Month. Robin Abramowitz, executive director, was featured as a guest speaker on a radio show dedicated to telling the stories of nonprofit organizations in the Kansas City area. Awareness activities continued as elected officials, including Mayor Carl Gerlach of Overland Park and Governor Jeff Colyer, signed proclamations recognizing March as Brain Injury Awareness Month. A delegation of survivors, staff, and board members traveled to Topeka March 19 to witness the signing of the proclamation. Two days later, BIAKS returned to Topeka for a Pie Rally, where each of the 165 representatives and senators were invited to have some pie and learn about brain injury. We distributed more than 165 brain injury information packets as we doled out slices of pie, and survivors, family members, and rehabilitation professionals visited their elected officials to help raise awareness.



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The month culminated with our 10th Annual Professional Conference, “Beyond Rehab: Succeeding at Life.” Attended by 180 professionals, conference highlights included keynote presentations by Alan Weintraub, M.D., medical director for the Rocky Mountain Regional Brain Injury System and Rolf Gainer Ph.D., CEO of Brookhaven Hospital.

BIAKS was honored to present Janet Tyler, Ph.D., CBIST, with its prestigious Leadership in Brain Injury award. The award recognizes an individual who has demonstrated exquisite leadership on behalf of BIAKS. Dr. Tyler currently serves as the Senior Brain Injury Consultant at the Colorado Department of Education. She has worked in the field of pediatric brain injury for more than 30 years, developing and implementing innovative statewide programs that provide training for educators serving students with brain injuries. Dr. Tyler has taught



▲ Governor Jeff Colyer signs a proclamation declaring March Brain Injury Awareness month.

graduate level courses on traumatic brain injury, served as a board member of BIAA’s Academy of Certified Brain Injury Specialists, and is past president of the Brain Injury Association of Kansas and Greater Kansas City.

(continued on page 28)

(continued from page 27)

MICHIGAN

The Brain Injury Association of Michigan (BIAMI) brought more than 170 people representing 30 different health and disability organizations to the House Office Building in Lansing for Civic Engagement Day March 22. This no-cost “crash course” in citizen advocacy included topics such as identifying your legislators, the best ways of reaching legislators, and finding legislation that matters to you. Attendees heard remarks from key members of health and disability-related legislative committees, attended a committee meeting to observe legislation in action, toured the State Capitol, and received recognition from the Michigan House of Representatives.

Joining BIAMI were the Arthritis Foundation Michigan Chapter, Disability Network, Disability Rights Coalition, Epilepsy Foundation of Michigan, Michigan Developmental Disabilities Council, Michigan Family Voices, Michigan Paralyzed Veterans, National Multiple Sclerosis Society Michigan Chapter, Sickle Cell Disease Association’s Michigan Chapter, Susan G. Komen Michigan Chapter, Michigan Hands &



▲ BIAMI teaches Michigan residents about citizen advocacy.

Voices, Area Agency on Aging 1C, American Diabetes Association, Justice in Mental Health Charter House Clubhouse, Michigan Physical Therapy Association, Peckham, Common Ground, Community Living Services, Autism Alliance, Michigan Protection and Advocacy, Michigan Education Association, and ARC.

The event’s success, and the extensive media coverage it generated, will ensure it becomes an annual activity.

MAINE



The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its third annual Maine Brain Injury Resource Fair March 29. The event, held at the Augusta Armory, had 45 exhibitors from across the state representing services, resources, and opportunities for Maine brain injury survivors, family members, caregivers, and professionals. The fair was a huge success with nearly 200 attendees.

BIAA-ME’s annual conference, “Defining Moments in Brain Injury,” will be held Oct. 16 in Portland. Susan Connors, BIAA president and CEO, will give the keynote.

◀ BIAA-ME staff member Barbara Howard shares information and resources at the 2018 Maine Brain Injury Resource Fair.
Photo credit: Sarah Gaffney

MISSOURI

To raise awareness throughout Brain Injury Awareness Month, the Brain Injury Association of Missouri (BIA-MO) created “Brain Injury Fact of the Day,” sponsored by the Missouri AgrAbility Project, which used radio ads, interviews, website visits, and social media posts to reach more than 500,000 individuals. A daily fact included information about brain injury prevention, causes, and effects of brain injury in rural Missouri.

The BIA-MO Donald Danforth Jr. Wilderness Camp for survivors of brain injury was held May 27 to June 1. Survivors enjoyed a week of fun, independence, and adventure with swimming, ziplining, dancing, arts and crafts, talent show, and more. For more information, visit www.biamo.org.



▲ Camp attendees enjoy archery at the BIA-MO Donald Danforth Jr. Wilderness Camp.

NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) held its 35th annual Brain Injury & Stroke Conference May 16 in Concord. Keynote speaker Carole Starr of Brain Injury Voices spoke about “Weasilience: Handling Life’s Wild Moments,” and attendees learned about topics such as concussion, intense aphasia, and dealing with the opioid epidemic during various sessions.



▲ Conference attendees learn about Weasilience at the 35th annual Brain Injury & Stroke Conference.

In August, BIANH will host its 35th annual golf tournament, sponsored by Northeast Rehabilitation Hospital. In September, a new event is coming to BIANH: the Tank Pull! Teams of 20 individuals will join together in a race to pull a WWII military tank on a flatbed truck. Hosted by the Seacoast Salutes, the Tank Pull will honor local military and their families.

RHODE ISLAND

The Brain Injury Association of Rhode Island (BIARI) is celebrating its 35th year and, so far, 2018 has proven to be a busy one! The wind and the rain of a powerful nor’easter did not deter BIARI from holding the 17th Statewide Brain Injury Education Conference, “The Professional Journey through Brain Injury,” March 2. Attendees braved the elements to hear speakers address a range of topics, including domestic violence and brain injury, brain injury rehabilitation outcomes, and estate planning for caregivers.

As part of Brain Injury Awareness Week, staff and volunteers set up information tables at the Rhode Island State House and advocated for the needs of the brain injury community. Many legislators stopped by for information and were very receptive to BIARI’s mission. BIARI was recognized by both chambers, resulting in senate and house resolutions and a proclamation from the governor of Rhode Island.

BIARI Executive Director Debra Sharpe participated in a panel discussion about neuro advocacy in the state. Speakers from various organizations encouraged attendees to advocate for improved services for patients and increased investments in

(continued on page 30)



▲ BIARI staff and volunteers visit the Rhode Island State House.

brain research at the local and federal levels. Staff members also participated in informational fairs at Brown University and the University of Rhode Island. An estimated 1,000 individuals and families stopped by BIARI's tables to play brain games and learn about concussion prevention.

BIARI has created a new social group for members, volunteers, and staff. The first outing was an afternoon of bowling, which was well attended and proved to be fun and relaxing for all.

VERMONT

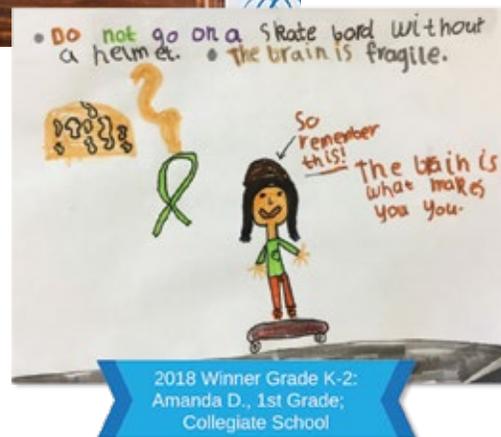
The Brain Injury Association of Vermont (BIAVT) is working with the State of Vermont Department of Aging and Independent Living to apply for a federal TBI grant. The Concussion Task Force is currently putting together a pilot project for a regional Brain Injury Consulting Team to educate schools about concussion and other brain injuries in the classroom. The Youth Concussion Task Force was created and is off to a good start, with plenty of high school and college student participation. BIAVT's Concussion Recognition Clipboards are being delivered to recreation departments around the state. BIAVT held its Walk for Thought May 19 and a Caregivers' Retreat in Stowe June 3.

VIRGINIA

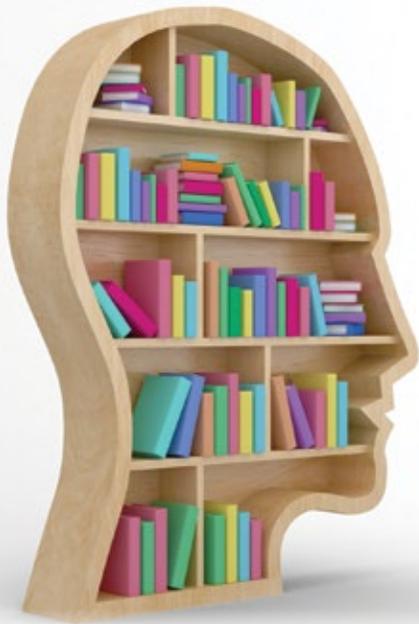
More than 100 donors, board members, and supporters joined the Brain Injury Association of Virginia (BIAV) to celebrate its history and achievements at BIAV's 35th anniversary benefit in March. Governor Ralph Northam presented opening remarks. A pediatric neurologist, Governor Northam has been a longtime friend to BIAV, and it was an honor to have him at the event. BIAV presented service awards to Dr. Greg O'Shanick, Senator John Edwards, and Dr. John Povlishock.



◀ BIAV Executive Director Anne McDonnell introduces Governor Ralph Northam at BIAV's 35th anniversary benefit.



As part of Brain Injury Awareness Month, BIAV hosted a Brain Injury Awareness Poster Contest to involve youth in brain injury awareness. Students learned about brain functions, injuries, and prevention techniques through a variety of resources including websites, books, and videos. BIAV offered themes for students to focus their posters: Safety on Wheels (bike safety), Play It Safe (sport safety), Ride Safe (car safety) and Watch Your Step (home safety). We received 48 entries from students in grades K-8 from across Virginia, and had a hard time picking the winners. To view the entries, visit www.biaav.net/events/sometimes-win-sometimes-learn.



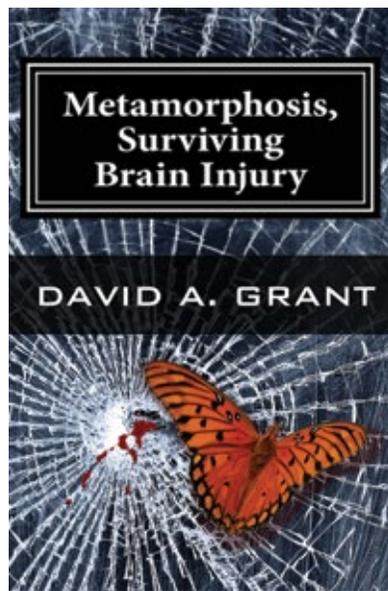
The BIAA BOOKSHELF

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

As odd as this sounds, it was an absolute joy to read David A. Grant's book "Metamorphosis, Surviving Brain Injury." At 49, David had become an avid bike rider, racking up more than 40,000 miles in just a few years. He rode 30 or more miles each day! But everything changed when he was broadsided at 30-40 mph while he was riding his bike. As he was catapulted 50 feet down Main Street, his helmet sheared hair off his head and he wound up in the hospital with a brain injury.

Like many people who have experienced brain injury, David left the hospital thinking he would soon be back to normal. Being self-employed, he resumed working the following week. It quickly became evident, however, that things were not the same. He frequently missed appointments, had a ringing in his ears that would not quit, and experienced PTSD that was so bad it caused him to have terrifying nightmares nearly every night.

With time, David found ways to compensate for his problems. The ringing in his ears was not a minor issue. He describes it as "a veritable freight train of sound that is with me every waking minute of every day." He eventually found that different kinds of white noise enabled him to work and sleep. Among the various other techniques he used to accommodate to



issues, David learned to rely on a digital calendar to meet deadlines and keep appointments.

Being an old support group worker, I wanted to jump up and yell "YES!" when David relates how helpful a monthly group meeting was and still is for him. Sharing with and learning from

others provided him with so much support and information, and hearing how recoveries varied gave David hope that improvement and recovery were still to come.

Part of what makes the book such a joy to read is that David takes you through his journey as he discovers different ways to succeed in his new life. He started an online blog so that others with brain injury had a place to talk, share, and learn from one another. His award-winning site, www.davidsnewlife.com, has brought together thousands of people all over the world.

Metamorphosis is upbeat and joyful because David never loses his optimism. As a bonus, it is printed in large font so that all readers can enjoy it. You shouldn't miss this book! Get your copy at shop.biausa.org

Brain Injury ADVISORY COUNCIL CORNER

Member Spotlight: Amy Zellmer

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

On February 3, 2014, at 8 a.m., it was ten below zero as I started to walk down my building's driveway with my dog, Pixxie, securely tucked under my left arm. It's funny how survivors remember the date of injury so clearly – similar to the way we remember birthdays or anniversaries. I stepped on a patch of black ice, causing my feet to go out from under me. Because of the incline, I landed head first on the driveway. I can still hear the awful thud of my skull making impact with the concrete before briefly losing consciousness.

When I sat up, I immediately knew something was terribly wrong. The pain in my head was excruciating, and my vision was fuzzy. It took every ounce of energy I could muster to grab Pixxie's leash and lead us back into my apartment before calling my neighbor for assistance. She asked me who was President, to which I answered "Bill Clinton" (the answer should have been Barack Obama, so I was off by several administrations). She asked what I ate for dinner the night before, and I couldn't think of anything – my mind was blank. She gave me an ice pack to put on my head and told me she would check on me later.

The fact that I wasn't able to read anything and that I was seeing spots in my vision left me feeling scared and concerned. I called another friend who instructed me to go see a doctor, her husband, immediately.



Against my better judgment (I mean, let's be real, I was concussed), I chose to drive myself the five miles to his office. He gave me a thorough exam and told me I had a pretty severe concussion, cervical spine C4 and C5 damage, a dislocated sternum, and torn muscles in my neck, chest, throat, and abdomen. I was instructed to take the next two weeks off and to get plenty of rest with no stimulation, including TV, computer, music, and reading.

I struggled with aphasia, dizziness, balance and coordination problems, short-term memory deficits, and a plethora of cognitive challenges for a solid 10 months. The neurologist I also visited had told me to "just give it more time," and I became more and more frustrated with my inability to do simple tasks without being exhausted.

At the 15-month mark, I went back to the neurologist and begged for help. I asked for therapies that might help with my memory or multi-tasking, to which she replied that she was skeptical I would ever get better since it had now been more than one year since my injury. She did concede to send me for craniosacral therapy and a neuropsychological test. The

How has BIAA changed my life?

In March 2015, just one year after my injury, I was invited by one of my fellow Tribe members to attend Brain Injury Awareness Day in Washington, D.C. This is where I was first introduced to the Brain Injury Association of America, which I had no idea existed up until this point. I was introduced to Paul Bosworth, who took me under his wing and helped me learn the ropes of “BIA Day.” It was shortly afterward that I was asked to join the Brain Injury Advisory Council (BIAC), where I have made the most incredible friends. The BIAC has taught me that, despite our deficits, we all have amazing strengths; when we work together, we can make an even bigger impact on the brain injury community.

neuropsychologist told me that I scored worse than a dementia patient, that I clearly must not have tried hard enough, and that it was likely psychosomatic. I got the distinct impression that she thought I was faking it. She then went on to tell me I should start taking Ritalin, anti-depressants, and sleeping pills. I politely declined her offer and ran out of her office as quickly as I could.

Feeling defeated, I plugged along at life for another year before a doctor read one of my Huffington Post articles and reached out to me. Dr. Jeremy Schmoe stated that he was certain he could help me. I blew him off for several months, feeling skeptical, as no one in the medical field had ever really bothered to take the time to listen to me, let alone believe me. He was persistent; he told me to come in for a complimentary exam, and since we both happened to live in Minnesota, I figured I had nothing to lose.

The exam was two hours long and included testing my eyes. Dr. Schmoe immediately told me my eyes weren't working together properly and that, combined with my cervical spine issues, this is why I was feeling so dizzy and off balance. After one week of intensive treatments with Dr. Schmoe, I started to feel less dizzy and foggy. Slowly, my other symptoms started to drift away, and I was feeling better than I had in more than two years. I still have flare-ups, but I feel good more days than not, which has given me back a quality of life that I was missing.

My passion for helping other survivors, caregivers, and healthcare providers has taken me across the



country speaking at conferences, writing various publications, moderating a large “Amy’s TBI Tribe” Facebook group, and publishing my first three books!

I believe that this invisible injury is incredibly misunderstood, but it doesn't have to define us. There is always hope – no matter how many years you may have been struggling. I have chosen to make the best of my situation and I've turned advocacy into my full-time passion. ●

A promotional graphic for the book "Rethink, Redo, Rewired" by Anthony Aquan-Assee, M.Ed. The graphic has a blue background. On the left, there is a white wireframe illustration of a brain. Below it, the text reads "RETHINK REDO REWIRED" in large, bold, white letters, followed by "Using Alternative Treatments to Heal a Brain Injury" and "ANTHONY AQUAN-ASSEE, M.Ed." in smaller white text. On the right side, the text "LEARN HOW TO IMPROVE YOUR HEALTH WITH ALTERNATIVE TREATMENTS" is written in white. Below this, a paragraph describes the author as a Motorcycle Trauma Survivor who shares how he used natural, alternative treatments like Kangen Water and Lase Therapy to heal his brain and body. A list of conditions treated includes Traumatic Brain Injury, Headaches, Sleep Disorders, Chronic Pain, Anxiety & Depression, and Gastro Problems. At the bottom, it says "Order the book today at: anthonyaquan-asee.com".

News & NOTES

BIAA RELAUNCHES PREFERRED ATTORNEYS PROGRAM

BIAA will launch a re-imagined and re-engineered Preferred Attorneys Program to connect individuals with brain injury and their families with attorneys who are knowledgeable about brain injury and experienced in personal injury, civil rights, or financial services, such as special needs trusts, conservatorships, and social security disability applications. BIAA's Preferred Attorneys are presented in an online directory that includes a photo, video (if available), contact information, firm description, and a website link. Individuals with brain injury and family members simply fill out an online form briefly explaining their legal problem. The Preferred Attorneys program will be a valuable service to all of BIAA's constituents.



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Upcoming WEBINARS

Visit www.biausa.org to register.

Carolyn Rocchio Caregivers Webinar – Fall Prevention and Home Safety Strategies to Improve Independence and Confidence after a Brain Injury

August 1, 2018, 3 p.m. ET/12 p.m. PT

Kristen Schreier M.A., CCC-SLP, and Jessica Heimall, PT, DPT, C/NDT, CBIS, HealthSouth Rehabilitation

Mitchelle Rosenthal Memorial Research Lecture – Risk for CTE in Football and Hockey

August 16, 2018, 3 p.m. ET/12 p.m. PT

John Leddy, M.D., FACSM, FACP, and Barry Willer, Ph.D., University at Buffalo

David Strauss Memorial Clinical Lecture –Cognitive Rehabilitation for the Aging Population

August 23, 2018, 3 p.m. ET/12 p.m. PT

Sarah Fischer, M.S., CRC, CBIS, and Mark Cola, CBIS, Main Line Rehabilitation

Robert Sbordone Memorial mTBI/Concussion Lecture – Vestibular Issues after Brain Injury

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

Amy Szalinski, PT, DPT, ReMed

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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and education programs. BIAA is grateful to the Corporate Partners for their financial contributions and the many volunteer hours their companies devote to spreading help, hope, and healing nationwide.

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

