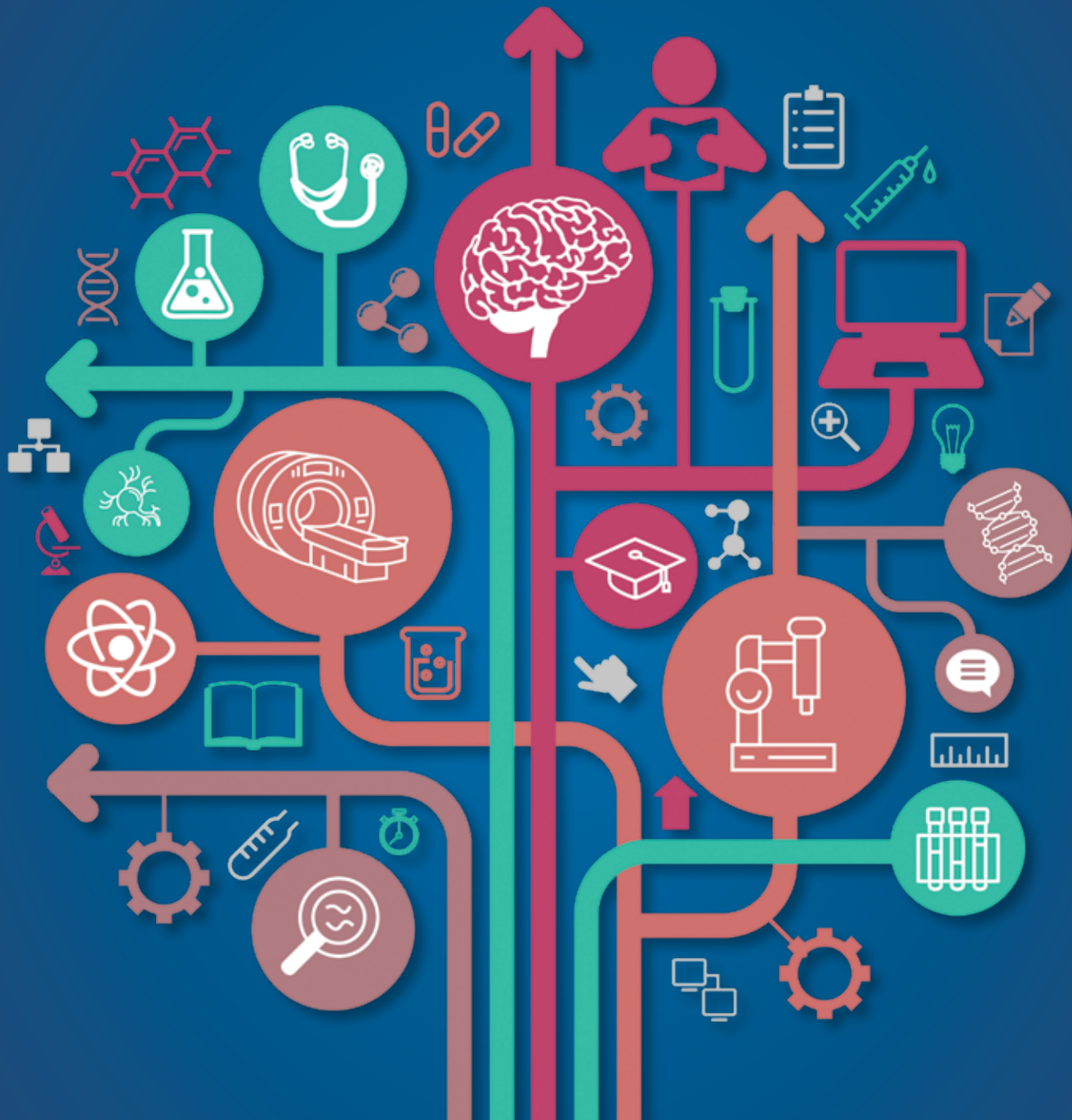


# THE CHALLENGE!



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FOR BRAIN INJURY

**SEPTEMBER 2019**

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## FROM MY DESK

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**T**he Brain Injury Association of America (BIAA) proudly dedicates this issue of *THE Challenge!* to research, shining a spotlight on the people and programs that advance brain injury science and medicine, including BIAA's new Brain Injury Research Fund.

Many people are surprised to learn how deeply the Association is involved in research. For starters, BIAA lobbies Congress every year for funding for the National Institutes of Health (NIH) and for the National Institute on Disability, Independent Living, and Rehabilitation Research. We write letters of support for many worthy applicants. Most recently BIAA supported University of California, Irvine stem cell scientist Brian Cummings in securing a \$4.8 million grant for pre-clinical testing of a stem cell therapy for traumatic brain injury (TBI).

BIAA staff members serve on advisory boards for several research projects involving brain injury and opioids, epilepsy, psychiatric problems, and other issues. We participate in the NIH Strategies to Innovate Emergency Care Clinical Trials Network (SIREN) external oversight board and the TBI Model Systems National Data Center advisory board.

We also assist researchers in recruiting participants for studies. Currently we are helping with an investigational drug for certain behavioral problems due to TBI. If someone you care about has experienced TBI and shows symptoms of aggression, agitation, and irritability, visit [www.biausa.org](http://www.biausa.org) and click on the link: "Opportunity to Participate in TBI Behavior Study."

BIAA continues to collaborate with the Brain Injury Research Center at the Icahn School of Medicine at Mount Sinai to identify and review the research literature on how much rehabilitation adults with moderate to severe TBI should receive, in what setting, and at what time after injury. We want to answer these questions to strengthen advocacy efforts for better access to care and improve quality of life for people who have been injured.

Speaking of research and care, I want to take a moment to remember Leonard Diller, Ph.D., who passed away in August. Dr. Diller was a pioneer in rehabilitation psychology, chief of psychology at the Rusk Institute of Rehabilitation Medicine, and Research Professor at New York University School of Medicine. He won BIAA's Caveness Award in 1987 and will be missed.

**If you'd like to support BIAA's research efforts, visit [biausa.org/supportresearch](http://biausa.org/supportresearch).**

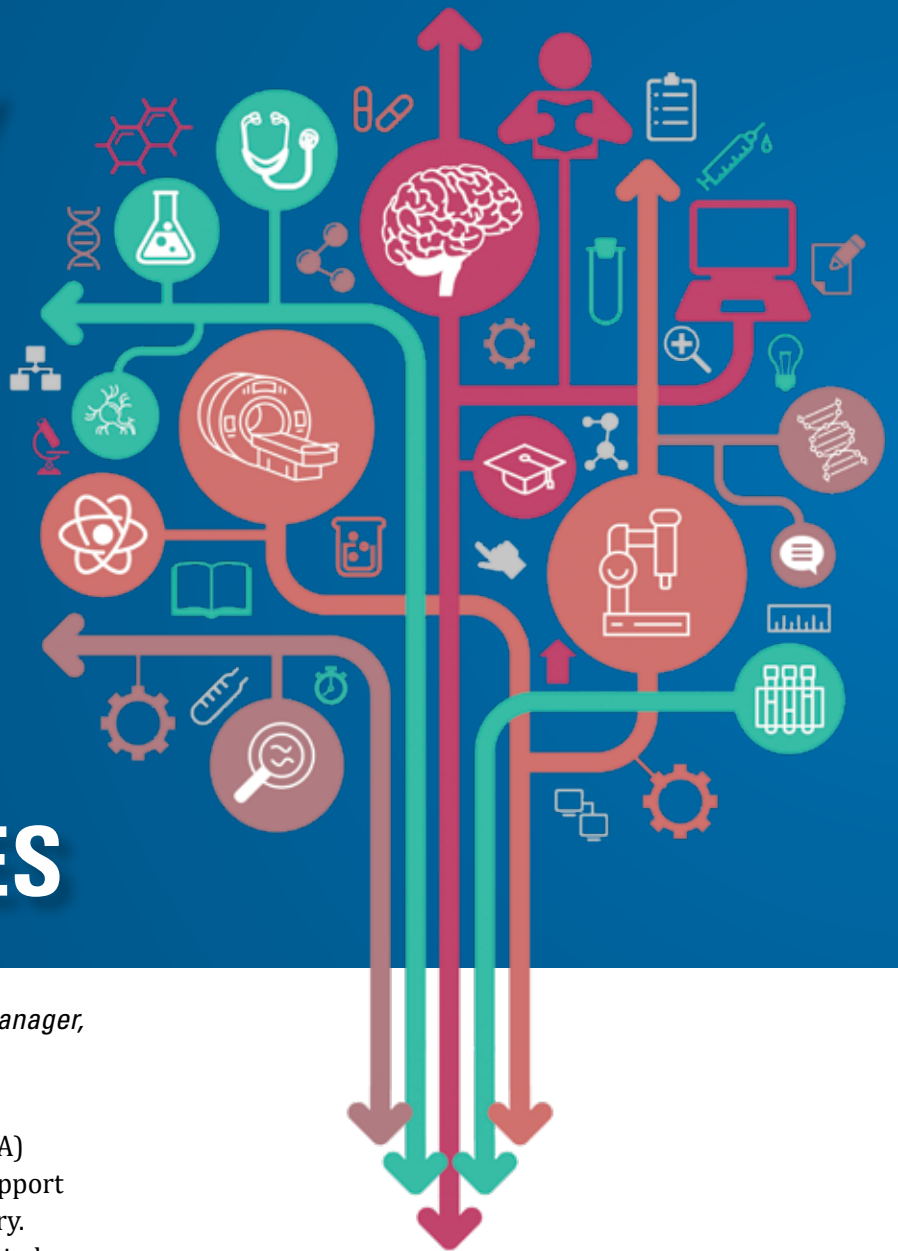
A handwritten signature in black ink that reads "Susan H. Connors". The script is fluid and cursive.

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

PS – Please join me in thanking Don Nolan and the Nolan Law Group (NLG) for hosting the summer meeting of BIAA's Board of Directors in Chicago. This was the 11th year NLG welcomed us with open arms. We are fortunate to have such generous and gracious friends, and we send a shout out to the BIA of Illinois leaders for their continuing participation at this annual gathering.



# BRAIN INJURY ASSOCIATION OF AMERICA LAUNCHES RESEARCH FUNDING OPPORTUNITIES



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

**T**he Brain Injury Association of America (BIAA) has created two funding opportunities to support research toward finding cures for brain injury. Thanks to a generous bequest from the estate of Linda Redmann, BIAA's Brain Injury Research Fund offers support to studies contributing to our understanding of brain injury as a chronic disease. In the inaugural call for proposals, BIAA sought novel approaches to understanding and ameliorating long-term effects of brain injury, such as the excess mortality associated with more severe injuries, neurodegenerative diseases that may be triggered by an injury earlier in life, or consequences of childhood brain injury.

"For many, brain injury evolves into a chronic health condition that accelerates multiple diseases," offered Susan H. Connors, BIAA's president and chief executive officer. "The launch of the Brain Injury Association of America's Brain Injury Research Fund marks a significant step in meeting many unmet needs after brain injury."

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## THE QUESTIONS WE'RE ASKING:

1

Chronic brain injury (CBI) can cause neurodegenerative diseases, such as Parkinson's Disease, Lewy Body Dementia, Chronic Traumatic Encephalitis and possibly Multiple Sclerosis and Alzheimer's Disease. Typically there is a marked delay from injury to disease onset. What neurological processes are triggered by CBI that cause these diseases and how can the progression from injury to neurological disease be halted?

2

Childhood traumatic brain injury (TBI), even when mild, is associated with adult problems of behavioral regulation, such as addiction, criminal behavior, and socially inappropriate behavior. Is this relationship causal or does TBI mediate other bio/psycho/social processes? What factors create the risk of adult consequences from childhood TBI and how can that risk be diminished?

3

Moderate and severe brain injury reduces life expectancy by 9 years. Even after living to one year post-injury, persons with this severity of injury are 50% more likely to die than age-, sex- and race/ethnicity-matched members of the general population. Causes of death involve all organ systems, not just those associated with behavioral or neurological pathology. What biological processes are responsible for this excess mortality and how can these relationships be ameliorated?

Through the Brain Injury Research Fund, BIAA offers two types of funding: Dissertation Awards, funded from \$3,000 to \$5,000, and Seed Grants, including two eligibility categories: Brain Injury Scholar and Young Investigator, funded up to \$25,000. The Association's research committee accepted Letters of Interest (LOIs) in July and August 2019 and will begin awarding grants within the next six months.

BIAA's research committee oversees the review process using National Institutes of Health review criteria. Subject matter expertise is drawn from leading researchers in the field, including members of the Journal of Head Trauma Rehabilitation Editorial Board. The Research Committee recommendations are submitted to the BIAA Board of Directors for final approval.

### RESEARCH COMMITTEE MEMBERS

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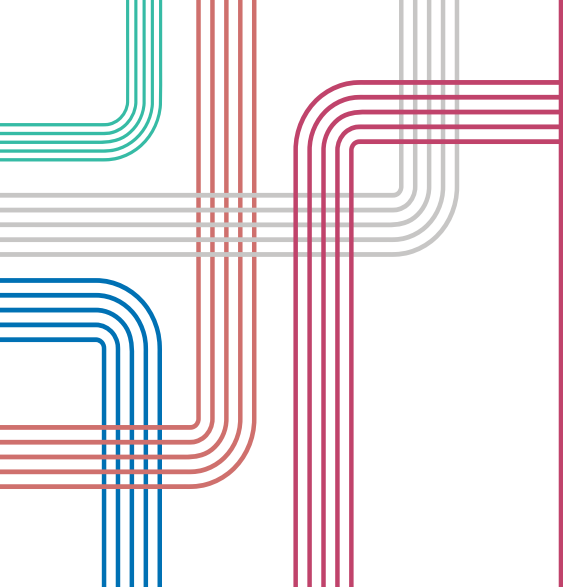
**Brent Masel, M.D.**, University of Texas Medical Branch

**Greg O'Shanick, M.D.**, private practice, Richmond Virginia

**Stacy Suskauer, M.D.**, Kennedy Krieger Institute, Johns Hopkins University

For more information about BIAA's Brain Injury Research Fund, visit [biausa.org/research](http://biausa.org/research).





## MEET JOHN D. CORRIGAN, PH.D.

# DIRECTOR OF THE OHIO VALLEY CENTER FOR BRAIN INJURY PREVENTION AND REHABILITATION

*By Rula Tareq, Communications Specialist,  
Brain Injury Association of America*

**T**he Brain Injury Association of America (BIAA) is proud to highlight an advocate and pioneer in brain injury rehabilitation and research, John D. Corrigan, Ph.D., ABPP, in this issue of *THE Challenge!* Dr. Corrigan has been a BIAA Champion for three decades and currently serves as a member of its board of directors and as the chairperson of its research committee.

Dr. Corrigan is emeritus professor in the department of physical medicine and rehabilitation at The Ohio State University. He is founder and director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation, the designated lead agency in the state of Ohio for Traumatic Brain Injury (TBI) policy and planning. He is also co-principal investigator for the Ohio Regional TBI Model System, a member of the Institute of Medicine Board on the Health of Select Populations, and serves on the Neurological and Behavioral Health Subcommittee of the Defense Health Board.

Dr. Corrigan previously served on the advisory committee to the National Center on Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC) and on the board of directors at CARE.

## RESEARCH

Dr. Corrigan's distinguished contributions to brain injury rehabilitation and research include the treatment of substance abuse as a co-occurring complication of TBI, the measurement and management of agitation occurring during the acute phase of recovery, and measurement of outcomes from rehabilitation. He is the editor-in-chief of the *Journal of Head Trauma Rehabilitation*, a peer-reviewed resource that serves as the official journal of BIAA and provides up-to-date information on the clinical management and rehabilitation of persons with TBI.

His 1995 literature review "Substance Abuse as a Mediating Factor in Outcome from Traumatic Brain Injury" has been and continues to be an instrumental tool in casting a light on the prevalence and effects of substance abuse among persons with TBI. In conjunction with this review, Dr. Corrigan conducted quasi-experimental and randomized clinical trials on treatment interventions for substance abuse in this population. He has also provided training and consultation internationally on the nature, extent, and treatment of substance abuse. Currently, Dr. Corrigan



is developing diagnostic and treatment techniques for early intervention in acute hospital and rehabilitation settings. He works in collaboration with CDC to develop a standardized method of identifying TBI in at-risk populations.

Dr. Corrigan has made great strides in agitation in the acute phase of recovery through his development of the Agitated Behavior Scale (ABS). This scale provides objective clinical and research data on agitation in persons with TBI emerging from coma. The ABS is widely used in the brain injury rehabilitation continuum. It has been adopted in research on agitation among persons with dementia as well as those experiencing psychiatric crises.

Dr. Corrigan aided in research on the measurement of rehabilitation outcomes. He contributed to the development and/or validation of the Functional Independence Measure (FIM), Community Integration Questionnaire (CIQ), and Satisfaction with Life Scale (SWLS). Dr. Corrigan is also among the leaders in

research addressing the generalizability of the TBI Model Systems National Dataset.

A prolific author, Dr. Corrigan has served as a voice for medically underserved populations, especially those with TBI, for many years. He earned two prestigious awards from BIAA and the highest honors possible from the American Congress of Rehabilitation Medicine, National Association of State Head Injury Administrators, and the Moody Foundation.

Dr. Corrigan's personal dedication and lifelong accomplishments in rehabilitation education, service, and research, particularly in the field of substance abuse, embody the spirit of a true advocate. His efforts have made significant contributions toward improving the quality of life for those with brain injury. BIAA President/CEO Susan H. Connors describes Dr. Corrigan as "[someone who] is known and liked by everyone in the brain injury community because he can be counted on to fulfill his promises and meet his obligations, all with good humor." Thank you, Dr. Corrigan. ●

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# PERSON-CENTERED, PARTICIPATION-ORIENTED BRAIN INJURY REHABILITATION

*By James F. Malec, Ph.D., ABPP-Cn, Rp, Senior Research Professor Emeritus, Physical Medicine and Rehabilitation, Indiana University School of Medicine, Emeritus Professor of Psychology, Mayo Clinic*

In the 1970s, we began to figure out how to provide brain injury rehabilitation. Before that, since emergency response services were very limited, people usually died shortly after a serious brain injury. Grimly, rehabilitation was not required. At its start, brain injury rehabilitation was prescriptive (that is, doctors ordered specific therapies) and focused primarily on reducing impairments. Then early brain injury rehabilitation pioneers like Yehuda Ben-Yishay and George Prigatano introduced the idea that brain injury rehabilitation should be holistic. Holistic rehabilitation addresses the needs of the whole person and his or her family group, not just obvious impairments. Since those early years, brain injury rehabilitation has become increasingly person-centered and participation focused. Person-centered, participation-oriented rehabilitation (PCPO) addresses the needs of the whole person as communicated by the person with brain injury and his or her close others rather than as prescribed by the

provider. PCPO only targets impairments for intervention that interfere with the person's return to participation in family and community life. We all have our strengths and weaknesses. Fortunately we do not need to be perfect to have a good life. PCPO focuses on resolving problems that make it difficult for the person with brain injury to have a good life and makes the most of the individual's strengths and resources in achieving this goal.

PCPO is grounded in both the medical model and the social model of rehabilitation. The medical model aims to fix what's wrong with you. PCPO offers treatments and therapies that remediate impairments that interfere with the person's participation in life. However, as people with spinal cord injury taught us in the 1970s, the environment in which a person operates can make impairments worse (stairs can't be climbed in a wheelchair) or better (available ramp or elevator). For people with brain injury, social model interventions include not only modifications



## Principles of Person-centered, Participation-Oriented Rehabilitation

KEY PRINCIPLE	RATIONALE
<b>Standardized holistic evaluation</b>	<b>Cognitive, physical, emotional, environmental, and other factors interact to affect outcome and are evaluated comprehensively for effective treatment planning</b>
<b>Match evaluation/treatment to case complexity</b>	<b>Maximizes efficiency; minimizes cost</b>
<b>Collaborative, participation-focused goal setting</b>	<b>Participation goals are most highly valued by the person served and family/close others</b>
<b>Specific goal-oriented treatment plan</b>	<b>Targets barriers and capitalizes on resources that support achieving valued participation outcomes</b>
<b>Standardized monitoring of progress</b>	<b>Standardized assessment increases reliability; treatment is modified based on ongoing assessment</b>
<b>Capitalize on nonspecific effects</b>	<b>Nonspecific effects maximize successful outcomes and are often necessary (but not necessarily sufficient) conditions for successful outcome</b>
<b>Family/close other participation</b>	<b>Support the participant emotionally and reinforce and support generalization of learning in rehabilitation</b>
<b>Post-discharge planning</b>	<b>Plan self-management strategies, follow-up refreshers to sustain gains</b>

to the physical environment like noise reduction and reminder systems but also adaptations in the social environment like developing understanding and support from family and co-workers.

The table describes the primary components of PCPO. The process begins with a standardized holistic evaluation that leads to an effective and efficient individualized rehabilitation plan. To be cost-effective, the extent of this evaluation as well as subsequent treatment should match the complexity of the case. A single provider may perform an initial evaluation and bring in other providers as needed. Individuals with a wide array of limitations due to brain injury or whose lives are complicated by psychological or social issues typically require evaluation by a rehabilitation team as well as other medical and community consultants. These evaluations are functional. The goal is to identify issues and resources, strengths and weaknesses that are relevant to the person's return to rewarding participation in family and community life.

Discussion of the results of a thorough evaluation leads to collaborative, participation-focused goal setting with the participant and close others. To begin with, one or two major goals are chosen, such as participating in more enjoyable family activities or getting a job. The major goals should be of high value to the participant and his/her close others. After that, the rehabilitation team helps map out the intermediate goals that need to be achieved in order to accomplish the major participation goals. For example, developing a memory compensation system may be needed to support getting back to work, or learning anger management techniques may make for more enjoyable family time. In some cases, the rehabilitation team or close others may feel that the participant's goals are unrealistic. In these situations, mapping out intermediate goals and starting to work on them will help the participant, close others, and the rehabilitation providers discover if these goals are realistic. If accomplishing intermediate goals is more challenging than expected, this usually means that the ultimate participation goal needs to be modified.

*(continued on page 10)*

(continued from page 9)

Once initial goals have been determined, the rehabilitation providers will need to develop a specific, goal-oriented treatment plan that describes the interventions and intermediate goals to help the participant achieve his/her ultimate participation goals. Although some aspects of the treatment plan may be technical like describing specific therapy techniques, the plan is thoroughly reviewed with the participant and close others. The participant may not agree with or see the sense of all aspects of the plan but should feel that it is “worth a try.”

An important part of successful rehabilitation is developing a therapeutic alliance. Therapeutic alliance means that the participant and the provider respect each other and have confidence that both will do their part to achieve the participant’s goals. Discussion of the evaluation and treatment plan begins this critical process. In a sense, the treatment plan is a contract between the rehabilitation provider and the participant that describes what the provider will do and what the participant is expected to do. To make sure that learning in therapy translates into real life, one of the participant’s responsibilities will be to work on goals outside of therapy (“homework”).

The treatment plan is a living document that can and should be modified if progress is not being made. Standardized monitoring of progress is one of the provider’s responsibilities using measures that have been shown by researchers to be reliable and valid. Overall gains in a program should be evaluated using a well-established outcome measure like the Mayo-Portland Adaptability Inventory (MPAI-4) as well as by tallying achievement of major participation goals. The overall outcomes of a program for past participants as demonstrated by gains on a measure like the MPAI-4 is one indicator of the quality of the program. Intermediate goals may be measured with more specific, standardized measures like those for functional memory, mood and behavior, or mobility. Goal Attainment Scaling provides a method for measuring and tracking highly individualized goals. Goal Attainment Scaling is a process of rating the achievement of an individualized goal on a 5-point scale ranging from “much less than expected outcome” to “much better than expected outcome.”



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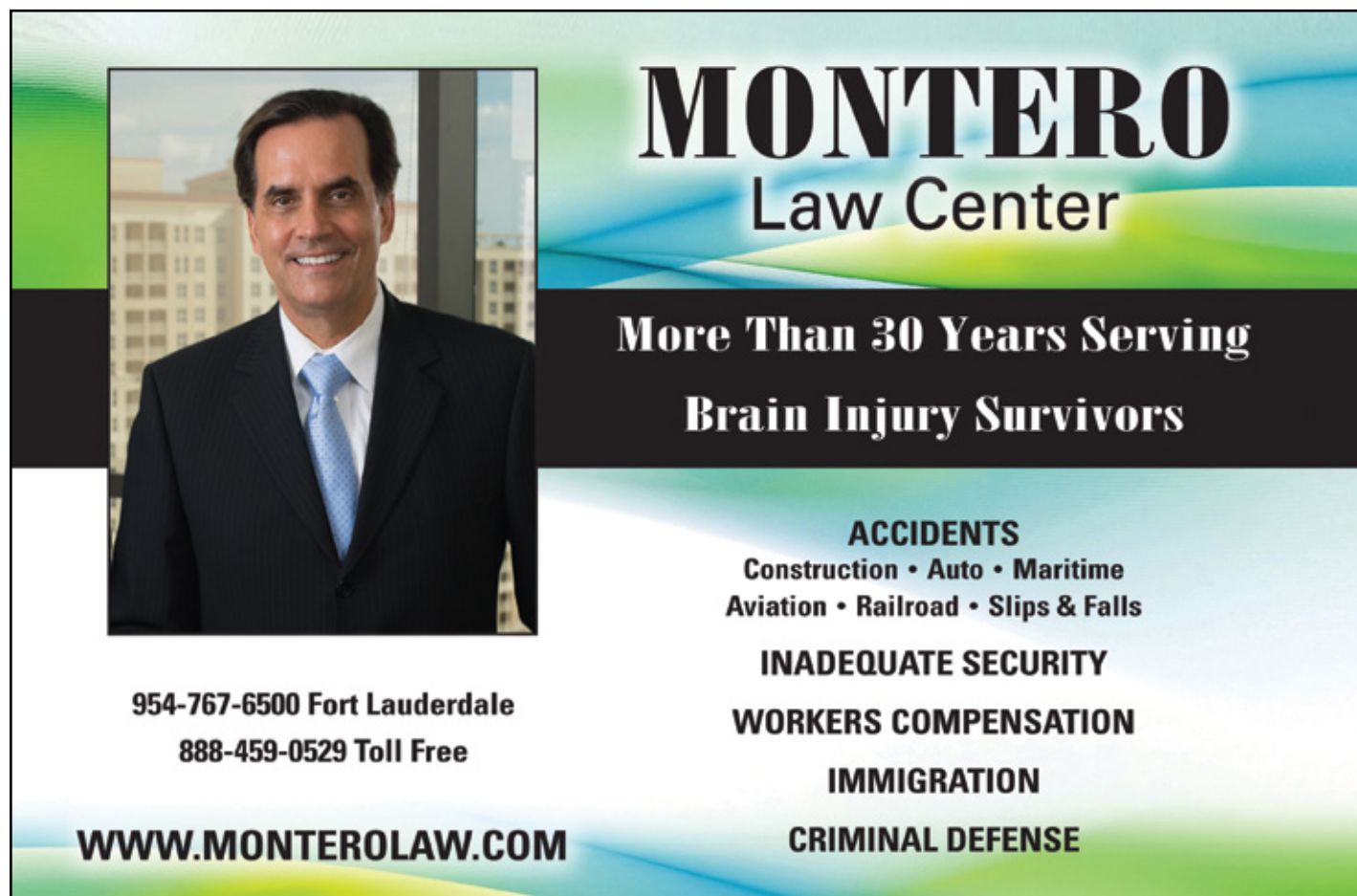
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High quality PCPO programs use evidence-based interventions, that is, interventions that have been found to be effective by the best scientific evidence available. Research to establish the effectiveness of interventions controls for nonspecific effects, also known as placebo effects, like belief or expectation on the part of the therapist or the participant that the intervention will be effective. However, in clinical work, good therapists who are using methods that have scientific support also make the most of nonspecific effects and work to help participants feel motivated and successful and to look forward to therapy. A positive therapeutic alliance can create a powerful nonspecific effect.

Good therapists also encourage the participation of family and close others to the degree that is comfortable for the participant. Close others provide emotional support for participants and help reinforce participants in practicing skills learned in therapy in their daily life. A participant's brain injury and rehabilitation are also often stressful for his or her close others. These individuals may need support, including psychological or family therapy if the stress and distress is severe.

From the very beginning of therapy, the rehabilitation team plans with participants and their close others for transferring skills learned in therapy to real life and maintaining gains after discharge. Such efforts often include independent living trials and trials of work or school. Post-discharge planning often involves assisting the participant to engage with other sources of environmental and social support in addition to close others. The discharge plan also typically includes a schedule for follow-up by rehabilitation providers to make sure progress made in rehabilitation is maintained with an option for further rehabilitation if gains are being lost.

PCPO finds its roots in the early work of brain injury rehabilitation pioneers and is also reflected in more contemporary approaches like Cognitive Orientation to daily Occupational Performance (CO-OP). The principles of PCPO described here are currently used in residential, outpatient, and community-based post-hospital brain injury rehabilitation programs in the United States and other countries as well as in the U.S. Veterans Administration. ●



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## FUNCTIONAL ACTIVITY LIMITATIONS AFTER TRAUMATIC BRAIN INJURY

*By Yelena Goldin, Ph.D., JFK Medical Center*

JFK Johnson Rehabilitation Institute is one of 16 Traumatic Brain Injury Model Systems (TBIMS) Centers. Each center conducts independent research with the aim of providing new information that can improve the lives of people affected by moderate and severe traumatic brain injury (TBI). Today, our understanding of TBI is much better than it was several decades ago. However, we still have an insufficient understanding of how people's ability to engage in important daily-life activities is affected by TBI and how that changes throughout the course of recovery.

The TBIMS project at JFK Johnson aims to evaluate changes in one's ability to perform functional activities important for independent living after TBI. TBI affects everyone differently, and these differences can result in variability in an individual's ability to perform functional activities of daily living. Recovery of functional activities can occur over the course of days, months, or even years after injury. Different functions may recover at different rates, and some functions may remain compromised or may even worsen, requiring specialized treatments. In order to develop and select the best treatments for each person, it is important to understand how the

ability to perform activities changes over time. Of equal importance is determining and demonstrating that treatment at various stages of recovery helps individuals with TBI live in the community.

Our project aims to track longitudinal changes in functional activities during acute rehabilitation and through the first year of recovery in individuals with moderate and severe TBI. To address this, we are recruiting patients admitted to our inpatient brain trauma rehabilitation unit. We also study treatment-induced changes in functional activities in individuals with TBI receiving outpatient rehabilitation. This is achieved by enrolling individuals in specialized outpatient brain injury rehabilitation at our facility.

To evaluate limitations in functional activities, we are using the Activity Measure for Post-Acute Care (AM-PAC). The AM-PAC was developed for the longitudinal study of activity limitations across the rehabilitation continuum and allows continuous evaluation in both inpatient and community settings. This instrument measures activity limitations in

three distinct functional domains: basic mobility (includes functions addressed by a physical therapist), daily activities (includes functions addressed by an occupational therapist), and applied cognition (includes functions addressed by a speech therapist and/or neuropsychologist).

The AM-PAC can be completed interchangeably by patients, therapists, or caregivers. It provides standard scores to help clinicians select interventions and track patient progress. Its functional stage grades also give patients and caregivers a concrete understanding of a person's level of independence and required assistance in various physical, cognitive, and daily-living activities. We recently conducted a preliminary data analysis on both our inpatient and outpatient samples. Our results show that individuals with TBI continue to make gains throughout their recovery. Among individuals receiving acute inpatient rehabilitation, patients improved from being significantly limited and largely dependent in all domains immediately after injury to being able to function in the community with various degrees

*(continued on page 30)*

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# BIAA AWARD WINNERS RECOGNIZED FOR CONTRIBUTIONS TO RESEARCH AND CLINICAL CARE

By Marianna Abashian, M.A., Director of Professional Services, Brain Injury Association of America

## Sougandi “Samantha” L. Backhaus, Ph.D.

The Brain Injury Association of America (BIAA) is pleased to announce Sougandhi “Samantha” L. Backhaus, Ph.D., as the recipient of the 2019 Sheldon Berrol, M.D., Clinical Service Award.

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 education in the field of brain injury.

Sougandhi “Samantha” L. Backhaus is a Clinical Neuropsychologist and associate director of the Outpatient Brain Injury Neuropsychology Services at the Rehabilitation Hospital of Indiana. Her roles include providing clinical services to persons with brain injury and their families as well as developing new programs to enhance patient outcomes. Specifically, she conducts neuropsychological examinations, leads the outpatient brain injury treatment team in facilitating rehabilitation care and treatment planning, and provides individual, couples, and group therapies.

Dr. Backhaus has developed evidenced-based treatments to help improve the long-term functioning of individuals with brain injury and family members. Among these programs, she co-developed a 16-week, evidenced-based coping skills group intervention to improve self-efficacy, neurobehavioral, and psychological functions after brain injury. She also co-developed a couples



program to help improve satisfaction, quality, and marital adjustment after brain injury.

Additionally, Dr. Backhaus works with an interdisciplinary treatment team in developing new programs using evidence-based research models, including a Cognitive and Life Skills Training Intervention based on evidenced-based treatment models recommended by the American Congress of Rehabilitation (ACRM), as well as a post-traumatic confusion treatment program called ASE – Assessment, Support, and Education.



## Jennifer Ann Bogner, Ph.D., ABPP, FACRM

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 people who have sustained brain injury. This year's award winner, Jennifer Ann Bogner, Ph.D., ABPP, FACRM, is a professor at The Ohio State University Department of Physical Medicine and Rehabilitation (PMR).

Dr. Bogner holds the Bert C. Wiley, M.D., Endowed Chair in Physical Medicine and Rehabilitation. Her roles within the department of PMR include being vice-chair of research and academic affairs and being the director of the division of rehabilitation psychology. She also serves as associate editor for the *Journal of Head Trauma Rehabilitation*, as secretary for ACRM, and as immediate past-chair of the Brain Injury Interdisciplinary Special Interest Group of ACRM. She is co-principal investigator for the Ohio Regional TBI Model Systems and chairs the National Institute on Disability, Independent Living, and Rehabilitation Research TBI Model Systems' Strategic Planning Committee.

The overarching goal of her research has been to improve long-term outcomes after traumatic brain injury (TBI). Specific areas of research include the comparative effectiveness of rehabilitation interventions, prevention and treatment of substance misuse following TBI, evaluating the impact of lifetime exposure to TBI on quality of life, and the development and validation of measurement tools to support rehabilitation research and clinical practice. In light of the medical community's history of taking an average of 17 years to implement research findings into practice, Dr. Bogner has taken an interest in improving methods for dissemination and implementation and is currently one of the leaders of the Health Services Research Special Interest Group within the TBI Model Systems.



Dr. Bogner's research has been guided by the priorities set by the Advisory Council of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation (OVC). Founded more than 25 years ago by her collaborator, mentor, and friend, John Corrigan, Ph.D., the OVC Advisory Council has helped to ensure that research being conducted by OVC is relevant, important, and accessible to persons living with brain injury. The Advisory Council is comprised of persons living with brain injury, family members, and advocates with an interest in doing work that has a positive impact on the wider brain injury community.

The awards will be presented at the ACRM annual conference, November 5-8, 2019, in Chicago, Illinois.



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**THANK YOU!**

## Make a Lasting Impact



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

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

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

Visit [biausa.org/support](http://biausa.org/support) to learn more.



# ADVOCACY UPDATE

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

## Congressional Brain Injury Task Force Hosts Briefing on Acquired Brain Injury

At Brain Injury Awareness Day in March, BIAA President/CEO Susan Connors announced the Association's intentions to raise awareness of acquired brain injury (ABI) on Capitol Hill. Through BIAA's leadership, the Congressional Brain Injury Task Force hosted a briefing on ABI in June. The briefing, "Not Just TBI and Concussion: Acquired Brain Injury's Impact on the Military and Civilian Populations," was very well attended. Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Neb.), co-chairs of the Congressional Brain Injury Task Force, spoke at the briefing. Panelists included the Centers for Disease Control and Prevention (CDC), a caregiver of an adult with ABI, BIA of New Hampshire, and a researcher actively pursuing studies on ABI. BIAA continues to highlight ABI through its work on Capitol Hill and through social media.



ABI Briefing Panelists (L-R): Michael J. Decker, Ph.D., Case Western Reserve University; Shirley Richardson, caregiver of an adult son with ABI; Matt Breiding, Ph.D., Centers for Disease Control; Steve Wade, Brain Injury Association of New Hampshire.

## BIAA Urges Brain Injury Advocates to Contact Senate

In July, BIAA sent an action alert urging grassroots advocates to contact their senators while they are in their home states. Stakeholders asked the Senate to support the \$1 million dollar increase for the TBI State Grant Program in the Senate appropriations bill. BIAA partnered with the National Association of State Head Injury Administrators (NASHIA) in sending a funding request letter to the Senate Appropriations Committee. The House appropriations bill included the \$1 million increase for the TBI State Grant Program. The total amount appropriated for this program in the House bill is \$12.321 million. The Department of Health and Human Services' Administration for Community Living (HHS ACL) funds programs impacting individuals with brain injury and families, including the Federal TBI State Grant Program. The Senate will mark up its appropriations bill later this fall or adopt a continuing resolution.

## House Passes Budget and Spending Caps Agreement

After negotiations between administration and Congressional leaders, the House of Representatives passed the Bipartisan Budget Act of 2019, H.R. 3877, which increased the budget for 2020 and 2021 by \$1.7 trillion and extended the debt limits for the next two years. The agreement allows for increased spending for the Department of Defense and avoids cuts to domestic and some entitlement programs that the administration had proposed. The bill offers a \$324 billion increase in discretionary spending over two years above existing budget caps. Without the measure, spending caps enacted in prior years would have required cuts in domestic spending beginning Oct. 1. Raising the debt ceiling allows the Treasury Department to borrow beyond the current debt limit scheduled to expire in September to avoid default on the U.S. debt. BIAA supports the letter from the Fiscal Policy Task Force of the Consortium for Citizens with Disabilities to Senators urging them to vote for the Bipartisan Budget Act of 2019.



## Senate Finance Committee Passes Bipartisan Drug Pricing Legislation

The Senate Finance Committee passed the Prescription Drug Pricing Reduction Act to address the problem of high and rising drug prices within the Medicare program. The bill, developed by Committee Chairman Chuck Grassley (R-Iowa) and Ranking Member Ron Wyden (D-Ore.), outlines a number of changes, including a redesign of the Part D benefit and the imposition of inflationary rebates. The bill places a \$3,100 cap on what Medicare beneficiaries pay out-of-pocket on prescription drugs, set to take place in 2022, and a limit on prescription drug price hikes under Medicare Part D.

## Lifespan Respite Care Reauthorization Passes in the House of Representatives

The House of Representatives passed the Lifespan Respite Care Reauthorization Act, sponsored by Reps. Jim Langevin (D-R.I.) and Cathy McMorris Rodgers (R-Wash.), authorizing \$200 million in funding over the next five years. The purpose of the bill is to strengthen coordinated respite services for family members who care for loved ones with disabilities and other chronic health conditions. The program is administered by the HHS ACL. It was first authored by Rep. Langevin in 2002. The bill has now been sent to the Senate for passage. BIAA supports the bill.

## House Passes Minimum Wage Hike Bill

In July, the House of Representatives passed the Raise the Wage Act, H.R. 582, which would increase the minimum wage for all people, including people with disabilities. The legislation phases out Section 14c of the Fair Labor Standards Act (FLSA) over six years. Established in 1938, the FLSA allows employers to obtain special certificates from the Department of Labor's (DOL) Wage and Hour Division to compensate workers with significant disabilities at rates below the current federal minimum wage. The Transformation to Competitive Employment Act introduced by Sen. Bob Casey, Jr. (D-Pa.) would end subminimum wages and would also provide funding to states and providers to expand capacity for competitive, integrated employment.

## DOL Sets Theme for 2019 NDEAM

The Labor Department has announced the theme for the 2019 October National Disability Employment Awareness Month (NDEAM) as "The Right Talent, Right Now." Observed annually in October, NDEAM celebrates America's workers with disabilities and emphasizes the importance of inclusive policies and practices to ensure that all Americans who want to work can work and can access the needed services and supports to enable them to do so. With continued advances in accessible technology, it is easier than ever for America's employers to hire people with disabilities in high-demand jobs. DOL provides materials for celebrating the month on its webpage at [www.dol.gov/odep/topics/ndeam](http://www.dol.gov/odep/topics/ndeam).

## CDC Announces Injury Center Reorganization

CDC has approved the reorganization of the National Center for Injury Prevention and Control (NCIPC) to better address both current and anticipated organizational needs across TBI, transportation safety, older adult falls, drug overdose, and emerging drug threats programs. NCIPC leadership will report to stakeholders and partners about Center priorities, including opioid overdose prevention, suicide prevention, and the prevention of adverse childhood experiences.

## Brain Injury Advocates Take Action!

This year, members of Congress will be working in districts at least one week per month! Brain injury advocates can take advantage of this opportunity to meet with elected officials in their district offices. Upcoming district work periods are: October 1-11, November 4-8, and November 25-29, 2019.

When meeting with elected officials or appropriate staff, bring copies of BIAA's legislative issue briefs available at [www.biausa.org](http://www.biausa.org). Invite lawmakers or their representatives to tour a facility, attend a support group, or visit a club house. Remember to ask your elected officials to join the Congressional Brain Injury Task Force, and connect with them on Facebook and Twitter so you can continue to share information about brain injury with them. ●

# Rep Payee Review Program

As of 2017,  
there are



8.1 million  
Beneficiaries



5.8 million  
Rep Payees



57 P&A  
Agencies

## WHAT'S THE REP PAYEE REVIEW PROGRAM?

Since August 2018, the Protection and Advocacy (P&A) Network received funding to conduct reviews on rep payee performance on behalf of the Social Security Administration (SSA). This program provides oversight to rep payees and their services to beneficiaries as well as giving them support to better understand their role and responsibilities.

## WHO ARE THE P&AS?

There is a P&A organization in each state, U.S. territory, as well as the Native American consortium, totaling 57 agencies. They have 40+ years of experience investigating abuse, neglect, and rights violations anywhere that serves people with various types of disabilities. P&As are uniquely positioned because of their relationship with their local communities and their other work.

## WHO IS AFFECTED BY THIS PROGRAM?

This program helps both beneficiaries and rep payees. Beneficiaries are the recipients of Social Security or Supplemental Security Income (SSI) benefits. Rep payees are the individuals or organizations who manage Social Security benefits on behalf of the beneficiary. SSA assesses a beneficiary's need for a rep payee on a case-by-case basis. SSA also automatically assign a rep payee to most child beneficiaries and to individuals who are found legally incompetent by a court.

## WHAT'S THE IMPACT?

- **EMPOWERMENT**  
Beneficiaries and others are empowered to report potential misuse more easily.
- **COST EFFECTIVENESS**  
P&A monitoring efforts will be more efficient in providing tailored support to rep payees and beneficiaries, reaching larger numbers of people. Previous efforts were costly and provided little administrative oversight to rep payees.
- **CENTRALIZED SYSTEM**  
Reviews are centralized through the collaborative efforts of SSA, NDRN, and the P&As.
- **RELATIONSHIP BUILDING**  
Beneficiaries will build relationships with their local P&As and have access to additional resources.
- **NEEDS REASSESSMENT**  
Beneficiaries can be reassessed to determine if they still need a rep payee, an aspect that is particularly important for youth aging out of foster care.



# WHO'S INVOLVED?

SSA, National Disability Rights Network (NDRN), and the P&As are collaborating together to conduct reviews and educational visits. Congress selected the P&As to conduct reviews and educational visits because of their involvement and knowledge of local communities. NDRN was selected as the National Association Grantee because of their extensive knowledge and demonstrated experience in providing training, technical assistance, and administrative oversight to the P&A network. SSA oversees Social Security benefits and will provide additional support, as needed.

# WHAT ARE THE TYPES OF REVIEWS?

## PERIODIC ONSITE REVIEWS

A continuation of reviews previously conducted by SSA. These include reviews of organizational rep payees and Fee for Service rep payees.

## PREDICTIVE MODEL REVIEWS

SSA-selected review cases for rep payees that serve organizational rep payees with less than 50 beneficiaries or individual rep payees that serve less than 5 beneficiaries.

## P&A INITIATED REVIEWS

Review cases that are identified by P&As and are suspected of potential misuse.

## STATE MENTAL INSTITUTIONS

State mental institutions can serve as a rep payee for beneficiaries living in their facilities and are eligible for review.

## QUICK RESPONSE CHECK

SSA may request a Quick Response Check outside of a rep payee's regular review schedule if there is suspected misuse.

## EDUCATIONAL VISITS

P&As will conduct check-ins with new Fee for Service rep payees and other rep payees that SSA has identified.

# THE REP PAYEE REVIEW PROCESS

1

P&A will call rep payee to schedule review appointment.

2

P&A will interview rep payee and conduct a financial record review.

3

P&A will conduct separate interviews with each beneficiary as well as any legal guardians or third parties.

4

P&A will provide rep payee with a Corrective Action Plan, if needed.

5

P&A will close case.

## P&A GOAL

To conduct 5000 reviews by August 2019.



# STATE AFFILIATE NEWS

## DELAWARE

The Brain Injury Association of Delaware (BIAD) continues to advocate for persons affected by brain injury throughout the state. Board members and Executive Director Kristy Handley have been busy attending events and providing education in various communities. BIAD works closely with the State Council for Persons with Disabilities to advocate for public policy changes that will benefit persons with brain injury.

BIAD provides support groups in each of the three counties throughout the state and has recently partnered with a post-acute medical rehabilitation hospital to offer a new support group in Kent county beginning in September. All of these support groups, facilitated by Certified Brain Injury Specialists, offer survivors and caregivers the opportunity to talk about the challenges and successes in their journey with brain injury. Guest speakers with expertise in treatments often present at these meetings as well.



BIAD staff share information at a concussion round table event.

Lastly, BIAD is pleased to announce that it has moved into a new office. The Association has plans to open a brain injury community resource center.

## KANSAS

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS-GKC) hosted the 32nd annual Memorial Day Run for Brain Injury May 27. More than 1,000 runners and spectators participated in the 10K, 5K and 1.5 mile walk in Kansas City's beautiful and historic Loose Park. Besides being BIAKS-GKC's largest fundraiser, the run is a powerful tool to raise awareness of brain injury.

In June, the Kansas House and Senate approved an expansion of the State's Medicaid brain injury waiver program to go into effect July 1. The expansion includes children under 16 and those with acquired brain injury – stroke, aneurysm, and poisoning. Spurred by advocacy efforts of BIAKS-GKC, the expansion allows individuals eligible for KanCare (Kansas Medicaid) who've had an acquired brain injury or are under 16 to receive home and community-based services that help build



Runners attend the BIAKS-GKC 2019 Memorial Day Run.

independence. Kansas is one of only a few states offering a publicly funded rehabilitation program for children under 16 with a brain injury.



## MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) has been busy advocating for individuals with brain injury throughout the state. After a busy legislative season during which BIAA-ME staff testified on behalf of several brain injury bills, Governor Janet Mills signed “An Act To Strengthen Brain Injury Resources for Underserved Populations, Including Opioid Overdose Brain Injury Survivors,” LD 297. The goal of the act is to ensure that all Mainers have consistent access to core brain injury supports and resources. The enactment of LD 297 is a huge win for the Maine brain injury community.

BIAA-ME’s 10th annual conference on Defining Moments in Brain Injury will take place Oct. 9 at the University of Southern Maine’s Abromson Center in Portland. Author and caregiver Abby Maslin will give a keynote address, “The New Normal: Welcoming Gratitude, Transformation, and Post-Traumatic Growth Following Brain Injury.”

BIAA-ME’s fifth annual Bowling for Brain Injury<sup>SM</sup> event is scheduled for Dec. 1 in Portland. Visit [biausa.org/maine](http://biausa.org/maine) to learn more.



A group of BIAA-ME staff, Maine brain injury advocates, and state representatives gather after the legislative work session for LD 297.

## MICHIGAN

The Brain Injury Association of Michigan (BIAMI) was among those chosen to receive grant funding for an exciting new program called Think aHEAD. Focusing on youth and adults, the statewide campaign will promote and boost the lifelong use of protective headgear among children and adults. The program will launch in September and focus initially on bicycle helmet-wearing among middle school-aged youth. Think aHEAD will be promoted through existing relationships with the media, featured in school curriculums, and expanded with increased community support. BIAMI will highlight

the program as a partner with the successful “Lids for Kids” events, during which more than 10,000 bike helmets have already been distributed to date. Although the initial focus will be on bicycle helmet-wearing, the program will extend throughout the year to encourage helmets to be worn in other seasonal recreational activities for which the choice to wear a helmet is optional. These activities include skateboarding, skiing, snowboarding, off-road ATVs, and horseback riding, among others.

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(continued from page 25)

## MISSOURI

The Brain Injury Association of Missouri (BIA-MO) Donald Danforth Jr. Wilderness Camp was held May 26-31 for 70 survivors of brain injury to enjoy a week of fun, independence, and adventure. Survivors ziplined across the lake, played sports, caught fish, danced to a variety of music, and showed off their talents. Family members had a week of respite to rejuvenate emotionally and physically. Campers raised nearly \$1,000 by participating in the Walk Float Swim challenge in which family and friends sponsored each lap the camper walked, floated, or swam around the pool or campground.



Survivors enjoy activities at the Donald Danforth Jr. Wilderness Camp.



Teammates have fun while raising money through Bowling for Brain Injury.

BIA-MO expanded its Bowling for Brain Injury event this year to 300 bowlers and spectators. The Association raised more than \$36,000 to increase awareness of brain injury and provide support for survivors and families in Missouri.

The BIA-MO Annual Statewide Conference will be held Oct. 3-5 in St. Louis. The conference is dedicated to innovative therapeutic strategies, cutting-edge treatment options, and current research. Sessions during the first two days will be of most interest to professionals, while the final day's sessions will focus on education and support for survivors of brain injury and their family members. For more information visit [www.biamo.org](http://www.biamo.org).

## NEW HAMPSHIRE

The first half of the year is always a busy time for the Brain Injury Association of New Hampshire (BIANH). The Vertical Challenge winter event was held in March at the pristine Bretton Woods Resort in the White Mountains. Underneath a brilliant blue sky with snow covered Mt. Washington as the backdrop, team members donned their skis and snowshoes to hit the slopes. Skiers were challenged to search for letters out on the trails and try to solve the anagram "The Silent Epidemic." Funds raised through the event will support New Hampshire veterans with brain injury.

The 36th annual Brain Injury and Stroke Conference was held in May at the Grappone Conference Center in Concord. Keynote speaker Francis R. Sparadeo, Ph.D., spoke about the opioid, substance abuse, and brain injury crisis. In June, the 33rd annual Walk-by-the-Sea & Picnic took place at the Hampton Beach State Park. Despite the cool and cloudy weather, nearly 450



Participants enjoy the slopes at the Vertical Challenge event.

participants turned out to walk and enjoy a day at the beach. BIANH would like to thank all of the individuals, organizations, and businesses that contributed to this year's event. We could not have done it without you!



## NORTH CAROLINA

Save the Date! The Brain Injury Association of North Carolina (BIANC) 2019 Professional Conference, "Back to Basics and Moving Forward," will take place Dec. 6-7. This interdisciplinary conference will be held in Asheville and will include an array of dynamic speakers, practical takeaways, and inspiring stories. BIANC suggests planning to stay an extra day or two to enjoy all that Asheville has to offer. Please contact Karen Keating with questions at [karen.keating@bianc.net](mailto:karen.keating@bianc.net) or visit [www.bianc.net](http://www.bianc.net) for more information.



2019 Professional Conference  
**"Back to Basics and Moving Forward"**

## RHODE ISLAND

The Brain Injury Association of Rhode Island (BIARI) spent the early part of spring raising awareness of brain injury. Staff participated in several community events and set up information tables at the Rhode Island State House to help educate others about the impact of brain injury.

BIARI held its first ever Bowling for Brains team event May 4. The day consisted of team bowling with awards

going to top fundraisers. The event also featured a Bowling for Brains costume contest, face painting for all ages, and a chance to win raffle prizes. Reactions to the event were overwhelmingly positive. As one bowler stated, "What an amazing experience with such wonderful people. They care so deeply about their cause and do everything they can to help. Absolutely outstanding!" To learn about future BIARI events, visit [www.biari.org](http://www.biari.org).



BIARI staff and volunteers host information tables at the Rhode Island State House.

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## SOUTH CAROLINA

The Brain Injury Association of South Carolina (BIASC) is proud to announce its new initiative, the Brain Injury Safety Net (BISN). The BISN program will provide resources and lay the groundwork for a network to support children with brain injury and their families. BIASC is working with partners across the state to develop educational materials and improve the coordination of medical and academic services that young people need to recover and thrive after brain injury.

Throughout the project, BIASC will be working closely with Dr. Karen McAvoy, a nationally renowned concussion management expert. Dr. McAvoy will assist with the customization and promotion of the Remove/Reduce, Educate, Adjust/Accommodate, Pace (REAP) Manual. The REAP Manual is a community-based interdisciplinary team approach to concussion management that has been customized in more than 10 states. Visit [www.REAPconcussion.com](http://www.REAPconcussion.com) for more information.



BIASC is thrilled to bring the REAP Manual to South Carolina, and the BISN Task Force has been working to customize the manual for our state. For additional information about the project, please contact Project Coordinator Katie Zenger at [safetynetcoordinator@biaofsc.com](mailto:safetynetcoordinator@biaofsc.com).



## VERMONT

The Brain Injury Association of Vermont (BIAVT) held its annual Walk & Roll for Brain Injury event May 18, raising more than \$30,000. This year was the first at a new location in the capital city of Montpelier. More than 150 individuals turned out for a beautiful (though windy!) day. BIAVT would like to thank all the hard-working volunteers and give a special mention to Lawson's Finest Liquids for donating more than \$10,000 through their charitable giving program where all tips collected for two weeks went to BIAVT!

The 31st annual Brain Injury Conference will take place Oct. 8 at the Double Tree in Burlington. Survivor and author Amy Zellmer is this year's keynote speaker. The conference features 11 sessions to choose from, a survivor panel, lunch, awards, and a silent auction. Visit [www.biavt.org](http://www.biavt.org) for more information.



Attendees pose at the Vermont State House after the BIAVT Walk & Roll for Brain Injury event.

**IS UPPER LIMB SPASTICITY TYING YOU DOWN?**

The JUNIPER study is now enrolling participants experiencing spasticity in the arms (also called upper limb spasticity or ULS).

If you have ULS after a stroke or traumatic brain injury (TBI), then you may be familiar with the discomfort and pain that can be associated with this condition. This discomfort is caused by muscle tightness, joint stiffness, involuntary jerky movements, spasms, and uncontrolled muscles of the fingers, wrists, arms, or shoulders. These symptoms may also make you feel tired, uncoordinated, and weak.

**To be eligible to participate in the JUNIPER Study, you (or a loved one) must be\*:**

- ✓ 18 to 70 years of age
- ✓ Diagnosed with moderate-to-severe ULS after a stroke or TBI

\*Please note this is not a complete list of eligibility criteria.

[LEARN MORE](#)

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# UPCOMING WEBINARS

**Mitch Rosenthal Research Webinar –  
Prevalence of Medical and Psychiatric  
Comorbidities Following Traumatic Brain Injury**

September 26, 2019, 3 p.m. ET/12 p.m. PT  
*Flora Hammond, M.D., Indiana University School of Medicine*

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

October 10, 2019, 3 p.m. ET/12 p.m. PT  
*Susan Vaughn, M.Ed., National Association of State Head  
Injury Administrators*

**Mitch Rosenthal Research Webinar –  
An Evidence-Based Care Model for Workers  
with Concussion**

October 16, 2019, 3 p.m. ET/12 p.m. PT  
*Aaron Thompson, M.D., M.P.H., FRCPC, St. Michael's Hospital*

**David Strauss Clinical Webinar –  
Cultural Competence in Rehabilitation**

October 24, 2019, 3 p.m. ET/12 p.m. PT  
*Christina Papadimitriou, Ph.D., Oakland University  
and George Washington University*

**Carolyn Rocchio Caregivers Webinar –  
Supported Decision Making and Independence  
After Brain Injury**

November 6, 2019, 3 p.m. ET/12 p.m. PT  
*Ned Solomon, Tennessee Council of Developmental Disabilities*

**Mitch Rosenthal Research Webinar –  
Multidisciplinary Concussion Clinics:  
State of the Practice**

November 14, 2019, 3 p.m. ET/12 p.m. PT  
*Jeff Bazarian, M.D., MPH, University of Rochester*

**Robert Sbordone Memorial mTBI/Concussion  
Lecture – Psychological Risk Factors for  
Persistent Post-Concussive Symptoms**

November 19, 2019, 3 p.m. ET/12 p.m. PT  
*Mark C. Bender, Ph.D., Tree of Life Services*

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

## FUNCTIONAL ACTIVITY LIMITATIONS AFTER TRAUMATIC BRAIN INJURY

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of assistance by the time of discharge. When we followed them at six months and one year after injury, they reported slow but steady improvements and were overall functioning at a much higher level of independence. The greatest improvements were in their ability to perform functional daily-living activities. Patients receiving outpatient rehabilitation similarly demonstrated greater functional independence in all domains from before to after treatment.

Our preliminary results are encouraging. They demonstrate that comprehensive rehabilitation, both immediately after the injury and long term, is important in improving real-world functioning in individuals with TBI. In our study, patients regained functional independence, reduced their limitations in performing activities important for community living, and maintained these gains. To learn more about the Traumatic Brain Injury Model Systems research, visit [www.msktc.org/tbi/model-system-centers](http://www.msktc.org/tbi/model-system-centers). ●

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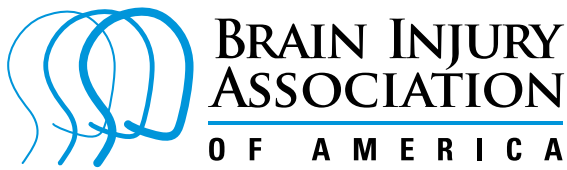


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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and 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](http://www.biausa.org) or contact Carrie Mosher at 703-761-0750, ext. 640 or [cmosher@biausa.org](mailto:cmosher@biausa.org).

