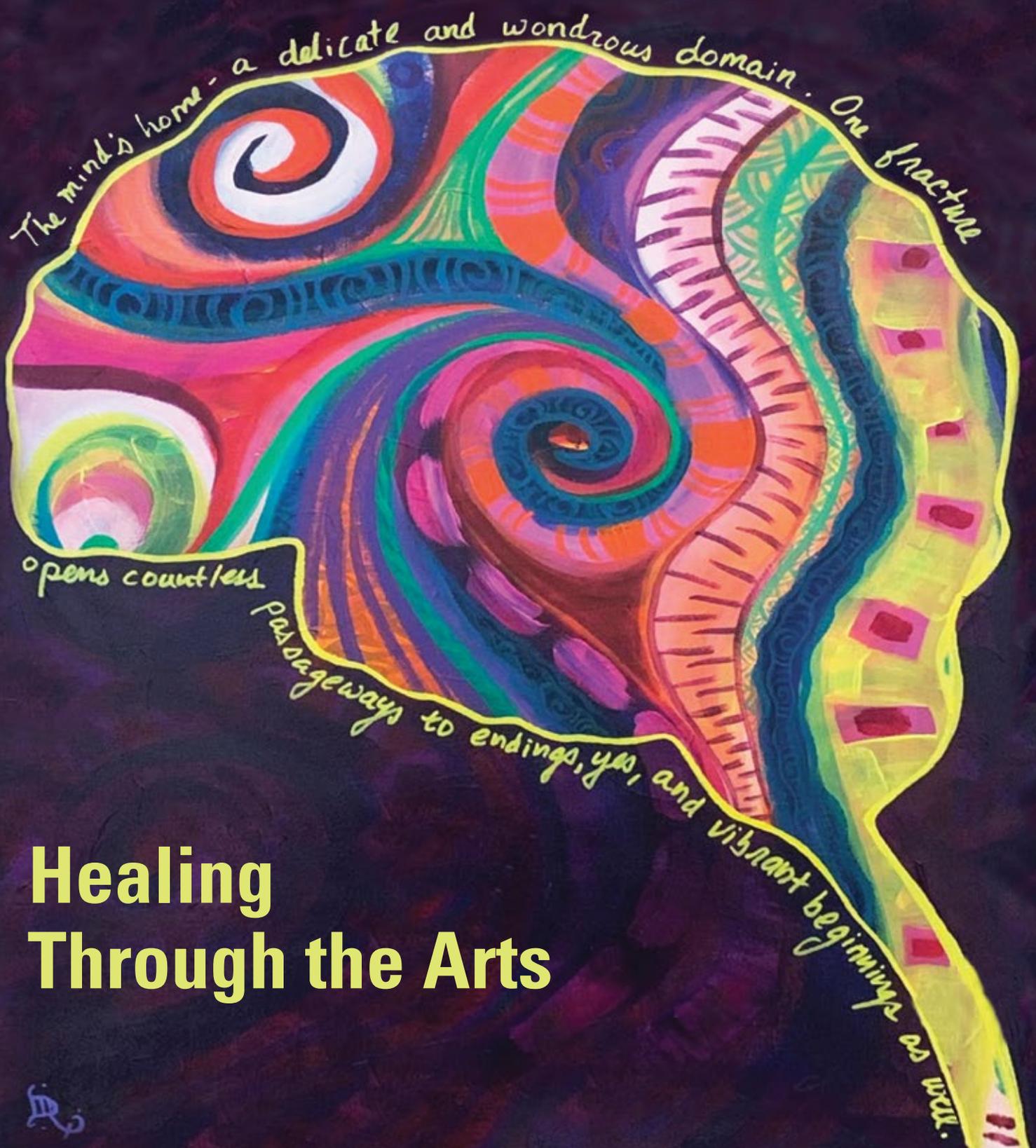


THE CHALLENGE!



Healing Through the Arts



DECEMBER 2019

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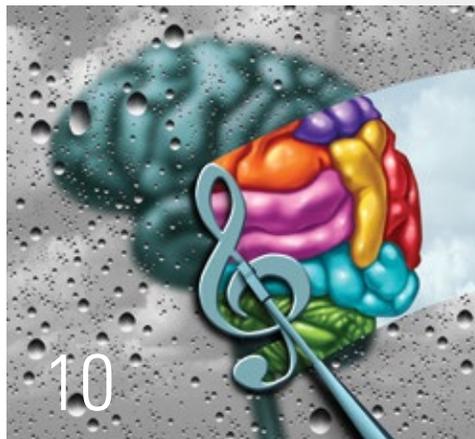
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FROM MY DESK

The Brain Injury Association of America's 24th Annual Affiliate Leadership Conference took place in October and offered sessions on team building, sponsorship programs, and strategies for resilience. As in previous years, the conference encouraged affiliate staff and volunteer leaders to connect with their peers from around the country and with BIAA's Board of Directors and staff. During the meeting, I was pleased to present these Awards of Excellence:

- BIA of Kansas & Greater Kansas City – Excellence in Advocacy
- BIA of Massachusetts – Excellence in Advocacy
- BIA of Missouri – Excellence in Advocacy
- BIA of Virginia – Excellence in Collaboration
- BIA of Louisiana – Excellence in Programs and Services
- BIA of New Hampshire – Excellence in Programs and Services
- BIA of North Carolina – Excellence in Programs and Services
- BIA of North Carolina – Excellence in Programs and Services
- BIA of Virginia – Excellence in Governance/Management



Martha Nield, chairperson of BIA of Michigan (BIAMI) received the Chief Volunteer Officer of the Year. She took the helm at time of tremendous challenges for BIAMI because of a change in staff leadership and a change in Michigan's No-Fault law. Her combined skills of "polite persistence" and "walk the talk" leadership stimulated board interest and involvement. She attended all events and contributed her time, talents, and financial support without fail.

Joyce Davis, CBIS, executive director of the BIA of South Carolina (BIASC), earned this year's Chief Staff Professional of the Year. Joyce has successfully lead BIASC for the past 12 years. In collaboration with the Board of Directors, Joyce has ensured that the brain injury services South Carolinians rely on were delivered without interruption despite significant funding challenges.

As the holidays draw near, BIAA is always mindful of what a tough time of year this can be for those who have experienced great loss. I encourage everyone to consider art, music, or poetry as a way to express your

feelings and work toward your own healing and that of those you love. Read this issue to learn about the positive effects of various art therapies in brain injury rehabilitation.

And finally, I'll take this opportunity to once again thank the generous donors who support the Brain Injury Association of America and our mission to advance awareness, research, treatment, and education to improve the quality of life for all people affected by brain injury. Our work is ambitious and our resources are limited, so every single dollar helps. We're proud to recognize those who have made recent donations and ask everyone to give whatever amount they can – no matter how large or small.

You have my best wishes for
a happy and safe holiday.

A handwritten signature in black ink that reads "Susan H. Connors". The signature is fluid and cursive, written in a professional yet personal style.

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

MEET THE COVER ARTIST:

DARYNE ROCKETT



By Daryne Rockett, Artist, Brain Injury Survivor

Five years after she sustained a brain injury while playing roller derby, Daryne Rockett opened her first exhibit of visual art. The exhibit, “A Show of Hands,” was a tribute to the many helpers essential to her recovery process.

Before the injury, Daryne was a clinical social worker who worked with combat veterans. She also had an undergraduate degree in theater and was regularly involved in the performing arts as a harper, songwriter, and singer – but she had very little experience with visual art. In the first 18 months after the accident, she found it too difficult to make music or be in settings where she used to play. She was unable to work as she recovered, and needed brain rest prevented her

from engaging in most of her previous meaningful activities. Longing for a way pass the time that would help facilitate her healing, she began “doodling” small mandalas on 3.5” square pieces of paper and coloring the works with magic markers.

The symmetry and repetition of patterns was a balm to Daryne’s foggy brain. As her healing progressed, she found enjoyment in larger formats and other mediums. Daryne asked the many people who supported her for the traced outline of their hands and turned these into colorful drawings. The hands were then used as inspiration for paintings expressing gratitude for the entire spectrum of help she has received

on her journey. From speech therapy to housekeeping, companionship, and support, her community inspired a beautiful new means of expression.

Daryne painted the cover for this issue of *The Challenge!* using acrylics on canvas. She created spirals of patterns to represent the movement and energy of neural pathways, overlapping and traveling in many directions, sometimes disappearing or diving deep into the painting. Over the patterns, she superimposed the shape of a brain before inscribing it with a statement about the duality of injury and recovery.

The Brain Injury Association of America thanks Daryne for her contribution to this issue! If you like the cover art and would like to submit your own work, please email communications@biausa.org.



USING DIGITAL THERAPEUTICS TO IMPROVE OUTCOMES

By Maya Pierce, Lauren Steidl, B.A., Brian Harris, M.A., MT-BC, NMT/F, and Chrissy Stack, M.S., MT-BC, NMT/F, CBIS, MedRhythms



Humans, for almost as long as we have existed, have been making and listening to music. Archeologists have discovered man-made drums and flutes that are believed to be more than forty thousand years old. Music remains an essential part of the human experience today, and we are all familiar with its unique and profound effects. It has the ability to motivate us, trigger our emotions, transport us to different times and places, and quite literally help us heal. Using music in rehabilitation is at the heart of the work at MedRhythms, a Maine-based digital therapeutics company that uses sensors, software, and music to address walking deficits caused by neurologic injury and disease.

Neurologic Music Therapy (NMT) is a research-based system of standardized clinical techniques for sensorimotor, speech, language, and cognitive training. These treatment techniques are based on the scientific knowledge in music perception and production and the effects thereof on nonmusical brain and behavior functions. Populations served by NMTs include stroke, traumatic brain injury (TBI), Parkinson's disease, multiple sclerosis, and others. Therapeutic goals and interventions address rehabilitation, development, and maintenance of functional behaviors (Thaut, 2015).

Neuroscience research has shown that music has the ability to simultaneously engage multiple regions of the human brain (Peretz and Zatorre, 2005). Additionally, there is profound evidence that engaging in music can aid in neuroplasticity (Moore et al., 2017). Neuroplasticity is a natural process by which the brain creates and strengthens internal connections, and it is the reason brain injuries can heal. NMTs witness neuroplasticity in action in clinical settings every



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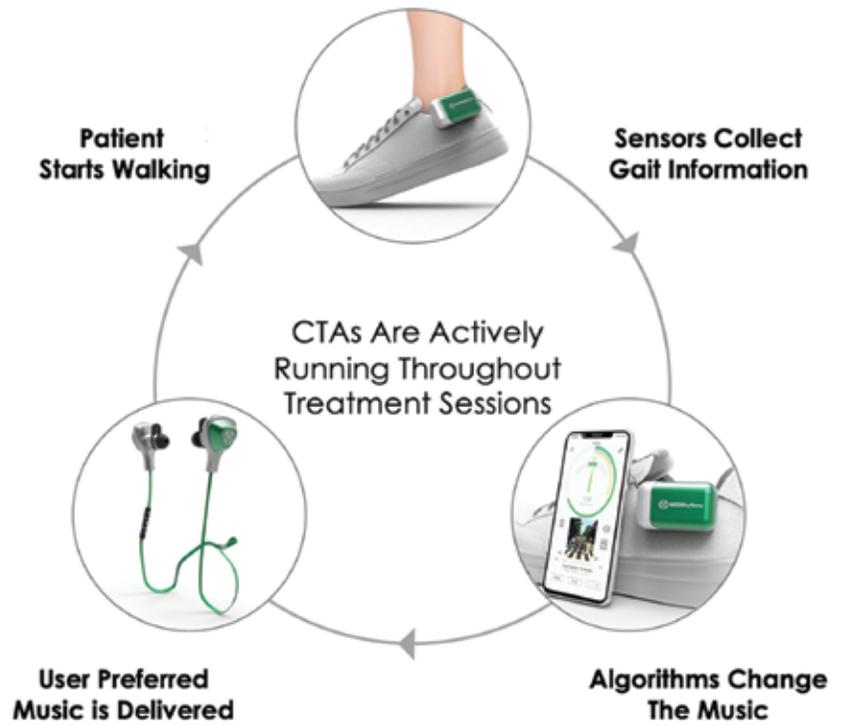
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day. They frequently see people who sustain neurologic injuries that result in walking problems begin to walk faster, farther, and more efficiently after receiving NMT for several months. This important research has set a foundation for how music can profoundly affect recovery from neurologic injuries and diseases.

Over time, clinicians began to notice that patients who received NMT recovered faster than with the standard of care alone. Patients noticed the dramatic improvement, too. Unfortunately, those receiving NMT often had to discontinue the treatment regardless of whether they showed functional improvement. Sometimes the discontinuation of treatment was due to the cost of therapy, as NMT is primarily funded out-of-pocket. Sometimes it was due to patients relocating and no longer having access to NMT services. There are millions of people who could benefit from NMT and only approximately 3,000 therapists worldwide with NMT training. Therapists turned to the field of digital therapeutics for solutions.

The digital therapeutics industry is made up of companies that develop evidence-based therapeutics through technology, including hardware and software programs. MedRhythms, founded by Brian Harris, therapist, and supported by Owen McCarthy, entrepreneur, is in the process of developing its first digital therapeutic, a prescription software system that uses 3D motion sensors and music to support the walking rehabilitation of adults with neurologic injuries or diseases, such as stroke. Walking rehabilitation has been the focus of this digital therapeutic because it shows the most quantitative, dramatic improvements when using music to improve walking. This intervention is known as Rhythmic Auditory Stimulation (RAS). There is substantial evidence that walking in sync with a beat can help those with brain injuries and neurological diseases walk faster, longer, and more symmetrically (Thaut, 2013).

The MedRhythms digital therapeutic system is designed to replicate RAS with a mobile app, sensors that attach to shoes, and headphones that play personalized music. Users walk to the beat of the music they hear as an algorithm, and embedded sensors take in data and change the music in real-time according to the



RAS protocol. Depending on how well the user is able to walk to the beat, the algorithm augments the tempo and rhythmic structure of the song being played through the headphones to drive users toward improved clinical outcomes.

The goal is for this device to make the benefits of NMT accessible to all who need it. It is designed for in-clinic use by physical therapists who are not trained in NMT as well as for in-home use without the need of any kind of therapist present. Along with developing this walking-focused product for stroke survivors in the chronic stage of their recovery, MedRhythms will continue its work toward gaining FDA approval, making this reimbursable by insurers, and commercializing the device as soon as possible.

This digital therapeutic for post-stroke walking deficits is just the beginning as there are many other patient populations that could benefit from RAS. These include those living with TBI, Parkinson's disease, multiple sclerosis, and Alzheimer's disease. In addition to improving walking function, NMT techniques are effective in helping people with certain neurologic injuries and diseases to regain language and cognitive skills. The possibilities are endless, and the work has only just begun. ●

References available at www.biausa.org/digitaltherapeutics.



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- Public funding programs
- Legal issues and access to Preferred Attorneys
- Resources for veterans
- Living with brain injury
- Coping with changes
- Planning for your future
- Counseling services
- Respite care



For general information about brain injury, visit www.biausa.org.

THE ARTS PROVIDE OPPORTUNITIES FOR COMMUNITY RE-ENTRY AND SELF-EXPRESSION AFTER BRAIN INJURY

By Amanda Mast, M.S., CCC-SLP, CBIS, Roger C. Peace Outpatient Brain Injury & Young Stroke Program

“We’ve all had 9/11s in our lives,” stated poet Glenis Redmond. “And through tragedy, there is opportunity for kindness and connectedness.” Redmond is Poet-in-Residence at the Peace Center for the Performing Arts in Greenville, South Carolina. Through a grant offered by the Broadway League last spring, a group of individuals recovering from brain injury, their caregivers, and clinicians participated in a series of events at the Peace Center that used the arts to explore and address communication, awareness, adjustment, self-expression, and community reentry after brain injury.

The Roger C. Peace (RCP) Outpatient Brain Injury & Young Stroke Program, a clinic based in Greenville, has always emphasized community reentry and facilitated both individual and group community outings. Given that a brain injury can affect a

“ The program enhanced my ability to read, pay attention, and remember. ”

person’s communicative, cognitive, physical, and emotional abilities, rehabilitation must help people cope with these changes and function in a variety of settings. The Broadway League grant allowed RCP to collaborate with the Peace Center, increasing access to local events and helping RCP enrich the therapy experiences of the individuals it serves.

The group discussed “Come from Away,” a Broadway show filled with stories told directly following the events of 9/11. After exploring the show’s themes, including personal identity and our place in the

world, Redmond led participants to create and express a personal poem. Patient and caregiver participants were invited to consider, process, and share their personal experiences about how brain injury has impacted their lives. Tracy Graham, a speech-language pathologist, reported that “writing a personal poem really empowered all of us. This was a great opportunity for patients and caregivers to come together and express very important events from their lives. As a clinician, this program helped me to have a better understanding of the emotional issues impacting my patients.”

Patient and caregiver participants were later invited to read or listen to “The Day the World Came to Town” by Jim Defede, the novel on which “Come from Away” is based. The community held a book discussion, allowing participants to connect with the themes of the novel. Attendees explored how their experience of 9/11 affected them differently at different ages or stages of life. Some readers related more personally depending on the city in which they lived or the people they knew who were directly affected by the attacks. Considering other people’s circumstances, perspectives, and reactions to the life-altering events unveiled in the text proved beneficial to supporting patient and



Peace Center staff and Broadway League grant participants gather to discuss “The Day the World Came to Town.”

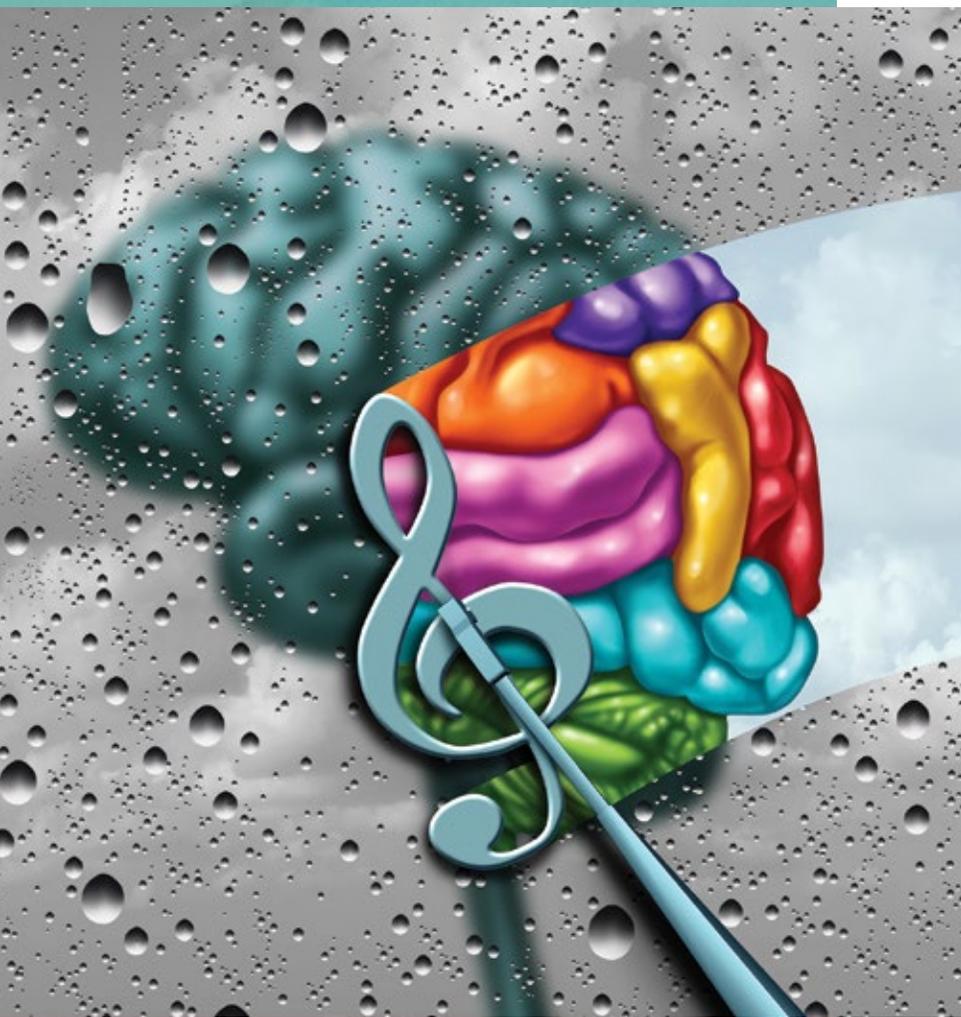
caregiver awareness, self-reflection, and adjustment in their recovery process. One patient participant stated, “The program enhanced my ability to read, pay attention, and remember. Most important was my ability to correlate the episodes from the play to those in the book. It helped me to better understand the play.”

Lastly, participants attended a live performance of “Come from Away” as a supported, group community outing at the Peace Center. The outing was a fun way to address community mobility, communication, social skills, attention, functional problem-solving, and more.

The arts are a useful platform to explore self-expression and help establish a new identity after brain injury. They present opportunities for creativity and self-exploration, encouraging individuality and leaving room for adjustment to a “new normal.” Creative community reentry opportunities like those afforded to the Broadway League grant recipients enrich the therapy experience of individuals recovering from brain injury, support the recovery process, and improve quality of life. ●



Participants attend “Come From Away” at the Peace Center.



Incorporating Music in Therapy for Individuals with Acquired Brain Injury

By Jenna Tucker, PT, DPT, NCS, CBIS
and Marina Polyak, OTR/L

If you've ever felt excited when your favorite song came on the car radio, had the time of your life dancing with loved ones at a celebration, or nourished your soul by playing an instrument, you have felt music speak to you in some way. There is no doubt that music is an integral part of our fabric as human beings. Music has the power to excite, to soothe, and to heal. The right combination of chords, melody, and words can elicit memories and draw out powerful emotions.

Music is equally powerful for people with acquired brain injury (ABI). ABI can result in impairments that affect physical and cognitive function as well as emotional and behavioral stability. These impairments can have a significant impact on the lives of individuals with brain injury. In addition to changes in personality and self-perception, individuals with brain injury need to adapt to lifestyle changes including new therapies, new relationships, and community reintegration.¹

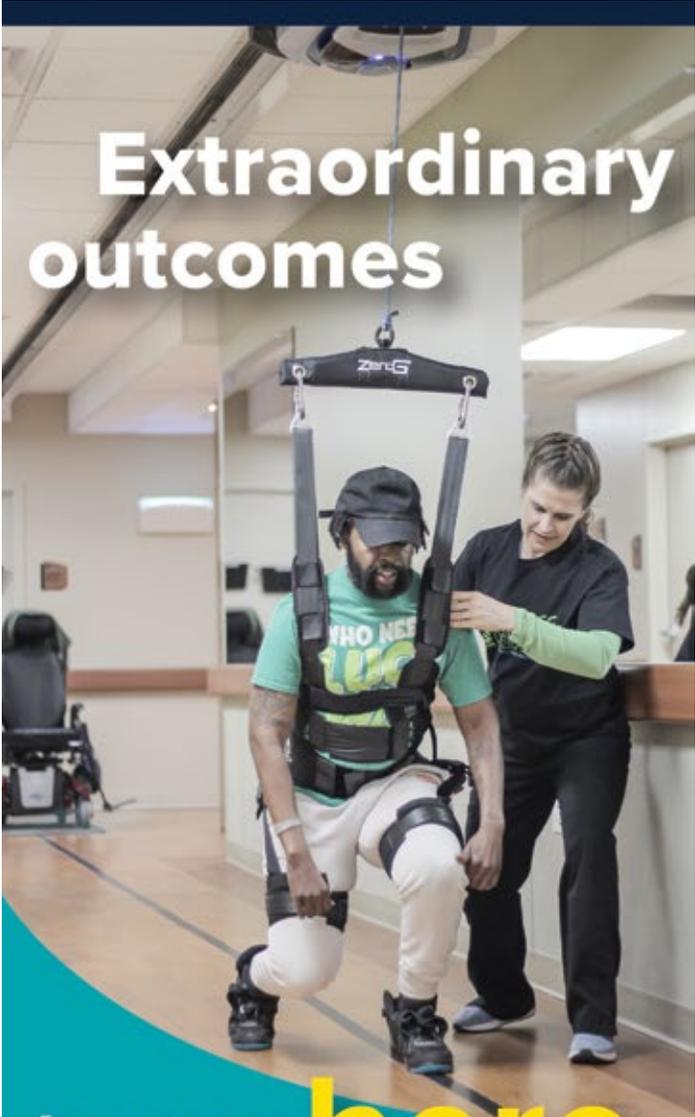
Most individuals with brain injury are at least partially aware of their limitations, which can lead to increased agitation and depression. Music has the potential to help people feel a connection to something familiar and consistent – a feeling often desired post-injury. In turn, this connection to music can have a positive effect on mood, socialization, and participation in daily activities throughout the recovery process.² Music can routinely be used as an effective tool during physical and occupational therapy sessions to improve motivation, participation, and socialization. Consider the following examples of patients with ABI who have been helped through the use of music therapies:

🎵 Alex is a 49-year-old man who suffered a gunshot wound resulting in injuries of the bilateral temporal lobes of his brain. Every day, like clockwork, Alex will ask for RUSH, a progressive Canadian rock band known for intelligent lyrics and expert musicianship, to be played on his iPad. Some days, Alex can be observed smiling

to himself as he listens. Other days, the music will make him cry and he will be unable to explain the emotions he is feeling. Alex has memory deficits that severely impact his everyday function, yet he finds an emotional connection to his past through music. The feelings associated with his listening to RUSH allow him to tap into memories and emotions that his brain is otherwise unable to access, which encourages him to engage with others. In a setting where music is being played and he feels comfortable, he is more interactive and motivated to complete therapeutic tasks. In addition to memory deficits, Alex has difficulty with sustained attention, which is exacerbated when it involves a task that does not interest him. The use of music allows him to work on sustained attention tasks for longer periods of time, such as scrolling through a playlist to search for a song or video, or playing a game of Wii bowling with fewer breaks.

 Morris used to be the lead singer in a band. At the height of his career, an injury to the frontal lobe of his brain left Morris with deficits in his problem-solving skills as well as loss of functional memory and attention. He experienced changes in personality and suffered from uncontrollable emotional and social behaviors. Despite these impairments, he is still an expert in musical trivia. When he is singing in a karaoke group or performing on his guitar, he has an opportunity to share an experience from his past connected to the song or the artist who created it. After his injury, Morris' social skills were affected and he frequently becomes distracted and tangential. This limits his ability to engage in meaningful conversations or teach others to play an instrument, a goal toward which he is currently working. When instructing others to play an instrument or participating in music trivia, Morris is able to maintain attention to the tasks at hand with minimal distractibility. This is an improvement as he sometimes requires maximum verbal cueing to maintain attention in other structured tasks that don't integrate music. The incorporation of music into the performance of therapeutic tasks results in a more meaningful session, and he is able to work toward his goals and connect with peers.

(continued on page 12)



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🎵 Jim is a young man with ABI. Despite suffering significant physical and cognitive symptoms, he maintains maximal awareness of his impairments. This awareness of his motor planning deficits exacerbates his baseline depression, anxiety, and self-consciousness. He is not quick to solve problems or grasp concepts in the way his peers can and rarely socialized with people after his injury as a result. During therapy, music is incorporated into his treatment sessions and helps to improve his mood and reduce his anxiety. This fuels a change in his perception of himself, and his improved confidence encourages him to socialize with his peers. During sessions that do not incorporate music, Jim is more likely to be withdrawn and disengaged. When music is played, he initiates and follows through with conversations. Selecting songs of his liking helps Jim engage muscle memory and participate in more challenging bilateral coordination and dynamic balance activities that are otherwise too difficult, such as getting dressed while standing.

People with ABI are at high risk for major depressive disorder, anxiety, and diminished function that can lead to poorer health and quality of life.³ Individuals with varied deficits often feel isolated and disconnected from others, particularly if they have impairments in communication or language. Clinicians often see the positive influence of music in therapy for clients who had a connection to music pre-injury as well as those who haven't. In addition to seeing the effects of music in various individuals, the impact can also be seen across group settings. Using music in a group fitness setting, for example, allows individuals to enjoy the same music while working on diaphragmatic breathing, stretching, strengthening, coordination, proprioception, and sustained attention. Playing relaxing music along with guided meditation can aid in decreasing anxiety and developing coping skills for stress.

Many individuals with brain injury are left with impairments that affect physical, cognitive, social, and emotional function, and these impairments often affect an individual's sense of self. This loss of identity can negatively affect participation in physical or occupational therapy sessions, which limits the benefits of therapeutic interventions. Music can be a useful tool in bridging the gap between past and present for these individuals, positively influencing their motivation, initiation, mood, attention, memory, and movement.⁴ Playing music during group sessions often leads to increased socialization and helps to create a sense of community. Therapists can incorporate music into individual or group sessions to facilitate enthusiasm, active participation, collaboration, and carry-over. Integrating music into therapy sessions helps maximize therapeutic benefits and therefore contributes to improved daily function and overall quality of life. ●

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.

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Healing With the Arts: A Survivor Reflects on Her Experience

By Rosalie Johnson, Survivor Representative, Brain Injury Association of New Hampshire

Any online search for information about art therapy after a brain injury or stroke will lead to dozens of websites. Many of these sites will explain the benefits of sculpting, weaving, painting, writing, music, dance – the list is as endless as the number of websites.

Combined with traditional therapies, art can be very powerful. In the late 1800s, Florence Nightingale noted the effects of art on recovery stating, “Variety of form and brilliancy of color in the object presented to the patients are an actual means of recovery.”

To see the benefits of art as a healing tool, it just takes a one-day visit to Krempels Center in Portsmouth, New Hampshire. A nonprofit organization dedicated to improving the lives of people living with brain injury,

(continued on page 26)



“ Variety of form and brilliancy of color in the object presented to the patients are an actual means of recovery. ”



Members work together to build fairy houses for entry in the Portsmouth Fairy House Tour Competition



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ADVOCACY UPDATE



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

BIAA Leads Concussion Awareness Resolution in Congress

Sens. Maggie Hassan (D-N.H.) and Shelley Moore Capito (R-W.Va.), along with Reps. Pascrell and Bacon, introduced a resolution to honor September 20 as National Concussion Awareness Day. The Brain Injury Association of America (BIAA) worked with each office to secure champions for this important resolution recognizing concussion. This was the first time a concussion resolution has passed both the House of Representatives and the United States Senate.

BIAA Advocates for Veterans Affairs Assisted Living TBI Program

In 2009, BIAA collaborated with the Wounded Warriors Project to persuade Sen. Lindsay Graham (R-S.C.) to support the establishment of an Assisted Living – Traumatic Brain Injury (AL-TBI) program within the Veterans Administration. The program was established as a pilot and ended in 2017. BIAA and others have been advocating to reinstate the program ever since. In September, Reps. TJ Cox (D-Calif.) and John Rutherford (R-Fla.) drafted a letter to Secretary of Veterans Affairs Robert Wilkie inquiring as to the VA's plans for the veterans with TBI who still require assisted living care. At BIAA's urging, Reps. Pascrell and Bacon circulated a Dear Colleague letter asking others to sign the letter to Sec. Wilkie. BIAA Government Affairs Director Amy Colberg obtained help from members of the Coalition to Preserve Rehabilitation to secure sign-ons in support of the VA inquiry from 55 Members of Congress.

BIAA Meets with New Director of the Division of Injury Prevention at CDC

The Centers for Disease Control and Prevention (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. BIAA President/CEO Susan Connors met with Judith Qualters, Director, Division of Injury Prevention, NCIPC, to discuss the re-organization and CDC's continuing role to support the TBI program within the agency. BIAA recently partnered with CDC for a special back to school e-newsletter that highlighted CDC's work in brain injury.

BIAA Advocates to Reauthorize PCORI

BIAA participated in a Capitol Hill fly-in day in September to advocate for reauthorization of the Patient Centered Outcomes Research Institute (PCORI). Funding for PCORI ended September 30. The short-term Continuing Resolution, H.R. 4378, that Congress recently passed extended government funding to November 21, 2019, and provided a similar short-term extension of several health care initiatives, including PCORI. While Congress did extend the life of the PCORI Trust Fund, which would have expired on September 30, 2019, lawmakers did not extend any of the funding mechanisms. This means PCORI will not receive any FY2020 funds during the short extension. BIAA will continue to work with stakeholders to make sure PCORI receives full funding.

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Senate Special Committee on Aging Holds Hearing on Older Adult Falls

The Senate Special Committee on Aging, chaired by Sen. Susan M. Collins (R-Maine) and co-chaired by Ranking Member Robert P. Casey, Jr. (D-Pa.), held a hearing, “Falls Prevention: National, State, and Local Solutions to Better Support Seniors,” Oct. 16. While the hearing focused on prevention, some of the information submitted, including a statement of record and questions for the panelists submitted by BIAA, noted the high incidence of fall-related TBI among older Americans and the need for screening and education. The committee produced a report that also noted that older adults are at a particularly high risk of sustaining fall-related TBIs and tend to suffer worse outcomes compared to other age groups.

Sens. Collins and Casey sent letters to four federal agencies – the Food and Drug Administration, the Centers for Medicare & Medicaid Services,

Department of Housing and Urban Development, and the Department of Veteran Affairs – requesting information about their falls prevention programs. Sen. Collins passed a resolution Sept. 25 on National Falls Prevention Awareness Day. Sen. Casey was among the co-sponsors.

President Signs Stop-Gap Funding Bill

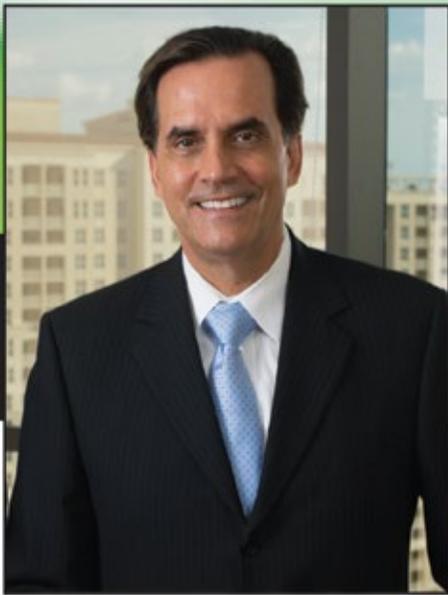
President Trump signed the Further Continuing Appropriations Act, 2020, and Further Health Extenders Act of 2019, H.R. 3055, to continue funding federal agencies through Dec. 20. The legislation funds most programs and activities at the FY2019 levels with several exceptions that provide funding flexibility and additional appropriations to various programs. The measure also extends several expiring health programs, including several public health, Medicare, and Medicaid authorities and programs, the Temporary Assistance for Needy Families program, and related programs. Federal funding was set to expire Nov. 21.

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BIAA Supports Provisions of the Proposed Prescription Drug Price Reduction Act

BIAA signed a letter drafted by the Consortium for Citizens with Disabilities Health Task Force to Senate Committee on Finance Chair Sen. Chuck Grassley (R-Iowa) and Ranking Member Ron Wyden (D-Ore.) regarding the Prescription Drug Price Reduction Act (PDPRA) of 2019. The CCD Health Task Force strongly supports capping out-of-pocket costs for Medicare Part D and many other provisions of the bill. The creation of an out-of-pocket cap will help people with disabilities and chronic conditions on Medicare who face significant prescription drug costs. The PDPRA sets a cap at \$3,100 beginning in 2022. The organizations urge Congress to institute the cap sooner and to lower the cap to \$2,000 as proposed in the Lower Drug Costs Now Act of 2019, H.R. 3.

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STATE AFFILIATE NEWS

DELAWARE

The Brain Injury Association of Delaware (BIAD) had a busy few months! The 12th Annual BIAD Crab Feast, in honor of Jonathan and Maureen Miller, was held in August and was a great success! The event raised funds to allow the organization to continue increasing



BIAD board members raise awareness of substance abuse through Delaware Goes Purple.

awareness and providing education for those affected by brain injury in Delaware.

BIAD continued outreach efforts by attending many community and professional events, providing education to families, children, and veterans throughout the state. Staff and board members joined the Delaware Goes Purple movement and wore purple clothing to raise awareness of substance abuse. Lastly, the organization created a fourth support group in the Kent County area.

The BIAD conference committee is working on the annual conference, which will be held March 5, 2020, at the Dover Downs Hotel. The conference theme is "Connections Through the Continuum." For more information about BIAD, visit www.biaofde.org.

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.

BIAKS-GKC collaborated with multiple statewide partners to host an educational event, "Life After Concussion and Brain Injury," at a state office in Parsons Oct. 11. The event featured more than five hours of education and training about brain injury, employment, mental health, advocacy, and measuring quality in-home and community-based rehabilitation.

Planning team members were from programs funded by the Administration for Community Living. These included the Disability Rights Center of Kansas, which provides protection and advocacy services; the Aging and Disability Resource Center, which performs functional assessments for Kansas' most recent Brain Injury Waiver; Southeast Kansas Independent Living



"Life After Concussion and Brain Injury" event planning members Rocky Nichols, DRC (left); Joan Newman, ADRC; Jennifer Carter, Kansas Vocational Rehabilitation; Robin Abramowitz, BIAKS; Debbie Chiappetti, University of Kansas Medical Center; and Shari Coatney, Southeast Kansas Independent Living Center, gather for a picture.

Center; Kansas Vocational Rehabilitation; and Kansas Department for Aging and Disability Services.

The event included continuing education units for track for health professionals with speakers Janet Williams, Ph.D., CEO and President, Minds Matter LLC; and Roscoe Burrows, Ph.D., NRI Program Director, Brookhaven Rehabilitation Hospital. The event was appropriately held in October during National Disability Employment Awareness Month. Several speakers focused their comments on awareness and employment services for people with brain injury.

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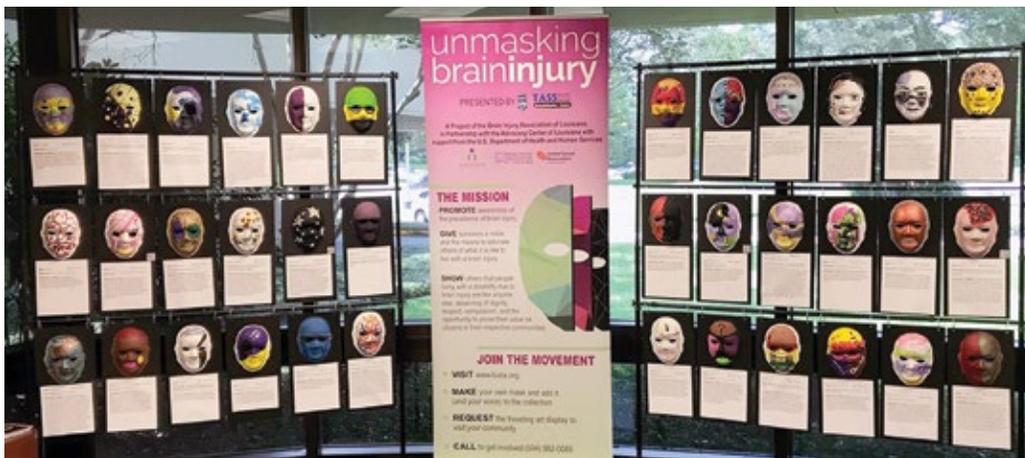
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LOUISIANA

The Brain Injury Association of Louisiana (BIALA) became the Unmasking Brain Injury state partner more than two years ago. Since then, a traveling art display has continuously moved throughout the state. The display consists of more than 90 masks painted by brain injury survivors and is intended to promote awareness about the prevalence of brain injury, educate others about living with the condition, and give a voice to persons with brain injury.

Many BIALA support group members participate in Unmasking Brain Injury, either by creating masks or attending exhibits to educate others about the initiative. Additionally, therapists at rehabilitation hospitals around the state integrate painting masks into therapy sessions, allowing their patients to share their feelings and improve their fine motor and cognitive skills. The exhibit has appeared at various locations including the state Capitol, rehabilitation hospitals, medical and allied health schools, art museums, and outpatient rehabilitation facilities.



The Unmasking Brain Injury exhibit on display in Baton Rouge.

Seeing the masks displayed together is powerful and thought provoking. BIALA is grateful to Together Achieving Self Sufficiency Brain Injury Rehabilitation Center for sponsoring the initiative. The exhibit is currently booked through March 2020. For more information, please visit www.biala.org.

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MAINE

After a busy legislative season, the Brain Injury Association of America – Maine Chapter (BIAA-ME) succeeded in getting “An Act To Strengthen Brain Injury Resources for Underserved Populations, Including Opioid Overdose Brain Injury Survivors,” LD 297, passed and signed by Governor Janet Mills. The goal of LD 297 is to ensure that all Mainers have consistent access to core brain injury supports and resources. Its enactment was a huge win for the Maine brain injury community.

BIAA-ME held the 10th Annual Conference on Defining Moments in Brain Injury at the University of Southern Maine in Portland Oct. 9. Author Abby Maslin gave the keynote and David Krempels gave the Beverley Bryant Memorial Lecture. BIAA-ME held its fifth annual Bowling for Brain InjurySM event, which took place Dec. 1 at Spare Time Portland.



BIAA-ME staff and community members with Governor Mills to celebrate the signing of LD 297.

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MISSOURI

The Brain Injury Association of Missouri (BIA-MO) Annual Statewide Conference took place Oct. 3. More than 350 professionals, survivors, and family members attended the event. Topics included reducing risk and readmission rates of stroke survivors, community integration strategies, and therapies with new technology, robotics, and adaptive equipment to enhance outcomes. The Survivor and Family Seminar Day provided practical suggestions for life with brain injury such as Brain Injury 101, coping with sensory overload, and improving thinking skills.

The BIA-MO Awards Luncheon and Annual Meeting recognized survivors of brain injury, key volunteers, and community leaders for their courage, prevention efforts, and increasing awareness and fundraising to create a better future for persons with brain injury and their families. Mary Bernickus received the BIA-MO Lifetime Achievement Award 2019 for the exceptional impact she has made as an ambassador in the brain injury community over the last 31 years.

Advocates across Missouri raised their voices in opposition to an effort to repeal the Missouri all-rider motorcycle helmet law. BIA-MO worked with medical, rehabilitation, safety, and insurance organizations to request a veto of the legislation, S.B. 147. The legislation was vetoed by the Governor, and motorcycle helmets continue to save lives, prevent brain injuries, and save tax dollars in Missouri. For more information visit www.biamo.org.



BIA-MO Board Member David Dyck, Jr., D.O. (left) presents Mary Bernickus with a Life Achievement Award.

NEW HAMPSHIRE

The Brain Injury Association of New Hampshire (BIANH) enjoyed its 36th Annual Golf Tournament, held in August at the beautiful Stonebridge Country Club in Goffstown. Northeast Rehab Hospital Network was the Title Sponsor for the third year. Despite heavy downpours throughout the day, the tournament had fantastic sponsorship and team involvement.

In November, the 13th Annual Caregivers Conference was held at the Grappone Conference Center in Concord. Dr. Donna McCarten White presented the keynote, "Caregiver Compassion Fatigue: Building Resilience as We Care for Others."

BIANH will once again host the Vertical Challenge, a fun, family event where participants can ski or snowshoe, in January. For resources from BIANH, including a new support group brochure and a specialty case management brochure, visit www.bianh.org.



2019 Vertical Challenge Winter Event participants.

ASSOCIATIONS WORK WITH PCORI RESEARCHERS TO LEARN MORE ABOUT MENTAL HEALTH ISSUES AFTER BRAIN INJURY

By Bryan Thomas Pugh, Executive Director, Brain Injury Association of Maryland

Since 2018, the Brain Injury Association of Maryland, Brain Injury Association of America, Johns Hopkins University School of Medicine, University of Colorado School of Medicine, and University of Maryland School of Medicine have been working on a project entitled, “Patient Centered Research on TBI Psychiatric Problems.” The project, funded by the Patient Centered Outcomes Research Institute (PCORI), has an overarching goal to establish a diverse group of TBI stakeholders and engage them in focus group discussions to:

- 1 Determine catalysts and challenges in the management of neuropsychiatric symptoms after TBI
- 2 Identify various strategies for engaging TBI stakeholders in future research projects and creating a Person Centered Outcome Research network
- 3 List important TBI neuropsychiatry research topics
- 4 Determine important policy changes related to neuropsychiatric symptoms after TBI

Participants highlighted several barriers for recovery, including embarrassment, stigma associated with experiencing neuropsychiatric symptoms, and inadequate insurance coverage for management of these symptoms. They identified tools that could improve opportunities for recovery, including:

- education about neuropsychiatric symptoms following TBI in the acute trauma period;
- provision of literature and resources on TBI mental health at discharge from emergency rooms and acute care trauma units; and
- dissemination of a comprehensive plan to caregivers of persons with TBI.



Through the project, the team found that the best strategies for engaging and continuing to maintain a brain injury person-centered outcome research network included working on a project with clear goals, having regular meetings, and providing continued education about neuropsychiatric symptoms to members of the network.

Participants were most interested in research topics addressing the relationship between brain injury and aging, the determinants of positive outcomes after TBI, and the relationship between addiction and TBI. The three most important policy changes included:

- making TBI mental health education accessible to all stakeholders;
- providing incentives for clinicians involved in care of persons with TBI; and
- improving affordability and accessibility of TBI neuropsychiatric care.

Study collaborators plan to use the results from this study to develop other projects meaningful to the larger brain injury community. In the future, we also hope to continue to engage our participants as partners in other research projects. For more information, the project abstract, and four infographic flyers summarizing the research, visit biamd.org/pcori-brain-injury-network.

The graphic on the following page was reprinted with permission from PCORI.

Let's Talk about TBI



In 2018, researchers from Johns Hopkins University in collaboration with the Brain Injury Association of Maryland brought together a diverse group of TBI (Traumatic Brain Injury) stakeholders. They included people with TBI, caregivers involved in the care of people with TBI, non-physician clinicians (such as occupational therapists, physical therapists, speech language therapists, mental health therapists), program coordinators and mental health administrators to discuss TBI mental health research. The project was funded by Patient Centered Outcomes Research Institute (PCORI) JUJ #7136

The purpose of the discussions was to help shape patient-centered research and policies to better meet the mental health needs of individuals with TBI and their families. The discussion was guided by four main questions.

1

What are common barriers and facilitators experienced in the management of neuropsychiatric problems after TBI?

2

What are the important and needed research topics pertaining to TBI mental health that should be investigated further?

3

What are the strategies that can keep a TBI stakeholder group active and invested in TBI mental health care so that patient centered research can continue?

4

What are the important and needed policy changes that can improve TBI mental health care in the US?

Perceived stigma

People with neuropsychiatric symptoms after TBI are often treated as "crazy/bad/impaired" by family, friends and even clinicians who are not knowledgeable in TBI

Educate family members; Help connect people with TBI to others who have the potential to understand them. Respect individuals with TBI as people with difficulties rather than disabled or impaired

Poor insurance coverage

Inadequate insurance coverage specifically for neuropsychiatric symptoms after TBI

Educate insurers and incentivize clinicians to provide more services

Management starts in acute trauma period

Education on neuropsychiatric symptoms to be provided in the acute trauma period in emergency rooms and acute care facilities. Acute care facilities to develop long-term rehabilitation plans that include education and management of neuropsychiatric symptoms

Address, educate and guide family members on management of problematic behaviors. Discharge materials to include literature on TBI and resource guide

Minimizing caregiver burden

Caregivers are burdened and overwhelmed by neuropsychiatric symptoms that arise following TBI. Addressing this with a comprehensive caregiver plan is beneficial

Create a caregiver plan

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Healing With the Arts: A Survivor Reflects on Her Experience

Krempels Center is open for three program days per week. The members attending travel from all over New Hampshire, Maine, and Massachusetts.

One program, “Creative Expressions: Art as a Form of Healing,” took place earlier this year. As members walked into the room where the program was being held, they could see four tables scattered about. Some tables contained projects that were already started, while others were topped with various objects waiting to be turned into art. There was also a fifth table covered with bits and pieces that people could incorporate into their projects. Members arranged themselves around the tables, awaiting instruction. Harry Reed, a caregiver to one of the members, volunteered to lead the group. They would be working on a community project for entry into the Portsmouth Fairy House Tour competition.

Each table contained the pieces to create tiny fairy houses on little islands. The islands would then be connected to form an imaginary fairy village. “As we have entered the Tour for a number of years now, I have to admit that there is a little competitive spirit also involved,” notes Harry. The members at each table worked in teams and used stones, bits of moss, branches, and other tiny found objects to create their fairy houses. They collaborated to decide what to use to build ponds, steps, or the walls to a fairy house, and checked the supply table as needed for items they could use.

This activity offered survivors the chance for meaningful self-expression, socialization with peers, and an opportunity to educate others about life after brain injury. Creating the fairy houses used their imagination, creativity, and dexterity. As they were building their structures, they also built friendships. Their laughter could be heard from the hall outside of the room – proof positive that art is a healing force!



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

