

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 14, Issue 3

THE CHALLENGE!



RESEARCH

OCTOBER 2020

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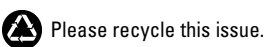


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FROM MY DESK

With apologies to Charles Dickens, 2020 has been the best of times and the worst of times. I am so pleased to announce the Brain Injury Association of America (BIAA) is the recipient of the Council on Brain Injury's organizational award for 2020. The nomination states:

"The Brain Injury Association of America is the national and parent organization of the state brain injury associations. This year, BIAA has provided exceptional guidance to both its state affiliates and service providers on how to safely manage in-person rehab, support survivors and caregivers virtually, and continue the education of brain injury professionals during COVID-19. This has included a council meeting of providers related to best practices during COVID-19, creating a forum through which individuals can make video messages of support to survivors, and offering BIAA webinars for free to professionals. They also created a COVID-19 Resource Guide on their website and dedicated an edition of *THE Challenge!* to this issue, including information about our STRIVE and THRIVE Facebook page. BIAA deserves recognition at this time for these extraordinary efforts as well as for their long-standing efforts to elevate the work that we do by information sharing and education, the development of the Academy of Certified Brain Injury Specialists, and their advocacy at a national level for increased funding and support for people with brain injury."



The award was presented on September 22 at the Council on Brain Injury's annual David's Drive golf tournament and awards luncheon. Remarkably, the Association celebrated its 40th anniversary the following day! Visit biausa.org to watch our anniversary video.

Beyond the award and BIAA's anniversary, this year will be remembered for police brutality, racial unrest, economic depression, and appalling inequities in healthcare for people with brain injury and people of color. This summer, BIAA joined with other disability leaders in filing an Office of Civil Rights complaint for illegal discrimination against Texas resident Michael Hickson, who was denied medical care after contracting COVID-19 in the nursing facility where he lived because of his catastrophic brain and spinal cord injury. Against his family's wishes, Hickson was also denied food and water, ultimately starving to death on June 11, 2020.

I sincerely thank *THE Challenge!* readers who have supported the Association this year. BIAA has not been on pause during the COVID-19 pandemic. We are more grateful than ever for your financial contributions.

Stay safe!

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

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



P.S. To help us commemorate our 40th anniversary, make your gift at biausa.org/40yearsofBIAA.

Racing to Understand COVID-19 and the Brain



By Kayt Sukel, *Cerebrum Magazine*

A 44-year-old male patient, with no history of cardiovascular disease, arrived at an emergency room in New York City after experiencing difficulty speaking and moving the right side of his body. The on-call physician quickly determined he had suffered a stroke – a condition that normally affects people who are decades older. In Italy, a 23-year-old man sought care for a complete facial palsy and feelings of “pins and needles” in his legs. Doctors discovered axonal sensory-motor damage suggesting Guillain Barré Syndrome, a rare autoimmune neurological disorder where the immune system, sometimes following an infection, mistakes some of the body’s own peripheral nerve cells as foreign invaders and attacks them. A 58-year-old woman in Detroit was rushed to the hospital with severe cognitive impairment, unable to remember anything beyond her own name. MRI scans showed widespread inflammation across the patient’s brain, leading doctors to diagnose a rare but dangerous neurological condition called acute necrotizing hemorrhagic encephalopathy.

At first glance, it may seem that these patients have little in common. Yet all three were also suffering from severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) disease, better known as COVID-19. While most individuals infected with this new virus exhibit fever,

cough, and respiratory symptoms, doctors across the globe are also documenting patients presenting with a handful of neurological manifestations – leading clinicians and researchers to wonder if COVID-19 also has the ability to invade the human nervous system.

“As more people are being tested and diagnosed with this virus, physicians are starting to see more uncommon symptoms and complications, including neurological ones,” says Diane Griffin, M.D., Ph.D., a researcher at Johns Hopkins University’s Bloomberg School of Public Health. “But as COVID-19 is a new virus, we aren’t yet sure why these things are happening. Is the virus getting into the brain directly? Is it affecting the brain through other means? These are important questions to answer.”

VIRUSES AND THE NERVOUS SYSTEM

Viruses, simply defined, are submicroscopic infectious agents that can only replicate inside the cells of living hosts. While experts still hotly debate whether these molecules of nucleic acid, protected by a protein shell, should be considered “living,” they are unquestionably insidious in their ability to hijack the inner machinery of cells for their own reproductive purposes, sometimes causing overwhelming damage to their host in the process.

Over the last century, the world has seen outbreaks of numerous virus-caused diseases, ranging from polio to influenza to the human immunodeficiency virus (HIV). Some of these have led to devastating pandemics, resulting in millions of deaths. Others, however, only cause mild symptoms, an expected nuisance to deal with each fall and winter. Kenneth Tyler, M.D., chair of the Department of Neurology at the University of Colorado (UC) Anschutz Medical Center, observes there are many viruses that affect the nervous system. Even garden variety flu can lead to neurological problems in certain patients – yet, it is important to remember that this remains a rare occurrence.

“Millions, perhaps even billions, of individuals are infected with different viruses all the time, and there’s never any issue with the brain,” he says. “Yet, in some cases, we do see encephalitis, or inflammation of the brain due to a particular infection. We are learning there are many reasons why that can occur – and it doesn’t always happen in the same manner or even cause the same type of damage. Some viruses can directly infect different brain cells, both the neurons themselves and glial cells. Others may get to the brain in other ways. It all gets rather complicated rather quickly.”



TAKING DIFFERENT DOORS INTO THE NERVOUS SYSTEM

Dorian McGavern, Ph.D., a senior investigator at the National Institute of Neurological Disorders and Stroke (NINDS), says it is difficult for viruses to gain direct access to the central nervous system (brain and spinal cord).

“It’s a relatively closed compartment,” he says. “To get into the brain or spinal cord, a virus has to essentially invade all the brain’s peripheral defenses like the blood-brain barrier as well as the different immune responses. It’s not that easy.”

Viruses may enter their hosts through the gastrointestinal tract, the respiratory tract including the nose (and the neurons that reside there), or through the bite of a mosquito or infected animal. The point of entry, and how the virus might spread from that point, likely determine which bodily systems may be most affected. For example, some scientists are hypothesizing that COVID-19 may be targeting blood vessels, which is why

we see such widespread damage across different organs. Blood vessel infection would help explain the blood clots seen in some of the young stroke patients, not to mention inflammatory syndromes observed in the brain.

“The blood-brain barrier is made up of blood vessels,” says Griffin. “So, if a virus can replicate in the cells of blood vessels, it has a rather direct entrance to the brain. But it could also come into the brain from cells in the blood that are allowed to cross the blood-brain barrier. It could come in through the olfactory neurons in the nose, which project to the rest of the brain. Given the number of direct approaches available, it’s actually amazing that we don’t see viruses causing neurological issues more often.”

But it’s just as possible that COVID-19 is not infecting the brain directly, causing neurological impairment through secondary pathways. One hypothesis that many hold is that damage comes from an overactive immune response to the novel coronavirus, a so-called “cytokine storm.” Proinflammatory cytokines, proteins produced by immune cells to fight off the virus, are released in overwhelming numbers and intensity at an infection site, enter the bloodstream, and produce severe and destructive inflammation in cells and tissues.

“Sometimes damage comes from the inflammatory process and immune response – that’s really the culprit,” says Griffin. “The immune system is there to get rid of the virus. But sometimes the kinds of molecules it produces to fight off the virus can be just as detrimental to the cells as the virus is. It’s a bit of a double-edged sword.”

Finally, some of the brain-related effects documented with COVID-19 may be the result of other bodily systems being compromised by viral infection. The lungs may not be able to supply sufficiently oxygenated blood to the brain, resulting in ischemia and cell death. The failure of those vital systems may also lead to more blood clots. Sherry Chou, M.D., an associate professor of Critical Care Medicine, Neurology, and Neurosurgery at the University of Pittsburgh Medical Center, says anecdotal evidence suggests that COVID-19 patients may be more prone to stroke.

“Right now, this is a hunch, based on what physicians are seeing, that needs to be investigated further,” she says.

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85 Million Americans live more than an hour away from the nearest Level One or Level Two trauma center. **This distance can be deadly.**

As COVID-19 cases overwhelm hospitals across the country, **air ambulances are being called on more frequently to** transport patients quickly and safely to less crowded facilities.

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*Nearly 16 percent of America's mainland is 30 miles or more away from a hospital with emergency care. Source: CNN analysis of data from Centers for Medicare and Medicaid Service

More than 70 percent of flights

Are for Medicaid or Medicare patients, or those without insurance. Because of out-of-date reimbursement rates, air medical providers are not being paid fairly for their services. On top of this, some health insurers deny emergency medical coverage, leaving patients with the bill.

1 closure per month

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The SOAR campaign supports efforts at the federal and state level to ensure that the millions of Americans across the country who rely on air medical resources continue to have access to them.

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“But, that said, we don’t fully understand what might be behind this phenomenon if it does exist. Could the blood vessels be infected, leading to clots? Could it be the fact that these patients are sick enough that organs start failing which means the clotting system isn’t doing what it is supposed to do and that’s the issue? We just don’t know yet.”



DAMAGE NOW, DAMAGE LATER

Viruses may also set the brain up for later problems. When Richard Smeyne, Ph.D., a neuroscientist at Thomas Jefferson University who specializes in Parkinson’s disease, viewed a video of a duck infected with bird flu (H5N1), his first thought was, “This bird has Parkinson’s disease.” After studying the brains of infected animals, he discovered the virus had the ability to directly infiltrate and destroy cells in the substantia nigra, the same part of the brain affected by the neurodegenerative disorder. While human beings with H5N1 did not show full-blown Parkinson’s disease, they did often exhibit symptoms such as tremors – the kind of movement disorder seen in Parkinson’s. Smeyne wonders if there might be a link between viral infection and this or other forms of neurodegeneration.

“We know, for example, that the 1918 flu pandemic killed a lot of people,” he says. “But what a lot of people don’t realize is that starting around 1936 to 1943, there was a dramatic increase in the rate of Parkinson’s disease. It’s the only time, I believe, in history, that the average incidence rate (number of newly diagnosed people at a specific time point) jumped from two to three percent in people over the age of 55. There could be a link between flu infection and later issues.”

H1N1, or the swine flu, does not directly infect neurons like its bird counterpart. Yet, studies consistently show that it can lead to a cytokine storm or hyperactive immune response in the brain. When Smeyne and his team gave mice that had recovered from a previous swine flu infection small doses of MPTP (1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine), a neurotoxin that can mimic Parkinson’s disease, they found that evidence of permanent damage.

“The animals that had been infected showed basically a Parkinsonian-type lesion in the (brain’s) substantia nigra. Those who hadn’t been infected showed no effect,”

he says. “It suggests that flus or viruses that cause these cytokine storms could prime the brain for later insult. It’s possible that your brain could sustain damage later from the virus you were infected with today.”



UNDERSTANDING COVID-19 AND THE BRAIN

As more case studies about COVID-19 are published, it is becoming clear that SARS-CoV-2 is a virus with immense reach. But to date, much of what doctors and scientists have to go on is anecdotal evidence – not hard data. Moving forward, UC neurologist Tyler says, there are many questions that need to be investigated so we can better understand how the novel coronavirus impacts the brain and neurological function.

“It’s hard to do research in the middle of a pandemic – doctors are focused on saving lives,” he says. “But these case studies are showing that we better pay attention. Future studies should look carefully at how this virus enters the host, what kind of cells it infects, how it spreads in the body, and what kind of damage it is doing. That’s going to take time.”

Pathological studies looking at individuals who have perished from COVID-19 have already started. A small pathological study of 18 patients, published as a letter in the *New England Journal of Medicine* in June, suggests that most damage occurred due to hypoxia, or a lack of oxygen to the brain. Researchers are also relying on organoids, so-called “mini-brains,” to see how the virus may affect the different cells in these three-dimensional, self-organization tissue culture models. Using this approach, researchers from Johns Hopkins University discovered that COVID-19 can both infect and spread across neural tissue – but they cannot say with any certainty that the virus can pass through the blood brain barrier to get into the brain in the first place.

While such studies are revealing curious and sometimes contradictory new insights about COVID-19, they are only a first step in a long scientific journey. To more fully understand how this virus affects the nervous system, researchers will need a good animal model and, until a vaccine is developed, a biosafety level 3 laboratory in which to do controlled experiments.

“One of the biggest challenges is finding an appropriate model – not all viruses affect mice or rats the same way

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they do humans,” says NINDS scientist McGavern. “A good model system allows us the ability to work out the molecular mechanisms and get a better idea of what the virus is doing, how it’s getting into the body, what cells it infects, and how it’s disrupting those cells.”

Such studies can help illuminate how COVID-19 does neurological damage now – and, potentially, in the future.

Human studies will be vital in developing treatments for the novel coronavirus. Pittsburgh’s Chou and colleagues have already started a multi-center international consortium to look at the links between COVID-19 and stroke.

“The initial phase 1 study is already up and running,” she says. “Its focus is really trying to describe the phenomenon that neurocritical care professionals are seeing. How many people with COVID-19 are having this problem? What does the problem look like, exactly? Once we know that, we can dive in more deeply to ask how this stroke may happen, as well as the possible mechanisms and risk factors involved.”

But both she and other researchers caution that it will take time to fully understand the nature of COVID-19 and how it affects the central nervous system. While that may sound daunting in the midst of the current pandemic, the good news is such research findings will likely better prepare both scientists and clinicians for the next.

“When you think about the different viruses that have emerged over the last century – AIDS, H1N1, Ebola, West Nile, Zika, just to name a few – the one predictable thing seems to be that new viruses are going to continue to emerge as human pathogens,” says Tyler. “It’s likely that many of them will have an impact on the human nervous system in different ways. The more we can understand the pathogenesis of these viruses, even though they are quite different, the more we can add to our base of knowledge so we can better understand and manage the next virus that comes along, whatever it may be.”

This article first appeared in the Summer 2020 issue of Cerebrum magazine and is reprinted with permission from The Dana Foundation.



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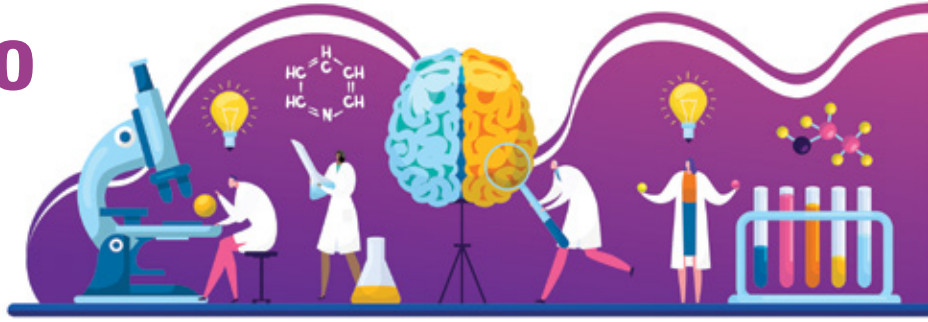
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Award Winners Recognized for Contributions to Clinical Care and Research



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

The Brain Injury Association of America (BIAA) is proud to announce that Lance Trexler, Ph.D., FACRM, has been named as the recipient of the 2020 Sheldon Berrol, M.D., Clinical Service Award and Angela Colantonio, Ph.D., OT Reg. (Ont.), FCAHS, FACRM, will receive the William Fields Caviness Award.



Lance Trexler, Ph.D., FACRM

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. This year's winner is Lance Trexler, Ph.D., FACRM. Dr. Trexler is the executive director, Brain Injury Rehabilitation

Research and Program Development at the Rehabilitation Hospital of Indiana, adjunct clinical assistant professor of PM&R at the Indiana University School of Medicine, adjunct assistant professor of speech and hearing sciences at Indiana University, and adjunct assistant professor of psychological sciences at Purdue University.

"I am most grateful for this award. It is easy to feel like one never does enough to help those with brain injury, but this recognition does help me feel like the teams with which I have had the pleasure to work have done something," shared Dr. Trexler. "I have had the pleasure of working with so many clever and committed

professionals – way too many to name, but I trust that all of you know that I am thinking of you. I have also learned so much from the tens of thousands of people with brain injury and their families that I have treated over the last 40 years. And to you, please know that I have tried to develop and research or disseminate new rehabilitation strategies based on what you have taught me that you needed. My sincere appreciation to all of you as well. I am also profoundly grateful for the love and support my wife Laura has shared over the years, as well from my four children, Christina, Elliot, Andrea, and Samuel."

Dr. Trexler was designated as a Fellow of the American Congress of Rehabilitation Medicine (ACRM) in 2013, and he received the Distinguished Member Award in 2015 and the Lifetime Achievement Award in 2019 from ACRM. In addition to serving as a clinician in rehabilitation neuropsychology since 1979, his overriding commitment as a neuropsychologist has been to develop, implement, and disseminate rehabilitation and social interventions for individuals with acquired brain injury. Dr. Trexler is an author on more than 50 peer-reviewed journal articles and book chapters.

The William Fields Caviness Award is presented 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 with brain injury. This year's award winner, Angela Colantonio, Ph.D., OT Reg. (Ont.), FCAHS, FACRM, is the director of the University of Toronto's Rehabilitation Sciences Institute and a professor in the department of Occupational Science and Occupational

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Angela Colantonio, Ph.D., OT Reg. (Ont.), FCAHS, FACRM

Therapy. She is a senior research scientist at the KITE/Toronto Rehabilitation Institute-University Health Network, is affiliated with the Dalla Lana School of Public Health at the University of Toronto, and is an adjunct scientist at ICES.

Dr. Colantonio leads an internationally recognized research program on

acquired brain injury, which focuses on women, sex and gender, return-to-work, violence, and underserved populations such as persons experiencing homelessness, intimate partner violence, and involvement with the justice system. Dr. Colantonio has led numerous cohort studies examining long-term outcomes after TBI by sex, including large, population-based studies documenting both traumatic and non-traumatic brain injury across the continuum of care.

Dr. Colantonio has written more than 270 publications and has presented to more than 500 audiences. She is a former board member of Brain Injury Canada and ACRM. She currently serves as research chair on the Pink Concussions Professional Advisory Board. She is a Fellow of the Canadian Academy of Health Sciences, ACRM, Ontario Brain Injury Association, and the American College of Epidemiology. She received the 2015 Robert L. Moody Prize for Distinguished Initiatives in Brain Injury Research and Rehabilitation and has received awards from Brain Injury Canada and ACRM. She is most grateful for the contributions of so many dedicated trainees, colleagues, staff, clinicians, funders, and other stakeholders that made this work possible. In particular, she is thankful for the generous mentorship and support provided by persons affected by brain injury throughout her research program.

The awards will be presented virtually at the ACRM annual conference in late October.

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ARE MEN FROM MARS AND WOMEN FROM VENUS WHEN IT COMES TO TRAUMATIC BRAIN INJURY?



By Ksenia Musaelyan, M.D., neuroscientist, and Beth McQuiston, board certified neurologist, registered dietitian, and medical director for Abbott Diagnostics Business

Gender differences in traumatic brain injury (TBI) have attracted both public and medical research attention in recent years. We are at the beginning of this journey with much research being undertaken to prevent, diagnose, and treat TBI using a comprehensive and individualized approach. Overall, TBI occurs in men more often than it does in women, and until very recently, has been perceived as a “male injury” as it may occur in those playing high-contact sports or in careers that are more physical in nature. However, when looking at specific age or occupation groups, the sex difference in the risk of sustaining a TBI disappears. For example, men and women over 75 years of age are equally likely to suffer from this condition. Moreover, it has been shown that some groups of women are, in fact, at higher risk of sustaining a TBI than their male counterparts. For example, female athletes in collegiate sports with similar rules as the male teams, such as soccer, basketball, and baseball/softball have a higher rate of concussion.

The diagnosis of mild TBI or concussion is not a trivial task, and many concussions go unrecognized, which makes the estimation of their occurrence in men and women more complicated. Currently, clinicians rely heavily on subjective symptoms and clinical exam findings to assess potential injury. While this

Sex differences are not limited to the diagnosis itself but extend into the way men and women experience and recover from TBI.

information can be useful, objective tools would help to paint a more complete picture. Fortunately, new technology is under development and may help achieve some of these goals. For example, blood tests under development by Abbott may detect proteins in the blood which are indicative of brain injury. Measuring such proteins may provide additional, objective information about the presence and the severity of the injury to the clinician and patient.

Sex differences are not limited to the diagnosis itself but extend into the way men and women experience and recover from TBI. It has been shown that women are more likely to feel the long-lasting and chronic effects of injury. For example, several studies have

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demonstrated that women may be more susceptible to depression in the first month to one year post injury. Others reported that women may have more nausea and sleep disturbances and have more headaches following injury. In addition, female athletes have been shown to have more post concussive symptoms and may require a prolonged recovery time in sports such as soccer and basketball.

Although women may suffer a higher rate of injury symptoms, they may be less likely to die or have a disability from a TBI. They are also more likely to return to work, school, or sporting activities than men sustaining similar injury. Of note, such results usually come from studies analyzing thousands of patient records rather than interviewing people individually, which can introduce differences related to the way TBI survivors report and deal with their symptoms.

Biologically, gender differences may play a role in TBI recovery. In women, post-injury factors such as higher pressure inside the skull and greater tendency for brain swelling may lead, in some circumstances, to worse outcomes after a TBI. At the same time, protective mechanisms such as a higher number of connections among certain brain regions and a higher resiliency of those connections can protect women from developing post-concussive symptoms in certain types of injury. The ability to accurately and objectively monitor brain injury is key to a better treatment and recovery from such symptoms. This is another area where measuring blood proteins which reflect how the injury unravels, can substantially improve patient care.

Interestingly, some female sex hormones, such as progesterone and estrogen, are believed to be protective against TBI and are believed to help patients, both men and women, to achieve better recovery. It is important to remember that men also produce these hormones albeit in smaller doses, and it is thought that they play important roles in body growth and development. Conversely, hormonal fluctuations can lead to increased risk depending on the phase of the menstrual cycle during which the woman is injured. Progesterone and estrogen have now been closely linked to brain health – so much so that some experts believe that these hormones also may play a role in depression and anxiety. The evidence for protective effects of progesterone is compelling enough to warrant

A number of collaborations between patient advocacy groups such as the Brain Injury Association of America, governmental agencies, industry, academia, and the military are underway with many promising results on the horizon that include more information about sex-based differences.

several clinical trials of treatment with progesterone-like compounds, with some finding and others not finding improved recovery after TBI. Why would studies have such conflicting results? Hormonal regulation is a highly intricate process and more research is needed in this area. At the same time, accurate selection and monitoring of patients can play a key role in the outcome of trials evaluating the effect of novel treatments like progesterone. This is another area where monitoring injury-indicative blood proteins to track the progress of patients taking part in new treatment trials may facilitate their success and lead to a speedy implementation of new effective interventions into clinical practice. This would ultimately mean better recovery and quality of life for people sustaining a TBI.

Brain injury is a complicated problem affecting much of the population. To best help all patients, a true team approach is needed. A number of collaborations between patient advocacy groups such as the Brain Injury Association of America, governmental agencies, industry, academia, and the military are underway with many promising results on the horizon that include more information about sex-based differences. This team approach, including a focus on all genders, will be critical in helping patients live their lives to the fullest.

References available at biausa.org/TBIandGender.



Should we accept Chronic TBI as a Permanent Disability?

By Bijan Nejadnik, M.D., Chief Medical Officer and Head of Research, SanBio Co., Ltd.

Recovery from a moderate to severe traumatic brain injury (TBI) can be limited and may leave individuals with long-term disabilities. Many of the treatments available today focus on prevention of further injury, but they do not address the potential to heal the injured part of the brain. However, some physicians and scientists believe it is possible to repair the brain after a TBI. The challenge is to develop new treatments that have the ability to repair the brain, address long-term disabilities, and improve the lives of individuals with brain injury.

The medical costs of treating TBI in the U.S. are extremely high, and are estimated to be \$76.5 billion a year. Once the trauma occurs, the patient is admitted to the hospital where they are treated and most likely recover, but many are left with long-term disabilities. For example, some survivors may be unable to regain full use their limbs, including difficulty walking, which in turn affects their ability to function in their daily lives. Others may experience loss of memory, sight, hearing,

swallowing, or speech, or they may experience emotional or behavioral problems such as depression and aggression. The effects of brain injury may be life-long and can impair an individual's ability to work or live independently.

Currently available drugs and rehabilitation services such as physical therapy may improve mobility, but often do not change the course of TBI. However, we should not accept that disabilities due to TBI are permanent. There is a huge potential for treatments that change the biology of the TBI-affected brain by replacing or repairing damaged brain cells and structures. One treatment that has the potential to successfully treat TBI and its associated chronic disabilities is stem cells. Stem cells are found in small numbers in the human body; but, when needed, they have the ability to change into different cells to help treat various conditions. For example, they can become skin cells, blood cells, bone cells, brain cells, or any other cell type in the human body.

Although stem cells are found in small numbers, they are present in organs throughout the body, where they can use their ability to change into different cell types to help repair damaged cells and replace old cells throughout our lives. Using this ability of stem cells to change into other cell types, stem cell treatments for TBI are being studied in clinical trials using donated adult stem cells from several sources, including bone marrow, with the aim of showing that stem cells can replace or aid in the repair of damaged brain cells. Stem cells are also being studied in clinical trials for their effect on other neurological conditions such as stroke, Parkinson's disease, seizure, and cerebral palsy.

The development of stem cells for the treatment of TBI is just beginning; however, early clinical trials of stem cells for the treatment of patients with a moderate-to-severe disability caused by TBI are promising. For example, a clinical trial has shown that unconscious patients with severe TBI who were treated with stem cells shortly after injury experienced better preservation of important brain structures and were

more likely to wake up from a coma than patients who did not receive stem cells. Two other clinical trials enrolled individuals with a TBI who were injured at least one year before entering the trial and who had suffered a moderate-to-severe TBI with long-term physical disabilities. In the trials, the patients who were treated with stem cells experienced greater recovery of upper and lower limb use, balance, and sensation than patients who did not receive stem cells. Importantly, patients who were treated with stem cells in these clinical trials did not experience greater side effects than patients who did not receive stem cells.

Early clinical trials of stem cells are beginning to show that it may be possible to change the biology of the brain and the course of TBI, and that there is hope that chronic TBI does not have to be a permanent disability.

References available at biausa.org/ChronicTBI.



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THANK YOU!

Provider Competencies for Disorders of Consciousness: Minimum Competency Recommendations proposed by the ACRM-NIDILRR Workgroup



By Theresa Bender Pape, M.A., CCC-SLP, Dr.PH, FACRM, Edward Hines Jr. VA Hospital, and Nathan D. Zasler, M.D., DABPM&R, FAAPM&R, FACRM, BIM-C, CBIST, Concussion Care Centre of Virginia, Ltd. and Tree of Life Services, Inc.

Patients with disorders of consciousness (DoC) after brain injury have complex medical and medical rehabilitation needs requiring specialized skills and high levels of care and surveillance. The need for standards of care for complex populations, like patients with DoC, was identified in the Medicare Payment Advisory Commission’s 2019 Report to Congress. This report, “The Medicare and Proposed Reforms to the Health Care Delivery System,” calls for a tiered regulatory approach to establishing provider competencies, and the second tier specifies provider competencies for patients with specialized or very high care needs.

Considering the long-standing need for standards that can be used to determine if providers and programs match the specialized care needs of patients with DoC, the DoC Special Interest Groups of the American Congress of Rehabilitation Medicine (ACRM) as well as National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) convened a multidisciplinary panel of experts to review the literature and draft recommendations. These recommendations, based on a modified Delphi voting process, provide standards of care for use in determining if provider competencies are aligned with care needs of patients with DoC.

The primary purpose of this paper was to provide evidence-informed guidance to programs, payors, and caregivers involved in the care of persons with DoC on the essential services and processes needed to address the specialized needs of this population by explaining the minimum competencies necessary to do so. The

recommendations emphasize neurorehabilitation-related care of persons with DoC and are generally applicable across settings, including but not limited to acute care hospitals, long-term acute care hospitals, community-based long-term specialized brain injury programs, and skilled nursing facilities. To focus on the functionally important elements of optimal care, the recommendations are framed according to required capacities, infrastructure, and operating procedures that should be deployed for evaluation, monitoring, treatment, and service provision more generally (such as family education and support).

The position paper includes 21 recommendations that are organized into four categories: diagnostic and prognostic assessment, treatment, transitioning care/long-term care needs, and management of ethical issues. Within each category, recommendations provide guidance for daily clinical decisions that are made with the goal of optimizing each patient’s function. With few exceptions, these recommendations focus on infrastructure requirements and operating procedures for the provision of DoC-focused neurorehabilitation services across subacute and post-acute settings. The position paper also includes an audit checklist, which providers, payors, and consumers can use to assess a DoC program’s compliance with the minimum competency recommendations proposed by the ACRM-NIDILRR workgroup.

A major strength of the ACRM-NIDILRR workgroup’s recommendations is that they provide guidance for routine clinical decision-making that have the potential

(continued on page 30)

Brain Injury Survivor Turned Advocate Helps Pay It Forward



Brain injury survivor Cathy Grochowski sings while playing guitar for a crowd.

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

Through her journey with brain injury, Cathy Grochowski learned an important lesson: be your own best advocate. Cathy sustained her injury in 2015 while on a professional development trip in Calgary, Canada. Many doctors dismissed her symptoms as psychological. Because she had a hard time explaining what she was going through, she wasn't feeling validated. Her neurologist told her that her symptoms didn't make sense and she shouldn't still be experiencing side effects from her injury.

"No one ever thinks they or a loved one will sustain a brain injury, but when it does occur it can be absolutely devastating," remembers Cathy. She had a lot of difficulty at first, but things got easier when she realized she

couldn't be embarrassed to ask questions, switch doctors, or stand up for herself. The "tough, ugly road" she travelled would eventually lead her to become an advocate for others.

During the months immediately following her injury, Cathy did daily research on the brain and brain injuries. She was desperate to find solutions to her lingering symptoms. The Brain Injury Association of America website, www.biausa.org, became her go-to website for finding information on terminology, diagnostic concerns, and other stressful neurological challenges after her traumatic brain injury (TBI). Cathy especially enjoyed the personal stories on the website; the

stories made her feel validated, and she realized that her physical disturbances were actually quite common among brain injury survivors.

Through her own hard work and research, Cathy was able to find a neuro-optometrist who not only understood what she was going through, but had ways to treat the symptoms. Cathy's experience led to an interest in neuroscience and neuro-optometry. Before her injury, she had been a middle school science and technology teacher for more than 15 years. Afterward, Cathy changed her career and now provides marketing and training assistance for two of the neuroscientists who helped her. She also started a technology training business in which she provides professional development for teachers and consults for companies in the virtual and augmented reality industry for health care and education integration.



Cathy enjoys time with her husband, Kirt, and her two children, Rachael and Ian.

Cathy is also devoted to raising awareness of brain injury and sharing hope. She presents nationally on TBI-related topics and is a co-administrator of an online TBI support group. She shares resources with survivors and family members about ways to improve TBI outcomes and often includes materials from BIAA, like articles from *THE Challenge!* For Cathy, BIAA was there when she needed it the most. She considers herself blessed to have found resources and support early in her journey and now makes annual donations to help pay it forward. “Patients, caregivers, doctors, friends, and family members all need to know about the intricacies and challenges of TBI,” shares Cathy. She supports BIAA because she wants the organization to thrive and continue to produce timely and essential resources for providers, survivors, and their families. ●

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VOTING IS MY SUPER POWER!

Voting Tips for People Living With Brain Injury



*By Flora Hammond, M.D., FACRM,
Indiana University School of Medicine*

WHY VOTE?

- ★ Voting gives you a voice in what happens in your city, county, state, and country.
- ★ In general, people with disabilities vote less often than people without disabilities. When this happens, people with disabilities have less of a voice.
- ★ Your vote matters! If you do not vote, you are letting other people make decisions for you. Some of these decisions may impact your rights and access.
- ★ Voting is both a privilege and responsibility that goes along with being a United States citizen.
- ★ Voting is your Super Power!

HOW DO I PREPARE TO VOTE?

- ★ Make a plan!
- ★ Register and remember to vote.
 - › Write important dates on your calendar or ask someone to remind you as the dates approach.
 - › Important dates include: voter registration, absentee ballot request and due date, dates for early voting, and Election Day.
- ★ Decide which election contests matter to you.
- ★ Become informed. See suggestions below.
- ★ Make notes and take your notes with you when you vote.

- ★ Check your state election board website to find out if you need identification to vote.
- ★ Request an absentee ballot if that is how you plan to vote. Follow the directions that come with the ballot to complete it and turn it in.
- ★ Find out which polling place is your assigned voting location.
- ★ Arrange for transportation to the polls if needed.

WHERE CAN I REGISTER TO VOTE?

- ★ Voter registration locations and processes vary by state. Check before you go to make sure that the location is doing voter registration and confirm what documents you need to bring.
- ★ Visit usvotefoundation.org to check your county or state board of elections website.
- ★ County Board of Elections office
- ★ Public libraries
- ★ Department of Motor Vehicles
- ★ Social Services offices
- ★ Post offices
- ★ Town Halls

HOW DO I BECOME AN INFORMED VOTER?

- ★ Decide what strengths you're looking for in a candidate.
- ★ Learn about the issues and the candidates' positions and leadership skills.
 - › Read newspapers, listen to radio, watch televised debates, and talk to other people.
 - › Visit candidates' websites where their positions on various topics may be listed.
 - › Obtain Voter Guides. Many newspapers and issue-specific organizations create voter guides, such as the League of Women Voters at lwv.org.

- ★ Learn how candidates and others may distort information.
- ★ Know who is running and what issues are on the ballot.
 - › Get the sample ballot.
 - › Sample ballots are often available from your County Board of Elections office, election precincts, early voting sites, libraries, or online.

WHERE DO I CAST MY VOTE?

Choose the process that is best for you.

- ★ Your assigned polling place on Election Day.
- ★ Curbside at the polling site or your local elections office. If you cannot get out of your car and into the polling place, a poll worker can bring your ballot to your car. You will have to have a friend or family member go into the voting place and inform the poll worker you need curbside voting. A location that offers one-stop, no-excuses early voting (often starts 2-4 weeks before Election Day.)
- ★ Absentee ballot allowing you to vote without leaving home. You must request the ballot before the election. You must follow the directions provided to submit the ballot.

WHAT IF I NEED A RIDE TO THE POLLS?

- ★ Take public transportation to the polling place.
- ★ Ask a family member, friend, neighbor, or someone else you trust about riding with them to the polling place.
- ★ Contact the party headquarters (e.g., Democratic, Republican, or other) in your county. Remember, the parties and candidates want you to vote!

WHAT IF I NEED HELP VOTING?

- ★ You can ask poll workers for the help you need. Poll workers cannot approach you to ask you if you need help, but you can ask them for the help you need. You

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can have the poll worker help with reading the ballot and using the voting machine.

- ★ Someone can go with you and ask the poll worker for assistance on your behalf.
- ★ Someone can also go with you to the polling place and into the voting booth to help you.

HOW CAN FAMILIES, FRIENDS, AND CARE PARTNERS HELP ME VOTE?

- ★ Consider the possible obstacles to voting and think about how you could use help to overcome these obstacles.
 - › Examples of obstacles include: a lack of initiation, fatigue, a desire to avoid crowds, memory challenges, inability to drive, and difficulty with moving around or communicating.
- ★ Mention to others that you are interested in registering and voting.
- ★ Ask for help, if needed, with remembering important dates (registration, absentee ballot request)

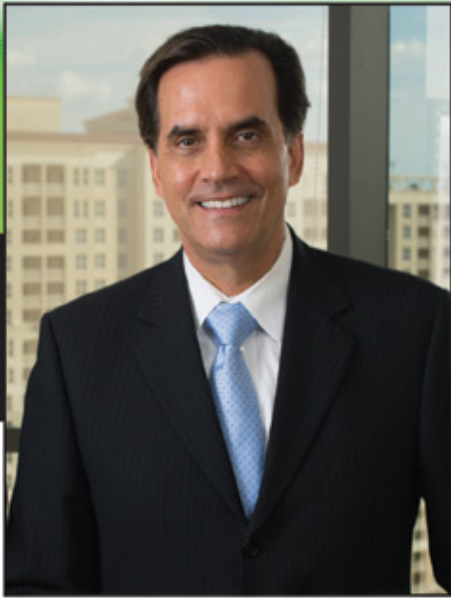
- ★ Discuss current events, political issues, and candidates with others.
- ★ Ask for assistance with voting as needed. “I would like your help with...”
 - › registering to vote
 - › remembering deadlines
 - › gathering information
 - › learning about the candidates
 - › getting a sample ballot
 - › making sure I have the right identification to vote
 - › requesting or submitting an absentee ballot
 - › getting a ride to the polls
 - › getting into the polling place
 - › reading the ballot

★ Someone else can read the ballot and the choices and ask you to pick one of the choices. They cannot pick for you.

WHAT ARE YOUR RIGHTS?

- ★ You have the right to vote.
- ★ You have the right to ask for assistance in voting.
- ★ You have the right to bring a friend or family member with you to help you vote.
- ★ You have the right to have your disability fully accommodated.
- ★ You have the right to ask the poll worker to explain how to use the voting machine.
- ★ You have the right to ask for an accessible voting machine.
- ★ You have the right to ask for a seat while you are waiting.
- ★ You have the right to take your time while voting.
- ★ You have the right to use curbside voting if you need it.





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- ★ You have the right to be treated with respect.
- ★ You have the right to advocate for yourself.

WHAT ARE YOUR RESPONSIBILITIES?

- ★ You may have to ask for the specific help you need.
- ★ You have the responsibility to become fully informed before voting

WHERE CAN I GET MORE INFORMATION?

- ★ Visit biausa.org/voting for a full list of resources.

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Authorship

"Voting is my super power! Voting Tips for People Living With Brain Injury" was developed by Flora M. Hammond, M.D., FACRM (e-mail address: flora.hammond@rhin.com); Mark A. Hirsch, Ph.D., FACRM; Christine S. Davis, Ph.D.; Julia Nelson Snow, M.A.; Martha Kropf, Ph.D.; Jason Karlawish, M.D. This information/education page may reproduced for noncommercial use for health care professional share with patients and their caregivers. Any other reproduction subject to approval by the publisher.

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This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

References available at biausa.org/voting.



STATE AFFILIATE NEWS

GEORGIA

The Brain Injury Association of Georgia (BIAG) hosted two awareness and educational programs in early 2020. The BIAG Think BIG Conference in February was a huge success thanks to our partnership with the Shepherd Center. The conference featured clinical tools for rehab professionals to improve the care for brain injury survivors and caregivers. In March, the Dream BIG: Walk, Roll or Run for Brain Injury event was held in downtown Atlanta. The survivors, families and students spent time together for mutual support and to enjoy the outside activities.

Within a few weeks, COVID-19 arrived and Georgians were asked to shelter in place, causing havoc everywhere. As a result, BIAG has gone virtual. Brain injury support groups around the state continue to hold virtual meetings to provide education and community support. In collaboration with partner hospitals and social workers, we have developed a seamless process for patients and family members to be virtually connected to a BIAG staff for Information & Referral services.



Dr. Adeyemo, BIAG Board Chair; Katie Metzger, Director of Shepherd Brain Injury Services; and Jane Jackson, BIAG Director pose together.

Our Community Response Committee is designing a short series to support the state of Georgia's brain injury community. They will consist of short and impactful videos dealing with a variety of home activities, such as yoga, caring for your loved one, cooking and eating healthy, and other practical resources.



Corporate sponsor and volunteers from LeasePlan USA attend Dream BIG: Walk, Roll or Run for Brain Injury.

KANSAS

Like every other nonprofit across the country, the Brain Injury Association of Kansas (BIAKS-GKC) has had to adapt, using virtual technology for the following:

- Five of our area support groups have begun holding sessions virtually. Though it's an adjustment, many have reported increasing attendance at each session.
- For more than 30 years, BIAKS-GKC has sponsored a Memorial Day run to focus on the impact a brain injury can have on someone's mind and body, and to raise funds for the organization. In April, we moved the run to Labor Day weekend, but as the infection rate rose, we reluctantly made the decision to move the run to a virtual event to protect the health of the runners and our volunteers.
- The Annual Professional Conference, postponed from March, will be held as a virtual event in early fall.

For more information about BIAKS-GKC, visit biaks.org.

LOUISIANA

Like other affiliates across the country, the Brain Injury Association of Louisiana (BIALA) has had to shift our outreach efforts, cancel events, and navigate this new, virtual world. However, through these challenging times, many positive things have happened for which we are truly grateful. Our monthly virtual support group meetings have been growing, connecting individuals from around the state so they can engage with guest speakers and provide support to one another. While our annual conference had to be canceled, our sponsors understand and notice the impact BIALA makes around the state, so all graciously donated the value of their sponsorship. With this money, we have focused on our "Ready, Relax, Eat" program, giving caregivers a respite from meal preparation by providing nutritious meals and delivering them to qualified family caregivers. Through a national partnership, BIALA has provided over 200 N95 masks to our members and given members the opportunity to apply for \$500 relief grants.

BIALA also received exciting news! Karen Roy, BIALA board member, was appointed to the Louisiana Rehabilitation Council by Governor John Bel Edwards. The Louisiana Rehabilitation Council works with Louisiana Rehabilitation Services to ensure the involvement of individuals with disabilities in the development and delivery

of vocational rehabilitation services to Louisianans with disabilities. Additionally, BIALA Executive Director Kimberly Hill was elected to the National Board of Directors for the United Spinal Association, where she will serve on the executive committee.



Karen Roy and Kimberly Hill advocate for individuals with disabilities on Capitol Hill in Washington, D.C.

(continued on page 28)

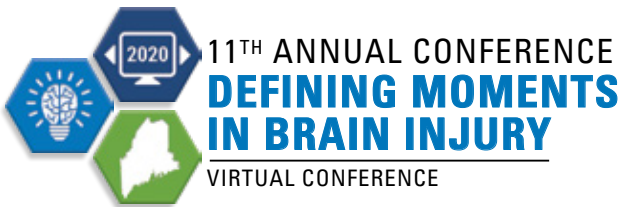
MISSOURI

The COVID-19 crisis is not stopping the Brain Injury Association of Missouri (BIA-MO) from serving survivors of brain injury, families, and professionals! Several BIA-MO support groups are offered online, and our Information & Referral service continues to help individuals and families learn about community resources.

Bowling for Brain Injury was successful as an online event. Teams and bowlers raised nearly \$20,000 through this event across the state of Missouri. Some teams were able to bowl in-person with safe, physical distancing while others enjoyed Wii bowling. The BIA-MO Annual Professional Development Conference was held as a virtual event Oct. 1 and 2. The conference is dedicated to innovative therapeutic strategies, cutting-edge and best practice treatment options, and current research. For more information about BIA-MO events, visit biamo.org.

MAINE

The Brain injury Association of America – Maine Chapter’s (BIAA-ME) held its 11th annual conference on Defining Moments in Brain Injury virtually Oct. 13-14, 2020.. Presentations covered research, treatment, and services pertinent to brain injury recovery and rehabilitation in Maine. Conference sessions provided essential information for brain injury survivors and caregivers, including support group basics, building caregiving teams, and information on assistive technology access. Professionals gained valuable knowledge on a variety of topics and earned continuing education credits.



BIAA-ME continues to focus on increasing awareness and resources related to the intersection of brain injury and substance use disorder through a TBI Partnership Grant through the Administration for Community Living. Accomplishments through the grant include a forum on the intersection of brain injury, mental health, and substance use disorder; a webinar on TBI and substance use disorder; and efforts to expand and improve the membership of Maine’s Acquired Brain Injury Advisory Council. In addition, through a contract with the Maine Department of Health & Human Services, BIAA-ME continues to expand access to core brain injury resources and supports for Maine brain injury survivors and families.

NEW HAMPSHIRE

Due to COVID-19, the Brain Injury Association of New Hampshire (BIANH) had to get creative in providing the neuro-resource facilitation and case manager services. Staff have been accessing Zoom meetings and making more frequent phone calls. Staff are also staying “connected” with each other via weekly Zoom team updates and support.

The 34th Annual Walk by the Sea and Picnic was modified to “Walk by the Sea or Virtually Anywhere – A Virtual Walk to Support Individuals Living with Brain Injury.” Participants and teams were asked to submit a video or photo of a short walk in support of this event. Despite not being able to host our usual event at the beach, 18 teams and 11 individual participants registered for the virtual walk. The top three teams that raised the most money by the day of the event were: Team Martin, raising \$1,680; B3 – Beautiful, Brilliant, Bruised Brains, raising \$1,590 and Team 891, raising \$995. To date, we have raised nearly \$10,000.

PENNSYLVANIA

The Brain Injury Association of Pennsylvania (BIAPA) made the difficult decision to cancel our in-person conference this year. Our 20th Annual Conference will be held as a virtual Education Series over a span of six months, bringing the high-quality conference content planned prior to the onset of COVID-19 to a wide audience in a safe way. It is our hope that presenting this year’s educational series virtually will make it available to even more people – including rehabilitation professionals, family members, and people who have experienced brain injury. Presentations will include a focus on cognitive functioning, neurobehavioral


treatment, memory, fatigue, employment, intimacy, sleep, fitness, domestic violence, quality of life, and caregiver issues. The Educational Series will include two presentations per month from Nov. 5, 2020 through April 22, 2021. Continuing education credits will be awarded. Registration details can be found on the BIAPA website at biapa.org/annual-conference. Plans are already underway to hold the 2021 conference in person at the Lancaster Marriott June 27-29, 2021.

VIRGINIA

The Brain Injury Association of Virginia (BIAV) closed out another fiscal year and is onto the next. Thanks to a partnership with Capital One through a board member, we started the year by completing a six-month long project to rebrand our Information & Referral program. Followers of BIAV can expect new visuals, new language, and a new approach to how we market one of our core services, all of which will help us reach more Virginians needing our help. Thanks to the hard work of one of our summer interns, we launched a four-part Facebook

Live series in August focusing on the intersection between brain injury and domestic violence. BIAV also finalized a partnership with Sheltering Arms Institute, a brand-new inpatient rehab facility that includes a state-of-the-art brain injury wing. Trained BIAV staff now hold monthly (virtual) meetings with patients being discharged to answer questions, direct them to appropriate services, and discuss how BIAV can assist with the transition out of the hospital. After all, we're here for what comes next.

BIAV is also working hard to prepare for three events happening this fall. Our first, the Annual Charity Golf Classic is happening in October with a modified schedule and all necessary safety precautions. Next, we are hosting a virtual Caregiver Forum in early November and, a week after that, we are excited to host our 20th anniversary Making Headway Conference. Both events will include live presentations, pre-recorded videos to watch on your own time, and plenty of networking. To learn more about our virtual Caregiver Forum and the Making Headway Conference, visit biav.net/events.



The only thing preventing discovery of brain injury cures is a lack of funding.

Imagine a world where we learn how to heal the brain, where people do not live with the lifelong effects of brain injury, and where, rather than accelerating a disease, we can stop it in its tracks.

BIAA is working to better understand brain injury through its Brain Injury Research Fund. Learn more at biausa.org/research.

BRAIN INJURY RESEARCH FUND
A program of the Brain Injury Association of America

Provider Competencies for Disorders of Consciousness: Minimum Competency Recommendations proposed by the ACRM-NIDILRR Workgroup

to influence a patient’s neurological and functional outcome. This is important when considering that clinical reasoning for patients in states of DoC occurs within a context of uncertainty. Clinical uncertainty includes, for example, the paucity of definitive evidence guiding clinicians in the use of results from clinical assessments in treatment planning and prognostication. This context of clinical uncertainty means that clinical decision-making is a trial-and-error process in many situations.

Given the goal of optimizing each patient’s function and neurorecovery, each recommendation provides clinicians with factors and circumstances to consider when making these daily and critical decisions. While the recommendations address the training and needs of caregivers, the guidance informs clinical reasoning and should not be regarded as the sole perspective for informing medical rehabilitation decisions. Providers should consider how to implement these recommendations to inform their reasoning, but this should not be considered guidance on shared decision making with the caregiver whose perspective is equally important during medical rehabilitation planning.

In conclusion, the minimum competency, evidence-informed, consensus-based recommendations are deemed crucial to assuring that those patients with DoC are both appropriately monitored and managed as many of them will regain consciousness as well as improve their functional capabilities. The position statement also emphasizes the importance of specialized multidisciplinary neurorehabilitation care of patients with DoC regardless of their time post-injury or their level of neurorecovery.

References available at biausa.org/docprovidercompetencies. ●

UPCOMING WEBINARS

Robert Sbordone Memorial mTBI/Concussion Lecture – Challenges in Diagnosing and Treating mTBI
October 29, 2020, 3 p.m. ET/12 p.m. PT
Brent Masel, M.D., Centre for Neuro Skills

Carolyn Rocchio Caregivers Webinar – Addiction, Barriers, and Recovery Resources
November 4, 2020, 3 p.m. ET/12 p.m. PT
John Shinholser, The McShin Foundation

Mitchell Rosenthal Research Webinar – Neuromodulation in TBI Neurorehabilitation
November 10, 2020, 3 p.m. ET/12 p.m. PT
Alexandra Aaronson, M.D., Theresa L. Bender Pape, Dr.PH, M.A., CCC-SLP/L, Ann Guernon, Ph.D., MS, CCC-SLP, Amy Herrold, Ph.D., and Joshua M. Rosenow, M.D.

David Strauss Clinical Webinar – Building Resiliency for Clients with Mental Health, Cognitive, and Substance Use Disorders
December 9, 2020, 3 p.m. ET/12 p.m. PT
Rick Krueger, M.A., LPCC, LADC, CBIS, Vinland Center

Carolyn Rocchio Caregivers Webinar – Live – Strive – Thrive: A Caregiver’s Mantra
December 16, 2020, 3 p.m. ET/12 p.m. PT
Donna O’Donnell Figurski

To register, please visit shop.biausa.org/livewebinars.

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

