

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 12, Issue 4

# THE CHALLENGE!

**FEELING CONNECTED**

**DECEMBER 2018**

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## From my **DESK**



“Our work is ambitious and our resources are limited, so every single dollar helps.”

The Brain Injury Association of America (BIAA) hosted the 23rd Annual State Affiliate Leadership Conference in November 2018. During the conference, BIAA celebrated the outstanding performance of the Brain Injury Associations of Massachusetts and Kansas & Greater Kansas City for advocacy; Pennsylvania for communications; South Carolina for fundraising; and Georgia, Michigan, and Virginia for Programs and Services. The Leadership Award for Chief Volunteer Officer went to Darcy Carroll from the BIA of Virginia and for Chief Staff Professional to Nicole Godaire from Massachusetts.

BIAA is pleased to celebrate the organizational and personal accomplishments of our affiliates and their leaders. However, we know the holidays can be tough for those who have experienced great loss. I encourage everyone, especially caregivers, to take care of themselves throughout the holiday season. For those for whom the holidays are especially difficult, I hope you will become inspired to create a new life for yourself in 2019 and beyond.

In the meantime, I hope you will join me in sending our thoughts and prayers to the millions of people in California who experienced devastating wildfires this fall. I'm confident that given enough time, they will re-build their homes and their lives – perhaps not exactly as before, but in what we all understand to be a “new normal.”

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 improve recovery and the quality of life for all people affected by brain injury and to promote a cure. 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 we ask everyone to give whatever amount they can afford – no matter how large or small. To make your donation, visit [biausa.org/SupportBIAA](http://biausa.org/SupportBIAA).

*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.

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

# The Brain Injury Clubhouse Model: Bridging Stability to Function

By Valerie Gotcher, M.S., CCC-SLP, Brain Injury Network of Dallas

**B**rain injury affects the day-to-day challenges of seemingly simple tasks, like making a cup of coffee, sending an email, or saying “I love you,” for more than three million Americans who have traumatic brain injuries or strokes each year.

Although many individuals with brain injury receive life-saving medical care and rehabilitation services, forty percent of Americans hospitalized annually with traumatic brain injury have at least one unmet need for services one year after injury – long after coverage for medical rehabilitation has ended. These include improving memory and problem solving, managing stress and emotional upsets, controlling one’s temper, and improving one’s job skills.

Perhaps even more devastating for brain injury survivors is social isolation, made more impactful by lack of return to work, where we tend to spend most of our time with others. Considering that less than half of persons with brain injury successfully reenter the workforce and that rates of depression rise as the years pass, it is evident that there is a gap in services. Rehabilitation professionals, concerned family members, and persons with brain injury struggle with these challenges.

In the early 2000s, advocates banded together and found inspiration at Clubhouse International. Clubhouse International is an organization dedicated to providing support in the community for adults with serious mental illness. Much like persons with brain injury, people living with

serious mental illness oftentimes face difficulty returning to their communities after the hospital and must navigate continued services on their own.

The Clubhouse International philosophy was established more than 70 years ago and has since grown to more than 300 mental health clubhouses and 17 brain injury clubhouses around the world. Those working with brain injury survivors formed the International Brain Injury Clubhouse Alliance (IBICA). IBICA received its formal identity in 2005 and its member clubhouses currently extend from as far east as New Jersey, north to Canada, and as far west as Texas.

IBICA is a nonprofit membership organization that supports the development, training, quality, and stability of Brain Injury Clubhouse programs across the United States and Canada. IBICA serves as the primary advocate for the adaptation of Clubhouse International standards of operation, which have been successfully applied within the mental health community since the flagship location opened in New York in the 1940s.

The mission of IBICA is to support and advance an international collaborative network of standards-based Brain Injury Clubhouses for people impacted by brain injury.

Brain injury clubhouses exist to support the realization of meaningful and productive life in the community after acquired brain injury. A brain injury clubhouse is a place for adults with brain injury who no longer receive traditional medical rehabilitation but find no resolve in staying home without a sense of



Its vision is that people impacted by brain injury worldwide will have access to lifelong support and the highest quality of life through Brain Injury Clubhouses.

purpose. Although each Clubhouse program bears its own unique identity and funding sources, the following core values are consistently honored:

### The Power of Membership

At the Clubhouse, survivors of brain injury are considered Members, not patients, and thus claim responsibility for making program decisions and directing the daily operations of the Clubhouse. Membership is empowering and provides each person with the confidence needed to reenter the community and live more independently. Members understand that their contribution to the program is needed.

### The Work-Ordered Day

The Clubhouse day is structured around meaningful work in a work unit. Members choose to complete tasks that directly support the operations of the Clubhouse – from training volunteers to advocating for brain injury services, writing a newsletter article, cleaning the facility, or preparing lunch. Members are encouraged to solve problems and control the sequence of projects within work units, leading to improved cognitive skills.

*(continued on page 6)*



Opportunity Project Members in New Jersey make holiday cards for children at a local hospital.



Flour to Empower at Synapse House in Illinois teaches valuable skills and supplements program funding.



BIND in Texas provides yoga, boxing, walking, balance, and strength activities daily.

## Peer Relationships

Members work side-by-side with staff at the Clubhouse and interact with staff and volunteers as peers. Through this relationship, Members receive necessary support while still maintaining ownership over their service planning at the Clubhouse. For many Members, friendships that develop within the program are the most valuable piece of recovery and strongly impact quality of life.

## Lifelong, Voluntary Membership

Clubhouse membership offers survivors of brain injury consistent, long-term support that is available for as long as the Member needs or desires. Many brain injury clubhouses do not rely on typical insurance (nor its limitations) and instead supplement program income through fundraising efforts. Lifelong membership also supports hope for continued brain healing long after traditional medical supports have been exhausted.

Recently, a Brain Injury Clubhouse Member shared this with IBICA: *"I truly believe that if it wasn't for the Clubhouse, my condition would have steadily worsened. Instead, I found this to be a safe place and an organization where the people will accept me for who I am: emotionally broken, anxious, confused, and worst of all, scared. The Clubhouse was the only place besides my home that I felt safe. Being by myself day after day was a pathetic and awful existence. But because of the Clubhouse, I am now going to embark on something that is incredibly important to me – educating and generating greater awareness about brain injury and its consequences."*

IBICA appreciates the opportunity to answer additional questions about its history, mission, vision, and especially values inquiries from community groups interested in starting their own Clubhouse programs. Please visit [www.braininjuryclubhouses.net](http://www.braininjuryclubhouses.net) for additional information, to send an inquiry, or to find a Clubhouse program near you.



IBICA program Directors and Members gather annually to teach, train, and grow clubhouse programs.

## IBICA programs track outcomes and are pleased to share the following:

- Brooks Clubhouse in Jacksonville, Florida, has served more than 300 persons with brain injury since opening in 2008 and has helped 71 Members reenter the workforce.
- Synapse House in Elmhurst, Illinois, houses a social enterprise bakery "Flour to Empower" run by its Members and 56% of Member families report improvement in caregiver burden.
- ADAPT Clubhouse in Alexandria, Virginia, reintegrates 100% of Members back to the community through volunteer work at a homeless shelter, a nursing home, a community garden, and the local farmer's market.
- Brain Injury Network of Dallas (BIND) in Plano, Texas, provides wellness activities five days a week and 76% of Members report stable or improved quality of life after attending the clubhouse for four months.





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In addition, the program addresses the burden that many families coping with brain injury face on a daily basis.

### WHO TAKES THE COURSE?

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# BREAKING FREE from Loneliness after a Brain Injury

*By Michael Cerreto, M.S., CPCRT, CSC, LDR, A Talented Mind Clinic*

**Y**ou wake up every morning certain that your life will remain relatively stable over the years. Then one day, you have a bad accident. When you awake after the accident, you are surrounded by nurses, tubes, beeping monitors. You are shocked – something serious has happened, but you aren't able to remember exactly what occurred. You find it hard to speak or move. You are staring down a future of doctors, rehabilitation, and uncertainty.

But time and resilience march on. After you are diagnosed with a brain injury, you receive wonderful support and treatment and get a little better each day. You are encouraged by your progress as time passes, but you still think about the job you have lost and the friends who have stopped calling. You feel guilty about the injury's effect on your family, and you feel powerless to care for them as you did before the accident.

## YOU WANT MORE OUT OF LIFE

The desire to make your life better is rooted in two basic human needs that guide your behavior: the need to feel connected to others around you and the need to contribute to your community. In other words, the need to receive and show love as well as the need to be constructive rather than feeling inadequate. These are powerful needs that can propel you to create a better life.

As you recover from brain injury, you begin to want more out of life. You may feel constrained, however, by your inability to follow conversations, to remember things, and to do physical activities that were once effortless. You feel lonely but reluctant to leave the house, so you withdraw into your own world of TV, reading, eating, and doctor's appointments. Greater isolation and loneliness set in. Your basic need to feel connected to others goes unmet.



As humans, we try hard to avoid isolation and loneliness by creating expansive lives through school, friendships, sports, art, religion, and family. After a brain injury, your world shrinks. You can quickly withdraw into isolation and loneliness, which feel like shackles that constrain recovery.

## **YOU CAN BREAK FREE FROM LONELINESS**

The good news is that you can break free from loneliness and expand your world again. Having a life of meaning and achievement can help you feel worthwhile and productive after a brain injury. You can have a renewed sense of control over your life, which is important to your recovery.

First, you need to learn how to create relationships from scratch. When you were a kid, you probably had a large variety of friends because you were around people your age each day. You had classmates, teammates, and neighborhood kids next door. These are called relationships of proximity; relationships that are quick to develop because you see the same

friends each day. You don't have to seek out people in unfamiliar places; your friends are at your doorstep. If you lose connection to work, school, and other groups after brain injury, you need to learn how to find places to meet people. In general, many adults complain that they have fewer friends as they get older and often question why. As we age, we tend to lose the daily proximity to people that helps us form friendships when we're young, and we need to learn how to find friends on our own by getting involved in different groups. The Breaking Free from Loneliness Discussion Questions at the end of this article can help you get started.

## **BE MORE ACCEPTING OF YOURSELF**

As a person with a brain injury, you may hesitate to explore new activities and meet new people because you have trouble getting around, following conversations, or finding the right words. You may worry about what others think of you. The likelihood is that many people are more understanding than

*(continued on page 10)*


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*(continued from page 9)*

you think, and that you are more critical of yourself than others are of you. Keep in mind that people will connect to your character, kindness, and interests, regardless of how well you speak or remember names and faces. Like you, they too have a need to connect and feel appreciated.

### **PREVIEW SOCIAL SITUATIONS**

If you find yourself hesitant to seek new opportunities to meet people, you can use a method called previewing. Let's say that you are invited to a party at a neighbor's house and you're worried about feeling overwhelmed by the noise and conversations. Before the party, you should sit quietly and imagine the faces of the people attending. Select a few people you want to speak with and what you want to discuss with them. Imagine having each conversation. When you go to the party, you should have those conversations, then decide if you want to stay or leave. Previewing helps you imagine how to make a socially overwhelming situation more enjoyable because you prepare for it ahead of time.

### **PLAN WAYS TO EXPAND YOUR LIFE**

Work with a friend or family member to answer the Breaking Free from Loneliness questions on the next page to determine how you want to expand your world.

Whatever you choose to do outside the home to rebuild your life, make sure you incorporate the activities into a scheduled routine each week. For instance, you may go to the gym from 11 a.m. to 1 p.m. every Monday, you take a painting class every Tuesday from 4-5 p.m., and so on. By incorporating your activities into your routine each week, you are more likely to follow through and be consistent.

### **YOU SHOULD SHARE YOURSELF WITH THE WORLD**

While many things may change after your brain injury, your two basic needs – connecting with others and contributing – will remain. Fulfilling these needs can help you break free from loneliness, expand your life, and share yourself with the world.



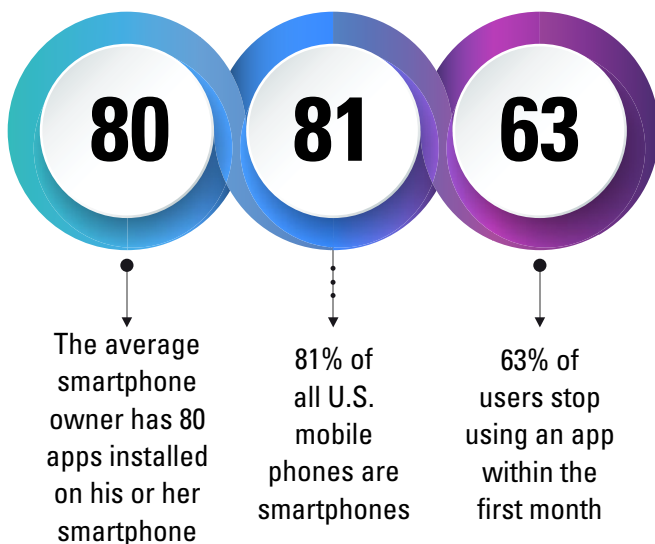
# SELECTING THE RIGHT APP WHEN YOU HAVE A BRAIN INJURY



By Michelle Ranae Wild, M.A.,  
*Making Cognitive Connections*

Have you ever thought, “There are so many apps – how do I choose?” With well over a million mobile applications in Apple’s App Store and Google’s Play Store, it’s no wonder. Let’s start with some interesting statistics and then explore some questions you might want to ask as you search for apps.

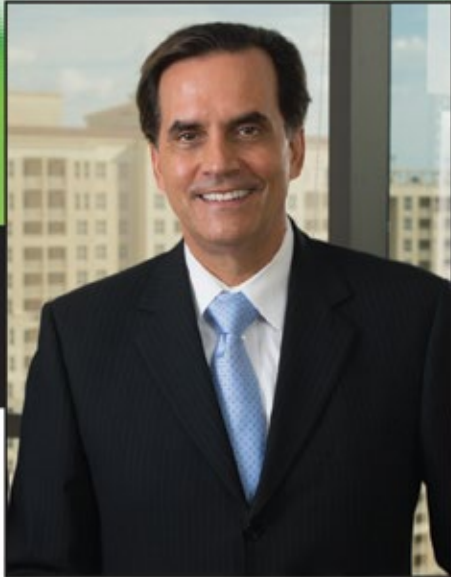
## DID YOU KNOW?



It’s amazing that 81% of mobile phones are smartphones! That means most of you probably have a smartphone of some type. Whether you have an Apple or an Android device, there are some key things you should consider before you choose an app:

### • What do you want the app to do and why?

Living with a brain injury is a daily challenge. You may be struggling with self-regulation, memory, and/or executive functioning issues, such as planning, organizing, strategizing, and time management, all of which affect you in your everyday life – at home, school, and work. You will want to look for apps that specifically address some of these challenges, such as a calendar app that helps you see when you are double-booking yourself, an app that helps you manage your energy, or an app that helps you identify and track the strategies you use and rate how effective they are in various situations. It’s important to identify your struggles and to find apps that can help address these issues. Before you download an app, you can review app-related information provided in the app store, such as a list of features, user reviews, and some app screen captures. This information can be very useful in figuring out if certain apps will help with the challenges you’ve identified.



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- **Where did you hear about the app or who recommended the app? Does the person understand brain injury?**

You may hear about apps from friends and family members because they have heard about an app or they use it themselves and like it. Unfortunately, this doesn't mean the app will work for you. You also might get a list of apps along with brief descriptions from a service provider or clinician. These lists can be very helpful because these professionals know about brain injury and may be able to provide some direction as to how you could benefit from an app.

- **How does one app compare to other similar apps?**

There are often multiple apps that do the same thing. For example, you could download literally hundreds of different note-taking apps. The problem is that people download multiple apps that do the same thing and either (1) end up with information in many different places, which becomes an organization and memory

nightmare; or (2) end up with too many apps on their home screens and can't find what they need, also a nightmare. Instead, compare similar apps recommended by reliable individuals and choose one that meets your needs. Give each new app a chance – you'll need time to use it and practice with it to know if it's going to work for you.

- **Is there training available?**

One of the best ways to learn to use an app is through trainings or tutorials. Look for online training available through the app developer, YouTube videos, blogs, and webinars. These options, however, may not meet your needs because they tend to be fast, incomplete, and overwhelming for persons with brain injury. Instead, look for trainings and blogs available through rehabilitation professionals who know how to use apps and understand brain injury. It is important to get lots of focused practice with the app during training so you can learn to use it effectively in your everyday life.

*(continued on page 14)*

### • Does the app have staying power?

Be sure to consider an app's "staying power" before selecting it. It's not always the latest apps that are the best; in fact, sometimes new apps may not last long in the marketplace and as a result can negatively impact the user. Apps that get frequent updates may also be difficult to work with as you will sometimes have to re-learn to use them. Some factors associated with "staying power" include:

- How long has the app been around?
- How frequently is the app updated?
- Does the app add new features or only fix bugs?
- Does the look and feel of the app stay the same across updates?

Here are a few other things to consider as you make decisions as to which apps to download:

**1** Don't be fooled by "free" apps. There are indeed free apps; however, many of them require "in-app purchases" to get the functionality you really need.

**2** Beware of ongoing subscriptions. More and more apps are moving to subscriptions. This means that you pay either monthly or yearly for the app, which makes it much more expensive in the long run.

**3** Use one app for many things. If you find the right app, it can be used for a variety of purposes so that you end up learning one app and using it in various areas of your life. For instance, a good note-taking app can be used to record audio, take notes in a class or meeting, create a shopping list, create a task analysis, save files, etc.

There are many benefits to using smart devices as cognitive prosthetics after an injury. They can help you with memory, sequencing, planning, organization, and lots of other cognitive tasks. However, due to your injury, you will want to look for apps that are practical, easy to use, and applicable to many aspects of your life. They should also be accessible, convenient, not visually overwhelming, and should have a consistent user interface to eliminate confusion.

Hopefully the questions above provide you with a place to start as you look for apps that can help after your brain injury. The apps below can help with many of the executive function issues you deal with on a daily basis:

- BEST Suite – three apps in one: PaceMyDay, ReachMyGoals, and StrategizeMyLife
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# Father Inspires Son to Give Generously



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

**A**s a psychology professor, Steven Roberts, Ph.D., is well aware of the complexities of the human brain. In addition to his background in psychology, Steven has also been personally affected by brain injury. His father was physically assaulted, resulting in a brain injury, and he was in a semi-conscious vegetative state for the final two years of his life. This experience changed how Steven viewed the human brain. He hopes that more people will learn about how brain injuries can alter someone's entire reality.

"The brain is infinitely important and unimaginably complex, and I can think of few things worse than suffering a traumatic brain injury. It is therefore

critically important for us to advance awareness, research, treatment, and education of such injuries, and to improve the lives of every single human being who is or who will be affected by them," Steven shares.

After watching a documentary on brain injury where he learned about the Brain Injury Association of America (BIAA), Steven became a monthly donor to the organization. Steven hopes that his donations, in memory of his father, will help educate people about BIAA. As he explains, "You can't support something you aren't aware of," so letting people know about the organization is one of his main priorities ●

***To become a monthly donor like Steven, contact us at [development@biausa.org](mailto:development@biausa.org).***

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**In support of the Christopher Conklin  
Memorial Golf Tournament**

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Mr. & Mrs. Thomas and Joanne Walker

*Special thanks to individuals  
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(continued on page 18)

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The Brain Injury Association of America (BIAA) is grateful for the individuals listed below who held fundraisers benefitting BIAA through Facebook for their birthdays. A complete list of donors to these fundraisers will be included in BIAA's 2018 Annual Report.

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***Thank You!***

# Advocacy UPDATE

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



## New Date: Brain Injury Awareness Day on Capitol Hill is March 13, 2019

The Congressional Brain Injury Task Force will host Brain Injury Awareness Day on Capitol Hill on Wednesday, March 13, 2019. Please save the date and join the Brain Injury Association of America (BIAA) in Washington, D.C., to advocate for access to care for individuals with brain injury. As in years past, there will be a brain injury awareness fair in the Rayburn House Office Building Foyer followed by a briefing and reception in the Gold Room in the Rayburn House Office Building. Visit [www.biausa.org](http://www.biausa.org) for more information.

## TBI Act Sent to the President for Signature

The U.S. House of Representatives passed the Traumatic Brain Injury (TBI) Reauthorization Act of 2018, H.R. 6615 Dec. 11. The bill was introduced by Congressional Brain Injury Task Force Co-chairs Reps. Bill Pascrell, Jr. (D-N.J.) and Tom Rooney (R-Fla.). The Senate favorably passed the TBI Reauthorization Act Dec. 18. The Senate version of the bill was voted on by the House of Representatives Dec. 19. The bill is to be signed by the President before the Christmas break.

The Senate Committee on Health, Education, Labor and Pensions (HELP) voted in favor of S.3657, the TBI Program Reauthorization Act of 2018, Nov. 29. The Senate bill was introduced Nov. 27 and is sponsored by Sens. Orrin Hatch (R-Utah) and Bob Casey (D-Pa.).

The bill reauthorizes programs administered by the U.S. Department of Health and Human Services' (HHS) Centers for Disease Control and Prevention (CDC) and the Administration for Community Living (ACL) through fiscal year 2024. The legislation allows CDC to establish a concussion surveillance program

and authorizes an additional \$5 million each year for implementation and administration of the program. The bill also specifies that the State Partnership Grant and the Protection & Advocacy Grant programs will be administered by ACL. The authorization level for the State Grant program was increased from \$5,500,000 to \$7,321,000 for fiscal years 2020 through 2024, and the state grants for protection and advocacy services from \$3,100,000 to \$4,000,000 for fiscal years 2020 through 2024.

## BIAA Attends the Celebration of NIDILRR's 40th Anniversary

ACL hosted a 40th anniversary celebration of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Oct. 18 in the Great Hall of the Hubert H. Humphrey Building in Washington, D.C. BIAA attended the event, which brought together directors from throughout NIDILRR's history, featured accomplishments and contributions made to the field by NIDILRR grantees, and focused on the future direction of disability, independent living, and rehabilitation research.

## Democrats Fail to Overturn Rule on Short-term, Limited Duration Insurance Plans

Senate Democrats unsuccessfully attempted to overturn the Trump Administration's rule allowing short-term, limited-duration health insurance plans – referred to as “junk plans,” which are not required to cover people with pre-existing conditions and often exclude basic health services including emergency care, rehabilitation, mental health, prescription drugs, treatment for substance use, and maternity care. The measure failed in a 50-50 vote with Sen. Susan Collins (R-Maine) joining the Democrats.

## President Signs FAA Bill that Includes Passengers with Disabilities Bill of Rights

President Trump signed the Federal Aviation Administration Reauthorization Act of 2018. The law includes the Airline Passengers with Disabilities Bill of Rights and increases civil penalties for harm done to passengers with disabilities or their wheelchairs and mobility aids, in October. The bill requires airlines to use “plain language” to spell out the rights of passengers with disabilities and includes provisions to ensure passengers with disabilities receive timely assistance and seating accommodations if requested. The law requires airline employees and contractors to undergo training on its bill of rights, as well as training for Transportation Security Administration (TSA) officials regarding screening passengers with disabilities. The law also directs the Department of Transportation to set a final rule for service animals on planes in the next 18 months, including service animal definitions and minimum standards.

## President Signs Spending Bill

President Trump signed fiscal year 2019 appropriations for the Departments of Defense (DoD), Labor, Health and Human Services, and Education (LHHS). Several continuing resolutions (CR) funded the remaining government programs until December 2018. At press time, a CR for the remaining programs in 2019 is unsure.

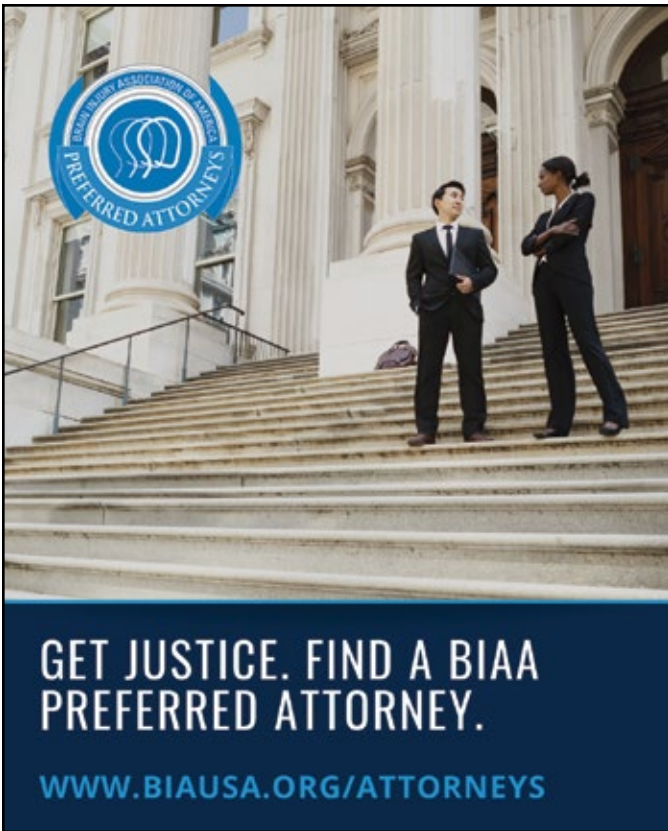
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*(continued from page 21)*

This is the first time in more than 20 years that Congress has passed a LHHs appropriations bill and the first time in more than ten years that it has passed a DoD appropriations bill prior to the end of the fiscal year. As reported previously, Congress appropriated level funding for the Traumatic Brain Injury (TBI) Act programs with regard to ACL State Partnership Grant and Protection & Advocacy TBI Grant programs as well as the CDC National Injury Center TBI program. The bill provides a \$4 million increase to ACL's NIDILRR to fund competitive grants to advance research that help individuals with disabilities, with a particular emphasis on seniors, to maintain or improve independence. The DoD appropriations included additional funding for TBI and psychological health research.

## BIAA Opposes CVS Caremark Drug Coverage Policy

BIAA joined more than 90 organizations in sending a letter to CVS Caremark opposing a new policy that would discriminate against individuals with disabilities and chronic illnesses. CVS recently announced that it would offer new insurance plans that exclude drugs if they exceed a subjective “cost-

effectiveness” measure. This approach discriminates against people with disabilities and other vulnerable groups, including older adults, because it assigns higher value to people in “perfect health” than people in less-than-perfect health.

## CDC Releases New Guideline on Pediatric Mild Traumatic Brain Injury (Concussion)

CDC’s new Pediatric Mild Traumatic Brain Injury (mTBI) Guideline was published in JAMA Pediatrics. The Guideline consists of 19 sets of clinical recommendations that are applicable to healthcare providers who care for patients with mTBI in all settings, and seeks to improve the care of young patients with this injury. The report includes five key practice-changing recommendations:

1. Do not routinely image pediatric patients to diagnose.
2. Use validated, age-appropriate symptom scales to diagnose mTBI.
3. Assess for risk factors for prolonged recovery, including: a history of mTBI or other brain injury, severe symptom presentation immediately after the injury, and personal characteristics and family history (such as learning difficulties and family and social stressors).
4. Provide patients with instructions on returning to activity customized to their symptoms.
5. Counsel patients to return gradually to non-sports activities after no more than two to three days of rest.

## House Democratic Caucus Elects Leadership

The House Democratic Caucus elected Rep. Nancy Pelosi (D-Calif.) to serve as Speaker of the House next year, a position she previously held from 2007-2011. Democrats also elected Reps. Steny Hoyer (D-Md.) as Majority Leader and James Clyburn (D-S.C.) as Majority Whip. The House will hold a floor vote for leadership positions Jan. 3, when the new 116th Congress convenes. The Democratic party won the majority in the House of Representatives in the midterm election; majority in the United States Senate remained Republican.

# State Affiliate **NEWS**

## FLORIDA

The Brain Injury Association of Florida (BIAF) is proudly closing 2018 with many successes. BIAF concluded its 2018 Camp TBi season having held five regional camps throughout the state: Winter Park, Plantation, Deland, Panama City, and Mt. Dora. The regional format enabled BIAF to reignite the greatest hallmarks of Camp TBi while increasing the accessibility of camp and sharing the benefits with almost twice as many survivors and caregivers as last year's statewide camp. Please visit [www.biaf.org](http://www.biaf.org) for the 2019 Camp TBi schedule.



Camp TBi attendees listen to the welcome session.



Camp TBi volunteers celebrate a successful event.

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Tim Rocchio participating in the 2015 BIAF Walkabout fundraiser.

With fiscal review and strict management, BIAF now commits 91 cents of every dollar directly to its programs, services, and resources, an increase of 6 percent from last year. Furthermore, BIAF resource facilitation coordinators are on pace to make more than 4,000 unique connections with brain injury survivors and their families in 2018.

The Rocchio family and the brain injury community lost a great advocate and hero, Tim Rocchio, earlier this year. Tim was the son of the BIAF's founder, Carolyn Rocchio. Tim will always exist in our memories, our hearts, and our laughter.

Special Note: The BIAF would like to extend our sincerest thanks to all of those that reached out to us in the wake of Hurricane Michael. Thankfully, BIAF staff families and executive offices sustained minimal damage. We thank you all for your concern and continued support of BIAF!

## MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its ninth annual conference, “Defining Moments in Brain Injury,” at the DoubleTree by Hilton Hotel in South Portland Oct. 16. Susan Connors, BIAA’s president and CEO, gave the keynote. Tina and Tom Callahan, accompanied by music therapist Patricia Mulholland, delivered the Beverly

Bryant Memorial Lecture. Approximately 275 people, including nearly 80 survivors and family members, attended the conference. BIAA-ME also held its fourth Bowling for Brain Injury<sup>SM</sup> event, which took place Dec. 2 at Spare Time Portland. For more information about BIAA-ME, visit [www.biausa.org/maine](http://www.biausa.org/maine).



Conference committee members Carole Starr (left) and Sue Bartlett pose with BIAA President and CEO Susan Connors and conference presenter Michael Mozzoni.



## MASSACHUSETTS

The Brain Injury Association of Massachusetts (BIA-MA) is thrilled to announce that it advocated for and secured an additional \$750,000 dollars, for a total of \$16,364,075, on behalf of the Statewide Head Injury Program under the Massachusetts Rehabilitation Commission. The additional money will maintain current services and supplement the Head Injury Treatment Services Trust Fund.

In an outside section of FY '19 budget, the state legislature voted to re-establish the Brain Injury Commission. The Commission will review data

concerning the epidemiology of brain injury, make findings regarding the status of rehabilitative support services, and make recommendations regarding the improvement of support services.

Unfortunately, the legislative calendar did not provide enough time to pass the Cognitive Rehabilitation bill. This bill, which BIA-MA will continue to champion, would require commercial health insurance plans to cover cognitive rehabilitation for persons with brain injury. The bill will be re-filed in January 2020.

## MICHIGAN

The Brain Injury Association of Michigan's (BIAMI) 38th Annual Fall Conference broke its attendance record with 1,688 attendees and 150 exhibitors. The conference featured a panel on the Flint Water Crisis and a Voter Rights Training presentation for persons with disabilities. The Flint Panel provided an overview of the events that caused the crisis, what remains to be done, and how the brain injury provider community can help. The Voter Rights Training was one of many training presentations that took place across the state during August and

September covering voters' rights, voting options available to people with disabilities, and available options and ideas to ensure a person's right to vote.

BIAMI was fortunate to have two terrific keynote speakers, Amy Blankson and Chris Ulmer. Ms. Blankson spoke on happiness in a digital era and is the best-selling author of "The Future of Happiness." Mr. Ulmer's keynote included moving interviews and testimonial videos that he has taken of kids living with special needs across the country.



Attendees listen to the conference panel on the Flint Water Crisis.

*(continued on page 26)*

## MISSOURI

More than 150 professionals attended the Brain Injury Association of Missouri (BIA-MO) 14th Annual Statewide Professional Conference in Chesterfield Oct. 4-5. National and local experts addressed best practices in rehabilitation as well as medical and mental health care. The conference agenda featured employment options for individuals with brain injury in rural and urban communities, examined the brain injury continuum of care, and discussed self-advocacy in a healthcare setting.

The post-conference Survivor & Family Seminar provided 175 individuals with practical suggestions for life with brain injury. The seminar featured an awards luncheon and annual meeting recognizing survivors of brain injury, key volunteers, and community leaders for their courage, prevention efforts, and fundraising to create a better future for persons with brain injury and their families in Missouri. Kathryn Dixon received the 2018 BIA-MO Lifetime Achievement Award for her exceptional impact as a Support Group Facilitator for more than 30 years. BIA-MO also presented educational scholarships to six survivors of brain injury pursuing post-secondary education.



Kathryn Dixon, left, receives the 2018 BIA-MO Lifetime Achievement Award.

These scholarships are supported by SSM Health Rehabilitation Network, Griggs Injury Law, and the BIA-MO Jim & Lori Winter Scholarship Fund.

BIA-MO collaborated with the Missouri AgrAbility Project at the Missouri Rural Health Conference Aug. 22-23 to inform health care, social work, and community professionals about agriculture as a self-employment option for the individuals they serve. For more information, visit [www.biamo.org](http://www.biamo.org).

## NORTH CAROLINA

The Brain Injury Association of North Carolina (BIANC) created an Online Crisis Management and De-escalation course, found at [www.biancteach.net](http://www.biancteach.net), to promote positive interactions between individuals with brain injury and first responders, including law enforcement, emergency response staff, and firefighters, in crises. The training course delivers a deeper understanding of brain injury and the brain, details experiences of individuals with brain injury and their family members, and presents practical scenarios and strategies for first responders. Senior Training Officer MJ Macario narrates the training. Working for the Raleigh Police Department at the Raleigh Police Training Center, Officer Macario has

prepared hundreds of recruits for the rigors of police work. His advice to fellow officers is, "Be ready, be patient, be professional! The formula is simple – treat everyone as you would want to be treated in similar circumstances."

BIANC continues to collaborate with local management entities and managed care organizations, law enforcement, and first responders to enhance knowledge and understanding of brain injury and promote the availability and importance of the training course. Visit [www.bianc.net](http://www.bianc.net) for more information about this free training course.

## PENNSYLVANIA

The Brain Injury Association of Pennsylvania (BIAPA) held Brain Injury Awareness Day Sept. 15 in Harrisburg with great success! Kevin McDonald and Melissa Carmen did an amazing job planning and organizing the day, which began with a Brain Injury Awareness Rally at the Pennsylvania State Capitol. More than 80 individuals visited legislators to educate them about the needs of individuals with brain injury. A panel of brain injury survivors and caregivers shared their experiences later in the day, followed by a reception honoring retiring Sen. Stewart Greenleaf (R-Bucks), a longtime champion for the brain injury community in Pennsylvania.

The National Partnership for Juvenile Services announced a position statement Sept. 21 entitled “Identifying and Responding to Youth with Brain Injury in the Juvenile Justice System.” The statement was informed by the work of the Pennsylvania Juvenile Justice Project, an initiative of the Pennsylvania Department of Health implemented by BIAPA. The purpose of the statement is to establish best practices within the state juvenile justice system. For more information about BIAPA’s work, visit [www.biapa.org](http://www.biapa.org).

## RHODE ISLAND

The Brain Injury Association of Rhode Island (BIARI) celebrated its emerald anniversary at the Hidden Treasure Gala, held at the Providence Biltmore Sept. 28. More than 200 friends attended the gala in celebration of the 35 years that the Association has dedicated to increasing awareness of brain injury and its consequences and providing education and advocacy in the community. As emerald symbolizes growth and reflection, the evening celebrated the growth of BIARI as well as reflecting back to its beginnings. To that end, BIARI honored one of its founders, Linda Densmore, with the BIARI Founders Award. After Linda’s husband sustained life-threatening injuries, including a traumatic brain injury, her life and the life of her family were catastrophically changed. Linda sought assistance for support and guidance and, finding no resources in Rhode Island, reached out to the Massachusetts Head Injury Association. It was then that she and a dedicated group of volunteers created what is now known as the Brain Injury Association of Rhode Island.

BIARI also awarded Veterans Assembled electronics (VAe) with the 2018 Corporate Partner Leadership Award. BIARI is proud to honor its past and celebrate the next 35 years of bringing awareness of brain injury and its consequences to the public, providing information and education, and supporting the needs of those with brain injury.



Linda Densmore receives BIARI’s Founders Award at the BIARI Hidden Treasure Gala.

*(continued on page 28)*

## VERMONT

The Brain Injury Association of Vermont (BIAVT) attended the National Association of Head Injury Administrators (NASHIA) State of the States conference and met with Administration for Community Living (ACL) staff regarding the Vermont ACL grant. The workgroups are starting to work on the grant goals and BIAVT will be partnering with the State of Vermont.



Attendees enjoy the awards ceremony at BIAVT's 30th Annual Brain Injury Conference.

The 30th Annual Brain Injury Conference Oct. 9 was well attended and received. The Governor's Awards were given to Jodie Casarico for Survivor of the Year, Dawn Peeters for Professional of the Year, Burlington Subaru/Hyundai for Employer of the Year, and Bryce Healy for Caregiver of the Year.

BIAVT's Annual Walk for Thought, rebranded as Walk and Roll for Brain Injury, occurs in Montpelier May 18, 2019. For more information, visit [www.biavt.org](http://www.biavt.org).

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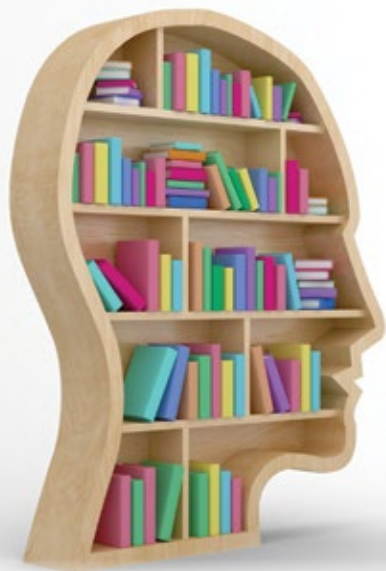
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# The BIAA BOOKSHELF

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



All parents dread the phone call telling them that their child has been in an accident. When 16-year-old Kaitlyn Johanson was in a motor vehicle accident, her parents were in two different states. Her father, Brian, had just started a new job in Wisconsin and was completing his training in Ohio. Kaitlyn's mother

and brother were home in Minnesota. Brian flew back home to find his daughter on a respirator with a traumatic brain injury, neck injury, and skull and cheekbone fractures.

"Kaitlyn's Hope: One Family's Journey through Traumatic Brain Injury" by Brian Johanson recounts the family's long road to recovery after brain injury. The story practically gives readers a day-to-day account of Kaitlyn's medical condition and her care, some of which was taken from real entries in the Johansons' online health journals on CaringBridge, a website they used to update family and friends during trauma.

Brian needed to keep his new job, so he traveled to Wisconsin during the week and returned home on weekends. He writes about the frustration of not

being there all the time for the family and marvels at his wife's strength. Throughout the book, you see how Brian and his wife face medical ups and downs with poise and come to know their hopes and fears as if you're sitting in the room with them.

The Johanson's amazing support network – their family, their church, their neighbors, and the children's school and activity groups – banded together to help. From hosting fundraisers to bringing meals and pet sitting, many people pitched in so the family could get through the roughest times.

Kaitlyn's Hope provides a great description of brain injury rehabilitation and portrays the small, incredible progress made over the course of treatment. You have to laugh when Kaitlyn, who initially couldn't talk, starts saying "no" to people, and the lengths that staff and family go to in order to get her cooperation.

This book paints a true picture of what families experience and how they survive and succeed. The prevailing theme is HOPE: Having Opportunity Present Everywhere. Get your copy from BIAA's Online Marketplace at [shop.biausa.org](http://shop.biausa.org).

# Upcoming **WEBINARS**

## **David Strauss Memorial Clinical Webinar – Neuroendocrine Function after Brain Injury**

January 10, 2019, 3 p.m. ET/12 p.m. PT  
*Lisa Kreber, Ph.D., CBIST, Centre for Neuro Skills*

## **Business of Brain Injury Webinar – “But They Said I’d Be Rich!” Protecting Vulnerable Populations from Exploitation**

January 16, 2019, 3 p.m. EST/12 p.m. PST  
*Katherine McKenzie-Meredith, Psy.D., and Brian White, MRC, M.S., LPC, CRC*

## **Carolyn Rocchio Caregivers Webinar – Taste and Smell Issues after Brain Injury**

January 31, 2019, 3 p.m. EST/12 p.m. PST  
*Ronald Devere, M.D., Taste and Smell Disorder Clinic*

## **David Strauss Memorial Clinical Webinar – Spasticity after Brain Injury**

February 7, 2019, 3 p.m. ET/12 p.m. PT  
*Cindy Ivanhoe, M.D., FACRM*

## **Business of Brain Injury Webinar – Clubhouse Works! Full Participation in Rehabilitation**

April 17, 2019, 3 p.m. EST/12 p.m. PST  
*Cindi Johnson, M.A., CBIST*

To register, please visit

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# News & **NOTES**

## **BIAA Releases New Brand Video**

The Brain Injury Association of America’s (BIAA) new video describes the organization’s work against the backdrop of one young man’s injury and fight for recovery.



The video features gunshot victim Michael Ross and his mother, Bridgette Brown, as well as the Association’s President and CEO Susan Connors, Board Chairman Emeritus Dr. Mark Ashley, and National Medical Director Dr. Brent Masel.

The video was filmed at TIRR Memorial Hermann Hospital and the Centre for Neuro Skills near Houston, Texas.

BIAA is grateful to Board member Shana De Caro and her partner Michael Kaplen, who nominated the Association for the all-expenses paid production by Crisp Video.

“We hoped to capture the reality of brain injury and its impact on everyone – the individual, the family, the treatment team – to emphasize why we do what we do at BIAA.” said Susan Connors.

You can watch the video on BIAA’s Facebook page or at [www.biausa.org](http://www.biausa.org).

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# RAINBOW

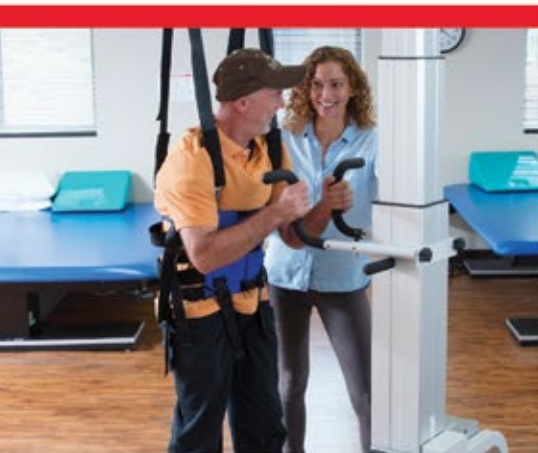
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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and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

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

