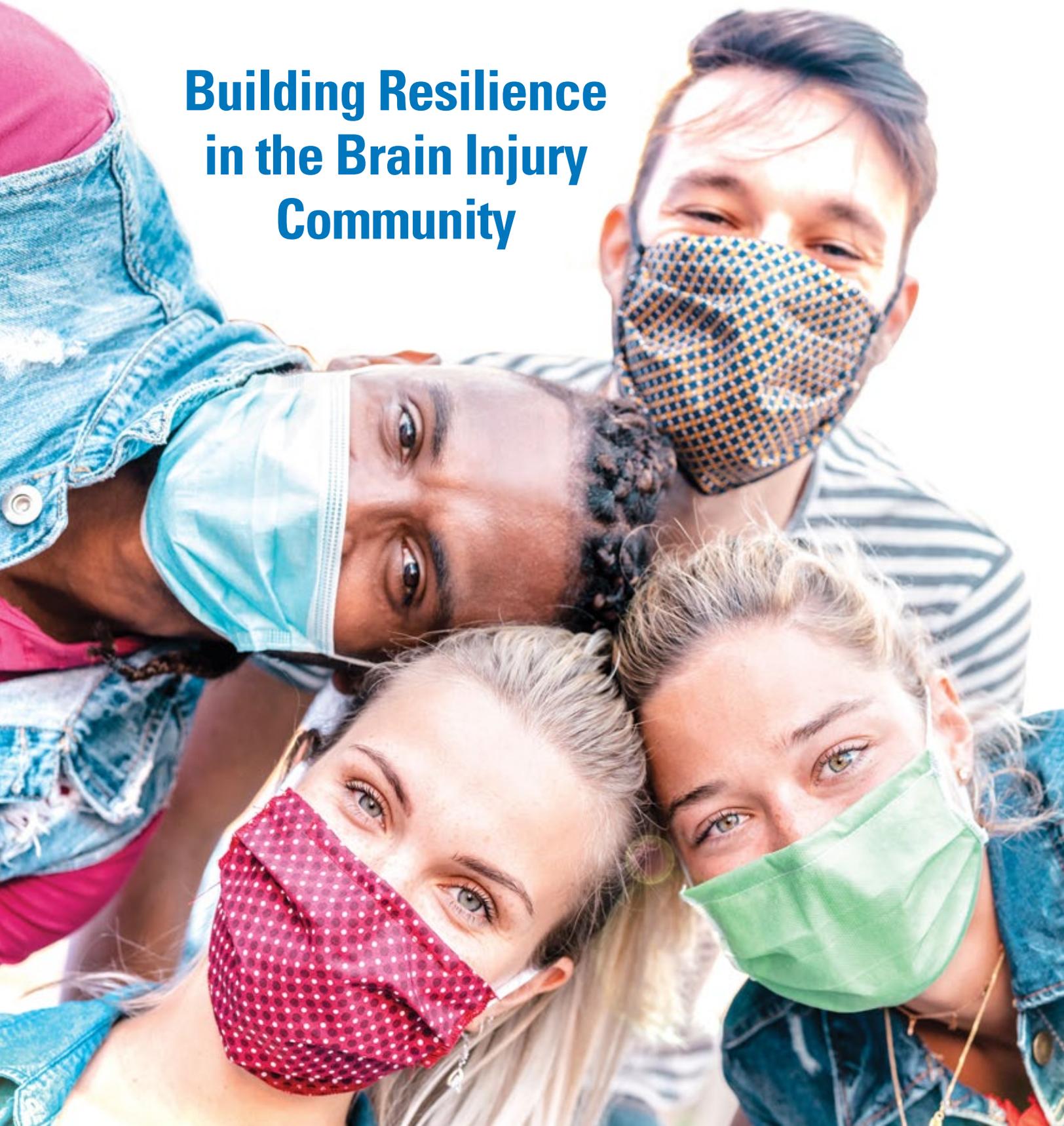


BRAIN INJURY ASSOCIATION OF AMERICA | Volume 14, Issue 2

# THE CHALLENGE!

## Building Resilience in the Brain Injury Community



**JULY 2020**

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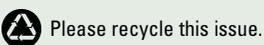
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## FROM MY DESK



**M**ore than 3 million children and adults in the United States have been infected with the coronavirus, and more than 130,000 people have died. More than 30 million Americans have lost their jobs – and their health insurance, too. It is truly astonishing that the Trump Administration and Republican state attorneys general are asking the Supreme Court to strike down the entire Patient Protection and Affordable Care Act (ACA) in the middle of a pandemic.

As explained in the Advocacy Update – Federal Response to COVID-19 (see page 22), Congress and the Federal Reserve have committed more than \$6 trillion in fighting the pandemic. Sadly, the allocation does little to combat the threats to the ACA or state-based programs and services for individuals with brain injury and their families.

The virus has wreaked havoc on state government budgets. Reduced individual and corporate income taxes and fewer sales and use taxes produce revenue shortfalls. Likewise, stay-at-home orders shrink gas taxes, traffic fines, and related surcharges for designated trust funds. Meanwhile, soaring unemployment claims absorb any “rainy day” funds that may exist.

As part of the new COVID-19 legislation, states are permitted to amend Medicaid State Plans, modify their Children’s Health Insurance Program (CHIP), and change Medicaid home and community-based services (HCBS) waivers. For example, states may cut the type, scope, frequency, or duration of services. States may change HCBS eligibility requirements or make other adjustments to reduce the number of persons served. They can also modify the size or scope of other brain injury programs.

Nationwide, advocates must be ready to protect brain injury-specific programs and services. We must be ready to explain the value of case management and resource facilitation. We must demonstrate the need for physical, occupational, and speech therapy and be ready to fight for cognitive rehabilitation and behavioral therapy. Certainly we will want to join with others to maintain local supports, such as housing, transportation, respite, and similar services. Be sure to check with the Brain Injury Association in your state for guidance.

The articles in this issue of *THE Challenge!* may help you cope with the pandemic and inspire hope for the future. In the meantime, I want to thank everyone who is supporting the Brain Injury Association of America financially and on social media – we couldn’t make it without you.

P.S. We need your help like never before. COVID-19 has impacted everything from our ability to answer the call from people in need to understanding how the virus is increasing the number of brain injuries. Flip to page 17 to learn more or visit [biausa.org/doubleyourimpact](http://biausa.org/doubleyourimpact) to make your gift today.



*Susan H. Connors*

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

# THE EMOTIONAL IMPACT OF SOCIAL DISTANCING



*By Theo Tsaousides, Ph.D., Clinical Assistant Professor, Icahn School of Medicine at Mount Sinai*

**F**or individuals with brain injury, unexpected change is nothing new. They know a lot about change, and the challenges that come with it – taking care of health problems they didn’t have before, working hard to learn how to use their brains and bodies in new ways, having to rely more on their loved ones for help, and rebuilding their identities are all examples of changes that occur after brain injury. Dealing with these challenges for months and years can lead to a fair amount of frustration, worry, dismay, anger, fear, sadness, grief, confusion, guilt, shame, or helplessness. Helping people with brain injury become better at handling all these distressing emotions is my area of expertise. For the past 15 years, my colleagues and I at the Icahn School of Medicine at Mount Sinai in New York have been working on cognitive rehabilitation interventions to help people with brain injury become better problem solvers. We noticed that what often gets in the way of being a good problem solver is... well, our own feelings. The better we are at understanding our feelings, the more effective we are at solving real-life problems. Through research, my colleagues and I have found that teaching people how to recognize and manage their feelings improves their ability to handle a variety of situations.

**All of a sudden, and while no one was expecting it, the world was dealt a big challenge that has affected everyone. The coronavirus pandemic has changed the lives of so many people and has caused a lot of suffering.**



The ability to recognize and manage our feelings is called emotion regulation. Emotion regulation allows us to explore what we are feeling at any given moment, why we are feeling this way, and what to do about these feelings. Strong emotion regulation skills are helpful in solving problems more effectively, and they are also the foundation of good mental health.

With new challenges brought upon us by COVID-19 and the changes it is causing in the way we live, work, and connect with other people, many distressing emotions will surface and intensify. The emotional struggle may become overwhelming. To help you deal with the emotional storm that is passing through all our lives at the present moment, I'm sharing three important strategies from our work on emotion regulation:

# 1. REMIND YOURSELF THAT FEELINGS ARE NORMAL

During these difficult times, you may experience a barrage of uncomfortable emotions: fear, anxiety, worry, insecurity, frustration, defeat, confusion, anger, despair, loneliness, gloom, sadness, grief, grumpiness, impatience, or resentment, to name a few. Remind yourself that having these feelings is completely normal. Emotions are part of being human; our brains are wired to create them. Emotions are the way in which our minds and bodies interact with our environment. When we perceive danger, we feel fear. When we encounter challenges, we feel frustration – but also motivation and determination. We can experience a wide range of emotions depending on our circumstances.



The risk of getting infected with coronavirus, the restrictions that limit what we can do and who we can see, and the uncertainty of when the situation will take a better turn means that we will experience a wide range of uncomfortable emotions – and that's OK. You don't have to fight the feelings. Just accept them and let them be, without letting them take over. And then use the next strategy.

# 2. SHIFT YOUR FOCUS TO WHAT MAKES YOU FEEL GOOD

How we feel is affected by what we pay attention to. This includes what we read, what we hear, what we talk about, and what we think about. Currently, for example, what many people pay attention to and focus on is news about the spread and the impact of the coronavirus and how to stay healthy. Because their focus is on something potentially dangerous, they are more likely to feel worried, scared, anxious, and depressed.

It is important to stay informed, especially about something that can have a serious impact on our health, our livelihood, and our communities. But we don't need to spend every minute of our day reading, hearing, or thinking about the pandemic. Instead, we can shift our focus to topics or activities that are uplifting and joyful. What are some things that you enjoy doing? Listening to music? Cooking? Watering your plants? Spend a few minutes and make a list of things that make you happy. Then, look through your list each day and choose one activity to do. You will notice that, when you shift your focus to an activity that you enjoy, your mood will also become lighter and brighter!



*(continued on page 6)*

# 3 USE TECHNOLOGY TO STAY CONNECTED

Finally, being around other people helps when dealing with difficult emotions. Whatever you are feeling these days, you are not alone. The majority of people are worried about their health, scared about the future, and often lonely from lack of contact. The good news is that our technology has advanced to a point that it allows us to stay connected with one another in ways that would have seemed like science fiction only 20 years ago.

Here are some ways to use technology and stay connected, especially if you have been affected by social distancing measures:

- Schedule video calls with family and friends. Many people are planning coffee or dinner dates online, so consider scheduling celebration dinners on video with family and friends for birthdays, anniversaries, or major holidays.
- Take a class online. Many instructors have switched to teaching their classes online, which is a great way to pursue your hobbies while also interacting with other people. One of my clients recently told me that her guitar class started meeting online. The students practice their “homework,” the teacher gives them feedback, and at the end of class they all play a song together. See if opportunities like this are available to you.



- Join an exercise session online. This is helpful especially if exercise has been part of your daily routine. Many applications allow people to join and follow an exercise routine with a trainer while in their own home. The sense of being in a group, sweating, and panting together is a great way to feel connected. It is also a good way to reduce anxiety and to elevate your mood.
- Stay in touch with your health care team. Many providers are now doing telehealth visits. This means that if you are in a state with “stay at home” measures, you can still “meet” with your providers. Most therapists are available to do video sessions. At Mount Sinai, we are doing a research study that focuses on teaching people with brain injury emotion regulation skills. We meet online in small groups for a few weeks and no one has to ever leave home. The feedback we get from our participants is that working in these groups helps them learn emotion regulation skills and feel connection and support.



Having worked in the field of brain injury rehabilitation for almost 20 years, I have learned that people with brain injury are resilient, tenacious, and persistent despite their challenges. Since you've dealt with unexpected change in the past, it will be easier to get through these trying times and come out stronger.

**Here is a little fun exercise to shift your focus away from distress and to improve your emotion regulation skills. I used a lot of different emotion terms in this article, and I did it intentionally. One of the ways to improve our emotion regulation skills is to increase your emotional vocabulary or the number of words that we use to describe our feelings. Here is the challenge for you: can you go through the article again and count how many emotion words you can spot?**



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# CAREGIVERS SHARE EXPERIENCES, STRUGGLES, AND ADVICE

By Kylie Akins, Communications and Media Relations Specialist, Craig Hospital

Since the COVID-19 outbreak began, people around the world have experienced jarring changes. It seems that no community has been left untouched by the impact of social distancing and stay-at-home orders. Caregivers of people with brain injuries already face a distinctive set of challenges in their day-to-day lives, and a pandemic has added a difficult new facet to their routines, activities, and wellbeing.

Meagan Beard, LCSW, an outpatient clinical care manager at Craig Hospital, has gotten calls from many of her patients' caregivers looking for support during this unprecedented and challenging time. "We tell our patients to go out and live life when they leave our hospital, to use community resources, get to know people, create social networks. But they can't do that

right now," Meagan says. "It's hard to provide enough encouragement when resources aren't there at the moment. I can only imagine how families are trying to manage their loved ones and their families with all of the uncertainty. These caregivers do so much for their loved ones, and we at Craig just want to support them in whatever way we can."

Cindy Slack, a retired registered nurse living outside Denver, Colorado, serves as a full-time caregiver to her 27-year-old daughter, Lauren. Lauren sustained a traumatic brain injury in a car accident in 2018 and has had a long journey of recovery that continues to this day. She has made much progress since her days in early rehabilitation at Craig Hospital, where she arrived unable to speak or walk. Now, Lauren often walks unassisted and is back to her talkative, social personality, but she still needs help with her daily routine.

Before COVID-19, Cindy's typical days with her daughter were filled with weekly physical therapy appointments, events with local community groups, social visits with friends and family, and keeping up with the medical care Lauren needs to continue her recovery. Lauren is doing well today, but Cindy recognizes that it took continual therapy to get her to this point – and they aren't done yet. Lauren was going to return to Craig Hospital in April for weekly outpatient therapy, and her family was looking into

◀ Former Craig Hospital patient Brittany visits with her rehabilitation team.



continuing treatment for the contractures in her hands before COVID-19 began spreading throughout the U.S. All that stopped when the outbreak began.

For the past six weeks, Cindy and her daughter haven't left their house except for walks around their neighborhood that stand in for some of Lauren's physical therapy. "It's hard to feel like life has stalled but we understand it is needed," shares Cindy. "We're nervous about contracting COVID-19. My husband and I are in our sixties, and if one of us were to be stricken with this and needed hospitalization, it would be very hard for the other one to do everything needed for Lauren. Lauren is also considered high risk, so limiting her exposure to the virus is critical."

The social changes have been an especially hard part of the COVID-19 outbreak. Cindy describes her daughter as a social butterfly. While Lauren has been using video calls to connect with her friends, she says it's just not the same. Cindy had planned to go on a caregivers' retreat this summer, but that was canceled along with other plans to connect with friends and family.

After going through a recovery like Lauren's, Cindy knows that a strong support system is critical to the recovery process. "Lauren's done well with all the people who have been there to support us. All of the positive thoughts in the world, the compassion – they have been critical for us in this two-year journey, as much now as back then. We still need all that."

Cindy says her family is making the best of it. Though life may look drastically different, their family is enjoying spending more time together right now. They've had more time to work on some of Lauren's goals, like becoming more independent in the kitchen, and the time at home has reminded them to be grateful and has given them the chance to have deeper, more meaningful conversations.

"It keeps you aware of what you have. I have family in Detroit, and the city has been hard hit by the virus. Friends and acquaintances have passed away. When it hits you that close, you reach in for the gratitude," Cindy says. "I look around, and the dust on the floor isn't bothering me today. We are healthy today. We are putting things in perspective."

Her advice for other caregivers: "Take time to breathe. Meditate if you can. One thing I've heard a lot from people at Craig is 'you are where you're supposed to be.' I still have to keep telling myself. I feel like there is more I could be doing, but I have to stop myself and say, 'I'm okay where I'm at.' I can't do everything. I'm where I need to be."

---

**"Be patient. We've come so far, and once we get past this, we'll continue to soar and get back to some normalcy. Hang in there. Love one another. We have our faith and we pray; we're just thankful for every day and everyone."**

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Not too far away, caregiver Ronda Romero and her daughter Brittany have also experienced the impact of the stay-at-home order in Lafayette, Colorado. When Brittany finished her inpatient rehabilitation at Craig Hospital in 2018, after she sustained a stroke during an emergency brain aneurysm surgery, she and her children moved in with Ronda, who became caregiver to them all. When she first came home, Brittany struggled to communicate and take care of herself and her

children, so Ronda and several others in their family stepped in to take care of her around-the-clock, turning Brittany in her bed every two hours overnight, helping her with activities of daily living, caring for her young baby, and keeping her teenager in his school routines. Today, Brittany is speaking again, though still struggling with aphasia, and has taken over some of her self-care. But the weight of social distancing has been heavy in their house, especially for Ronda, who lost her husband of 38 years unexpectedly just weeks before Brittany's stroke. Ronda and Brittany have many family members who live nearby, but COVID-19 has halted their ability to visit in person.

*(continued on page 10)*

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(continued from page 9)

“It’s been a big change. Sometimes as a caregiver, it gets lonely, even though you know you’re doing this for all the right reasons. In my situation, I lost my husband, so I just think I felt every emotional – frustrated, angry, happy, sad. And yet, when I see that Brittany is doing so much better, I’m grateful for that,” Ronda says. “Before, we went places, we did things. I do hope that opportunities can arise that we can explore things for Brittany to do. There are days she says, ‘I just want to go somewhere.’ And you try to redirect that request. I think she understands that there’s something very serious going on, that people are getting sick and dying from this. I don’t know if she understands how long this may carry on and how to deal with it.”

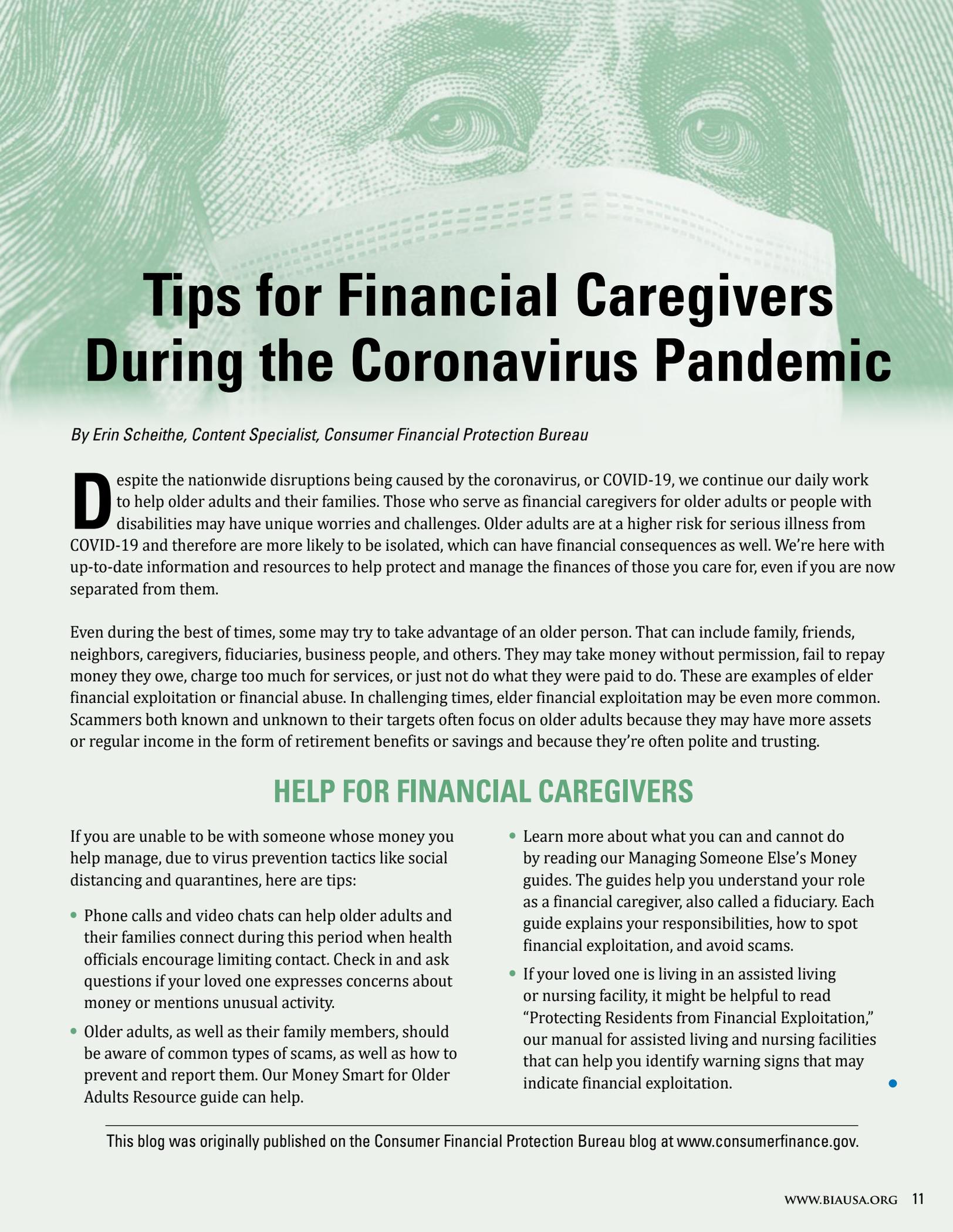
In the meantime, Ronda has found ways for her family to enjoy connecting over dinner, games, and simply sitting on the porch to talk – something they haven’t had as much time to do before this. They still celebrate birthdays and other occasions, but it’s done through video calls now. She also reaches out to Brittany’s Craig Hospital physical and occupational therapists for at-home exercises her daughter can do, and she texts

with a caregiver she met during Brittany’s rehabilitation at Craig.

“I’ve reached out to her to see how they’re doing and to get ideas and see how I might be able to help Brittany. Puzzles, games, walking – we’re doing all those things,” Ronda says. “If anything, it’s nice to hear that they’re doing so well. It just kind of reinforces why we’re doing this labor of love.”

Ronda’s advice for other caregivers: “Be patient. We’ve come so far, and once we get past this, we’ll continue to soar and get back to some normalcy. Hang in there. Love one another. We have our faith and we pray; we’re just thankful for every day and everyone.”

If you are a caregiver and are looking for support, please visit [www.craighospital.org](http://www.craighospital.org) for free online resources. Craig Hospital’s Nurse Advice Line is also available to help provide advice and information for people across the country living with brain and/or spinal cord injuries, their families, caregivers, and healthcare providers. You can contact the Craig Nurse Advice Line at 1-800-247-0257 or 303-789-8508.



# Tips for Financial Caregivers During the Coronavirus Pandemic

*By Erin Scheithe, Content Specialist, Consumer Financial Protection Bureau*

**D**espite the nationwide disruptions being caused by the coronavirus, or COVID-19, we continue our daily work to help older adults and their families. Those who serve as financial caregivers for older adults or people with disabilities may have unique worries and challenges. Older adults are at a higher risk for serious illness from COVID-19 and therefore are more likely to be isolated, which can have financial consequences as well. We're here with up-to-date information and resources to help protect and manage the finances of those you care for, even if you are now separated from them.

Even during the best of times, some may try to take advantage of an older person. That can include family, friends, neighbors, caregivers, fiduciaries, business people, and others. They may take money without permission, fail to repay money they owe, charge too much for services, or just not do what they were paid to do. These are examples of elder financial exploitation or financial abuse. In challenging times, elder financial exploitation may be even more common. Scammers both known and unknown to their targets often focus on older adults because they may have more assets or regular income in the form of retirement benefits or savings and because they're often polite and trusting.

## HELP FOR FINANCIAL CAREGIVERS

If you are unable to be with someone whose money you help manage, due to virus prevention tactics like social distancing and quarantines, here are tips:

- Phone calls and video chats can help older adults and their families connect during this period when health officials encourage limiting contact. Check in and ask questions if your loved one expresses concerns about money or mentions unusual activity.
- Older adults, as well as their family members, should be aware of common types of scams, as well as how to prevent and report them. Our Money Smart for Older Adults Resource guide can help.
- Learn more about what you can and cannot do by reading our Managing Someone Else's Money guides. The guides help you understand your role as a financial caregiver, also called a fiduciary. Each guide explains your responsibilities, how to spot financial exploitation, and avoid scams.
- If your loved one is living in an assisted living or nursing facility, it might be helpful to read "Protecting Residents from Financial Exploitation," our manual for assisted living and nursing facilities that can help you identify warning signs that may indicate financial exploitation.

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This blog was originally published on the Consumer Financial Protection Bureau blog at [www.consumerfinance.gov](http://www.consumerfinance.gov).

# We've Been Here Before

By Laurie Rippon, Writer, A Brain Injury Life Blog

In some ways, the COVID-19 pandemic feels like living with brain injury. The world's been turned on its head, the future's uncertain, and every assumption about life has been challenged. Having been here before doesn't help. Our daily struggle managing pre-existing conditions is exacerbated by the palpable fear around us. Being bombarded with constant updates, advice, and new rules every day is overwhelming, and everyone's on edge.

People are coming together by sewing face masks, checking in on their neighbors, even banging pots for front line workers. The news keeps saying we're not alone even when we're isolated. I don't know about you, but I still feel alone. Screen time is no substitute for human contact, nor is shouting hello from across the street.

Before I ever heard about "social distancing" I went to Florida to visit my three-year-old granddaughter, Mila. Coronavirus hadn't clobbered us yet, and I wasn't scared enough to cancel. But I was feeling edgy. Really, my most pressing concern was if she'd recognize me and I wasn't disappointed. The moment I arrived, she ran to me then back to her friend and said, "My grandma's here!" I swept her up in my arms, her mom took photos, and I was set for the weekend.

For those few days, I was happy and relaxed. Coronavirus hadn't gone away; instead, I'd turned away from it, entirely engrossed by what is truly important and good in life. Back in New York, anxiety returned with a vengeance. But looking at photos of Mila sent COVID-19 packing. Unintentionally, I'd stumbled on a way to cope.

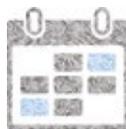
Mila taught me well. Although we can't change the world, we can change how we face the world, managing our fears by immersing ourselves in what we love – family, music, a walk in the park, or, for me, setting a challenge that demands focus, attention, and creativity.

## What helps me might help you



### Avoid information overload

Stop the assault of COVID-19 news. Turn off the TV, delete unnecessary emails, and avoid social media and streaming (I know myself – once I start, I can't stop).



### Find some structure

Everything falls apart if I don't have a schedule. I have no idea what day it is, the date, month, or year. The answer?

- Create a routine. Every morning wake up, shower, get dressed, and eat breakfast before starting your day.
- Use a calendar. Schedule your week including laundry, shopping, even washing your hair.
- Set alarms: a nap, take meds, bedtime, and a reminder to call a friend. Put big signs on your fridge: "WEAR A MASK OUTSIDE," "TURN OFF THE STOVE," and a shopping list.



## Take a breather

Slowly breathe – in through your nose, out through your mouth. Release the tension in your body and let your mind wander. Be in the moment, as you are, worries pushed away. Make space for ideas to start dancing in your head. Just stay like this for a few minutes, and now you're ready for the day.



## Make a clean sweep

Make a list of the things you've been meaning to do around the house.

- Toss old papers. Clean out the fridge. Organize closets, drawers, and the kitchen. It's hard work deciding where to put things so you can find them again, especially with a brain injury. I've tried, then tried again and again. It's a cognitive workout, but that's good, too.
- Look around and reimagine your space. Mix it up – maybe that chair is better in the corner or the table by your bed. Then try something else.



## Get up and move around

Try different kinds of physical activity to improve overall health.

- Put on music and dance.
- Practice chair yoga, tai chi, or other gentle exercise.
- Really go for it. YouTube has millions of videos for anyone from seniors to seasoned athletes, sitting or standing, or whatever works for you.
- Go outside for a brisk walk (but remember to keep your distance).



## Exercise your imagination

Have fun – the best antidote to isolation.

- Pick up a pencil and draw. Remember, it's about the process, not the result.
- Take photos from your window.

*(continued on page 14)*



The philosophy of **Beechwood NeuroRehab** is to maximize each individual's ability to participate in meaningful roles within their community. We accomplish this by providing specialized, brain injury rehabilitation for people who have sustained any kind of acquired brain injury. Beechwood NeuroRehab uses a person-centered, transdisciplinary approach, utilizing innovative treatment concepts, applied technology, and evidence-based research to help each individual to achieve a fulfilling life.



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- Speech & Language Therapy
- Occupational Therapy
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(continued from page 13)

- Play virtual games with friends online: a sing-along, karaoke, or video charades.
- Put pen to paper. Write something, anything. Maybe start a journal.
- Have clay or Play-Doh? Mush it around. Who knows? You could be a sculptor in disguise.
- Put together a jigsaw puzzle or do Sudoku.



## Stay connected with loved ones

Everyone's in the same situation, and some are fragile, have brain injuries, or need support. Check up on your neighbors and reach out to friends and family, always. We all need to hear someone else's voice or see their smile. Email, phone, text, or FaceTime; it doesn't matter how, but talk to each other – about anything but coronavirus or politics. We have nothing but time and there's no better way to use it. This is an opportunity to

really listen to people, learn what makes them tick, and to open up to them in return.

## We are community

I'm no stranger to living alone and self-isolating. Home is my "nest," where I retreat when I'm overwhelmed by the world outside. In silence, surrounded by what I love – books, art, light – I am calm, re-centered. But for now, coronavirus is at the door and alone is no longer a choice.

This long, painful experience has deepened my gratitude for community, and I know that same community will be waiting for us when we return. After all, even when scattered and afraid, we are here for one another. Keep that in your heart, knowing that we truly are not alone even when we are apart, even in a time of isolation. Even now.

To read more of Laurie's work, visit [www.abraininjurylife.com](http://www.abraininjurylife.com).



Laurie joins other members of the Brain Injury Association of New York State NYC Chapter group.



# STRIVE AND THRIVE

## with the Council on Brain Injury

By Joanne Finegan, MSA, CTRS, FDRT, President of the Council on Brain Injury (CoBI)



Our world has certainly changed over the past few months. Things we once took for granted have been challenged as we restrict access and distance physically from family, friends, co-workers, and our community. We are social beings so this is not easy, especially since we don't like to be told what to do or that we can't do something. It just goes against our very grain.



For those living with brain injury, isolation and loneliness are all too familiar. Many times, after the injury, individuals lose their family, friends, job... and need to rebuild not only a new life, but also a new and different social network with those who accept and celebrate the person they have become.



These exact influences of change and social isolation were the hallmarks of developing the Council on Brain Injury (CoBI) Facebook Group called "Strive and Thrive During Social Distancing." Early on, as states were asking people to stay at home and distance, we thought it important to find a way to reach out to help support individuals with brain injury and the staff and families on the front lines who may be providing care and support. Our growing group of followers from around the country continue to share ideas, information about activities, online resources and classes (mostly free), support groups, and basic arts and crafts that can easily be done with things right in your home. We have found that others outside of our brain injury community – substance misuse staff, long term care staff, parents, and others have joined in as the ideas and resources can benefit any of us.



Using technology, we have posted ways to virtually explore all of the national parks, turn our leftover vegetables into beautiful house plants, take a photography class, practice yoga, and hear music and plays from around the world while also feeding our social need to connect and share through live streams, support groups, and classes. What was unexpected is that it has become a place where, just by its existence, people are connected, taking the suggestions themselves and sharing with their families as we all are in need of finding ways to keep busy, have fun, relax, and rejuvenate.

As a recreational therapist, I have always known the important roles that recreation, leisure, and having a social network play in reinforcing our need to have physical, intellectual, social, emotional, and spiritual activities in our lives.

Through the creation and connections of our CoBI Strive and Thrive Facebook Group, we are helping others to also recognize the importance of recreation and leisure. As we come through this challenging time, my hope is that we remember these lessons of simple walks, taking deep breaths, sharing laughter with friends, looking at the stars, and making our future brighter, healthier, and certainly more connected. Join us at: [www.facebook.com/groups/192376202209559](https://www.facebook.com/groups/192376202209559).

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Joanne Finegan, MSA, CTRS, FDRT is the former CEO of ReMed, a multi-state provider of brain injury rehabilitation services. She is the current President of the Council on Brain Injury (CoBI), a non-profit whose mission is to fund education and opportunities related to brain injury, support research for improved treatment, and to be an advocate for improved services.



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# People with brain injury count on us.



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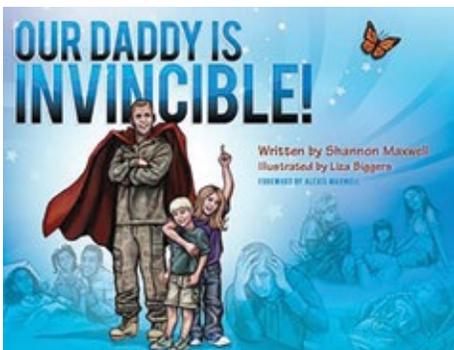
# Nine Ways to Support BIAA from Your Home

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

Raising awareness about the impact of brain injury and ensuring that people have access to the resources they need is essential – perhaps now more than ever. Here are nine ways you can help while you’re practicing social distancing.

## ONE

Entertain the kids with family-friendly stories from the Brain Injury Association of America’s (BIAA) online shop. Books like “Our Daddy is Invincible” are a great addition to any book shelf. Writer Shannon Maxwell wrote this story after her husband sustained a brain injury, and she found no available resources to help explain the situation to her children. Check out this book and many others at [shop.biausa.org](http://shop.biausa.org).



## TWO

Start a Facebook fundraiser to benefit BIAA and the brain injury community, or hold an online fundraiser in honor of someone you love. Visit [facebook.com/braininjuryassociationofamerica](https://facebook.com/braininjuryassociationofamerica) to learn more.

## THREE

Shop online using Amazon Smile. Go to [smile.amazon.com](https://smile.amazon.com), register BIAA as your charity of choice, and start shopping! A portion of everything you buy will go to helping individuals with brain injury.

## FOUR

Check out our Carolyn Rocchio Caregivers webinar series for useful webinars made with caregivers in mind. You can download each webinar from the comfort of your home by visiting [shop.biausa.org/caregivers](https://shop.biausa.org/caregivers).

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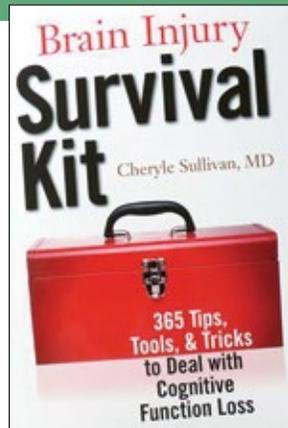
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Stay connected with us by signing up for our e-mail list. You will receive regular communications about advocacy, education, and general BIAA news. Please visit [biausa.org/signmeup](http://biausa.org/signmeup) to get on the list.

## SEVEN

Find tips, techniques, and shortcuts in the Brain Injury Survival Kit, available from BIAA's online shop.

**Bonus:** When you buy books in our shop, you support BIAA!



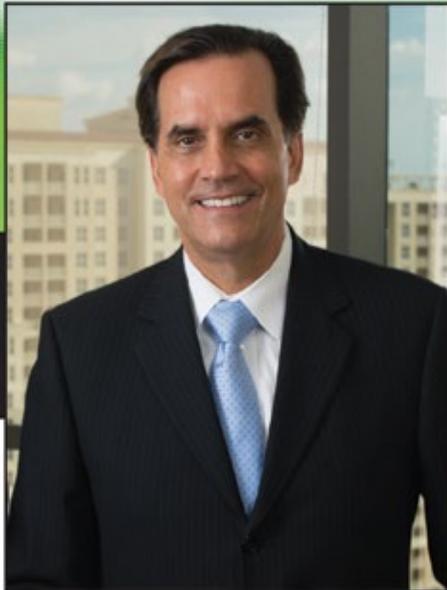
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Join us by engaging with others facing brain injury on the Personal Stories blog. Visit [biausa.org/personalstories](http://biausa.org/personalstories) to read reflections from members of the brain injury community, or share your own story today.



## NINE

Make a donation online by visiting [biausa.org/donate](http://biausa.org/donate).



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# ADVOCACY UPDATE

By Susan Connors, President/CEO, Brain Injury Association of America

The United States is responding to a respiratory disease pandemic caused by a new coronavirus, or COVID-19. This virus poses a serious public health risk. Over the past several months, state governments have focused on slowing down the spread of COVID-19 and ensuring that hospitals are prepared for an influx of people who need care. White House officials have concentrated on setting guidelines for all citizens to follow and on supporting states where possible. Meanwhile, Congressional lawmakers have enacted several legislative packages to combat the health crisis and backstop the nation's economy.

## COVID-19 Legislative Package 1.0:

### The Coronavirus Preparedness and Response Supplemental Appropriations Act

*Signed: March 6, 2020*

President Trump signed the first emergency supplemental appropriations bill, providing \$8.3 billion for the development of a vaccine, support for state and local governments, grants for community health centers, funds for the construction and renovation of non-federally owned facilities, and funding for the purchase of medical supplies. Nearly \$1 billion is appropriated for the Small Business Administration (SBA) to make loans and \$1.25 billion is allocated for overseas prevention and response to the virus.

Importantly, the law authorizes the Secretary of Health and Human Services to waive certain Medicare requirements to reach more coronavirus patients through telehealth. For safety, the Centers for Medicare and Medicaid Services (CMS) announced specific new measures for infection control in nursing homes. These include restrictions on all visitors, cancellation of group activities and communal dining, and implementation of active screening for residents and health care personnel for coronavirus symptoms.

## COVID-19 Legislative Package 2.0:

### The Families First Coronavirus Response Act

*Signed: March 18, 2020*

President Trump signed into law the second COVID-19 emergency appropriations bill, providing more than \$2 billion in additional appropriations to bolster the first package. This bill includes funding for nutrition and emergency food assistance programs as well as funds for testing and treatment through state and federal agencies. The package includes \$250 million for the Administration for Community Living for Aging and Disability Services to supplement funds to Independent Living Centers and Aging and Disability Resource Centers.

The Family and Medical Leave Expansion Act (FMLA) and the Emergency Paid Sick Leave Act are embedded in the Act to provide eligible employees with the option to take up to twelve weeks of leave if the employee is unable to work (or telework) due to illness or the need to care for a child whose school or usual care provider is unavailable due to the public health emergency.

The law also includes provisions to stabilize and enhance access to unemployment benefits by increasing the benefit amount by \$600 per week and by extending benefits up to a year. The extended benefits will be fully funded by the federal government when states experience more than a 10% increase in unemployment, instead of the usual 50-50 split between state and federal funding.

Finally, a variety of additional health care provisions to combat the pandemic are included in the law, such as assurances of free coronavirus diagnostic testing nationwide and a temporary increase of 6.2% in the federal match for all state Medicaid programs.

## COVID-19 Legislative Package 3.0: Coronavirus Aid, Relief, and Economic Security (CARES) Act

*Signed: March 27, 2020*

President Trump signed the CARES Act, the third legislative package to provide relief and support during the pandemic – this time at a cost of \$2.2 trillion to federal taxpayers. In addition to direct one-time payments for taxpayers, the law also authorizes \$349 billion for a Paycheck Protection Program to provide loans to small businesses, including certain nonprofit organizations, to maintain their payrolls.

The CARES Act requires private health plans, Medicare, and Medicaid to pay for COVID-19 diagnostic testing, treatment, and a vaccine when it becomes available. The Act also makes substantial investments in health professions workforce grant programs, including scholarships for disadvantaged students, loan repayments and fellowships, and educational assistance

in health professions. Special attention is given to pediatric specialties as well as physician and nurse workforce development.

The legislation codifies a series of regulatory flexibilities, temporary waivers, and other actions to help health care providers respond to the ongoing coronavirus crisis. These include a loosening of restrictions on inpatient rehabilitation hospitals and units, and advanced and accelerated payments to Medicare providers. Certain restrictions on home- and community-based Medicaid waiver programs are also temporarily lifted. The Act addresses medical supply shortages, particularly personal protective equipment, and provides for expedited review of new medications by the Food and Drug Administration.

Importantly, the CARES Act extends the Money Follows the Person demonstration program, Spousal Impoverishment Protections program, and Community Mental Health Services demonstration program within

*(continued on page 24)*

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(continued from page 23)

Medicaid. It also extends the Health Professions Opportunity Grants program and Temporary Assistance for Needy Families programs.

The first \$300 in charitable donations made by individuals in 2020 are 100% deductible, whether you itemize or not. Limits on deductions for charitable contributions by individuals who itemize, as well as corporations are also increased. For individuals, the 50% of Adjusted Gross Income (AGI) rule is suspended for 2020. For corporations, the 10% limitation is increased to 25% of taxable income. The provision also increases the limits on deductions for contributions of food from 15% to 25%.

### COVID-19 Legislative Package 3.5: Paycheck Protection Program and Health Care Enhancement Act

*Signed: April 24, 2020*

President Trump signed into law an interim emergency aid measure of \$484 billion. The majority of the funds are allocated toward the Paycheck Protection Program, which was authorized under the CARES Act, to keep small businesses afloat. The legislation also provides funding for hospitals, virus testing, and disaster loans to small businesses.

### COVID-19 Legislative Package 4.0

*Signed: To Be Determined*

BIAA and our partners across the health and disability communities urge congressional action on key health care priorities in the next COVID-19 legislation. In particular, we are pushing Congress to advance specific policies that will:

- Ensure access to affordable health insurance coverage for all.
- Provide states, localities, and tribes with the financial support they need to respond effectively.
- Protect the health and safety of the health care workforce.
- Organize national public health capacity.
- Protect all patients' access to care and prohibit price gouging of health care services.
- Prioritize children's health and well-being.

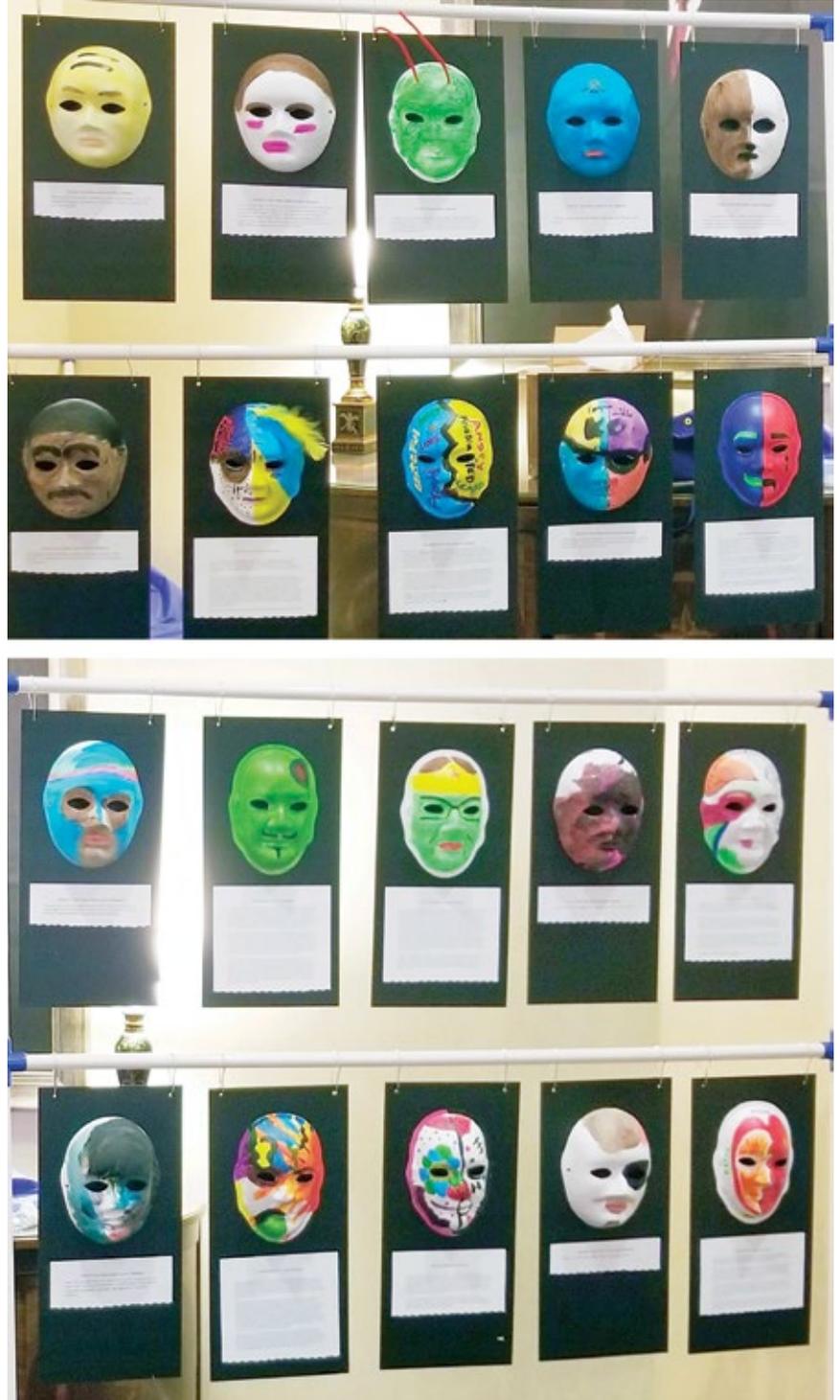


# STATE AFFILIATE NEWS

## DELAWARE

The Brain Injury Association of Delaware (BIAD) has been busy these past few months. In March, BIAD held its 29th Annual Conference, “Joined Voices, Shared Journeys: Connections Through the Continuum” to celebrate Brain Injury Awareness Month. A record number of survivors, caregivers, and service providers joined together to network and gain access to valuable resources and education surrounding brain injury. Nicole Bingaman, mother of a brain injury survivor and blogger, provided a heartfelt keynote message to the audience as she described her caregiving experiences with her son. Lt. Governor Bethany Hall-Long made a wonderful surprise presentation to BIAD Past President Sharon Lyons and offered inspirational remarks to attendees. BIAD also provided survivors with the opportunity to design their own masks for the Delaware Unmasking Brain Injury display, which will travel throughout the state to raise awareness.

As the COVID-19 crisis moved across the nation, BIAD was confronted with instituting new support systems for the brain injury population. The COVID-19 crisis posed isolation challenges for survivors and caregivers; however, BIAD was quick to devise a solution. BIAD implemented virtual support groups, provided links to valuable resources, offered virtual education, and made check-in calls and sent emails to the population we serve. For more information about BIAD, please visit [www.biaofde.org](http://www.biaofde.org).



▲ BIAD displays Unmasking Brain Injury masks created by conference attendees.

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## GEORGIA

The Brain Injury Association of Georgia (BIAG) believes very strongly in support groups, especially now! For this reason, BIAG has continued to host monthly support group meetings, regardless of what is happening in our world today. To stay compliant with all federal, state, and local organization guidelines, we asked all of our support groups to change from physical meetings to virtual ones so that our groups could continue to offer a forum for listening and sharing. Our goal is to provide a safe place to practice social and life skills and receive education from guest speakers.

One of the risk factors for a difficult recovery after a brain injury is social isolation. Humans are social animals; we need plenty of contact and connection with one another to thrive. But for brain injury and stroke survivors who may have a wide range of disabilities, social contact can be difficult – even when your family is helping. We are fortunate to be able to offer two weekly, four monthly, and one bi-weekly online support group every month. If you are interested in being a part of our virtual groups, contact Kelly Campbell at [kellymc620@gmail.com](mailto:kellymc620@gmail.com).

▼ Brain injury survivors and caregivers participate in a virtual Zoom group meeting.

## LOUISIANA

While much of the fundraising world has slowed down during the COVID-19 crisis, the Brain Injury Association of Louisiana (BIALA) could not put our brain and spinal cord injury survivors and their family caregivers on pause. Since so many of us in Louisiana have been ordered to isolate, especially in hard-hit metropolitan New Orleans, we decided to launch an online Sustainers Circle to help keep alive our caregiver program: Ready, Relax, Eat. Beginning in April, our donors were asked to support this vital program with small recurring monthly gifts.

Ready, Relax, Eat launched in November 2019 in partnership with our New Orleans-based partner Swegs Kitchen. The program delivers nutritious meals to caregivers and the loved ones in their care. It was designed to give caregivers a break from sometimes overwhelming responsibilities, including meal preparation. To date, more than 1,000 meals have been delivered. When COVID-19 is safely behind us, we will maintain the program for various other fundraising needs. We are grateful to all the generous individuals who joined together to become a powerful force for good during a difficult time. For more information, visit [www.biala.org](http://www.biala.org).



## NEW HAMPSHIRE

Due to COVID-19, much has changed for the staff of the Brain Injury Association of New Hampshire (BIANH). Our independent service coordinators and supervisors began working strictly from home and making weekly follow-up phone calls to the community. Most of the administrative staff began working from home, and our office hours of operation were cut back.

BIANH has been an essential partner with the state and providers regarding services and supports for individuals living in community residences. We've held weekly conference calls to discuss issues regarding personal protective equipment (PPE) supplies and how providers would be able to isolate one individual if needed.

For the first time in the history of BIANH, the Brain Injury and Stroke Conference was cancelled. The 34th Annual Walk by the Sea and Picnic was modified and held virtually in early June. Participants and teams were asked to submit a video or photo of a short walk in support of this event, and donations were accepted online. For information about upcoming events, visit [www.bianh.org](http://www.bianh.org).

## MAINE



BIAA-ME held its fifth Annual BIAA-ME Brain Injury Resource Fair in Augusta March 2. Nearly 200 individuals attended. The event was held at the Augusta Armory and had 50 exhibitors from

across the state representing services, resources, and opportunities for Maine brain injury survivors, family members, caregivers, and professionals.

In response to the COVID-19 pandemic and social distancing recommendations, many of Maine's brain injury support groups have quickly shifted to online meetings to continue to offer support and connection to Maine's brain injury survivors and caregivers. To learn more, visit [biausa.org/maine](http://biausa.org/maine).

## PENNSYLVANIA

The Brain Injury Association of Pennsylvania (BIAPA) dedicated the April issue of HeadLines, our monthly e-newsletter, to the many ways in which we are all adjusting to the challenges of social distancing brought on by COVID-19. One new project we highlighted is the Survivor Support Video Project. The goal of the project is to collect videos with messages of encouragement, providing a fun way for individuals to make their voices heard to help others. This is a time when so many are feeling more isolated than usual, and we hope that these videos help survivors know that they are not alone.



We ask people to record short videos with messages of encouragement: what helps them during this time of social distancing, ideas of fun things to do or watch at home, coping suggestions, or other messages of hope. BIAPA is grateful to Cristabelle Braden, an individual with brain injury and extraordinary advocate, who is helping to manage this project. You can watch the videos on the BIAPA Facebook page at [facebook.com/biapenn](https://facebook.com/biapenn).



▲ Brain Injury survivor and advocate Cristabelle Braden shows her support by wearing the #ChangeYourMind t-shirt.

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## VIRGINIA

There have been few times in our history that have demanded as much from us as the coronavirus pandemic, but the brain injury community is one of the most resilient groups we have had the honor to serve. Our lives will be forever changed, and the Brain Injury Association of Virginia (BIAV) will change as a result, but we are confident we will get through this and come out stronger on the other side.

Here at BIAV, we started working remotely before the governor’s stay-at-home order in mid-March, and have since adjusted to new systems and processes for accomplishing tasks. We have begun implementing and creating new plans for serving the community in ways we are excited to continue even after the world goes back to “normal.” We’ve launched our new online resources directory, started online support groups, created a temporary assistance fund, designed a virtual conference package, hosted guest speakers on Facebook and Instagram live, and are continually figuring out how to help persons with brain injury and their families engage with this technology to be there for each other.

Providing the critical services that advance and support healthy, strong communities is one of the many powerful ways BIAV contributes to the people of Virginia. We are tenacious and committed to achieving our mission, no matter what the pandemic throws at us next. We’re not going to let anything get in the way of creating a strong future for those we serve and care about. For more information, visit [www.biav.net](http://www.biav.net).

## VERMONT

Like many affiliates across the country, the Brain Injury Association of Vermont (BIA-VT) had to reschedule live events. The 18th annual Walk and Roll for Brain Injury will now take place August 22 and will be a virtual event! Sign up at [biavt.org/events](http://biavt.org/events) and help us raise funds and awareness. Plans are also underway for our 32nd annual Brain Injury Conference, “Building Connections, which will be held virtually October 14.

BIA-VT is continuing work with the state of Vermont on deliverables for our Administration for Community Living grant, which include an increase in outreach, education, and awareness. Along with the Vermont Brain Injury Advisory Board, we have three subcommittees working on media, needs assessments, and an overall workgroup. We are also working with mentor states on transitions and employment, using data to connect people to services, and criminal and juvenile justice. We spend a lot of time in “Zoom Rooms!” As always, we welcome feedback and additional committee members for various projects and advisory boards. For more information email [support@biavt.org](mailto:support@biavt.org).



▲ BIAVT staff’s pet “co-workers” keep us company during remote working. Clockwise from top-left: Bode, Yuffie, Lyla, and Leia.

The new physical distancing rules during the pandemic have us working remotely, with one person in the office to answer the help line during the weekdays. So with that, we have included a photo of our newest BIA-VT “co-workers.”



# NEWS & NOTES

## BIAA Forms Partnership with TeachAids

The Brain Injury Association of America (BIAA) is pleased to announce a new partnership with TeachAids, a nonprofit leader in global education innovation. Our combined resources and expertise will help arm people across the nation with the latest concussion education.

Through this partnership, BIAA is providing TeachAids' CrashCourse curriculum to raise awareness of the latest science around concussions. The goal is to shift the conversation about concussion, or mild traumatic brain injury, away from fear and silence toward one of knowledge and empowerment. The base curriculum is offered in both HD and Virtual Reality and includes a short interactive film. The video helps correct common myths and misconceptions, enabling young people and parents to better recognize and address symptoms of a concussion. Advisors for the program include dozens of leading medical experts from across the nation.



John D. Corrigan, Ph.D., member of BIAA's Board of Directors and medical advisor for CrashCourse, remarked, "I am excited that two such outstanding organizations dedicated to the advancement and knowledge of brain health are working together. Collectively, BIAA and CrashCourse represent a meaningful and impressive collaboration that has the potential to benefit millions of people in the United States and beyond."

Through its National Brain Injury Information Center and a nationwide network of chartered state affiliates, BIAA provides help, hope, and healing to



individuals living with brain injury, their families, and the professionals who serve them. The Association offers training and certification through its Academy of Certified Brain Injury Specialists, supports new research and treatment guidelines, and advocates for quality healthcare through legislative action. BIAA will be including the CrashCourse materials on its website, allowing anyone to learn from this compelling medium.

"Our mission is to advance awareness, research, treatment, and education and to improve the quality of life for all people affected by brain injury," said Susan Connors, president and CEO of the Brain Injury Association of America. "Distributing CrashCourse by TeachAids moves our mission forward, providing an essential and comprehensive education that is well-researched and truly impactful."

"We are proud to announce our partnership with BIAA during Brain Injury Awareness Month," said Piya Sorcar, CEO of TeachAids. "BIAA is an incredible and respected organization that seeks approaches for a widespread understanding of concussions and brain injuries. We are grateful to be a part of that effort." To access CrashCourse, visit [biausa.org/crashcourse](http://biausa.org/crashcourse).

# Have you or your loved one had a brain injury?

(also known as a head injury, concussion, or coma)

Call our toll-free number to speak with a brain injury specialist. Monday through Friday 9 a.m. to 5 p.m.

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Receive individualized, confidential resources and support.



**We understand. We can listen.  
We can help.**

For general information about brain injury, visit [www.biausa.org](http://www.biausa.org)

## UPCOMING WEBINARS

### David Strauss Memorial Clinical Lecture Webinar – Opioids and Traumatic Brain Injury

August 6, 2020, 3 p.m. ET/12 p.m. PT

*Lance Trexler, Ph.D., FACRM, Rehabilitation Hospital of Indiana*

### Robert Sbordone Memorial mTBI/Concussion Lecture Webinar – Supporting a Successful Return to School After Mild Brain Injury

September 10, 2020, 3 p.m. ET/12 p.m. PT

*Melissa McCart, Ed.D., Center on Brain Injury Research and Training*

### Mitchell Rosenthal Memorial Research Lecture Webinar – TBI and Inflammation Across the Adult Lifespan

September 17, 2020, 3 p.m. ET/12 p.m. PT

*Keisuke Kawata, Ph.D., ATC, Jacob R. Powell, M.S., LAT, ATC, and Hilaire Thompson, Ph.D., RN, ARNP, with an introduction by Lisa Brenner, Ph.D., ABPP*

### Business of Brain Injury Webinar – Dignity of Risk Following Brain Injury

September 24, 2020, 3 p.m. ET/12 p.m. PT

*Katherine Meredith, Psy.D., and Robert Perna, BSN, Ph.D., ABN, ABPdN*

### Carolyn Rocchio Caregivers Webinar – Managing Emotions After Brain Injury

October 8, 2020, 3 p.m. ET/12 p.m. PT

*Dawn Neumann, Ph.D., FACRM, Indiana University School of Medicine*

**To register, please visit [shop.biausa.org/livewebinars](http://shop.biausa.org/livewebinars).**

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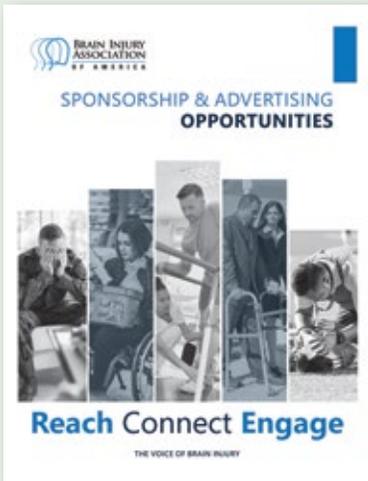
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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and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

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

