

BRAIN INJURY ASSOCIATION OF AMERICA | Volume 11, Issue 4

THE CHALLENGE!



FALL 2017

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From my **DESK**



I send a great big shout out to the many generous contributors who donated their precious time and money to BIAA throughout 2017 – we would be lost without you.

Thank you to the many readers who expressed appreciation for the summer issue of *THE Challenge!*, focused on research. The Brain Injury Association of America (BIAA) is always pleased to highlight the work of government agencies, hospitals, universities, and other institutions in our shared goal to advance brain injury research. Recently, we teamed up with SanBio to help recruit participants for a clinical trial called STEMTRA (Study of Modified Stem Cells in Traumatic Brain Injury). To learn more, visit <https://tbiresearchstudy.org>.

Thank you to the volunteer leaders and paid staff professionals from BIAA affiliates across the country who gathered for the 22nd Annual Leadership Conference, Nov. 8-10, in sunny Florida. In addition to the training and networking that occurs throughout the meeting, BIAA also takes this opportunity to recognize affiliates that deliver exceptional programs and services. This year's Award of Excellence winners are: the Brain Injury Associations of Georgia, Kansas and Greater Kansas City, Louisiana, Maryland, Massachusetts, Michigan, New Hampshire, and New York State. BIA of Missouri's chief volunteer leader, David Dyck, Jr., DO, and chief staff professional, Maureen Cunningham, CFRE, were also honored.

November is National Family Caregivers Month. *THE Challenge!* readers will want to take a moment to acknowledge how important caregivers are in helping individuals who have been injured regain the maximum level of independence possible. If there is a special caregiver in your life, please say thank you! #GivingTuesday also takes place in November, and SanBio has agreed to be our sponsor for the online event. They'll be matching gifts up to \$2,100, so please consider making a donation on that day. For more information about #GivingTuesday, follow us on Facebook, Twitter, and Instagram.

And finally, I send a great big shout out to the many generous contributors who donated their precious time and money to BIAA throughout 2017 – we would be lost without you.

The brain injury community has BIAA's best wishes for a happy and safe holiday season.

A handwritten signature in black ink that reads "Susan H. Connors".

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



RETURNING TO WORK AFTER BRAIN INJURY

By Margaret Koch, Director of Vocational Services, Hope Network Neuro Rehabilitation

Work is such an important part of our lives — it gives us meaning and purpose. Having a job that we do well allows us to feel competent and successful. Work is a good place to meet people and make friends. Earning a paycheck also helps us meet our needs and support our families.

But a brain injury can throw a big wrench into the picture. You may experience challenges with memory and attention, making it hard to manage the various stimuli in the environment. You might have physical challenges and your social skills may be affected. Things that used to be easy may now be more difficult.

You might wonder what's to come or have other questions and concerns. For example, you may ask: Will I be able to do the things I did before my injury? Will I be able to go back to work? Will I need to find a different job? Who will help me with my return to work journey?

No wonder it can be difficult to figure out how to get back to work! Fortunately, there are resources to point you in the right direction and help you meet your goals of returning to work after a brain injury, whether that means building skills, returning to a previous job, or finding a new job.

ELEMENTS OF A RETURN TO WORK PLAN:



Vocational Rehabilitation: Where to Begin?

Vocational rehabilitation (VR) programs can be helpful to you and your family as you begin the process of returning to the workforce. These programs can help you determine where you are, where you want to go, and how to get there. This might include services such as:

- **Vocational evaluations**
- **Situational assessments**
- **Work adjustment services**
- **Interest testing**
- **Vocational counseling**
- **Job analysis**
- **Identifying job accommodations**

VR programs help you get back to work. If you were working before your injury, it is best to start thinking about VR sooner rather than later. As you consider your options, it is also helpful to talk to your social worker, case manager, and doctor about returning to work. Here are some other tips to get you started:

KNOW YOUR RIGHTS

The Americans with Disabilities Act (ADA) was signed into law to make American society accessible to everyone, including people with brain injuries. Title I of the ADA deals with employment and requires companies with 15 or more employees to provide reasonable accommodations to applicants and employees with disabilities. The law also prohibits discrimination on the basis of disability in all aspects of employment. For more information about the ADA and reasonable accommodations, visit the Job Accommodation Network website: <http://Ask.JAN.org/links/adalinks.htm#1> or visit <https://www.dol.gov/general/topic/disability/ada>.

(continued on page 6)

CONTACT HUMAN RESOURCES

The human resources department at your employer will be able to help you determine if you qualify for any benefits, such as short- or long-term disability insurance. If you have worked for your employer for at least one year, you may also qualify for the Family Medical Leave Act (FMLA), which protects your job for up to 12 weeks while you are recovering. FMLA may also be available to your family members if they need to take a leave of absence to care for you. When you are ready to return to work, you should talk to your employer about allowing you to come back with accommodations to help you with your transition.

How to Pay for Vocational Rehabilitation

Unfortunately, private health insurance benefits do not cover vocational rehabilitation; however, there are other options available.

- 1 If you were injured at work, you are entitled to Workers' Compensation insurance, which provides wage replacement and medical benefits (benefits vary from state to state).
- 2 If you were injured in a motor-vehicle accident, you may be entitled to medical and rehabilitation benefits through your automobile insurance. Some states have Auto No-Fault Insurance for treatment that is reasonable and necessary, including brain injury rehabilitation. For more information, contact your insurance company.
- 3 If neither of those options are available to you, contact the VR agency in your state. These programs provide vocational and rehabilitative services to individuals with disabilities to help them prepare for, obtain, regain, or maintain employment. To find the VR agency in your state, visit: <http://www.askern.org/state-vocational-rehabilitation-agencies/>.



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What if I'm not ready to go back to work right now?

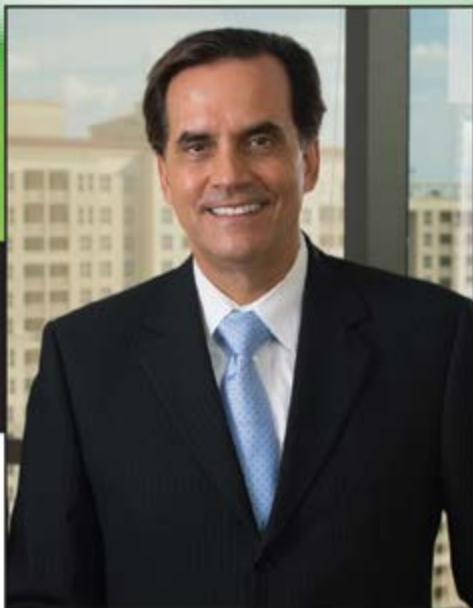
Even if you aren't ready to go back to work yet, you can take other steps to become prepared. First, contact your human resources department to find out your benefit status. Next, make sure that your family, employer, doctor, and rehabilitation team know that you want to go back to work. Participate in vocational assessment and counseling and in vocational rehabilitation to identify your current strengths and challenges.

Going back to work, whether it's the job you did before or a different one that matches your new strengths, is a major goal for many people with brain injury. Thinking about returning to employment early on can help you and your family develop a plan that will help you to be successful.

Margaret Koch, B.A., is a Certified Brain Injury Specialist (CBIS) with more than 35 years of vocational rehabilitation experience. She has been the leader of the Grand Rapids Chapter of the BIA of Michigan for more than 20 years. Margaret can be reached at 616-940-0040, ext. 18270 or by email at mkoch@hopenetwork.org.



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New Website in 2018!



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HART AND WEINTRAUB Named as BIAA Award Recipients

AWARD WINNERS RECOGNIZED FOR CONTRIBUTIONS TO RESEARCH AND CLINICAL CARE

Each year, the Brain Injury Association of America (BIAA) presents the William Fields Caveness Award in recognition of an individual who, through research on both a national and international level, has made outstanding contributions to bettering the lives of individuals with brain injury.

Tessa Hart, Ph.D., is the recipient of the 2017 William Fields Caveness Award.

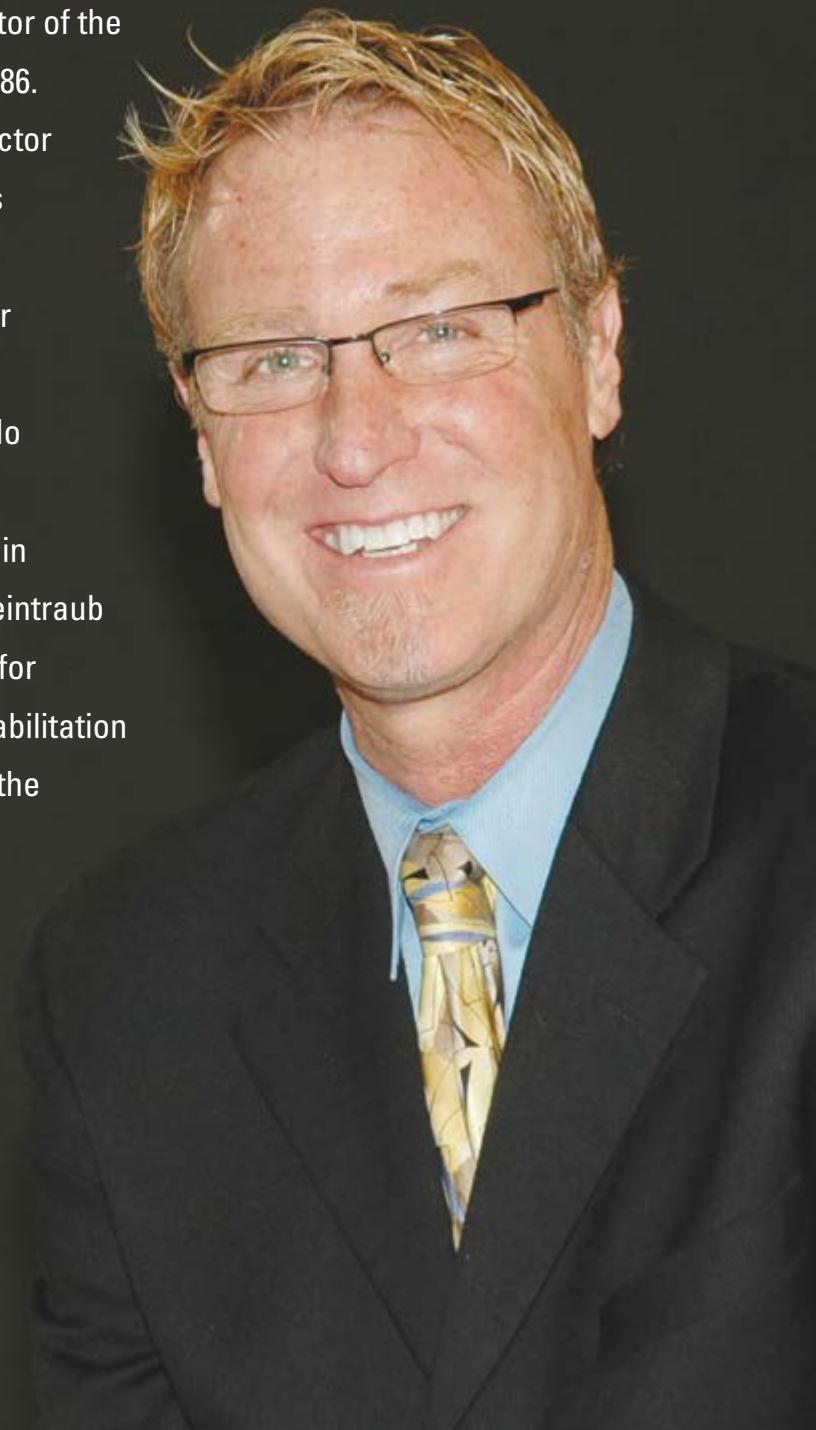
Tessa Hart, Ph.D., is institute scientist at the Moss Rehabilitation Research Institute in Elkins Park, Pennsylvania, where she directs the Traumatic Brain Injury (TBI) Clinical Research Laboratory and the Moss TBI Model System. She is also research professor in the department of rehabilitation medicine at Sidney Kimmel Medical College, Thomas Jefferson University, Philadelphia. Dr. Hart's wide-ranging research interests include creating and testing treatments to improve executive function, emotional function, and self-regulation. Her other interests include vocational rehabilitation for TBI and the use of assistive technology for cognition. Dr. Hart further advances the field of brain injury rehabilitation by serving on multiple peer review panels, editorial boards, and national and international task forces.



The Sheldon Berrol M.D. Clinical Service Award is presented annually to an individual who, through a long service career, has made outstanding contributions to improving the quality of care, professional training, and/or education in the field of brain injury.

Alan Weintraub, M.D., is the Sheldon Berrol M.D. Clinical Service Award winner.

Alan Weintraub, M.D., has been medical director of the brain injury program at Craig Hospital since 1986. Dr. Weintraub has also served as medical director of post-acute residential brain injury programs and several long-term subacute brain injury programs. He is an associate clinical professor at the University of Colorado Health Sciences Center and an active consultant to the Colorado Division of Workers' Compensation Medical Treatment Guidelines TBI Task Force. As a Brain Injury Medicine Certified Subspecialist, Dr. Weintraub has special interests in predictive biomarkers for recovery, neuroimaging, pharmacological rehabilitation management, sports-related concussion, and the long-term consequences of brain injury. He is actively involved in local, regional, and national organizations and is devoted to addressing the aging and long-term needs of persons with brain injury and their families. For more than 30 years, Dr. Weintraub has lectured extensively to broad audiences and written on a number of specific topics related to both traumatic and acquired brain injury.



The awards were presented at the conference of the American Congress of Rehabilitative Medication (ACRM), held Oct. 23-28 in Atlanta, Georgia.





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GOAL SETTING



By Celeste Campbell, Psy.D.

Come with me on a trip! Ready? Let's go!

Imagine most of you are thinking, "A trip to where? How far is it? How are we getting there? Who else is going?"

This is the essence of goal setting. You would not set out on a trip without a plan; getting somewhere in life also requires a plan.

A well-developed goal is a map. It should clearly define where you want to go and must clearly state the steps you have to take to get there. In this high-speed world, there are many demands upon our time, our energy, and our focus. Having specific goals helps us get back on track when life throws little detours and distractions at us — and it will!

Most of us have had the experience of feeling as though we have done a lot of work but have not accomplished anything. Most of the time, this is because the work was not organized or focused on a specific purpose. Setting goals helps us see whether what we are doing is getting us where we want to go. Setting goals also gives us motivation to keep moving. If it doesn't really matter where we end up and if we have no place to go, it is hard to be motivated to move at all.

SMART is an acronym developed to help us remember the elements of a strong goal. SMART reminds us that a goal must be **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-bound. Let's look at each one of these components.

A SMART goal is specific.

If you say you want to travel, does traveling to the corner store count? Does it count if it is to another state? Another country? Do you want to go to a tropical place or travel to historically significant sites in Europe? If you define a specific destination, it is easy to tell when the goal has been achieved. Your brain focuses on the information you feed it. If your goal is vague, your brain doesn't know what to focus on. If you have defined your goal very specifically, on the other hand, your brain will focus on recognizing opportunities that will move you toward that goal.

A SMART goal is measurable.

How are you going to measure your goal and how will you know when you have reached it? A goal like, "I want to have more money," is not measurable.

(continued on page 12)

If someone hands you a nickel, will you check this goal off your list? On the other hand, a goal that says, "I want to have enough money to buy a car," is measurable. You can find out what that amount is and then figure out how much you have to set aside each week or month to achieve it by a specific date. You can even measure your progress each step of the way.

A SMART goal is achievable.

It is within the realm of physical possibility so long as you have sufficient time, effort, and resources. Now, I am sure there are some people who have been told that their goals are unrealistic. I would argue that there are few goals that are unrealistic if enough time, effort, and resources are devoted to them. So, while a goal such as, "I want to sprout wings and fly to Jupiter on a skateboard," may be unrealistic, other goals such as getting a job, getting married, living on your own, or traveling may seem beyond your reach now but are certainly achievable. The questions you should ask are, "What will it take to achieve it?" and "Am I willing to do what it takes?" Many goals labeled as unrealistic are in fact achievable, but require so much

time, effort, and resources that the cost far exceeds the benefit of achieving them. It is OK to change goals, especially if working on one goal means that the rest of your life will be thrown out of balance. Set your goals based on an honest assessment of what it might take to achieve them.

A SMART goal is relevant (to you).

Setting goals to please other people is not going to motivate or excite you. A goal is something that will make a significant change in your life for the better. While a goal like, "I will learn to balance my checkbook," may be meaningful, a goal like, "I will save up enough money to buy a car," might be more motivating. Learning to balance the checkbook may be important, but will it be enough to excite or motivate you?

A SMART goal is time-bound.

Many of us only take action when there is a sense of urgency. When you have a specific deadline for getting something done, you are more likely to get it done. Set a timeline for achieving your goal. This



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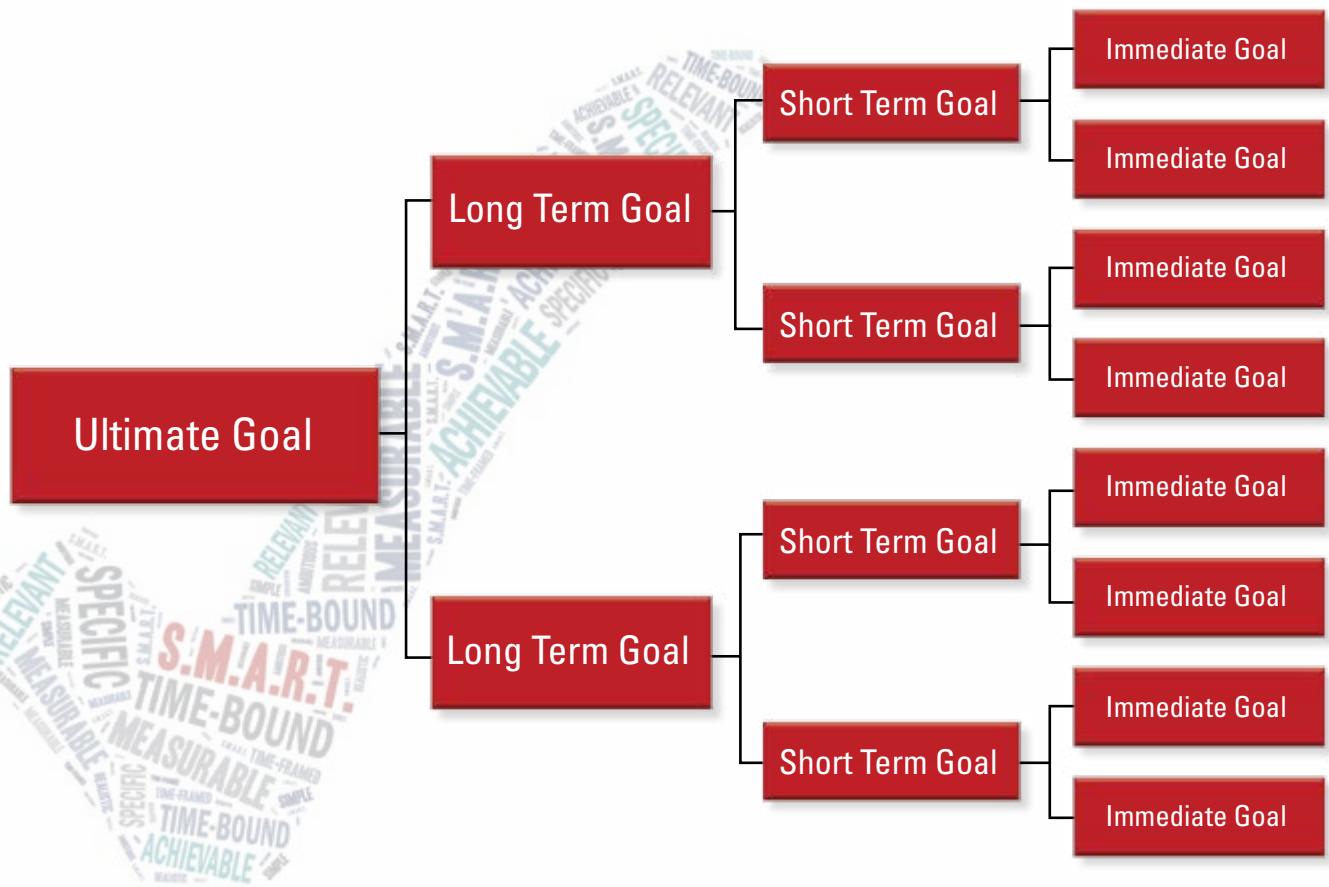

helps provide accountability and helps you measure how far along you are in achieving your goal. Setting time limits for each step helps to keep you moving at a steady pace toward it.

How do you go about goal-setting? Write Your Goals Down!

First, develop your ultimate “big picture” goal. Create a vision of how you want things to be. Make your goal as detailed as you can by describing who, what, when, where, and why you want to achieve this goal.

Second, break down your ultimate goal into long-term goals. Break down your long-term goals into smaller, short-term goals, and then again until you have a series of immediate goals. An immediate goal is something you could do today. If your goal is not broken down into something you could potentially do today, break it down even further. This way, you will have a very clear next step.

*Above all, remember
the #1 Rule of Goal
Setting: Write Your
Goals Down!*



Dr. Celeste Campbell is a neuropsychologist who has been practicing for more than 25 years. She received her undergraduate degree at Yale University, holds a doctoral degree from Drexel University, and has completed a postdoctoral fellowship in rehabilitation neuropsychology at National Rehabilitation Hospital in Washington, D.C. She is licensed in Georgia and Virginia. When she is not practicing neuropsychology, Dr. Campbell might be found on the stage of a local community theater. Or she might be on a beach in Hawaii.

“The Concussion Girl”

By Audrey Taylor

Soccer was (and still is) my entire life. It was where I found peace, felt challenged, met some of my closest friends, made some of my most precious memories, and even met my husband. Unfortunately, my love and dedication to the sport also came with a high price. It almost cost me my life — more than once.

I started playing soccer when I was in elementary school; piano and dance classes quickly took a backseat. I played on three different travel teams and eventually on our school team. When I was 14 years old, however, things took a sudden shift. I sustained my first concussion during a travel game. I took an elbow to my right temple, but was sent back out for the second half of the game anyway. Today, we know this is a major mistake; the increased risk of getting another concussion within hours after suffering the first one is significant. I was lucky I was not injured again during that game. Little did I know, however, that my brain would never be the same from that day forward.

When I made the high school varsity team during freshman year, I was over the moon. I attended as many extra training sessions as I could and began planning the steps I needed to take in order to achieve my dream of becoming a professional soccer player. Sadly, the hits to the head just kept coming. I was smacked by flailing arms, thrown onto the ground repeatedly, and pushed into goal posts. My health deteriorated, and eventually I was forced to stop playing the sport I loved so much.

Sadly, the beautiful game wasn't the only part of my life that was different. My grades suffered. I lost friends, lost my way, and ultimately felt like I had lost myself. There were constant whispers about how I was “weird,” “different,” and a “freak.” I became “the concussion girl.” Instead of finding my own way, I just followed along. Had it not been for my best friend, Rachel, and my wonderful boyfriend (and future husband), Ryan, I would have lost myself altogether.



Once I graduated high school, I attended Auburn University. My health was worsening, but I kept my issues hidden. I put on the best face I could and tried to have a “normal” college life. In 2012, I was in a head-to-head collision that injured my neck horribly and left me with a moderate traumatic brain injury. I had to withdraw from college.

Many doctors were shocked that I was still alive, let alone able to function. Behind closed doors, I was suffering from fainting spells, severe migraines, horrible cluster headaches, issues with fine motor skills, aphasia, loss of hearing, loss of vision, and extensive memory loss. Most of my childhood memories were completely gone. If I “remembered” anything from that missing period, it was only from photographs or what people would tell me about my past. There was no waking up from this nightmare.

Although I was bedridden and in a very dark place, my incredible doctors worked magic and God worked miracles. I finally returned to college and thrived with help from the wonderful disability program at Auburn. My treatment was working and the medicine helped tremendously. The original dark outlook began to turn brighter and I was able to take on my Montana dream with Ryan, now my fiancé, by my side.

We moved across the country so I could attend my dream college, the University of Montana. I became a member of the most prestigious honor society in the nation and graduated with high honors and a degree in graphic design. My designs and articles have been published in books, blogs, and other media outlets, and my story has appeared in various magazines. Ryan and I got married at Walt Disney World and built our dream home in the gorgeous Rocky Mountains.



When people ask me how I was able to find the strength to accomplish my goals, my answer is simple: I had plenty of help. Rachel, Ryan, and my family were there with me every step of the way. They gave me shoulders to cry on and always found ways to make me laugh. I was blessed with incredible, selfless, and patient guardian angels who never gave up on me, even when I gave them so many reasons to do so. For that and so much more, I am forever indebted to them.

My dance with death has been quite the adventure, but it has taught me a great deal about life. Yes, it is short. Yes, it is a gift. But most importantly, life is truly delicate. The way you choose to live greatly determines your life’s outcome. If I could share any advice with those reading this, it would be the following:

Surround yourself with the ones you love and do not take anything for granted. In the blink of an eye, your moment to appreciate life and those within it could be gone. I will end with one of my favorite quotes by Rikki Rogers: “Strength doesn’t come from what you can do. It comes from overcoming the things you once thought you couldn’t.”

Stay strong, my friends.

Audrey is a graphic designer based in the gorgeous city of Missoula, Montana. She specializes in typography, print design, branding, advertising, web design, and motion graphics. She loves finding the beauty in the ordinary and is inspired by the natural world. She also has a professional background in photography and videography. Her work has been published in various magazines, books, brochures, and multiple online media outlets (including the Fall 2013 edition of *THE Challenge!*) When she is not designing or spending time at Walt Disney World, you will find Audrey in the mountains with her husband, Ryan, and their two dogs, Cooper and Si.

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Thank You!



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

Twenty-two years ago, life handed Deborah Einhorn what she describes as an amazing opportunity, although she didn't realize it right away. It was the opportunity to learn about herself — to use her inner strength, to discover how to be resilient, and to find alternate paths to accomplish new tasks.

In 1995, Deborah was in a car crash. She sustained a variety of critical injuries, including a broken arm, fractured rib and pelvis, spinal cord injury, traumatic brain injury, injuries to nerves controlling her vocal cord and eyes, and bruises to most of her major organs. She was paralyzed and could not move, speak, or see. She was on a ventilator to help her breathe and was sedated for a week to allow the swelling in her brain to go down. Deborah was in a rehabilitation hospital for about six weeks and continued with regular outpatient therapy for six months. She was out of work for nine months, did not eat for seven weeks, and did not speak for five weeks.

“The often-repeated story of the bumblebee is that aerophysicists studied the bumblebee and concluded that there was no way that the bumblebee’s wings could support its body. However, nobody told the bumblebee. So the bumblebee flew. And so can we.”



Starting that day in 1995 and continuing each and every day, this experience has taught Deborah how to navigate through unexpected and unimagined difficulties and rebuild her life into one that works for her. Deborah asserts, "It's never too late to start from where you are. At 35 years old, with the knowledge of the world and myself that I had gained over those 35 years, I was given the incredible opportunity to redefine myself. To start, from where I was at that moment, to build the life and self that I wanted and that worked for me."

Deborah wanted to learn from her struggles, failures, and successes, and to share these lessons with others. She created a blog to express ideas about overcoming challenges, using her injuries as an example. Deborah's advice about how to be your best self is to be a bumblebee. "The often-repeated story of the bumblebee," she explains, "is that aerophysicists studied the bumblebee and concluded that there was no way that the bumblebee's wings could support its body. However, nobody told the bumblebee. So the bumblebee flew. And so can we."



Deborah supports the Brain Injury Association of America (BIAA) because she believes that the information, community, and empathy we provide are incredibly important in helping people with brain injuries and their loved ones. "People with brain injuries need organizations like BIAA to help them navigate a new world, to help them understand why the world around them (and sometimes their own selves) suddenly seems so unfamiliar. In addition, [BIAA] advocates for us with government and business and helps with medical research and assistive technology development. BIAA helps us live with our injuries in the world, recover as best we can, and helps make the world a more accommodating place for people with brain injuries." To read Deborah's blog, visit <https://walkingdeb.wordpress.com>. ●

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Advocacy **UPDATE**

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

Thank you to the many advocates who continue to rally and fight for access to care for individuals with brain injury at the federal level and in the states.

Expert Panel Discusses TBI and Domestic Violence

The Congressional Brain Injury Task Force (CBITF), co-chaired by Reps. Bill Pascrell, Jr. (D-N.J.) and Thomas J. Rooney (R-Fla.), hosted a briefing, "The Silent Epidemic – TBI and Domestic Violence," Oct. 25 in the Congressional Visitors Center. Susan Connors, president and CEO of the Brain Injury Association of America (BIAA), moderated the session, which included these distinguished panelists, pictured at right: Anne McDonnell, Brain Injury Association of Virginia; Donna D. Ferguson, Esq., U.S. Army Military Police School; Pam Hallman, domestic violence and TBI survivor; Valerie Maholmes, Ph.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development; and Javier Cárdenas, M.D., Barrow Concussion and Brain Injury Center.

President Seeks to Dismantle the ACA

In October, President Trump announced his desire to discontinue cost-sharing reduction payments to insurers. These payments offset out-of-pocket costs for low-income enrollees in individual health plans under the Affordable Care Act (ACA). The president signed an executive order to begin dismantling the program. The order directs the Departments of Labor, Treasury, and Health and Human Services to study how to make it easier to



Brain Injury Association of Virginia Executive Director Anne McDonnell, left, gathers with other panelists at the briefing, "The Silent Epidemic – TBI and Domestic Violence."

buy health insurance through nationwide association health plans, to purchase coverage insurance across state lines, and to allow consumers to buy short-term policies with less coverage and protections for those with pre-existing conditions. None of the changes will take place until the federal agencies work through the

regulatory process. BIAA will continue to advocate to Congress to prevent a repeal of the ACA or enactment of other policies harmful to individuals with brain injury.

BIAA Supports on to Proposed Payment Model Rules

Bundled payment, also known as episode payment, case rate, or package price, is a way of compensating hospitals and physicians for the health care they provide to persons with a specific illness or injury. BIAA opposes this payment model because each brain injury is different and requires a different scope of care. Often times, bundled payment programs achieve savings through efficiencies or by stinting on patient care. As a member of the Coalition to Preserve Rehabilitation, BIAA signed a letter to the Centers for Medicare and Medicaid Services regarding the proposed rule that would cancel of the Episode Payment Models. (remove everything after Models).

House and Senate Move to Pass Budget Resolutions

The U.S. House of Representatives passed a \$4.1 trillion budget for fiscal year 2018. The budget resolution provides a blueprint for committees as they consider spending and tax bills. The measure increases spending for defense, and cuts nondefense spending by \$5 billion. It also includes plans for massive cuts to Medicaid and Medicare over the next 10 years. The House proposal reduces \$203 billion in spending for public assistance programs, such as SNAP/food stamps, Temporary Assistance for Needy Families and Supplemental Security Income (SSI) for low-income seniors and people with disabilities, tax credits for low-income workers, K-12 and college education assistance, housing aid, public health services, medical research, environmental and consumer protections, and most other domestic programs.

The Senate Budget Committee released its fiscal 2018 budget resolution in early October. It will allow Congress to advance a major tax bill that would lower income tax rates for individuals and corporations and could lead to major cuts to Medicaid, Medicare, education, transportation, and other community-based services similar to the House version. Even

Now Enrolling Participants

Are you 18 years old, with a history of spinal cord and/or traumatic brain injury and can share prior medical records/imaging?

The National Center for Testing Treatments in Chronic Spinal Cord and Traumatic Brain Injury (NCTT) is performing an observational research study allowing participants to be entered into a database for future interventional studies.

Benefits include a no-cost examination and the information collected may help future patients who have spine or brain injury.

Risks may include minimal discomfort upon blood sample collection.

To learn more, visit med.uth.edu/neurosurgery/nctt, call 713-704-6900 or email nctt.wec@uth.tmc.edu.



with the proposed cuts, the resolution could result in an increase in the deficit by \$1.5 trillion during the next decade.

House and Senate Committees Advance CHIP Reauthorization

The Senate Finance Committee and the House Energy and Commerce Committee voted on legislation to extend the Children's Health Insurance Program (CHIP). The House Energy and Commerce Committee voted on the bill, known as the "Helping Ensure Access for Little Ones, Toddlers, and Hopeful Youth by Keeping Insurance Delivery Stable Act of 2017," or the "HEALTHY KIDS Act," to extend funding for five years. The Senate passed its version, the "Keeping Kids' Insurance Dependable and Secure (KIDS) Act." CHIP allows states to cover children in families earning too much to qualify for Medicaid but cannot access or afford private insurance. CHIP covered nearly 9 million children in 2016. Together with Medicaid, has helped reduce the uninsured rate for children to a record low of 5 percent. The program expired at the end of September, leaving states to cover funding until Congress reauthorizes the program.

(continued on page 22)

House Advances Medicare Bills

The House Energy and Commerce Committee advanced health care-related bills, which BIAA supported, including:

- H.R. 1148, the Furthering Access to Stroke Telemedicine Act of 2017, authored by Reps. Morgan Griffith (R-Va.) and Joyce Beatty (D-Ohio), which would expand the ability of patients presenting at hospitals or at mobile stroke units to receive a Medicare-reimbursed neurological consult via telemedicine.
- H.R. 2465, the Steve Gleason Enduring Voices Act of 2017, authored by House Republican Conference Chair Rep. Cathy McMorris Rogers (R-Wash.), House Majority Whip Rep. Steve Scalise (R-La.), and Rep. John Larson (D-Conn.), which would make coverage of speech-generating devices under “routinely purchased durable medical equipment” permanent under the Medicare program.
- H.R. 3263, to extend the Medicare Independence at home Medical Practice Demonstration program, authored by Chairman Michael Burgess (R-Tex.) and Rep. Debbie Dingell (D-Mich.), which would extend the Independence at Home Medical Practice Demonstration Program that provides a home-based primary care benefit to high-need

Medicare beneficiaries with multiple chronic conditions, allowing them to avoid unnecessary hospitalizations, ER visits, and nursing home use, for two additional years.

BIAA Supports Access to Manual CRT Wheelchair Accessories

As a member of the Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition, BIAA signed a coalition letter urging Congress to pass H.R. 3730, bipartisan legislation sponsored by Reps. Lee Zeldin (R-N.Y.) and John Larson (D-Conn.), to permanently exempt manual Complex Rehab Technology (CRT) wheelchair accessories and components for people with disabilities and chronic conditions from Medicare's Competitive Bid Program. This important legislation will protect Medicare beneficiary access to manual CRT as well as essential components known as wheelchair “accessories.”

NIDILRR Awards TBI Model Systems for FY2017-FY2021

The Administration for Community Living's (ACL) National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) awarded grants to 16 institutions to carry out the work of the Traumatic Brain Injury (TBI) Model Systems for fiscal year 2017-2021. The TBI Model Systems provide coordinated systems of rehabilitation care and conduct research on recovery and long-term outcomes. The grant recipients are: Albert Einstein Healthcare Network, Moss Rehabilitation Research Institute; Baylor Research Institute; Craig Hospital; Icahn School of Medicine at Mount Sinai; Indiana University; JFK Medical Center; Kessler Foundation; Mayo Clinic; Memorial Hermann, TIRR; New York University Medical Center, Rusk Institute; Ohio State University; Spaulding Rehabilitation Hospital; University of Alabama at Birmingham; University of Washington; Virginia Commonwealth University; and Wayne State University.

BIAA advocates for increased funding for NIDILRR. BIAA also advocates for directed funding, known as line-item status, for the TBI Model Systems.

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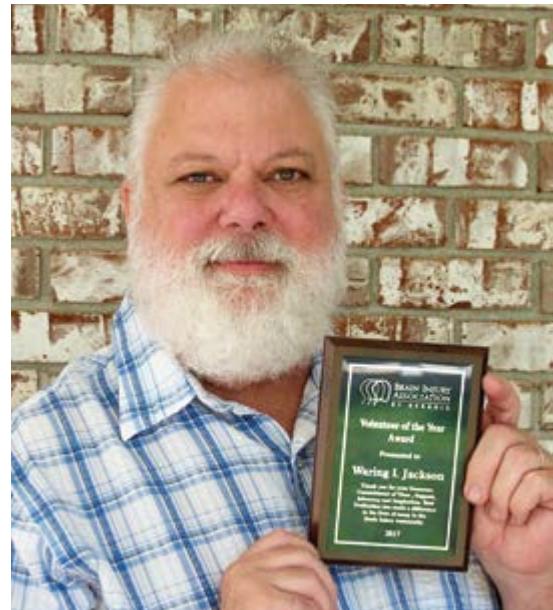
State Affiliate **NEWS**

GEORGIA

The Brain Injury Association of Georgia (BIAG) held its first "Betting Big on BIAG" fundraiser. This silent auction was a huge success and helped to raise money for BIAG programs, including support groups and Camp BIAG. Waring Jackson, a brain injury survivor and advocate who is no longer able to work, received the event's Volunteer of the Year award for his dedication and willingness to offer a helping hand at BIAG.

Camp BIAG was postponed due to power outages resulting from Hurricane Irma. While campers and volunteers were disappointed, they had their bags packed ready to go the week of Oct. 12. We appreciate the understanding of our donors and sponsors who agreed to the change in schedule.

BIAG's "Recovery in Motion" symposium, hosted jointly with WellStar Health, took place Oct. 28. Topics included emotional changes after brain injury, neuroplasticity, and finding one's purpose. To learn more about other events and activities, visit www.braininjurygeorgia.org.



▲ Waring Jackson, brain injury survivor and advocate, receives the Volunteer of the Year award.



▲ Attendees enjoy themselves at "Betting Big on BIAG."

(continued on page 24)

KANSAS

The Brain Injury Association of Kansas and Greater Kansas City (BIAKS) presented two family and survivor seminars in October. "Life after Concussion and Brain Injury" was presented Oct. 14 in Hays, providing attendees with the opportunity to meet others facing the same hurdles, speak with service providers, and learn more about brain injury. The seminar offered continuing education credits for nurses, social workers, physical therapists, occupational therapists, and other allied health professionals in attendance.

As major portions of Kansas qualify as medically underserved, and one-third of the state's counties are considered frontier counties (i.e., fewer than six people per square mile), BIAKS is proud to be able to bring this seminar to this medically underserved area in our state. We are grateful to the Anthem Foundation, Dane G. Hansen Foundation, KU Area Health Education Centers, and our sponsors for their support.



▲ Survivors enjoy the opportunity to meet and connect.

Our second seminar, "Life After Brain Injury," was presented Oct. 21 in Prairie Village. Survivors, family members, and caregivers learned about a variety of topics, including strategies for coping with challenging behaviors and understanding fatigue after brain injury. For more information, visit www.biaks.org.

MAINE

The Brain Injury Association of America – Maine Chapter (BIAA-ME) held its eighth annual conference, "Defining Moments in Brain Injury," at the DoubleTree by Hilton Hotel in Portland. Tim Feeney, Ph.D., gave the keynote, and Daryne Rockett delivered the Beverley Bryant Memorial Lecture. The conference offers five tracks and is open to professionals, survivors, family members/caregivers, students, and anyone interested in learning more about living with brain injury in Maine.

BIAA-ME is also gearing up for its third Bowling for Brain InjurySM event, taking place Dec. 3 at Spare Time Portland.

MICHIGAN



The Brain Injury Association of Michigan (BIAMI) was fortunate to have two terrific keynote speakers, Montel Williams and Tiana Tozer, at its annual fall conference. Mr. Williams gave an impassioned keynote on the important role that medical professionals, especially doctors and nurses, play in our community. Afterward, he spoke with scores of attendees at the BIAMI booth and with two brain injury survivors about their Unmasking Brain Injury masks.

◀ Montel Williams learns about Unmasking Brain Injury masks while speaking with a survivor.

The conference included a record 1,629 attendees and 145 exhibitors. Prominently featured was the new BIAMI Advocacy Station, an area where attendees could contact their state senators and representatives electronically in defense of Michigan's Auto No-Fault system – the only auto insurance system in the country that covers the entire cost of a survivor's health care and rehabilitation as long as it is medically necessary. By the end of the conference, more than 1,000 letters were sent urging Michigan state legislators to protect Auto No-Fault while incorporating much-needed reforms to help reduce costs and prevent fraud.

BIAMI conference attendee uses the BIAMI Advocacy Station to contact her senator. ▶



MISSOURI

In August, the Brain Injury Association of Missouri (BIA-MO) partnered with the Missouri AgrAbility Project at the Missouri Rural Health Conference to inform health care, social work, and community professionals about agriculture as a self-employment option for the individuals they serve.

More than 150 professionals attended the BIA-MO 13th Annual Statewide Professional Conference, held Oct. 5-6 in Chesterfield. Experts addressed issues, such as the public health burden of brain injury, health care reform, pediatric brain injuries, best-practice therapies, and other topics of interest to professionals of various disciplines. The Survivor and Family Seminar, held the following day, provided practical suggestions for living with brain injury. During the seminar's Awards Luncheon, BIA-MO recognized key volunteers for their efforts to create a better future for individuals with brain injury and their families.

Planning is underway for new seminars on "Sports Concussions: Facts, Fallacies, and New Frontiers," which will be held in early 2018. For more information, visit www.biamo.org.



NEW HAMPSHIRE

In August, the Brain Injury Association of New Hampshire (BIANH) held the 34th Annual Charity Golf Tournament, presented by Northeast Rehabilitation Hospital Network and hosted by Robin Hill Farm. Over 90 golfers played in the tournament at the beautiful Oaks Golf Course in Somersworth.

For the fourth consecutive year, BIANH and Camp Allen hosted a summer camp for adults living with brain injury. Campers enjoyed a variety of activities this year: nature walks, tie-dyeing, a percussion instrument session, and amazing animal encounters. A volunteer presented campers with Chautauqua, a type of acting where the actor emulates a historical character. Campers were enthralled by the presence of Calvin Coolidge, president of the United States from 1923 to 1929. Attendees also created their own Unmasking Brain Injury masks and learned how to use art to express what life is like with a brain injury.

◀ A golfer perfects his swing at the 34th Annual Charity Golf Tournament.

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RHODE ISLAND

Again, this year, the staff of the Brain Injury Association of Rhode Island (BIARI) and its army of 44 volunteers donned CVS Health Classic Charity baseball caps and t-shirts and spread out along the tees and fairways of the scenic Rhode Island Country Club in Barrington. BIARI is ecstatic to be one of the 100 recipients of the CVS Health Charity Classic Golf Tournament, held in late June on the shores of Narragansett Bay.



▲ BIARI Board President Michael Baker, second from left, works with volunteers during the CVS Health Charity Classic.

For the second time, we joined with other charities for Newport Polo's All-Charity Day. It was an opportunity to honor our members, volunteers, and board of directors. The staff took charge of the catering and pampering as a thank-you to our wonderful support system. We had nearly 100 guests relaxing in lawn chairs to view the polo match, enjoy the food, and participate in a raffle.

Attendees view the action on the field during our annual volunteer and member appreciation party at the Newport Polo All-Charity Day. ▶



▲ Attendees have fun at a BINGO fundraiser.

BINGO, anyone? BIARI is hosting regular BINGO nights to a growing audience. Additionally, the Hidden Treasure Gala has a new venue – the Biltmore in downtown Providence. We hope to increase attendance by attracting the after-work crowd on a Friday night. We have already gathered some jaw-dropping travel and golf packages for the live and silent auctions. For more information, visit www.biari.org.



VERMONT

The Brain Injury Association of Vermont (BIAVT) held its annual conference Oct. 10 in Burlington. This year's theme was "Weasiliance: Handling Life's Wild Moments." Throughout the year, BIAVT staff members delivered presentations about concussion to college faculty, recreation departments, physical education teachers, dance instructors, school nurses, and radio audiences. Concussion is a hot topic around the state! The association is also working with the Vermont Department of Health and the University of Vermont Medical Center on various research initiatives and will participate in a state-sponsored Alliance for Intake and Referral Specialist (AIRS) workshop.

Brain Injury ADVISORY COUNCIL CORNER

Member Spotlight: STEPHANIE FREEMAN

By Amy Zellmer, Brain Injury Association of America Advisory Council member

When she was only 14 years old, Stephanie Freeman was involved in a rollover car crash, flipping five times on a country road. She sustained lung and brain damage as well as a shattered pelvis and other physical injuries.

Stephanie spent two months in a coma at Palmyra Park Hospital in Albany, Georgia, and would go on to spend a total of four months and eight days in the hospital.

After being released from the hospital, she spent another six months completing rehabilitation before she was allowed to go back to school.

Finding herself a year behind her classmates, Stephanie went to summer school to catch up. She graduated with the class of '96 and took a year off before attending Georgia Southwestern State University. She later graduated from Wiregrass Technical College with a degree in business.

In 2003, Stephanie began running to combat depression and anxiety. She's a strong believer in physical activity and became committed to running and working out on a daily basis. She ran her first marathon in 2006 and has since run 10 marathons as well as numerous half marathons and 5Ks. On July 10, 2006, Stephanie gave birth to her son, Range. She considers him to be her miracle baby, as she had been told after her accident that she would never be able to conceive a child.



Years later, Stephanie was working at the Boston Marathon at mile marker 25.5 when the Boston Marathon Bombing occurred. This event triggered Post-Traumatic Stress Disorder (PTSD) and brought up unresolved emotional trauma she had not dealt with as a teenager after her car accident. This event prompted her to start her foundation, Share Your Strong. The foundation took more than two years to be established, and she now uses it as a way to bring health, help, and inspiration to people who are going through brain trauma. She raises money through the marathons she runs and has even competed fitness competitions to show that mental health can be combated without drugs.

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In 2014, Stephanie ran the Boston Marathon – one year after the bombing – as a way to come full circle with all she had been through in her life. Stephanie attended Brain Injury Awareness Day in March 2015 and was invited to join the Brain Injury Association of America Advisory Council shortly afterward. She is currently furthering her education in natural healing reflexology and neuromuscular massage therapy to help others promote natural healing of the brain. Stephanie is also a certified trainer and mentor to high school kids who want to improve their health; she helps them with their eating and exercise plans and encourages brain-healthy foods.

Her motto in life is “Never, ever give up!”

When asked how BIAA has changed her life, Stephanie said:

“Being part of something that completely changed my life allows me to help others with the same problems that I have faced. It touches my heart, and I am living with purpose by being part of this.”

FIVE TIPS FOR BEING YOUR BEST SELF:

- 1. Look within and realize what's important in your heart.**
- 2. Keep your focus.**
- 3. Stand strong.**
- 4. Don't let the odds get you down.**
- 5. Keep moving forward and never, ever give up!**



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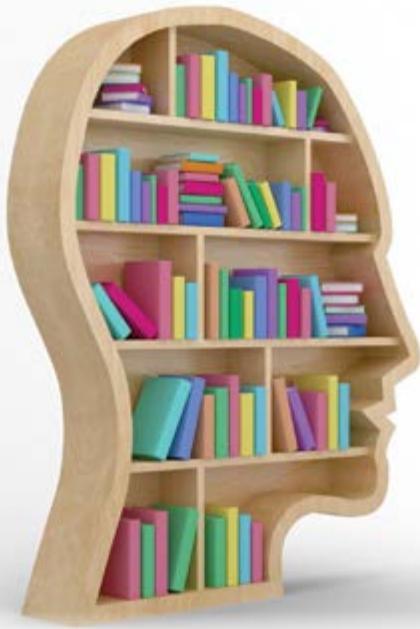
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The BIAA BOOKSHELF

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

In 1989, Dale and Leone Nunley and the two youngest of their five sons moved to the island of Maui. They planned to be there for one year because of Dale's work. In October, their 21-year-old son, David, a junior at Washington State University, was in a motorcycle crash. David sustained a severe brain injury, a coup-contrecoup injury with diffuse swelling, rising intracranial pressure, seizures, and high fevers. Weeks later, doctors declared David to be in a persistent vegetative state and had little hope that he would ever recover.

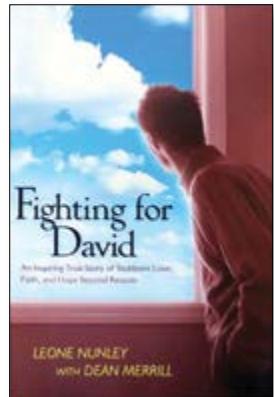
"Fighting for David: An Inspiring True Story of Stubborn Love, Faith, and Hope Beyond Reason," written by Leone Funston Nunley and Dean Merrill, is Leone's account of the many ways that family and friends helped bring David back from the injury.

When David was stable enough, he was transferred to a hospital in Yakima, Washington, the family's hometown. By Christmas, the boys and Dale came home from Maui. David was admitted to a rehabilitation hospital, where he was treated by dedicated staff who recognized that he was aware and could follow directions. After six weeks, unfortunately, he had to be discharged, and the rehabilitation doctor who evaluated him recommended nursing home placement. The family made a unique arrangement to care for David during the day and have him sleep at a nursing facility at night. One diligent therapist appealed to another rehabilitation doctor for more rehabilitation. In June, eight months after his accident, David was accepted

into an intensive rehabilitation program. By the end of August, when he went home, he could navigate the parallel bar with help and propel his wheelchair 100 feet – a remarkable achievement for someone who was never going to recover!

The Nunleys made their garage into a therapy gym and worked with David every day. They learned about "patterning," a technique that tries to retrain the brain. Five people (one for each arm and leg and one holding the head) move the person, mimicking crawling. Since we learn to crawl before we walk, the premise is to embed those old routines into the brain. David's family and friends were dedicated to patterning him every day for four years. He eventually learned to crawl, then to pull himself up, and finally to walk with the aid of a walker.

There were many ups and downs in David's story, including numerous fights with insurance companies, Social Security, and state assistance programs. "Fighting for David" is not just about the devastating results of brain injury, but a tale detailing how love, dedication, overwhelming community support, and unwavering faith can sustain a family. Leone admits that this is not the answer for every person with a severe traumatic brain injury – she just knows that her family had to give David every chance they could to live in the community and thrive. As a reader, I really admired the Nunley family and the tremendous support that saw them through the initial injury toward recovery. To purchase your copy, visit BIAA's Online Marketplace at <https://shop.biausa.org>.



News & **NOTES**

USA Student Wins World Neuroscience Competition



In August, future neuroscientists from around the world met in Washington, D.C., to compete in the 19th World Brain Bee Championship, hosted by the American Psychological Association. The World Brain Bee is a neuroscience competition aimed at inspiring young men and women, ages 13 to 19, to pursue careers in brain-related professions.

This year's champion is Sojas Wagle, a high school sophomore from Arkansas. Among his many accomplishments, Sojas placed third in the 2015 National Geographic Bee and was chosen for "Who Wants to be a Millionaire" Whiz Kids Edition in 2016, where he won \$250,000! He also plays the violin and is first chair in the Arkansas Philharmonic Youth Orchestra.

We Want Your Feedback

We love sharing brain injury information, stories, and updates with you through *THE Challenge!* four times each year. As part of our community, your voice is important — and we want to hear more about what you like to read. Please visit www.biausa.org/fallsurvey and complete this brief reader survey.



Upcoming **WEBINARS**

David Strauss Memorial Clinical Webinar – Cognitive Rehabilitation: Memory Deficits and Rehabilitation

November 15, 2017, 3 p.m. ET/12 p.m. PT

Thomas Bergquist, Ph.D., L.P., Mayo Clinic and Mayo Graduate School of Medicine

BIAA Distinguished Speakers Webinar – Neurophysiological Optimization: Life and Neurological Health after TBI

December 7, 2017, 3 p.m. ET/12 p.m. PT

Mark Ashley, Sc.D., CCC-SLP, CCM, CBIST, President/CEO, Centre for Neuro Skills

Carolyn Rocchio Caregivers Webinar – Management of Challenging Behaviors in the Community

December 12, 2017, 3 p.m. ET/12 p.m. PT

Kyle Haggerty, Ph.D., and Sheryl Berardinelli, Psy.D., Bancroft NeuroRehab

To register, please visit

<https://shop.biausa.org/products/livewebinars>

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