

LIVING with APHASIA EDITION



**Guest Editor
Ed Danielak
Shares His
Aphasia Story**



From the Desk of Ed Danielak, Survivor & Aphasia Edition Guest Editor

Hello Friends,

As many of you in our community know, I survived a life-changing brain injury. It upended my ability to work just as I was hitting my stride as a professional. Six years later, I am still navigating the daily challenges of aphasia and partial blindness, which were a result of my injury. Like many survivors, I struggle with finding new ways to feel fulfilled and productive outside of paid employment.

The brain injury community is vibrant and dynamic. As Guest Editor of this edition of *The Noggin* I wanted to ensure that shined through. I am thrilled to share my story on these pages and elevate the stories of others, expanding and adding to our community's understanding of aphasia. Aphasia is a neurologic disorder that affects a person's ability to communicate. It causes difficulty in understanding, producing, or using language. Right here in the United States, around two million people are currently living with aphasia. This year alone, 180,000 new cases will be diagnosed.

As many have reported, there are also some "silver lining" moments in my post-injury journey, I have met some incredible people and tried several new things. Maybe you have even seen the well-traveled photo of me getting ready to dive into a vegan cheese pizza at a survivor social lunch sponsored by the Brain Injury Association of Arizona. I can remember hearing from several new survivors at that event that they sat in the parking lot of the restaurant before lunch, unsure if they would fit in or worried that they might stand out for being "different". By the end of the event, it was clear we were not only among people who understood us, but we were all becoming friends. I hope to see many of you this summer, either online or at an educational event. Until then, happy reading.



Ed Danielak
Guest Editor, *The Noggin*



Your generous support is crucial for the Brain Injury Association of Arizona to continue providing brain injury survivors, their families, and caregivers with free programs and services. Please scan the QR code and donate today.

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OUR VISION—A world where all individuals impacted by brain injury thrive in their community

OUR VALUES—

Integrity:

Being dependable and following through on commitments

Excellence:

Modeling a positive example as we pursue high expectations

Collaboration:

Actively listening and working together for a common purpose by brain injury thrive in their community

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Two Brain Injuries Gave Ed Danielak Aphasia, But He Hasn't Forgotten His Passion

BY CHRISTINA EICHELKRAUT

A brain cancer diagnosis is a life-altering challenge for anyone. Surviving the cancer and its treatment, only to sustain a traumatic brain injury afterward, seems utterly impossible. Yet that's exactly what Ed Danielak has been through, surviving two successive brain injuries. Despite the ongoing challenges that stem from both experiences, he's finding a way to reconnect with his passions and thrive.

Danielak's brain injury survivor story begins quite some time before his brain cancer diagnosis during the fall of 2019.

SOMETHING WAS JUST OFF

Before the official diagnosis, Danielak noticed something was just off.

"We knew something was going on," Danielak said. "I was having difficulty comprehend-

ing what was going on, and my memory was getting very spotty.”

At the time, Danielak was doing work he loved, creating schools for children with autism. But his mounting cognitive issues eventually forced him to quit.

“I stopped working full time in a world that I loved because I was having difficulty focusing,” Danielak said. “To leave my job was strange. It does tell you something is not going on well.”

Changing course, Danielak decided to pursue a Ph.D in psychology. But there, too, his difficulty focusing made him believe school wasn’t the right path for him. He even blamed the school itself.

“In hindsight, we know now it was because I had a massive tumor,” Danielak said.

Danielak began working at a retail store. By now, his short-term memory loss had become completely debilitating. Much to Danielak’s surprise, there were times he struggled to recall even the simplest things, like which item he was in the middle of restocking.

Ultimately, Danielak realized he couldn’t work any longer.

CANCER AND RECOVERY

This is when Danielak and his husband moved to Florida.

Danielak’s eye doctor noticed a spot and, to be on the safe side, ordered a CT scan. That scan became what Danielak recalls as the worst day of his life.

The first indication that something was seriously wrong was when the clinicians wouldn’t let Danielak leave after the scan.

Eventually, Danielak was told he had a massive, cancerous tumor in his skull that needed to be operated on as soon as possible.

“It was terrifying and everything you would think of when you find out you have cancer,” Danielak said. “All I could think of was, ‘Let’s get into surgery, I want this cancer out of me now.’”

Danielak underwent a craniotomy, a surgical procedure in which part of the skull bone is removed so doctors can access the brain. Afterward, he underwent concurrent radiation and chemotherapy treatments.

The treatments finished in November 2019, at the height of COVID-19. The pandemic hit home for Danielak when he showed up for his last MRI treatment.

“They didn’t even let me change into a gown,” Danielak said. “They made me run in, get the MRI, and run back out.”

Despite the world-stopping pandemic outside, with his tumor gone and his cancer treatment finished, Danielak felt optimistic.

He shifted his focus to the future, thinking, “We’ll get this [tumor] out of me, and then maybe it’ll clarify things for me, and we’ll get back to life.”

But, as Danielak puts it, “that was not the path we ended up in.”

REINJURY AND APHASIA

Danielak and his husband decided to move to Hawaii, a lifelong dream of theirs. The cancer forced the couple to reassess their priorities, and with COVID-19 transitioning jobs into remote roles, his husband could

continued next page

now work from anywhere. It seemed like the perfect fresh start.

While setting up his new home office, Danielak slammed his head against his desk. Though he hit his head hard enough to see stars, he decided to wait until the next day to go to the hospital. After his cancer battle, he was exhausted with hospitals, the pandemic was in full swing, and Danielak believed he would be OK despite the lingering pain in his skull.

In the middle of the night, however, Danielak woke up and vomited. He then had what doctors believed was a full seizure. He was taken to the emergency room, intubated at the hospital, and released a few days later.

But the incident was far from over.

Danielak's brain cancer had displaced his brain, shrinking it lower into his skull. That meant banging his head on the desk had given him a concussion. That was indeed serious, especially given Danielak's history. Still, it wasn't until a few days after being released from the hospital that the full impact of his brain's reinjury hit Danielak like a truck.

"A handful of days later, that's when I suddenly couldn't read what my coffee cup said," Danielak said. "And it was just gone. And I just couldn't read."

This was a devastating development for Danielak, an avid and passionate reader.



Even today, years later, his voice cracks with tears when he recounts the memory.

"That's one of those memories that will stick with me forever because [reading] was what I did," Danielak said. "I couldn't read, which was something that I loved."

Adding to the sudden reading loss, Danielak became partially blind in his right eye.

"It was just one thing after another," he said.

APHASIA

Knowing Phoenix had more comprehensive brain injury medical resources and fearing the cancer had returned, Danielak and his husband moved back to Phoenix.

Fortunately, testing showed that the cancer was still in remission, and the swelling from the desk accident had gone down.

Danielak was, however, diagnosed with verbal aphasia.

Aphasia, usually brought on by brain injuries such as blunt force trauma or stroke, impacts the language center of the brain. It makes it extremely difficult for a person to read, write or verbally communicate.

"I had never heard of it; I didn't know what aphasia was," Danielak said. "I didn't know what a cup was, I couldn't name things, I

didn't know what was going on."

For someone used to operating on a very high cognitive level, it was a terrifying and baffling change.

"It was scary, upsetting, and very confusing," he said. "It was like going to bed in one country and waking up in another country. I couldn't read the language, I couldn't understand the language."

Ever resilient, Danielak began to work with a speech pathologist. He also changed his medication, some of which were thought to possibly be exacerbating the issue.

Slowly, Danielak began to improve. Thinking that being around friends and family would help rebuild his linguistic ability more, Danielak and his husband moved from Phoenix to Connecticut, where Danielak grew up.

However, with the onset of winter, Danielak knew his days of enduring freezing temperatures were behind him. So, he and his husband packed up again and moved back to Florida.

Though the weather was better, Danielak and his husband ultimately moved back to Arizona for his husband's job. Phoenix also offered Danielak access to his favorite speech pathologist.

So, for the third time, Danielak found himself back in Phoenix. Here, through his connection with the Brain Injury Association of Arizona, he's found support, acceptance, and peace.

THE NEXT CHAPTER

Now, Danielak hopes to share his story to help others who may lost in the fog and confusion that aphasia thrusts brain injury survivors into.

"That's so important to me that people are not sitting alone," Danielak said.

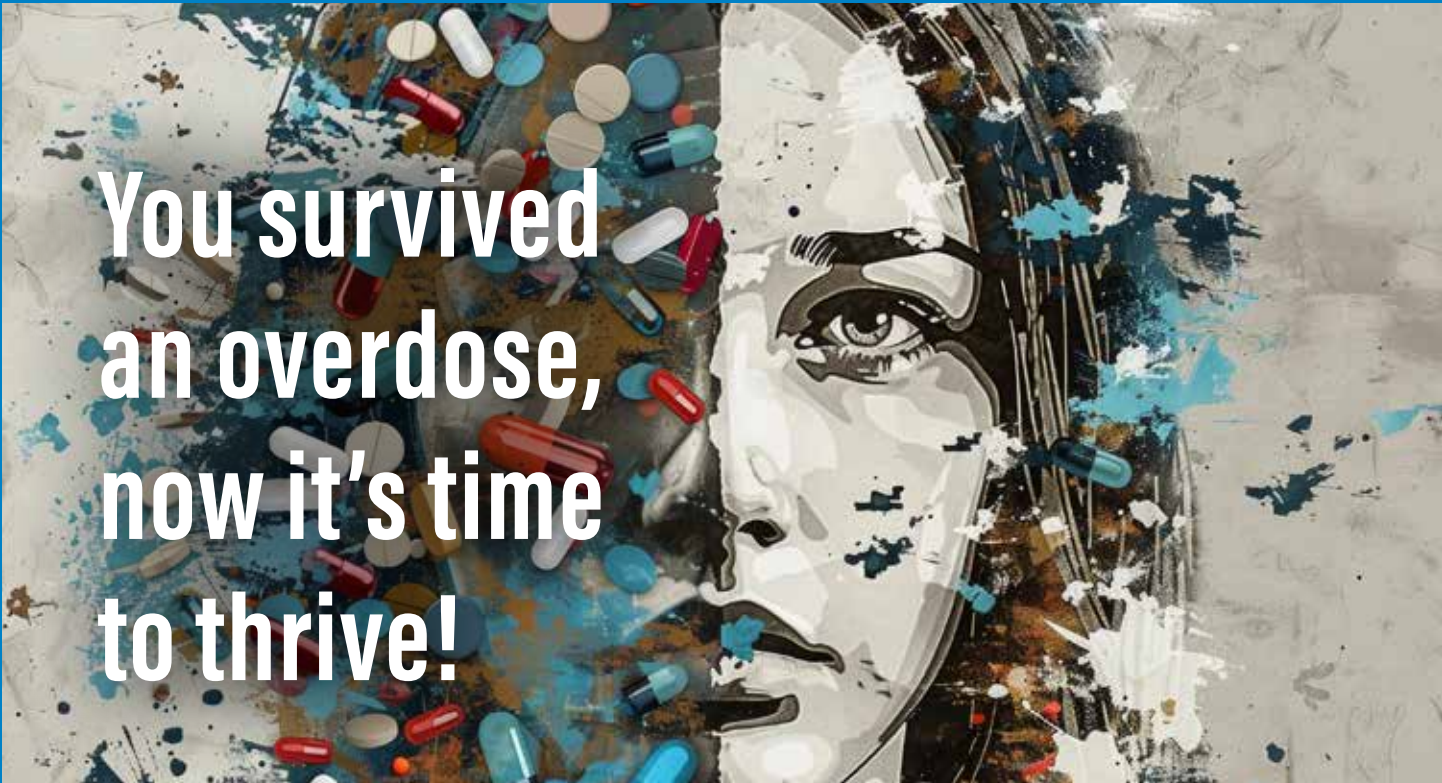
Although he doesn't know exactly what his future looks like, he knows he wants to help empower others with aphasia.

Danielak is also reclaiming his love of reading and language by helping to co-edit this edition of *The Noggin*. In addition to sharing his own story, he offered key guidance as to topics for other articles to include and what information would be truly useful for those with aphasia and their caregivers.

Ultimately, the message Danielak wants other aphasia survivors to hear is simple: keep going.

"It's going to be a lot of work, and it's going to be hard," Danielak said. "But you have to keep walking through quicksand to get to the other side."





You survived an overdose, now it's time to thrive!

If you have a brain injury or cognitive issues as a result of an overdose, one of our support groups can help you navigate these changes.

IN PERSON

★ Phoenix Survivor & Caregiver Support Group

For brain injury survivors and their family, friends and caregivers
— meets the second Thursday of the month, 6:00-7:00 PM

★ Tucson Support Group

For survivors and family members age 18+
— meets the fourth Friday of the month, 2:00-3:00 PM

VIRTUAL

★ Brain Cave — Men's Discussion Group

Discussion group for men who have survived any type of brain injury
— meets the first Wednesday of the month from 6:00-7:00 PM

★ Families of Brain Injury

For family members and caregivers of brain injury survivors
ONLY — meets the first Tuesday of the month, 6:00-7:00 PM

★ Brain Injury Association Statewide Support Group

For brain injury survivors and their family, friends and caregivers
— meets the fourth Thursday of the month, 6:00-7:00 PM

★ She Shed — Women's Group

Discussion group for women who have survived any type of brain injury
— meets the first Thursday of the month, 5:30-6:30 PM

★ Distracted & Drunk Driving Survivor Support Group

For those who survived an accident caused by a drunk or distracted driver
— meets the fourth Friday of the month, 2:00-3:00 PM

★ Southern Arizona Support Group

For brain injury survivors and their families — meets
the second Tuesday of the month, 5:30-6:30 PM

★ East Valley Brain Injury Support Group

For brain injury survivors and caregivers — meets the
second Wednesday of the month, 4:00-5:00 PM

BIAAZ.org | info@biaaz.org | HELPLINE (888) 500-9165

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**BRAIN INJURY
ASSOCIATION
OF ARIZONA**



**FOR MORE INFORMATION AND
REGISTRATION, SCAN QR CODE OR
VISIT BIAAZ.ORG/SUPPORT**

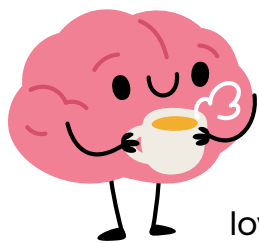
**All support groups open to those
18 years of age and older.**



ED'S TIPS FOR

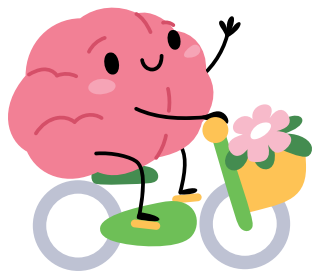
Thriving With Aphasia

As a brain injury survivor with aphasia, Ed Danielak has learned quite a bit about coping while on the long road to recovering his linguistic abilities. Below are the main tips he recommends for maintaining patience and equilibrium while recovering.



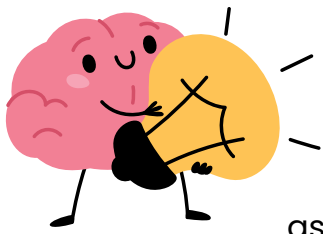
Take your time

When it comes to finding the right word for something or remembering certain words, don't rush it. Unless the house is on fire, taking those few extra seconds or even a few extra minutes won't hurt anything. If you are speaking to a loved one or co-worker, chances are they are aware you are living with an invisible disability and will be patient and supportive as you find your way amongst words. If you are speaking to a stranger or feeling pressured – say other people are waiting in line behind you – remember these extra few moments are an investment in your lifelong ability to communicate. They can wait a few extra moments, even if they don't think so.



Connect with others with aphasia

Whether it's a support group, an online chat forum or even just another person with a brain injury, connecting with other people who fully understand your context can be immensely helpful in dealing with the sudden, confusing changes aphasia brings. In a world that can be impatient with, if not outright hostile to, invisible disabilities, being able to speak with, vent to, or get advice from someone who just plain gets it can be an emotional life raft during challenging times.



Pivot to a new purpose

File this one under the “easier said than done, but still necessary” category. Often, aphasia leads to an inability to return to work or at least a prior career. This can be devastating and, in some cases, even lead to an identity crisis. Properly grieving the past is important, but so is learning to find new meaning in your everyday.



You are still a gift

An inability to generate income or needing financial assistance can often lead to depression or self-esteem issues. It can be challenging to remember that your income does not define your worth, no matter how much society tells you it does. Ultimately, you can still help people, contribute to creating a kinder, healthier society, and be a valuable part of your community. What that looks like within your current capabilities, even with aphasia, is up to you. This can be anything from being a great pet parent to a would-be street cat to volunteering for a cause you believe in. Sometimes, this means being a supportive and caring friend, partner, or family member. As long as you get up every day and do your best for yourself and others if you can, you have value and purpose.



MORE TIPS

APHASIA TIPS for ordering at your favorite coffee shop:

Get your phone ready, if you plan on using it to assist.

Practice your order ahead of time.

Don't forget to say "thank you" and tip.

Be gentle with yourself.



Aphasia Tips for practicing speech with your pet:

Brush your pet while practicing conversation skills by telling them how amazing they are and all the ways they improve your life.

Practice standard commands like sit and stay.

Next time you are on the couch with your pet, practice speech by telling your pet where each item in the room came from.

Take your dog outside for a walk and practice saying all of the objects that you see along the way.



SAVE THE DATE!

TUCSON Survivor Social Lunch

September 13, 2025 • 11:30 am – 2:00 pm
Culinary Dropout Tucson in The Coop Room
2543 East Grant Road Tucson, AZ 85716

SPECIAL PRESENTATION

Family Dynamics After Brain Injury:
Nurturing Relationships Through Communication



FEATURING

Emily Kade, Psy.D.
Licensed Clinical Psychologist

The Reuter Center for
Neuropsychology and
Integrative Counseling

Communication with loved ones after a brain injury can be essential to recovery. However, this can also be a source of stress and misunderstanding. Join us for a buffet social lunch as we talk about shifting and changing dynamics that occur with spouses, children, friends, and family members following brain injury.

This event is for adult survivors of brain injury, age 18+, and their adult family members.



REGISTRATION & INFORMATION

Scan QR code or visit
biaaz.org/09-13-tucson



Advice for Aphasia Survivors & Caregivers from Dr. Ileana Ratiu



Ileana Ratiu is the program director and clinical associate professor for the Speech and Hearing Science Unit in the College of Health Solutions at Arizona State University. She is also a long-time supporter of the Brain Injury Association of Arizona and has served on both the board of directors and the advisory board.



Dr. Ratiu sat down with us to offer general advice for people with aphasia, their caregivers, and their family members.

Above all, Dr. Ratiu said, remember there is hope.

“People do make really substantial recoveries often,” Dr. Ratiu said. “So, it’s not as dark as it seems in the initial stages, there is some light at the end of the tunnel.”

WHAT IS SPEECH THERAPY AND HOW DOES IT WORK?

Modern speech therapy practices are evidence-based and help a person with aphasia regain language functions such as speech and reading.

“Our goal is always to get somebody to be as independent as possible in their communication,” Dr. Ratiu said.

The methodologies and practices used by clinicians are generally built around three components: research-based data, the individual goals of the patient, and the clinician’s own expertise and experience. Many of the techniques used have led to consistent positive results for patients.

"People do make really substantial recoveries often. So, it's not as dark as it seems in the initial stages, there is some light at the end of the tunnel."

Another important facet of speech therapy is caregiver support and education. This means helping caregivers understand how to help the patient best and what they can expect in terms of symptoms and recovery.

"We can never make definitive predictions about prognosis, but we can kind of let caregivers know some of the things to expect in terms of symptoms and how those symptoms may play out in day-to-day life," Dr. Ratiu said.

HOW DO YOU KNOW IF SOMEONE NEEDS SPEECH THERAPY?

Most people tend to think of speech therapy as simply talking and maybe reading and writing. However, speech and hearing play a far more integral role in a person's ability to function on a basic daily level than most people realize.

That's just one reason the need for speech therapy may not be immediately obvious, especially if someone experiences a right-hemisphere injury or stroke. Although speech may still seem grammatically correct, there are other symptoms present that may be tied to language abilities.

"If you're not already referred to a speech therapist by a physician, it never hurts to ask," said Dr. Ratiu. "It's much better to ask and find out you don't need services than to

not receive something that you would have really greatly benefited from."

GENERAL GUIDANCE FOR PEOPLE WITH APHASIA

Allow time to process the event emotionally.

While it's always best to get treatment as soon as possible after a brain injury, it's still important for the person with aphasia to take a second to really recognize what's happened. Aphasia can sometimes happen without warning after an initial brain injury. But even when aphasia presents immediately, such as is frequently the case when the brain injury stems from a stroke, the loss of the ability to speak, read, and write can be a huge shock to a person.

"Someone who has experienced a stroke [or other brain injury] has experienced something pretty traumatic," Dr. Ratiu said. "You have to allow time for someone to process that emotionally."

Have some kind of goal in mind.

Most speech therapists will use the patient's own goals as a guidepost for the treatment they receive and the overarching goals of speech therapy.

"We want to know what the client wants

continued next page

to get back to doing; that's what we use to guide our therapy," Dr. Ratiu said.

It's important that this goal is realistic and based on a return for the patient's normal functioning, as well as what the patient wants to accomplish.

"So if you have somebody who's had a stroke, but maybe they never managed the finances of their household, that's not going to be a goal for them," said Dr. Ratiu.

However, if their goals are to return to cooking meals for themselves, then their speech therapy may focus on understanding and articulating the steps in making a sandwich or following a recipe.

GENERAL ADVICE FOR CAREGIVERS

Make an active effort to prevent caregiver burnout.

In addition to helping the brain injury survivor, most caregivers are also juggling a host of regular life activities, from managing a household budget and meal planning to still going to their own jobs if they have to continue to work. It's not surprising that caregiver burnout continues to be a rampant, silent epidemic in America.

So it's important to use resources such as support groups or respite services. BIAAZ has a wealth of caregiver support resources and offers a great place to start. The American Speech and Hearing Association also has a wealth of information about aphasia.

Use every tool and resource available to you.

Even most neurotypical, non-caregiver people need a planner, a Notes app on their phone or a reminder text. As a caregiver

juggling multiple doctor appointments, hairy finances, insurance communications and possibly more, know there is no shame in using any and every tool available to you in order to keep on top of everything. This might be a reminder app on your phone, a physical planner, or even asking a doctor's office to send you an additional reminder text.

This includes your own self-care. That morning quiet cup of coffee or tea, a nail appointment, or even just a 10-minute meditation session while sitting in the car between appointments all count and are equally important. Call your best friend and vent. Watch that Netflix show. Treat these small moments with the same prioritization you treat your loved one's doctor appointments.

Use alternative communication tools if necessary.

When a person with aphasia is just beginning treatment or is unable to articulate things verbally, alternate communication methods can help. This can be a board with pictures of common daily activities or foods a loved one can point to or a board or other way for the person with aphasia to indicate simple answers or requests like "Yes" or "No."

Integrate as much of the treatment protocol at home as possible.

Speech therapy sessions only last about an hour or two each, sometimes only once a week. So, it's important to integrate as many of the speech recovery practices into the person with aphasia's home life as possible.



Aphasia Fact

Aphasia is a loss of language, NOT a loss of intellect

SAVE THE DATE



LEADING *the* WAY

Brain Health Professionals' Conference

January 10, 2026

This conference is designed for professionals working at the intersections between brain injury, mental health, housing insecurity, and justice involvement.



FEATURED KEYNOTE SPEAKER

Eric Bailey, Human Relationship
& Communication Expert
& Author of, *The Cure for Stupidity*

FOR UPCOMING INFORMATION AND REGISTRATION

Scan QR Code, or visit biaaz.org/pro-bhc



Out & About in the Community



A Wicked Good Time Was Had by All

BIAAZ hosted 50 members of the brain injury community for a very special screening of Wicked. Don't take our word for it, scan the code and check out our video from the event.



BIAAZ Team Presents at Arizona Military Coalition Symposium

Serving military members and their families was top of mind as our team presented at the AZCMF 2025 Symposium.



Queen Creek Schools Welcomes BIAAZ

We were thrilled to share with Queen Creek High School students the ins and outs of recovery from brain injury.



Celebrating Survivors in Tucson

Thank you to everyone who came out to our survivor celebration and social lunch in Tucson. We had a deliciously good time



“Stand Down” in Page AZ a Success

We were thrilled to be there and ready to serve veterans at the first-ever Stand Down in Page, Arizona.



Survivor Night @ Jarrod’s Coffee

Thank you to Jarrod’s Coffee in Mesa for hosting our Survivors Only Night. We were entertained by AZ Winehouse with soft acoustic vocals.



Survivors Take Over Candle Chemistry

Dozens of survivors had the chance to craft their own candle. Scan the QR code and check out our video to see all the fun.



Throwing Strikes In Tucson

We celebrated the end of March – Brain Injury Awareness Month – with a social bowl in Tucson.

PROFESSIONALS IN OUR COMMUNITY

Meet Brittany Soch

Brittany Soch, the stroke program coordinator for Carondelet Neurological Institute, brings a dual perspective to the Brain Injury Association of Arizona support groups she now helps to facilitate.



As a brain injury professional, Brittany understands both the clinical and personal challenges survivors of brain injury face. But her experience as the relative of a brain injury survivor is what ultimately spurred her interest in becoming a BIAAZ support group facilitator.

For over 15 years, BIAAZ has facilitated both virtual and in-person support groups in Tucson.

Brittany said she's looking forward to continuing the tradition of "creating a safe and open environment for people where they can share without being judged."

When she was 8-year-old, Brittany's sister, 10, sustained a traumatic brain injury, or TBI, after falling off a spooked horse. Witnessing the aftermath of the accident, including the way it changed her sister's personality, was deeply formative for Brittany. She especially remembers how the changes in her sister impacted the entire family's dynamics.

"I understand how all the people around the TBI need support," Brittany said.

Her interest in the more physical aspects of brain injury also has its roots in Brittany's childhood. Both she and her father have

endured lifelong migraines. After working in data and analytics, helping to audit and accredit healthcare programs, Brittany became a nurse in 2019. She has worked in outpatient programs with children who sustained sports-related TBIs.

In addition to her work, Brittany has a 10-month-old who keeps her busy, but she also enjoys being outdoors. That includes hiking and exploring national parks.

"The most relaxed I ever am is floating on a kayak," she said.



BIAAZ offers nine support groups for survivors of all types of brain injury as well as caregivers and loved ones of survivors.

For more information or assistance registering, reach out to info@biaaz.org, call our Helpline at 888-500-9165, or text 520-310-3301.



Thank you for powering socialization and recreation in Arizona

We cannot thank you enough for being part of our seventh annual Run, Walk, & Roll, held in honor of Brain Injury Awareness Month this March.

You were part of an incredible community that came together to raise funds for Camp Brain and create meaningful social opportunities for survivors of all types of brain injury across Arizona. We are incredibly proud of all that we've accomplished together, and we look forward to seeing you again next year.

With heartfelt gratitude,

**\$78,941
RAISED**



Mike & Tommy Robertson
2025 Run, Walk, & Roll
Event Chairs



Jim Ledgewood
2025 Run, Walk, & Roll
Event Committee Chair

**167
DONORS**

**47
TEAMS**

**SAVE THE DATE!
See You
March 21, 2026!**

**32
VOLUNTEERS**

**725
PARTICIPANTS**

SAVE THE DATE

BRAIN HEALTH Leadership Breakfast

ARIZONA BILTMORE GOLF CLUB

Celebrating Return to Work Champions

Your annual business update on the professionals, research,
and programs that help Arizonians get back to work after
an accident, illness, or injury.

October 17, 2025

REGISTRATION & BREAKFAST: 8:00am – 9:30am



FOR MORE INFORMATION
Scan QR code or visit biaaz.org/bhl

Brain Injury Association of Arizona
5025 E. Washington St., Ste 106
Phoenix, AZ 85034