



Brain Injury Alliance of Washington

MINDMATTERS
PREVENTION ■ SUPPORT ■ EDUCATION ■ ADVOCACY

April 2021

MindMatters is a
publication of BIAWA



Brain Injury
Alliance
WASHINGTON

WHAT'S NEW

Inspiring • Learning • Growing



Brain Injury Today

PODCAST

Brain Injury Today is the official podcast of the Brain Injury Alliance of Washington hosted by Deborah Crawley and is produced in collaboration with Goal 17 Media. We've been putting out episodes since the start of this pandemic in March 2020 to stay connected and informed with our community. You can listen on our website www.BrainInjuryTodayPodcast.com or you can also listen on Google Podcasts, Spotify, or Apple

Brain Health and Wellness staying virtual for Summer 2021!

2020 definitely challenged us all to adapt to a new way of communicating and staying connected. While BIAWA is excited to see COVID-19 vaccination progress, we are keeping Brain Health and Wellness classes virtual through Summer 2021. Click [here](#) to see the Summer 2021 catalog! We are hopeful that numbers of COVID-19 cases will continue to decrease with continued vaccination efforts, and that we might be able to hold some in-person events late this Summer! We will keep you posted on the status of in-person events (including our annual Art Show!), but are looking forward to our in-person B.I.G. Brain Injury Gala on November 6th, 2021. More information on the Gala can be found at <https://www.biawa.org/biawa-gala>.

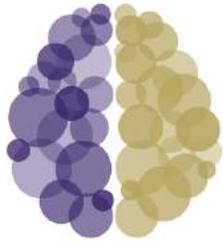
Contact BIAWA for help finding a COVID-19 vaccination appointment!

On April 15th, Washington State approved all residents 16 years of age and older to be eligible for the COVID-19 vaccination. Please understand that finding an appointment can be extremely difficult, as everyone is racing to get an appointment. If you need assistance getting on a waitlist or filling out electronic forms to get an appointment, please call the BIAWA Resource Line at 877-982-4292.



Visit us on Facebook to stay up to date on what BIAWA is doing in your community. We utilize this social media platform to share information on upcoming opportunities, resources, and fun photos from our community!

Connect with us! @BrainInjuryWA



UNIVERSITY OF WASHINGTON

TRAUMATIC BRAIN INJURY
MODEL SYSTEM

PATIENT CARE • RESEARCH • EDUCATION & TRAINING

What is BRITE?

The **Brain injury Rehabilitation: Improving the Transition Experience**, or **BRITE** is a **Patient-Centered Outcomes Research Institute (PCORI) funded** study at the University of Washington. The study is for people who have experienced a moderate to severe TBI (traumatic brain injury) and receive inpatient rehabilitation from six TBI Model System centers across the US (University of Washington, Indiana University, Ohio State University, Mount Sinai Hospital, Moss Rehabilitation, and Baylor Institute for Rehabilitation). The BRITE study investigators have collaborated with a group of 13 patient & family members who experienced a TBI in their lives. BRITE stakeholders helped design the study and continue to provide their feedback and advice throughout the duration of the project. The BRITE study is intended to improve the transition from rehabilitation to home by using trained TBI Care Managers (TCMs) to support the process

“Ways to Think about “Recovery” after TBI

“Recovery” after TBI is a topic the TBI Care Managers (TCMs) discuss with participants a lot. Important questions come up. What does it even mean to be “recovered”? What is the best way to balance talking about the impacts of TBI on one’s life and the hopes and dreams of ongoing growth and development? The TCMs reached out to our Patient & Family Stakeholder group to engage in a discussion around this and ask for their feedback about what they think would be most helpful to hear about recovery after a TBI? Here’s what they said.

What does the word “Recovery” mean to you?

- “I prefer “rehabilitation” over “recovery.” Recovery is a loaded word. It sounds like it has an end point whereas rehabilitation is something that may be ongoing for TBI.”
- “The word “recovery” insinuates that you need to get ‘better’, but I’m not worse, I’m just different. You may never recover to be your “old self” and that is okay.”
- “I see full recovery as unattainable for me. I miss who I was, but that person is gone...Instead of using the word “recover” what about using the word “renew”?”

- “I wouldn’t be who I am without my injury.”
- “One can be or feel recovered and not be the same person at all. I have disabilities and abilities that I didn’t have before. So you can be a different version, but better.”
- “Alternative words/expressions to use in the place [of] recovery: renewal, journey, rehabilitation, upgrade, version 2.0, even adding on the word “process” to “recovery” really improves it because there is no end to recovery. Recovery is a process. We are all recovering from something.”

What advice would you give providers working with patients who had a TBI about ways to discuss the "recovery process"?

- Communication is key. Look closely at the person with TBI or their caregiver and see that this is a person who has knowledge and experience you don’t have and value that human being as a partner in their care (rather than from a hierarchical perspective) before saying anything. What is said will likely stick with them or their family.
- Meet people where they are rather than focusing only on the numbers.
- There is a way to give hope without making false promises. There is no such thing as false hope, hope is hope!
- Make sure you are speaking directly to the person with the TBI, even if you think they do not understand. That means a lot.
- Allow yourself to say “I don’t know.”
- Fully explain any procedures to the person with the TBI AND the caregiver. Writing it down can be helpful as details may not be remembered well or verbally understood.
- Note every success, even small improvements matter. Speak positively.

What advice would you give caregivers about ways to discuss the "recovery process"?

- Caregivers need support to understand what their loved one needs and what they need. The challenge is knowing what you need!
- Find people who can listen and understand-support groups and others who can help you.
- Take photos and videos to show the progress. Pointing out even small changes encourages hope. Success can increase motivation for more efforts and this in turn can help relieve depression.

- Get connected with services while still in the hospital and rehab. This is critical as it becomes very difficult to navigate when you leave.
- Document and keep records of providers (contact info, specialty, treatments).
- Take time for yourself.
- Take care of your own health. Eat well, exercise, sleep. See your health care provider. You are recovering, too.
- Stay away from negativity. Many people told us “Your (loved one) will never do XY or Z” and they were wrong. Keep the hope and faith that they will progress.
- Begin the work of accepting the NEW parts of this person.

What advice would you give someone who experienced a TBI about ways to think about the "recovery process"?

- It's important to get good information about brain injury, including coping skills
- Get feedback early on about how you're doing that enables you to be self-aware (caregiver/ family AND professionals are key).
- Try to figure out what you do not know. Document changes large and small that you see and ask someone you trust (family/caregiver) to also document what they see. Be open to their feedback.
- Do not make any life changing decisions/ changes in the initial part of your healing.
- Be gentle with yourself!
- Be aware of day to day difficulties that may have big implications, for example, keeping track of time or a new habit of going on talking tangents.
- When you start the recovery process, you have a lot to gain back and you may gain a lot quickly, but you reach a certain point when there are fewer abilities left to gain back, and the ones left take longer, so it *appears* to plateau – but know that you're still regaining abilities. It's a process over your life. Continue to trust those people you trusted before the TBI. Your awareness of time and events may not match theirs. Explain your perception, listen to theirs without anger. Consider their feedback.

This content originated from the BRITE Patient and Family Stakeholders, including: Richard Anderson, Cavin Balaster, Deborah Fandel, Susie Fitt, Elaine Howard, Paul Howard, Jonathan Leiser, Audrey Self, Julie Self, William Svihla, Gail Weingarten, Irene Ziaya and compiled by Megan Moore, MSW, PhD, Leslie Kempthorne and Taylor Obata with help from BRITE Co-Principal Investigators Jeanne Hoffman, PhD, Jesse Fann, MD, MPH.

UPCOMING EVENTS

Upcoming Webinar! COVID & You: The Neurologic, Cognitive and Social Effects of COVID-19— COVID-19 has affected us all in many ways. BIAWA is thrilled to host Dr. Alina Fong and Dr. Jaycie Loewen on Wednesday, May 19th at 1:00pm to discuss the effects of COVID-19 and how they relate to TBI. We will discuss the neurological, cognitive, and social effects of COVID-19, as well as vaccine safety, concerns, and benefits. Click [here](#) to register! And stay tuned for information on an upcoming COVID-19 podcast!



Dr. Alina Fong :

Alina K. Fong received her Ph.D. in Clinical Neuropsychology with an emphasis in neuroimaging from Brigham Young University. She proudly serves as the president of the Brain Injury Alliance of Utah (BIAU). She is also a Board member of the United States Brain Injury Alliance (USBIA) and is a member of the public policy and governance committee of the USBIA. She also serves on the Professional Advisory Board of PINK Concussions.

In addition to her continuing research activities, Dr. Fong is currently the Director of Cognitive FX, the premiere concussion treatment center that utilizes functional Neuro-Cognitive Imaging technology.

Dr. Jaycie Loewen:

Dr. Jaycie Loewen is a Clinical Neuroscientist who received her Doctorate of Neuroscience at the University of Utah. Her background includes the study of basic and clinical brain injury, including the publication of research regarding mechanisms of epilepsy pathophysiology. Dr. Loewen's focus is firstly patient care and education. She also provides literature analysis and aids in the publication of Cognitive FX's research. Her goal is to improve Cognitive FX's ability to help patients through equal interaction and communication, as well as the furthering of concussion and mild traumatic brain injury treatment and science.



Funding provided by the Fred Hutchinson Office of Community Outreach & Engagement and the Partnership for the Advancement of Cancer Research: NMSU & Fred Hutch.



UPCOMING EVENTS

the
B.I.G.
brain injury gala

SATURDAY, NOVEMBER 6, 2021

Building Hope Together



B.I.G. Brain Injury Gala — The B.I.G. Brain Injury Gala, presented by UBS Special Needs Group, will take place on Saturday, November 6, 2021 at the Westin Hotel in Seattle. Our annual 2020 Gala was disrupted by COVID. We are looking forward to gathering this fall to celebrate! We can't wait for a fantastic event. Stay tuned for more details.



Brain Injury Golf Tournament — BIAWA's Brain Injury Tournament is BACK on Thursday, September 2, 2021!

Be part of our come back! Enjoy a great afternoon of golf while helping to prevent all preventable concussions and brain injuries in children and youth. Keep Youth Safe Playing the Sports they Love— and ensure the availability of necessary resources and support during their lifetime. For more player information or sponsorship opportunities, contact Suzette Hart at suzetteh@biawa.org.

BIAWA Academic Scholarships— The Brain Injury Alliance of Washington's 2021 Academic Scholarship Program is NOW OPEN! The application deadline is June 30th!

Our vision is a world where Brain Injury is prevented and every person already affected by its impact benefits from resources to maximize their quality of life. Our three annual academic scholarships are one way BIAWA strives to actualize that vision. Click [here](#) for more information.



PAST EVENTS

Walk, Run, Roll & Ride — THANK YOU to everyone who supported, participated, donated, and/or sponsored our second *VIRTUAL* Walk, Run, Roll & Ride! 2021 continues to require some flexibility. We usually hold this event at Green Lake in Seattle- coming together to walk, run, roll or ride around the lake as a community and build awareness. While we couldn't do that in-person this year, it was amazing to feel the same excitement virtually during our Facebook Live event on April 10th. Check out all these awesome photos of people getting out in their own neighborhoods to support survivors of Brain Injury! We thank everyone for their support in raising almost \$40,000!



This event was proudly presented by



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Personal Injury Law

www.adlergiersch.com

STAFF SPOTLIGHT



Kelsey Rauenhorst, Support Services Specialist:

Kelsey joined BIAWA in November 2020 as the new Support Services Specialist. She graduated in December 2019 with a Bachelor of Arts in Organizational and Interpersonal Communication from the University of North Carolina at Chapel Hill. She has an exciting work history that includes working at Disney World! Her passion for equity drew her to BIAWA, and she is excited to learn more about the TBI community.

In her free time, Kelsey loves to hike, travel, and kayak (when the weather permits). She has 2 precious kitties and practices yoga and meditation to keep as calm as possible during COVID.



Taylor Wood, Resource Manager:

Taylor joined BIAWA in November 2020. She attended Central Washington University, studying Sociology, American Sign Language and Accessibility. She was drawn to BIAWA because it is an avenue under the disability umbrella that she had not explored/worked in before. She has worked with individuals that are Deaf, Blind, Deaf-Blind, Paralyzed to some degree and on the Spectrum. So being able to expand her knowledge on how best to help individuals with varying ability is what really drew her to BIAWA. For fun, she likes to read books, cuddle with her cat and two dogs, and prior to COVID-19, attend Deaf Coffee Chats in her local area.



Tabitha Dominguez: Resource Manager

Tabitha joined the BIAWA team last October, leaving the Department of the Army after a combined total of service 15 years. Her dedicated service to our Country includes 7 years as an Active Duty Army Medic, 6 years working military contracts training Medics for deployment and 2 years as a Basic Life Support (BLS) Program Administrator. She graduated with her Master of Science in Public Safety and BS of Workforce Education and Development from Southern Illinois University (Go Dawgs!). She is excited and humbled to serve as a Resource Manager for our Veteran community and Western Washington as she understands first-hand the unique needs of this underserved population. During her free time, she is likely to be found sitting on her back porch listening to an Audio Book or Podcast, hiding from her children.



Washinton Brain Injury — Resource Center —

A PROGRAM OF BIAWA

The Resource Line is available Monday
through Friday from 9:00 am — 5:00 pm

Call 877-982-4292

Are you having a hard time finding resources in your community for...

- Navigating the Medical System
- Applying for Social Security Benefits
- Developing Education Interventions
- Planning Vocational Training
- Finding Legal Help
- Talking to Loved Ones about Brain Injury
- Facing Any Complex Issue Related to Brain Injury

We're here to help! All of our services are FREE! Give our **Resource Line** a call to talk with a specialist who can point you in the right direction: **877-982-4292**

***YOU Can Make A Difference
in the Lives of Survivors of
Brain Injury***



When You Become a Brain Champion:

- Your monthly donation is automatic and paper-free
- Gifts will occur monthly on the date of your choice
- You can modify your gift at any time through our portal or by contacting us

All Brain Champions Receive:

- A subscription to our quarterly newsletter, MindMatters
- Discounts on BIAWA event tickets
- BIAWA Swag
- Knowledge that you are making a meaningful impact in the Brain Injury community

Learn more about our Brain Champion Membership Program [HERE](#).

If you are not in a place to donate right now, don't worry! Our Resource Center services will always be available free of charge. You do not need to be a member to utilize services or participate in events!



Brain Health & Wellness

A PROGRAM OF BIAWA

The Brain Health & Wellness Program provides FREE classes on topics such as communication, relationships, health and fitness, cognition and memory, and social skills. Click on a class to register or go on our website at www.biawa.org/calendar to see all the classes and register! If you need help getting signed up, call Kelsey at 206-467-4807.

All classes are being offered VIRTUALLY online via Zoom for Spring/Summer 2021!

Registration is REQUIRED to participate in these classes.



pact[®]

The
Pooled
Alliance
Community
Trusts[®]

Building Lifetime Trust

BIAWA has 39 years of experience in supporting individuals to achieve their highest quality of life. Recently, it was brought to BIAWA's attention that individuals receiving government assistance after sustaining a disabling injury often find themselves in a paradox where acquiring assets (e.g. from a dispute settlement) jeopardizes their qualification for government benefits.

To fill this gap, BIAWA has created The Pooled Alliance Community Trusts (PACT)[®] in partnership with leading investment and trust management firms including UBS Financial Services, Inc., True Link Financial, and The Zielke Law Firm (Trust Manager). Together, we provide Pooled Special Needs Trusts (for individuals affected by disability) as well as Pooled Basic Support & Maintenance Trusts.

PACT Trusts are open for enrollment. Please contact us via the form on our webpage PACTTrusts.org or email us at info@PACTTrusts.org or call 877-448-7228.