



# TBI

## Model System Updates

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Volume 15, Issue 1



### Life After TBI: Where Do I Go From Here?

By: Staff

During a long stay in the hospital recovering from a serious traumatic brain injury, most people are focused on getting back home and continuing with their usual routines. Unfortunately, they may not be aware of the difficulties they may experience with getting back to their lives. There are many

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## Life After TBI (continued from cover)

By: Staff

difficulties that can arise after hospital discharge, and knowing what resources are available can make this ongoing adjustment to brain injury a bit easier. This diverse array of difficulties may include: having to negotiate logistics, such as transportation; knowing which providers to contact for follow-up care; and finding help to manage changes in one's abilities, such as coping with memory loss, expressing oneself or even thinking slower.

For those who are experiencing difficulties after a TBI and are looking for ways to address them, the following list of resources is a good place to start:

- Do you need more social support or help engaging with others? Beyond reaching out to friends and family members, consider trying local TBI groups and organizations for support.
  - ◇ [Washington TBI Support Groups](#) – A list of TBI Support Groups here in Washington
  - ◇ [Seattle BrainWorks \(SBW\)](#) – See a profile of this organization on [page 7](#)
  - ◇ [Brain Injury Alliance of Washington \(BIAWA\)](#): **(877) 824-1766** (Brain Injury Resource Center)
  - ◇ For mental health care concerns, there is the King County 24-hour Mental Health Crisis Line: **(206) 461-3222**
  - ◇ 24-hour Washington Recovery Help Line, which handles issues related to mental health, substance abuse, and problem gambling: **1 (866) 789-1511**
- Do you need help finding a safe place to live that can accommodate physical and/or cognitive limitations?
  - ◇ Terry Home is an organization with two state licensed boarding homes for young adult survivors of TBI: [Terry Home](#)
  - ◇ Check out the Department of Social and Health Services [Database](#) of Adult Family Homes
  - ◇ Be sure to know what to consider when choosing an Adult Family Home or Assisted Living Facility by reading this [guide](#) from Sound Generations
- Do you need specialty care for your difficulties? See a rehabilitation medicine specialist – this doctor will assess your condition and help you to set



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realistic goals as you recover and adjust to brain injury

UW Medicine

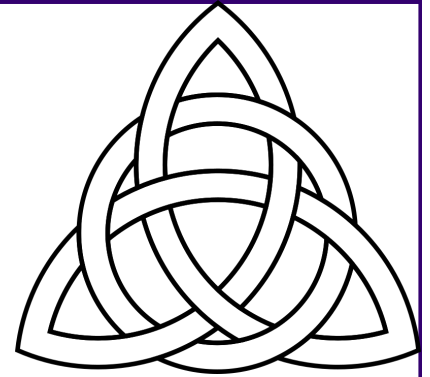
- ◇ UW Rehabilitation Medicine Outpatient Clinics
  - ◆ [UW Medical Center](#): (206) 598-4295
  - ◆ [Harborview Medical Center](#): (206) 744-5862
- Do you need to find ways to fill your time and return to productive activity?  
Volunteer with a local organization or try out a recreational activity – these activities can be alternatives to or steps on the way to returning to work after a TBI.
  - ◇ [Tips for choosing an accessible volunteering program](#) – A resource from Mobility International USA (MIUSA)
  - ◇ [Outdoors for All](#): A local Pacific Northwest organization that connects people with disability to outdoor recreation opportunities – also a great place to volunteer!
- Do you want to give back to those who helped with your medical care? Participate in TBI research – although participation in a research study may not benefit you directly, it will increase our knowledge of how people recover from TBI and the best ways to heal the brain and treat common symptoms of TBI
  - ◇ [Current UW TBIMS Research Studies](#)
  - ◇ [ResearchMatch](#) - a great resource for finding open studies that you may be eligible
  - ◇ [Participate in Research](#) - another great search tool from the Institute of Translational Health Sciences (ITHS)
- Do you need help with returning to work? If so, contact your local Department of Vocational Rehabilitation.
  - ◇ DSHS has a list of DVR locations [here](#)
- Do you need more information about brain injury and what to expect? Utilize online TBI resources for information and connection to additional resources not listed here
  - ◇ [UW TBIMS Website](#) - Check out past Forums, Newsletters, and other resources
  - ◇ [Brainline](#) - Find articles on a wide variety of topics related to TBI
  - ◇ [Model Systems Knowledge Translation Center](#) - Accessible information based on Model Systems research
  - ◇ [TBI Infocomics](#) - Alternative format for learning about TBI and related issues



The path to recovery is different for each person, but these steps and resources can be helpful for anyone.

## Survivor Perspective: Finding a New “Normal”

*Marilee Goebel runs a workshop in the Seattle area called “Articulating Strengths Together” for people who have experienced a TBI and are looking for a supportive, community setting in which to gain perspective on their recovery process. Marilee experienced a TBI in 2010, and is now using her own experience with TBI recovery to help others with theirs.*



### **Building a Strengths-focused Identity After TBI**

*By Marilee Goebel*

What is this “New Normal” we all hear so much about? It’s certainly an oft repeated phrase on TBI recovery road. In her review of Paul Kalanithi's wise and eloquent book "When Breath Becomes Air", Maria Popova describes a sobering revelation of how much our sense of self is tied up with our sense of personal potential and possibility. How our sense of self is inextricably tied up not only in who we are today but also in the selves we would like to become, the selves we work tirelessly toward becoming. Popova asks, "Who are we, then, and what remains of "us" when that possibility is suddenly snipped?" ([Popova 2016](#)).

I was "suddenly snipped" on a sunny August day in 2010. The day of my final mountain bike ride. As Mr. Kalanithi explains in his book, the brain is the crucible of identity. He explains that “every operation (and I would include every injury) to the brain is a manipulation of the substance of ourselves”. ([P. Kalanithi 2016](#)). Post TBI, I became a stranger to myself. I failed to resemble the woman who I’d effortlessly been the day before that life altering mountain bike ride.

That autumn I began hearing about the new normal; a notion which I was assured existed, but to me seemed mysterious and foreboding. After a few years of psychological skirmishes with my new normal, I suspended the resistance and began to find my way forward into a sort of self-identity perestroika; literally a rebuilding, reorganizing and reframing of who I am.

My solitary struggle, which has become a pursuit of meaning, brought me to a person and a process which turned my perspective of my new normal on its head. Pre-injury I was fortunate to work in the exciting world of leadership development; I've long been a believer in the effectiveness of strengths-focused coaching. My post injury quest for meaning had led me back to the power of focusing on strengths.

In the spring of 2014 I met a talented and dear Emeritus Professor from the University of Washington who generously helped me to begin this journey and has stuck with me since. He coached and mentored me through his method for discovering and articulating strengths and taught me a practice for building a strengths-focused identity, all of which is based on his research.

Working through this process as a participant, and now leading others through it in small group sessions

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has provided me a front row seat to both experience and witness the science of neuroplasticity – the brain’s astonishing ability to essentially rewire itself – as it takes place. Focusing on my strengths has also made it possible for me to live my new normal in a new way. Even though at times I still see myself with missing parts, I no longer look through the lens of loss fearfully searching for "what remains". Instead, I've come to recognize myself and my “new normal” through my strengths.

My “identity perestroika” continues. TBI erased some of my strengths, but in their place others were seeded and have begun to flourish. This shifted perspective has become the foundation for my sense of potential and possibility about who I am now and who I might work tirelessly to become. I have become acquainted with, and have even made friends with, who I am post injury. Yes, I am different now. And I am equally valuable.

*If you are interested in joining an Articulating Strengths Together workshop with other TBI survivors in Seattle, you can contact Marilee at [marileeq@hotmail.com](mailto:marileeq@hotmail.com).*

*Also, please visit <http://www.strengths-focused-identity.org/contents/an-introduction.html> a website authored by Jerald Forster, Professor Emeritus University of WA to learn more about his research on building a strengths-focused identity. You can also view a video of one of Marilee’s speaking engagements about her experiences with building a strengths-focused-identity.*

## What’s Your Survivor Story?

Send your story to [uwtbi@uw.edu](mailto:uwtbi@uw.edu) and we may be able to feature it in our next newsletter!

## Announcements:

**BIAWA’s annual Walk, Run & Roll for Thought is coming up on April 2, 2017!**

This year the event will again be held at the Green Lake Community Center, with 5K and 1 mile route options. For more information and to register or donate, head to the event’s website [here](#).

Hope to see you there!

## Looking to get involved in TBI Research?

We have multiple studies that are currently recruiting participants. The first two studies are for individuals that are experiencing new or worse headaches since their injury. The last is for current TBIMS participants.

If you are interested in participating in research, check out our studies below:

### The TWIST Study

**Study Contact: Taylor Obata, [tobata@uw.edu](mailto:tobata@uw.edu) or by phone at 206-685-8354**

**The TWIST Study** looks at whether Sumatriptan (also known by the brand name *Imitrex*™) an FDA-approved medication for treatment of migraine, shows similar effectiveness for treatment of chronic post-traumatic headache. Eligible subjects must be **16 to 65 years of age**, within **2 weeks to 5 years post TBI**, and experiencing **new or worse** headaches since their TBI. Subjects are asked to keep a headache diary while enrolled.

### The LE-TBI Study

**Study Contact: Taylor Obata, [tobata@uw.edu](mailto:tobata@uw.edu) or by phone at 206-685-8354**

**The Late Effects of TBI or LE-TBI Study** aims to learn more about the long-term effects of TBI in the general population. This study is for individuals who are already enrolled in the TBI Model System Study, are over 40 years of age, and at least 1 year out from their injury. You must be able to undergo an MRI and be willing to have a brain tissue sample donated in the event of your passing during the course of the study. Please give us a call for more information.



**\*All studies are voluntary and will not affect the care you receive at the University of Washington\***

# Seattle BrainWorks

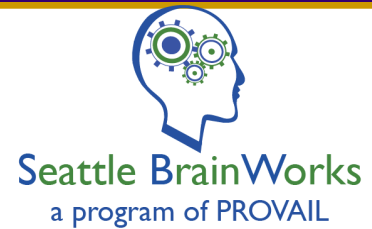
By: Taylor Obata

[Seattle BrainWorks \(SBW\)](#), part of Provail, is a fabulous

program here in the Seattle area. I spoke with the Program Director, **Nicole Fullerton**, to learn more about SBW. Below is our interview:

**Taylor: What is the mission of Seattle BrainWorks (SBW)?**

Nicole: Our mission is to encourage survivors of brain injury to relearn skills and create strategies that will help them reintegrate as happy and successful members of the community.



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nicolef@provail.org

**Who does SBW serve as far as the type of injury and geographic area?**

BrainWorks primarily serves individuals who have experienced a TBI, but we also serve survivors of acquired brain injuries as well. As for geographic area, most of our members reside in King County due to the proximity to our location. However, we have also members that travel all the way from up in Bellingham to all the way down in Tacoma. We are happy to assist any survivor that comes into our center regardless of home address.

**Walk us through the process of joining SBW...**

We encourage most first time visitors to set up an appointment to visit so we can make sure to dedicate time specifically to introducing them to our program. That being said, if making appointments is too difficult, we absolutely welcome drop-ins. Once at BrainWorks, a tour is provided as well as an explanation of the program. This is a chance for us to get to know each individual as well as for people to ask questions. The last step is filling out a simple application and you're all set. You are officially a member of Seattle BrainWorks. The best part is that we are a free program, so members don't have to worry about insurance coverage or fees.

**How is the program structured? Are there daily activities? Special events?**

BrainWorks is a drop-in center. Due to this, members have the opportunity to participate as frequently or infrequently as they wish. A monthly calendar spells out both enrichment and return-to-work activities occurring during the week, and members can attend part or all of any activity they choose. Enrichment activities are designed to target the areas of learning that people recovering from brain injuries can benefit from – mindfulness groups, classes on organization, support groups, yoga classes, public speaking, positive interactions, stress management, volunteering at a local food bank – the list goes on, and is ever-changing. Brainworks also offers monthly outings that encourage members to get out into the community in a safe and fun way.

**What are your goals for the program? What would you improve/add to if more funding were available?**

Our goals are very similar to our mission in that we want to assist our members towards independence in the community. Our main focus is to help members work towards their goals whether that be education, employment, socialization, or independent living skills. The sky's the limit and ultimately BrainWorks is successful when a survivor is succeeding in their community and no longer needs our support. As for what I would improve, I would love to be able to increase our partnerships with more community programs beyond the ones we already partner with. I'd also like to increase our reach in regards to offering more classes and enrichment activities by possibly being able to pay instructors or interns to provide them. We are still figuring out all of our changes and growth from the last year, so I know more improvements will be explored and sought out.

**What are some major accomplishments of the program (especially considering recent changes to the structure)?**

I would say our biggest accomplishment thus far is being able to collaborate with so many community partners and our previous/current members to design and create the wonderful program we have today. Without that collaboration, we would not be as far along as we currently are. Other accomplishments include securing a contract with the Division of Vocational Rehabilitation to provide independent living skills training for pre-employment as well as developing an employment track for our members interested in returning to work. Lastly, BrainWorks has been able to expand its reach and support to more members than ever before!

**Are there any other aspects of BrainWorks that you'd like to share? Any noteworthy stories that characterize the intent of the program?**

BrainWorks is the only program of its kind in Washington. We pride ourselves on providing a safe space for brain injury survivors to expand their horizons and also to meet other survivors that understand what they are going through. Some of the best learning that occurs here is the organic interactions that take place between members, whether it be having coffee together, mentoring each other or offering support on rough days. The program is member driven, meaning the program is tailored to fit the needs of each individual through listening to the voices of those we serve. We encourage people to speak up and advocate for the things they want and the program they would like to see. I am so proud of all of the accomplishments that many of our members have made over the last year that it is hard to focus on just one noteworthy story. A few of my favorite highlights include members increasing their ability to read and write, gaining strength to stand independently of a walker, returning to work, going back to school, finding the confidence to speak their mind, learning assistive technology, leading groups and so much more.

## Healthy Recipes for the New Year

Here are some brain healthy recipes to try during the new year. The first uses cold water fish (Arctic Char is similar to salmon or lake trout) which tend to be high in Omega-3 fatty acids, and the second takes advantage of nutrient rich squash.

### Arctic Char with Yogurt Sauce

Serves 4

#### Ingredients:

- 1/2 cup plain Greek yogurt
- 1/4 cup peeled and finely chopped cucumber
- 2 Tablespoons chopped fresh cilantro
- Juice of 1 lime
- 2 teaspoons olive oil
- 4 arctic char fillets, about 5-6 oz each\*
- Lime wedges for serving
- Salt and pepper



#### Instructions:

- ◇ In a small bowl, combine yogurt, cucumber, cilantro, and lime juice. Season with one or two large pinches of salt.
- ◇ Heat olive oil in a nonstick saute pan over medium high heat. Season fish fillets with salt and pepper on both sides.
- ◇ When oil is hot, add fillets to pan in a single layer.
- ◇ Cook about 3-4 minutes per side, until cooked through.
- ◇ Remove fillets to serving plate and drizzle sauce over the top. Garnish plate with lime wedges.

Source: [BrainHQ](#)

\*Can substitute salmon or rockfish/cold-water snapper

### Winter Squash Soup with Roasted Pumpkin Seeds

Serves 8

#### Ingredients:

- 4 Tablespoons unsalted butter
- 1 medium onion, coarsely chopped
- 1 celery rib, coarsely chopped
- 2 garlic cloves, coarsely chopped
- 1 cup dry white wine
- 1 quart (4 cups) chicken stock or low-sodium broth
- 1 quart water
- 4 pounds winter squash (such as butternut, acorn, hubbard or any other variety) - peeled, seeded, and cut into 1-inch cubes
- Freshly ground pepper
- Large pinch of freshly grated nutmeg
- Roasted pumpkin seeds and honey, for garnish (optional)



#### Instructions:

- ◇ In a large pot, melt the butter
- ◇ Add the onion, celery, and garlic, and cook over moderate heat, stirring until softened, about 5 minutes
- ◇ Add the white wine and simmer for 3 minutes
- ◇ Add the stock and water and bring to a boil
- ◇ Add the squash, cover partially, and simmer over moderately low heat until tender - about 30 minutes
- ◇ Use an immersion blender to puree the soup or add in small batches to a blender and puree until the soup is smooth (DO THIS VERY CAREFULLY! Blending hot liquid can cause it to “explode” out of the blender if the lid is completely closed and air cannot escape. Crack the lid a little while blending and put a towel over the top).
- ◇ Return the soup to the pot, bring to a simmer, and season with pepper and nutmeg
- ◇ Garnish with pumpkin seeds and a drizzle of honey (opt)

Source: [Brain Healthy Cooking](#)



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## **Who's Who at UW**



Sylvia Lucas M.D., Ph.D. is an investigator with the UW TBI Model System Study. She is Clinical Professor of Neurology and Neurological Surgery and adjunct Clinical Professor of Rehabilitation Medicine. She is the recipient of the Wadsworth Clinical Professorship in Headache Research and Practice. Her clinical and research interests focus on headache and TBI, and she is the study physician for the TWIST headache study. This study is currently recruiting participants who are experiencing new or worse headache since sustaining a TBI.

Dr. Lucas is a UW alumnus, having completed a B.S. from the UW School of Pharmacy; a Ph.D. in physiology and biophysics from the UW, including postdoctoral research in muscle physiology, and an M.D. from the UW School of Medicine. She did her residency at the New York Hospital-Cornell Medical Center and Memorial Sloan Kettering Cancer Center. She is past president of the Puget Sound Neurological Society and board of directors of the Headache Cooperative of the Pacific. She is also a Fellow of the American Headache Society.

Aside from being a doctor, professor, and researcher, Dr. Lucas is an avid traveler. She has traveled to the Antarctic or Arctic regions 6 times and is interested in the effects of decreasing polar ice mass and its effects on wildlife.



## The Washington Traumatic Brain Injury Resource Center

BIAWA is first and foremost a source of support for those affected by Brain Injury, and the Resource Center is a critical part of this.

[Brain Injury Alliance of Washington](http://www.biawa.org/): [www.biawa.org/](http://www.biawa.org/)

[BIAWA Support Center](http://www.biawa.org/getsupport.php): [www.biawa.org/getsupport.php](http://www.biawa.org/getsupport.php)



## TBIMS Updates

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