

# **Model System**

**Updates** 

September 2018 Volume 16, Issue 2



# Traumatic Brain Injury - 20 Years Later A Survivor's Perspective

Joshua was the first person enrolled in our long-term follow-up study 20 years ago, when the UW became a TBI Model System. He graciously agreed to answer some questions about his recovery.

Injury and recovery

I was injured in August of 1998 in a five-vehicle pile-up (one of the five was a semi) on the I-5 freeway south of Seattle. It happened while I was driving home from my work as a legal courier. After the accident, I spent 3½ months in Harborview Medical Center as an inpatient (in a coma for 17 days).

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## **Survivor's Perspective** (continued from cover)

Then I moved home and spent roughly the next 9 months traveling back and forth between home and the hospital for outpatient rehab. I have not yet returned to work. I've only done volunteer

work (in all, many years of it!) in preparation for a hopeful return to paid work.

Immediately upon discharge and for the next 2-4 years, I worked on regaining pretty complete control over my physical functions (walking, talking, and other activities of daily living). To date, I still fatigue faster than I used to, and I continue to have difficulty organizing my thoughts (and am much slower at it than "normal"). My biggest two hurdles to overcome are problems with my communication and my memory deficit.



### Thinking and communicating

Communication continues to be my biggest problem, followed by my memory. Both have improved over the last 20 years, but both are still very much lacking. To elaborate, I have a very hard time organizing my thoughts into clear, concise, cohesive statements and expressing them to others on the spot. With time to prepare, however, I do quite well. I do expect my communication to continue to improve over time, with God's help and by practicing it.

My memory has also improved; things that I know I would not have remembered years ago I can remember now, such as various conversations, plans, things regarding work, etc. I would also say things are still changing, even though it is extremely hard to see improvements day to day or week to week from my perspective.

### **Emotional adjustment**

As far as my emotional and psychological adjustment has gone, I still have trouble in those areas, although less and less as time has gone by. I have a big problem with anger. While I learned fairly early on how to control my anger in public where it's especially inappropriate, at home and around those I love and am comfortable with I still have episodes that concern me and those closest to me.

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# Looking to get involved in TBI research?

# **TBI Care Study:** The Effectiveness of Collaborative Care Versus Usual Care for Pain after Traumatic Brain Injury

We are recruiting volunteers to participate in a study called "TBI Care" to compare a collaborative care approach to pain treatment to the usual care approach. Collaborative care may also improve treatment of other conditions that happen frequently with chronic pain, including depression, anxiety, and sleep.

You may be eligible for the study if you have had a mild-to-severe TBI, have had pain during the last 6 months, and get your care from a TBI physician at either Harborview or UW Medical Center Rehab Clinics. Participants are randomly assigned (like a coin toss) to either the TBI Care treatment group or the group receiving usual care.

For information, contact Laurie Peabody, 206-744-3607 or lpeabody@uw.edu

ClinicalTrials.gov Identifier: NCT03523923

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



## **New Grant Award Announced**

The UW TBIMS is one of nine TBI Model System centers, along with a Veterans Administration (VA) TBI center, collaborating on a new study called **Characterization and Treatment of Chronic Pain after Moderate to Severe Traumatic Brain Injury** funded by the <u>National Institute on Disability</u>, <u>Independent Living</u>, and <u>Rehabilitation</u> Research (NIDILRR).

The study aims to do an in-depth analysis of different types of chronic pain after moderate to severe TBI in order to understand the many factors that affect severity, treatment success, coping and function. Results will have a direct impact on clinical practice and targeted treatment for people who have had TBI and have pain.

Participants will be recruited from those already enrolled in TBIMS and invited to join the study when they are contacted for one of their routine follow-up interviews. This study has not yet been IRB approved. More information to come soon!

## **Survivor's Perspective** (continued from page 2)

They are usually primarily internal struggles I deal with, but to those I love and who are around me a majority of the time, they are apparent (and a problem). A big portion of that problem I believe is spiritual and something that I can overcome with God's help. I am working hard at it.

#### **Advice**

First, don't be too hard on yourself, and second, **never**, **ever give up**. I have learned that when you're hard on yourself or others around you and you get angry, it does something in your brain that clouds your perception and thinking, and therefore affects your immediate reactions and decisions. Also, when you strive to overcome problems that you have (whether you are first aware of them or they are brought to your attention), that perseverance only strengthens your brain (can build new neurons), as well as building character and stamina.

Practically speaking, the three things that have helped me the most are 1) my faith, 2) family & church family support, and 3) therapy (which helped build structure and routine).

### My life today

My father moved down to California a few years ago and we bought a house together. At that point, I began volunteering approximately half time as an administrative assistant. Currently, I am hoping and preparing to do some online transcription work as well, and at some point in the future I hope to start an Amazon store.

I am very active in my church, participating in the men's group and a couple of bible studies each week, as well as serving on the tech team.

Don't be too hard on yourself, and never, ever give up.

Joshua, TBI survivor

Overall, even with my struggles and problems, I am living a pretty happy and fulfilling life.

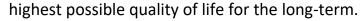
### Why I participate in the TBI Model System study

people with TBIs in the future.

It has been nice over these 20 years to receive a check every so often from the UW TBI Model System organization for answering a few questions on the phone every year. It has been great to be able to take part in various studies and answer questions about my injury and condition, knowing that the answers I've given have helped and will help to provide further insight into TBIs, **and to help** 

# Long-Term Recovery after TBI: What Does the Research Say?

eople who have had a traumatic brain injury—along with their families—naturally want to know if they will recover from their injury, how long it will take, and whether they will ever get back to "normal." But the long-term outlook after TBI is difficult to predict. Every person, injury and situation is unique, and many different factors affect recovery. Researchers at the UW and elsewhere work to understand these effects, with the goal of improving treatment and helping each patient attain the





The severity of the injury is a major factor in recovery. Severity is based on several different measurements, including the Glasgow Coma Scale, or GCS (which rates depth of coma), length of coma, and a lack of memory of things that happened before or after the injury. The more severe the injury, the more likely there will be long-term problems like personality changes or the inability to live independently or work.

The location of the injury (what part of the brain was hurt), the number of places the brain was injured, and the type of injury also affect recovery. Poor health and older age at the time of injury can make recovery harder. Strong social support and access to specialized rehab therapy can improve the chances for a good recovery.

According to one recent study, half of people with mild TBI recover fully within 6 months. After a year, only about 10-15% continue to have cognitive, physical or emotional problems. Those who hadn't yet fully recovered tended to be older, have pre-existing mental health problems and lower education levels. After a year, only about 10-15% continue to have cognitive, physical or emotional problems. Those who hadn't yet fully recovered tended to be older, have pre-existing mental health problems and lower education levels.

For people with severe TBI, one study found that the greatest predictor of long term recovery was how long a person stayed confused and agitated after regaining consciousness. This is called post-traumatic amnesia (PTA), and the shorter the duration of PTA, the better the patient's long-term recovery.<sup>3</sup>

Recovery is often seen as being able to function independently in major aspects of life. A UW study found that 3-to-5 years after moderate-to-severe TBI, about 65% of people said they were back to performing their own personal care. About 40% reported that they had recovered their cognitive ability and returned to employment or school, leisure and recreation.<sup>4</sup>

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Research findings are helpful as guidelines and important for treatment planning, but they cannot predict exactly any one individual's eventual recovery. The response "we don't know" can be an unsatisfactory answer to questions from patients and families about recovery, but it is a realistic one that also leaves room for possibility.

#### References

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## **UW TBI Investigators Out and About**

#### **VA Review Committee**

Jeanne Hoffman, PhD and Jennifer Zumsteg, MD—both investigators from the UW TBI Model System—are serving on the Committee on Veterans Affairs Examinations for Traumatic Brain Injury in the National Academies of Sciences, Engineering, and Medicine. This committee will review the examinations conducted by the VA of individuals who receive medical services for TBI from the VA.

#### **Down Under**

Chuck Bombardier, PhD, UW Rehabilitation Medicine professor and co-investigator on the UW TBI Model System, has been invited to talk about depression in spinal cord injury and traumatic brain injury for the Research and Education Series of the State Insurance Regulatory Authority in New South Wales, Australia on September 11, 2018. Dr. Bombardier is an internationally recognized expert in this area. He will be presenting research data on the prevalence, costs, treatments and health outcomes related to depression in individuals with traumatic brain and spinal cord injuries.

## Meet our TBI Fellow: CJ Plummer, MD

CJ Plummer, MD ("CJ" stands for Clausyl Julius) joined the UW Medicine's brain injury rehab team as a TBI Fellow last month. For the next year, he will see patients in acute rehab and outpatient clinics, and be a rehab consultant for patients throughout the hospital when brain injury rehab expertise is needed.



The son of Jamaican immigrants, Plummer was born in Maryland. He has moved around a lot all his life: multiple moves for his father's military career; college in Alabama; medical school in Washington, D.C.; residency rehabilitation medicine in Texas. Now he is at the UW working toward his brain injury specialty accreditation.

Plummer first became interested in rehab medicine and brain injuries through his interest in sports concussions. He has been an athlete all his life, and thinks he probably had a couple of concussions from participating in sports in the past.

Plummer says he fell in love with the field of brain injury medicine when he saw "the great potential for recovery. Patients can start from a very low level of functioning after injury, and over time, with the right medical attention and dedicated therapy, they can do quite well."

He thinks of rehab medicine as almost an art form. "There is no cookie-cutter way to treat people with TBI," he says. "You need to tailor the treatment plan for each specific person." TBI can affect many aspects of a person's life besides cognitive function—mood, balance, sleep, muscle tone, bowel and bladder function. It's complex and challenging, and makes working with these patients very rewarding.

Furthermore, right now is an exciting time to be in the field of TBI. The topic of sports head injuries as a cause of long term problems like chronic traumatic encephalopathy (CTE) is often in the news. And military personal are coming home from combat with severe head injuries in large numbers. As the public has become more aware of head injuries, there is increased interest in finding effective prevention and treatment strategies. Plummer is excited about getting involved in prevention as part of his research requirement for his fellowship.

Outside of work, Plummer is very busy with family. He and his wife have a two-year-old son and another baby on the way. Family time is extremely important, but he also continues to be as physically active as he can. "It's a big stress reliever for me," he admits.

After this fellowship, Plummer hopes to find a position that allows him to do a mix of inpatient and outpatient care, hopefully one that includes training medical students and rehab residents so he can pass on his love of rehab medicine to the next generation of physicians.



# TBIMS Staff Project Director: Jeanne Hoffman, PhD

#### **Investigators:**

Chuck Bombardier, PhD Sureyya Dikmen, PhD Jesse Fann, MD, MPH Sylvia Lucas, MD, PhD Nancy Temkin, PhD Jennifer Zumsteg, MD

#### **Research Staff:**

Jason Barber, MS
Mary Curran, MSW
Silas James, MPA
Leslie Kempthorne
Melissa Mayes, MSW
Taylor Obata
Laurie Peabody
Cynthia Salzman, MHA
Erica Wasmund

Contact Us: uwtbi@uw.edu 206-543-0219

@UWTBIMS www.facebook.com/ UWTBIMS





## Who's Who at UW?



ary Curran, MSW is a care manager for the TBI Care study (see page 2 for more info) at the UW Department of Rehabilitation Medicine. She is a Licensed Independent Clinical Social Worker (LICSW) and works on research projects with the Department of Rehab Medicine and UW School of Social Work. Ms. Curran received her Master of Social Work from the University of

Washington in 1994.

Curran brings over 25 years of experience working in public health and medical clinics, domestic violence emergency shelters, an immigrant legal assistance program and youth and family service programs. She has expertise in mental health for pregnant and new mothers, treating depression and chronic pain in neuro rehab populations, addressing domestic violence, and working with economically disadvantaged, racially and ethnically diverse women and families.

She joined Rehabilitation Medicine in 2014, to focus on research to improve quality of life in people with multiple sclerosis (MS) and traumatic brain injury (TBI) who have chronic pain and/or depression. For the TBI Care study, Curran partners with patients and their providers to coordinate care. She meets with patients weekly up to 12 sessions, either over the phone or in the clinic, to talk about symptoms and discuss whether medications are working. She also teaches patients self-management skills that help reduce pain. Curran enjoys helping folks living with chronic conditions like TBI and MS build upon their strengths and discover ways to enjoy activities and relationships despite the pain.

Outside of work, she finds joy in being with her three children and partner, hiking in the mountains, gardening, playing soccer and practicing yoga.

### The Washington Traumatic Brain Injury Resource Center

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

Brain Injury Alliance of Washington: www.biawa.org/

BIAWA Support Center: www.biawa.org/getsupport.php















## **TBIMS Updates**

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**University of Washington Traumatic Brain Injury Model System** 

1959 NE Pacific St. ● Box 356490 ● Seattle, WA ● 98195

Main office: 206-543-0219 Email: uwtbi@uw.edu www.tbi.washington.edu