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TBI Updates

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UNIVERSITY OF WASHINGTON
TRAUMATIC BRAIN INJURY
MODEL SYSTEM



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Treating post-traumatic headaches



Image courtesy of stockimages

Headaches are hard to live with, as anyone who has headaches can tell you, and headache is one of the most common complaints after a traumatic brain injury. Headaches can impact work and school performance, social interactions, and family life. For those interested in learning more

about headaches after Traumatic Brain Injury, be sure to come to the next TBI Model System Forum, where we will get to hear several doctors from the TBI Model System discuss headaches after TBI, or post traumatic headache (PTH).

As we reported early last year, we began a study that is investigating headache prevention after mild Traumatic Brain Injury (TBI) with a medication called Amitriptyline. This study is ongoing and actively recruiting patients who have a had a mild TBI. Now in addition, there is a study that is investigating the treatment of post traumatic headache in people who have experienced a moderate to severe TBI,

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and this study is called the *TWIST* study.

TWIST: Treatment With Sumatriptan for TBI Headache

What will this study be doing?



The **TWIST study** will be investigating how people experience their headaches and whether treatment with Sumatriptan (also known by the brand name, Imitrex™) is effective in treating post-traumatic headache pain in people who have had a moderate to severe TBI. Since 1991, Sumatriptan has been FDA approved and can be prescribed to treat migraine headache in the general population; so Sumatriptan itself is not new, but using it in the TBI population is new.

The mechanism of post-traumatic headache (PTH) is not well understood. PTH may come in many forms, often including tension-type pain and intermittent migraine-like attacks. Once post-traumatic headaches occurs, the cycle of ongoing headaches can be more complicated and difficult to treat. If treatment is started early, posttraumatic headache may not become a permanent problem. Because we want to see if the medication will work early after injury, enrollment for this study will take place between 3–12 months after brain injury and is for people who are having between 4-15 headaches per month. Participants in this project will track their headaches using a headache diary (daily questions about activities and headache characteristics). If you are interested in participating in this study, please call or email Leslie at (206) 543-0219 or ette@uw.edu.

TWIST Study Daily Headache Check
Headache Tracker

Have you had a headache today?

☐ Yes

☐ No

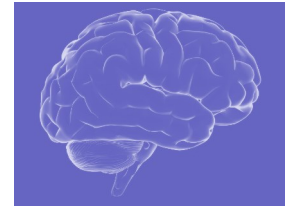
Study Contact:

Leslie Kempthorne ette@uw.edu

(206) 543-0219



Are there any other studies that are researching headaches after TBI at UW?



The APP Study:

Researchers at our TBI Model System became interested in testing possible treatments which could prevent headache from developing into *chronic* headache. This study is looking at whether early treatment with a medication called, “Amitriptyline” can help prevent the development of chronic headache after a mild traumatic brain injury. Amitriptyline is commonly prescribed for treatment of depression. Participants in this study must have had a **concussion, or mild TBI, within the last 12 weeks**, and must have experienced headache after injury. There are 2 groups: one group begins the study medication right away and the other group will start 30 days after they begin the study. Each day while in the study, headaches are tracked using the headache diaries, which has participants rate the frequency and characteristics of each. If Interested, Contact: Danielle Lozier, dlozier7@uw.edu, (206)744-5196.

Botox Study:

This study will provide evidence on whether the use of BOTOX®, an FDA-approved therapy for treatment of chronic migraine, shows similar effectiveness for treatment of chronic post traumatic headache. Patients must be within **3 months to one year of a mild traumatic brain injury** with recurring migraine or probable migraine headaches. Eligible subjects will receive injections of study medication every 3 months for 9 months. Subjects will keep a headache diary while they are enrolled. This study requires 5 visits to the UW Headache Clinic. If Interested, Contact: Elisa McGee, emcgee@uw.edu, (206)598-9260.

Participating in research studies is voluntary and will not affect the care you receive at Harborview Medical Center or University of Washington Medical Center.

Who's Who?

Danielle Lozier



We want to welcome a new member to the TBI Model System! Danielle Lozier, recently relocated to Seattle, and joined the TBI Model System in February 2014. Danielle recently graduated from The University of Vermont in May 2013 with a degree in Neuroscience. Danielle completed her thesis on neuroimaging for concussions, and knew that she wanted to gain more experience in clinical research. Her primary focus will be working on the APP study, aimed at determining the safety and efficacy of Amitriptyline to prevent post-traumatic headaches. When she isn't working at Harborview Medical Center, Danielle enjoys running, biking, and exploring the mountains of Washington.

A unique way to look at information:

The TBI Info Comic Project

Since December 2012, Silas James has been working on developing an idea to make information about TBI more accessible and in a visual format. Initially referred to as the "TBIMS Graphic Factsheet project", this project has recently been funded to produce and distribute eight educational comics about the symptoms of TBI and how to deal with them. As the project has developed, a new name has been chosen, the **TBI Info Comic Project**. The project is in the final stages of defining the strategy for getting the educational comics to the target audience, and then evaluating the response of readers. There have been focus groups recently to help in the development of future educational comics, and there may be more of those to come. This is an exciting, and unique way of educating the public on the various issues that have been approached with the TBI Factsheets generated by the TBI Model System. Stay tuned for more updates and information about how the project evolves. Silas James, Project Manager for the TBI Info Comic Project, will be giving an update in the next newsletter on the progress—so stay tuned on how you may be able to help.

Learn more about Headache after TBI

We welcome all to come and join us for our next informational event, on May 14th, 2014 at 6:30pm at the University of Washington's South Campus Center Building (Located just behind the University of Washington's Medical Center). The TBI Model System presents several events throughout the year, to educate and discuss issues related to Traumatic Brain Injury. Our next scheduled event will focus on:

“Headache after Traumatic Brain Injury”



Speakers:

Dr. Jeanne Hoffman, Ph.D.

(Lead Researcher on Natural History of Headache Studies)

Dr. Kathleen Bell, M.D.

(Medical Director, TBI Rehabilitation)

Dr. Sylvia Lucas, M.D., Ph.D.

(Director, Concussion Headache Clinic)



Event Details:

May 14th, 2014

6:30pm—8:00pm

University of Washington

South Campus Center Building

Room 303

Traveling after a TBI

We were fortunate to have **Anne Crylen** and **Marilee Goebel** present at our January 2014 Forum. Both Anne and Marilee are TBI survivors, and we really appreciated their presentations at the University of Washington's South Campus Center. If you were not able to make the forum, we wanted to summarize some of the great information that they offered.



Preparation is KEY !

Both Anne and Marilee enjoyed traveling before their injuries, and shared some valuable tips from their experiences. Getting back to traveling to far off places was something that both of them felt was necessary to regaining part of who they were.

Healing after a brain injury takes time, and this needs to happen on a personalized and individual plan. Taking recovery in small steps, planning, and setting goals is important. For Anne, who sustained a head injury 22 months ago, early in recovery she first started getting around by bus with friends. It was difficult at first. Within a few months, with the help of friends, she then traveled home to Chicago. With friends accompanying her on that trip, she learned things along the way, and felt a sense of accomplishment. For Anne, the next step was traveling alone, and having someone meet her at the gate. Help with navigating the airport and baggage claim was needed, and Anne learned which airlines were most helpful and gained insight into how to get her needs met. Anne has gone on to travel extensively both domestically and internationally, and has become

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an advocate for survivors of Traumatic Brain Injury.

For Marilee's first flight after her injury she and her husband decided to do a "dry run" at the airport just to get used to the noise and commotion at the airport to help her prepare. Her first flight was a short 45 minute flight to the other side of the state to visit family. By traveling to a familiar place, Marilee felt a sense of accomplishment without the added challenges of figuring out a new landscape. Sometimes referring to her travel items as "armor", Marilee is well prepared for the sights and sounds that can pop up during traveling.

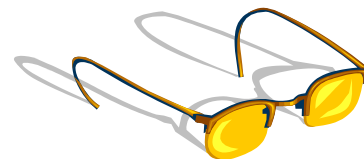
Some of the items that she finds especially helpful are:



Sunglasses



**Noise cancelling headphones
or musicians earplugs**



**Dark tinted glasses
for brightly lit places**

**All of the above can provide a barrier to the outside
world if needed**

A final reminder that our speakers left ended the presentation on was this....

Remember to allow yourself some downtime.

Schedule downtime into your plans, and try to pace things a little differently than you used to. Sometimes the best times of traveling are the times we spend just relaxing together.

If you would like to hear more on traveling after TBI in the future, let us know by visiting our website, and giving us feedback. We look forward to seeing you all at our next forum! (See Page 5 for details).



Traveling after TBI

Helpful Tips

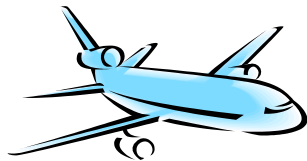
Hotels:



If you think you might need to minimize noise or distractions while staying in a hotel, consider calling to:

- **Ask for a quiet room.** This might mean a room away from a courtyard or pool.
- **Ask if they are doing any construction or renovating,** which might be noisy.

Flying:



If you think there might be accommodations that you need, consider calling the airline directly to ask before your ticket is purchased. You can search for flights online, and then call the airline directly once you choose the best option. The only way to find out whether something is possible, is to ask. So if having someone with

you, while you go through security is needed, let the airline know ahead of time.

- **Get the right seat.** This might mean having an aisle seat, or a seat that is further from the wing of the airplane. (Sometimes the noise over the wing is too intense for those who are noise sensitive.)
- **Priority seating might be needed.** When you get to the gate, if you let the crew know that you have a disability; you do not have to state the specifics of your disability. The noise and activity in the airport terminal can be overwhelming, and/or if extra time is needed to get your things settled before the plane departs.
- **Stay hydrated.**
- **Bring medications** in the original packaging, and prepare for possible delays by bringing extra.
- Consider bringing noise canceling earphones, earplugs, sunglasses, or any other items that might help with any sensitivities to lights and sounds.


Save the Date

4th Annual Walk, Run, & Roll for Thought 2014



Sunday, July 27th, 2014
Magnuson Park
Seattle, WA

WALK, RUN & ROLL
FOR THOUGHT
Because Your Mind Matters
2014

 **Brain Injury Alliance —**
WASHINGTON

 **Seattle BrainWorks**
a program of PREVAL

Compete For PRIZES!
Pledge Goals
Individual \$100.00
Team \$500.00

To register or learn more [Click here](http://biawa.org/walk2014.php), or visit the following link: <http://biawa.org/walk2014.php>

Save the Date!

The 2014
B.I.G.
brain injury gala

The Gala & Auction is the largest Brain Injury fundraiser in the country.

Event Date: **Saturday, November 1, 2014**
Location: **The Westin Seattle Hotel**

Formerly known as Brain Injury Association of Washington.



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. Services through the Resource Center include:

[Statewide Toll-Free Resource Line](#)

[In-Person Resource Management](#)

[Pediatric Services](#)

Recruiting African American and Latino/Hispanic Caregivers of Individuals with TBI for a Health Information Needs Study

Model Systems Knowledge Translation Center Research Study

Are you an African American or Latino/Hispanic partner, family member, or caregiver of someone who sustained a traumatic brain injury in the past five years? Would you like to share your experience in research to help others in the future?

The Model Systems Knowledge Translation Center (MSKTC) is recruiting African American and Latino/Hispanic individuals over 18 years old who are the primary caregivers of someone who sustained a traumatic brain injury in the past five years. Participants will participate in an interview about caregivers' health information needs.

Participants will be compensated \$75.

The study is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and conducted by the American Institutes for Research (AIR) and George Mason University. The study has been approved by the Institutional Review Board (IRB) at AIR. If you are interested, please call (202) 403-5531 or email msktc@air.org for more information.

See more at: <http://www.msktc.org/tbi/recruitment/Health-Information-Needs-Caregivers/#sthash.jlJPXOL4.dpuf>

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