

Brain-e-News

SPRING 2018

RESOURCES

MOSS REHABILTATION RESEARCH INSTITUTE www.mrrl.org

MOSSREHAB RESOURCE NET www.mossresourcenet.org

THE CENTER FOR OUTCOME MEASUREMENT IN BRAIN INJURY www.tblms.org/combl

BRAIN INJURY ASSOCIATION OF AMERICA WWW.BIAUSA.ORG

BRAIN INJURY RESOURCE LINE 1-800-444-6443

BRAIN INJURY ASSOCIATION OF PENNSYLVANIA www.blapa.org 1-866-635-7097

BRAIN INJURY ALLIANCE OF NEW JERSEY www.blanj.org 1-732-745-0200 FAMILY HELPLINE 1-800-669-4323

BRAIN INJURY ASSOCIATION OF DELAWARE www.blausa.org/Delaware/bla.htm 1-800-411-0505

PENNSYLVANIA DEPARTMENT OF HEALTH BRAIN INJURY HELPLINE 1-866-412-4755 TTY 1-877-232-7640

MODEL SYSTEM KNOWLEDGE TRANSLATION CENTER (MSKTC) www.msktc.org

www.Brainline.org

Pain Study Wraps Up — With Encouraging Results



Pain is a common problem after severe brain injury, but many patients are unable to tell us about their pain until they regain consciousness and are able to communicate. As a result, they may receive the wrong amount of pain medication, or none at all.

In this study we developed a measure of pain that doesn't rely on communication—the Traumatic Brain Injury Pain Assessment Measure (TBI-PAM). This is a scale in which we rated certain behaviors, such as moaning, rocking, and making a distressed facial expression, and used physical measurements such as blood pressure and pupil size, to see if we could determine the presence of pain from a combination of those signals.

In collaboration with Glostrup Hospital in Copenhagen, we enrolled more than 150 patients with severe TBI and observed each person on two days. On one day they received acetaminophen (Tylenol) and on the other day, no acetaminophen. Each day they were observed in different rehabilitation activities that one would expect to be more and less painful—for example, sitting quietly in a chair versus being "manipulated" during Physical Therapy.

We were excited to find that 10 of the scale items turned out to be good measures of pain, and that they could be reliably rated with only 10 minutes of observation. Importantly, the scores observed on acetaminophen were lower than the no-medication scores, and the scores during activities such as Physical Therapy were higher than those taken during rest. These findings demonstrate that the TBI-PAM may be able to be used to guide pain treatment for patients with severe brain injury before they regain the ability to communicate.



Moss TBIMS Launches New Collaborative Projects

In every 5-year cycle of the Traumatic Brain Injury Model System (TBIMS) program, clusters of centers get together to conduct collaborative studies called Modules. A module project is proposed by each center that receives funding in a given cycle, and other centers "sign on" to projects that interest them. **Continued on page 2**



The Faces of the TBI Model System: Jennifer Keller

Jennifer Keller, a Clinical Social Worker with a Masters in Social Services from Bryn Mawr, joined the TBI Clinical Research Laboratory in January of this year. Jen is already immersed in the BRITE study (Brain Injury- Improving Transition Experience), a pragmatic trial running in 6 TBI Model System sites and funded by the Patient-Centered Outcomes Research Institute. Before coming to Moss, Jen worked for 10 years at the Quaker School in Horsham, and she also has experience in pediatric and adult oncology, including work in clinical trials, at Fox Chase Cancer Center.

When asked what she likes to do in her spare time, Jen sighed deeply and noted that she loves to read, but that she has three teenagers and two dogs at home. We understand, and sincerely appreciate the time and expertise that Jen devotes to her new role at Moss. Welcome, Jen!



New Collaborative Projects (cont'd from page 1)

The Moss TBIMS has signed up for 4 module projects in the 2017-2022 cycle, as described below. These projects are just getting started, so we'll follow up with progress reports in future issues of *Brain e-News*.

Led by the University of Alabama TBIMS, the **driving module** seeks to learn more about return to driving after TBI—a very important topic because it means independence for many people. In this module, we will interview participants to find out when and if they have resumed driving, and how their driving safety has (or has not) changed since the injury and what factors affect safety. We'll also learn more about how driving is related to emotional well-being and independence in the community.

The TBIMS at Craig Hospital (CO) is leading the **crosswalk module**. "Crosswalk" is a statistical term that refers to one's ability to predict one score or number from another that we think is closely related. For example, if you rated your headache pain on a 1-10 scale, and also filled out a pain questionnaire, we would expect those scores to be related to each other. But are they close enough that one score could be substituted for another? The crosswalk module will use the large database from the National TBIMS project to answer that question for several scales and measures, so we can cut down on duplication—and on the time participants need to spend on phone follow-ups!

The **physical activity module**, led by the University of Washington TBIMS, will examine whether people with TBI become less active over time and the potential consequences of lower activity. We will ask participants to wear wrist accelerometers (like "Fitbits") for a few days at several points after their injuries, and measure sleep, fatigue, and emotional status as well as physical activity to look at the interrelationships.

Last but not least, the **cognitive trajectories module**, led by the Mt. Sinai (NY) TBIMS, will examine the patterns of recovery of cognitive abilities (such as memory and attention/ concentration) over several years following TBI. Participants will take a brief series of cognitive tasks by telephone, each year for several years. We will see what patterns emerge and whether those patterns can be predicted, by age, general health, and other factors.

Brain Injury Association of Pennsylvania's Annual Conference



"Confronting the Challenges of Today for a Stronger Tomorrow" is the theme of this year's conference of the Brain Injury Association of Pennsylvania. Mark your calendars for Sunday, June 24th through Tuesday, June 26th at the Lancaster Marriott in Lancaster, PA. The conference offers

three days of keynote speakers, 18 workshops, social events, and networking for survivors, families and professionals. The keynote speakers on Sunday evening will be Dr. Grace Dammann and Mark Lipman. Dr. Dammann will share insights from her recovery process and Mark Lipman, filmmaker, will discuss the documentary that he produced about her recovery, *"States of Grace."* The film will be shown later that evening. JJ Virgin will present the Monday Keynote presentation, "You Are Stronger Than You Think," focusing on how caregivers can stay physically strong and healthy. Dr. Brian Greenwald will address the topic of agitation after TBI in a keynote presentation on Tuesday morning. Ajani "AJ" Murry, an actor with a disability, and Cynthia McFadden, AJ's mother, will talk about the importance of strength through a network of personal support during their keynote address on Tuesday afternoon. Information about the conference, including the registration brochure, can be found at **www.biapa.org.** June 24th-June 26th

Websites to Watch: MS Knowledge Translation Center



Model Systems Knowledge Translation Center

The Model Systems Knowledge Translation Center (MSKTC) summarizes research, identifies health information needs, and develops information resources to support the Model Systems programs in meeting the need of individuals with traumatic brain injuries, spinal cord injuries, and burn injuries.

Knowledge translation is the process by which new knowledge is transformed into information that benefits society through changed policies, behaviors, programs and practices. The Center maintains a website that consumers and professionals can access: www.msktc.org., as well as a blog spot, focusing on brain injury information: http://msktctbi.blogspot.com/



EMPOWERMENT and SUPPORT GROUP INFORMATION

PENNSYLVANIA EMPOWERMENT GROUP

The Elkins Park Empowerment Group meets on the second Monday of each month from 5-6:30 at 60 Township Line Road, Elkins Park, PA 19027.

For more info, contact Debbi Eisen at 215-663-6857, Bernadette Evangelista 215-663-6757, or, Jessica Dzurinko 215-663-6785.

NEW JERSEY SUPPORT GROUP

The New Jersey Support Group meets *most* months on the fourth Tuesday from 3:00-4:00 at 135 S. Broad Street, Woodbury NJ 08096.

For more info, contact Dayna Scott at 856-853-9900. MossRehab at Elkins Park Hospital 50 E. Township Line Road Elkins Park, PA 19027 ATTN: Lauren McLaughlin



The Moss TBI Model System

The National Institute on Disability, Independent Living and Rehabilitation Research has designated MossRehab as a Model System for traumatic brain injury since 1997. The TBI Model System program seeks to improve lives by creating and disseminating new knowledge about the course, treatment and outcomes of TBI.

