

Brain-e-News

RESOURCES

MOSS REHABILITATION
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

Moss TBIMS Welcomes New Researcher

The Moss TBIMS is delighted to welcome Amanda Rabinowitz, PhD to the TBI research faculty of Moss Rehabilitation Research Institute (MRRI). Amanda completed her doctoral degree in 2012 from The Pennsylvania State University, where she studied clinical psychology with a concentration in neuropsychology. She was then awarded two post-doctoral fellowships, one at MRRI where she was a trainee in the Translational Neuro-Rehabilitation training grant funded by the National Institutes of Health (NIH), the other at the University of Pennsylvania as a Ruth L. Kirschstein National Research Service Award Postdoctoral Fellow, also funded by the NIH, studying the role of neuronal injury in concussion-related cognitive dysfunction.



Amanda's TBI research to date has focused mostly on mild TBI in both athletes and clinical populations, and has included basic science research on diffuse axonal injury. At MRRI she will continue this focus, working to add a clinical research component to the busy Concussion Center at MossRehab. Her interests extend to moderate and severe TBI as well, and her work will capitalize on the Moss TBIMS's existing studies and rich opportunities within that population. Amanda is especially interested in the psychological outcomes of TBI, and in only a few weeks since joining MRRI, she has begun to develop projects that will improve our understanding of emotional outcomes and point us in new directions for effective treatment. In addition, she has already begun working with TBIMS collaborators nationwide on projects using the National Database. In her (relatively scarce) spare time, Amanda enjoys cooking, yoga, and chasing after her energetic toddler.

Welcome, Amanda; we're very happy—and lucky—to have you on board!

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 pm at 60 Township Line Road, Elkins Park, PA 19027.

For more info, contact
Debbi Eisen at 215-663-6857.

NEW JERSEY SUPPORT GROUP

The New Jersey Support Group meets on the Fourth Tuesday of each month from 3:00-4:00 pm at 135 S. Broad Street, Woodbury, NJ 08096.

For more info, contact
Dayna Scott at 856-853-9900.

Federal Interagency TBI Research

As of January 15, 2015 we have been participating in a year-long pilot study to evaluate the feasibility of incorporating our TBI Model System study data into a larger database known as the Federal Interagency Traumatic Brain Injury Research (FITBIR) informatics system. This database is funded by the National Institutes of Health, partnered with the Department of Defense, and its purpose is to serve as a central and secure data repository for a variety of TBI databases, for use by multiple researchers, treatment centers, and communities.



Newly enrolled TBI Model System participants as well as participants who are receiving their follow-up interviews are being asked whether they would like to participate in this pilot study, which simply involves our sharing their Model System data anonymously with this FITBIR database. FITBIR houses both qualitative as well as quantitative data surrounding TBI, ranging from questionnaires and surveys to imaging and research findings. FITBIR allows for researchers to collaborate, share data, and re-analyze existing data in hopes of not only accelerating research, but also creating a common and centralized space for TBI researchers to communicate and compare results across studies (and multiple studies on the same individual).

We are excited to be a part of such a synergistic system and we hope to contribute to this expanding TBI research effort.



Websites to Watch: www.clinicaltrials.gov

This useful site puts information about clinical trials (treatment studies) at your fingertips. Type “traumatic brain injury” into the search box on the home page, and you will immediately see that there are 784 trials registered... click on the global map and you will find that 480 of them are in the US. Further easy-to-use search tools will help you find treatment studies in your region on topics that may be of interest, and tell you whether the studies are open or closed to enrollment. Clinicaltrials.gov is a good place for researchers and research participants to get together, and for everyone to be able to see the results when studies are completed.

Rehabilitation Access for Patients with Severe Brain Injury

In the 1980s' fee-for-service health insurance market, patients with prolonged unconsciousness after brain injury ("disorder of consciousness" or DOC) were admitted to intensive "coma stimulation" programs, sometimes for months at a time. The overuse of such programs and the lack of clear evidence of benefit led many insurance companies to shut the door to rehabilitation facilities for patients with DOC. Currently, most patients who do not regain consciousness by the time they are able to leave an acute care hospital either go to a skilled nursing facility or to their family's home with support services. This means that many patients with the most severe brain injuries never receive comprehensive brain injury rehabilitation.

A joint task force of the TBI Model System and the American Congress of Rehabilitation Medicine's Brain Injury Interdisciplinary Special Interest Group are working to change that. Task force members believe there is benefit to early evaluation and treatment by brain injury rehabilitation specialists, not only to promote quality care at the outset but also to enhance care at a skilled nursing facility, since they will have a connection to a specialist should future needs arise.

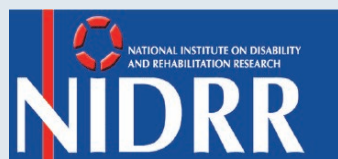


One of the first activities of the joint task force was to organize the publication of a collection of articles relevant to the care needs of individuals with DOC (Archives of Physical Medicine and Rehabilitation, Volume 95, Supplement 1, 2014). These articles, written by researchers and clinicians from the United States and Europe, demonstrate that a substantial proportion of patients who make it to rehabilitation in an unconscious state regain consciousness and improve rapidly during their rehabilitation stay. Moreover, nearly a quarter of these individuals eventually are able to live independently. The articles also document the large number of complex medical problems that such patients experience early on, suggesting the need for specialty care during this phase. Finally, the articles present descriptions of innovative care models for patients with DOC and cutting-edge prognostic evaluation strategies that promise to improve care. Establishing such a system of care would not only improve the management of current patients with DOC, but would also accelerate research, with subsequent improvements in clinical management.

What's In a Name? Our Funding Agency Becomes NIDILRR

Due to reorganization at the federal level, the National Institute on Disability and Rehabilitation Research (NIDRR), which has funded the Moss TBIMS and other centers since the inception of the TBIMS program in 1987, has moved under the aegis of the Administration for Community Living (ACL) in the Department of Health and Human Services. Accordingly, NIDRR's name has been changed to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

The core mission of NIDILRR is to award grants and contracts that maximize the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities, especially individuals with the most significant disabilities; and improve the effectiveness of vocational rehabilitation and other rehabilitation services. Thus far the move to ACL appears to be a smooth one, and we wish our federal partners well as they complete this transition.





MossRehab at Elkins Park Hospital
50 E. Township Line Road
Elkins Park, PA 19027
ATTN: Kelly Bognar

The Moss TBI Model System

The National Institute on Disability, Independent Living and Rehabilitation Research has designated MossRehab as a Model System of Care 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.

**The Traumatic
Brain Injury
Model System
(TBIMS)
Centers for
the current
funding cycle
(2012-2017)**

