



Defense Health Board Meeting

March 9, 2009



Traumatic Brain Injury Family Caregiver Panel Update

**Margaret Campbell-Kotler MPH, RN
Manager, DVBIC Office of Education**

**Lead Agency: Defense and Veterans Brain Injury Center
A component center of the Defense Center of Excellence for
Psychological Health and Traumatic Brain Injury**



Presentation Objectives

- Review purpose of the TBI Family Caregiver Panel
- Review curriculum development process
- Describe modules, content, formats, pilot testing, refinement, distribution
- Review timeline
- Outline agenda for final panel meeting

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National Defense Authorization Act of 2007 (NDAA), Section 744

Mandated the establishment of a 15-member panel:

“to develop coordinated, uniform, and consistent training curricula to be used in training family members in the provision of care and assistance to members and former members of the Armed Forces with traumatic brain injuries.”

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National Defense Authorization Act of 2007 (NDAA), Section 744

- Law stipulates that certain categories of individuals must be included on the panel:
 - medical professionals specializing in TBI (combat TBI as well) including psychologists with expertise in the mental health treatment and care of TBI
 - family caregivers and representatives of family caregivers or family caregiver associations
 - DoD & DVA health & medical personnel with expertise in TBI
 - experts in the development of training curricula
 - family members of members of the Armed Forces with TBI
- Panel members were appointed after receiving DoD and White House approval on 6 March 2008

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DVBIC/DCoE Role

- Provide programmatic and logistical support to ensure
 - Development of curriculum according to congressional mandate
 - Content accuracy
 - Implementation and ongoing maintenance of the curriculum

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Tasks of the Panel

- Review literature and developing an evidence-base for the curriculum
- Develop consistent curriculum for TBI caregiver education
- Recommend mechanisms for the dissemination of the family caregiver curriculum throughout DoD and VA

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Benefits of Curriculum

- Uniform resource for caregivers through:
 - Consistent message
 - Tools for coping and gaining assistance
 - Giving hope while navigating life after TBI
- Curriculum will:
 - Be informative and accurate
 - Provide self management skills
 - Teach skills for communicating with health care and other teams
 - Be user friendly and culturally appropriate
 - Be based on real life needs and experiences



Modules

- Module 1- Lead Content Oversight - Anne Moessner
- **Introduction to TBI** (learning about the brain, causes and types of TBI, acute care issues, possible complications, recovery process, helpful suggestions)
- Module 2 - Lead Content Oversight – Dr. Sharon Benedict
- **Understanding Effects of TBI and What You Can do to Help** (physical, cognitive, communication, behavioral, and emotional effects; related practical strategies)



Modules

- Module 3 - Lead Content Oversight – Dr. Rose Mary Pries
- **Becoming a Family Caregiver for a Service Member/Veteran with TBI** (starting the journey, caring for your service member/veteran, caring for yourself, helping children cope, addressing family needs, everyday issues, planning for the future, becoming an advocate, finding meaning in caregiving)



Modules

- Module 4 - Lead Content Oversight – Dr. Barbara Cohoon
- **Navigating the System** (recovery care, eligibility for compensation and benefits, compensations, rehabilitation medical support, entitlements & benefits related to employment and community reintegration)



January 2009 Panel Meeting

- 17 of 22 panel members, 5 DVBIC staff, and curriculum writers in attendance
- Consensus to work with Center for Excellence in Medical Multimedia (cemm.org) for the multimedia component of the curriculum
- Consensus to work with the Henry Jackson Foundation for graphic design and packaging of the curriculum



January 2009 Panel Meeting

Caregiver Definitions

- Family Caregiver Panel Definition:
Any family or support person (s) relied upon by the service member or veteran with Traumatic Brain Injury, who assumes primary responsibility for ensuring the needed level of care and overall well-being of that service member or veteran.

For the purposes of the curriculum, “family” or “family caregiver” will include spouse, parents, children, other extended family members, as well as significant others and friends.



January 2009 Panel Meeting

Caregiver Definitions

- DoD/VA: Uses term “Committed Designee” in place of Caregiver *
- “Any person legally designated by the SM/V who provides support, deemed necessary by medical authority, to seriously injured or ill SM/V following the occurrence of wound or injury or onset of illness, to his/her recovery. These might include:
 - Parents, Siblings, Fiancées, or other family members or close friends



January 2009 Panel Meeting

- Intellectual Property Concerns

In accordance with 17 U.S.C. Sec 105

“Copyright protection under this title is not available for any work of the United States Government...”

The United States Government has no rights to designate copyright to a non-profit organization



January 2009 Panel Meeting

Intellectual Property Concerns

Any publisher can republish a U.S. Government work, but the publisher cannot itself legally assert copyright unless it has added original, copyright protected material. In such case, copyright protection extends only to the added original material



January 2009 Panel Meeting

- Discussion of Overarching Issues
 - Assure appropriate literacy level of the curriculum
 - Recommend medical providers receive orientation to the use of the curriculum
- Panel members offered specific additions/changes to modules 1-4
- mTBI/Concussion - a separate stand alone product to address the needs of service members with sequelae and their families



January 2009 Panel Meeting

- Panel members formed the following working groups for the remainder of the meeting
 - Design and Editing – Anne Moessner
 - Multi-media – Michael Welsh
 - Qualitative Process Review – Dr. Rose Mary Pries
 - Dissemination – Col Nancy Fortuin & Dr. Megumi Vogt



January 2009 Panel Meeting

Design and Editing Workgroup

- Writers and HJF graphic staff participated
- Final module editing assignments given
- Packaging options reviewed
- Graphic options reviewed
- Coordination with CEMM to ensure design continuity between print and on line versions
- 200 copies for Qualitative Review Process



January 2009 Panel Meeting

Multi-media Work Group

- CEMM participate via conference call
- 508 Compliant – Disability Access
- Work toward a Spanish language version
- Recommend links from DoD sites



January 2009 Panel Meeting

Qualitative Process Review Work Group

- Focus Groups were recommended
- Stratified by severity, caregiver relationship to patient, AD/VET status, geography
- Sample questions developed
- Goal of 150 total participants



January 2009 Panel Meeting

Dissemination Work Group

- Identified multiple audiences
- Determine when the curriculum will be given to families and by whom
- Command to receive a trifold tool summarizing purpose, contact information, important phone numbers and web sites.
- Provider instruction on use prior to curriculum being provided to families
- Distribute widely and often
- Need for timely and massive marketing campaign
- Dissemination for mTBI/ Concussion information will differ

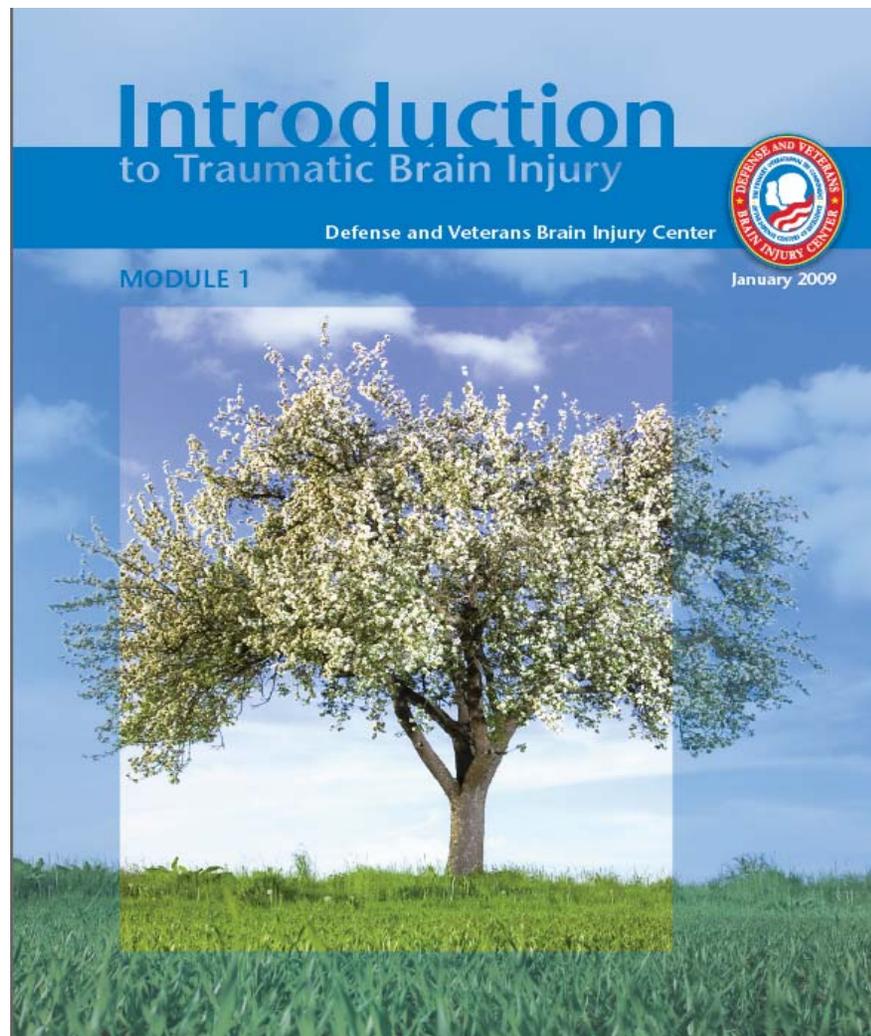
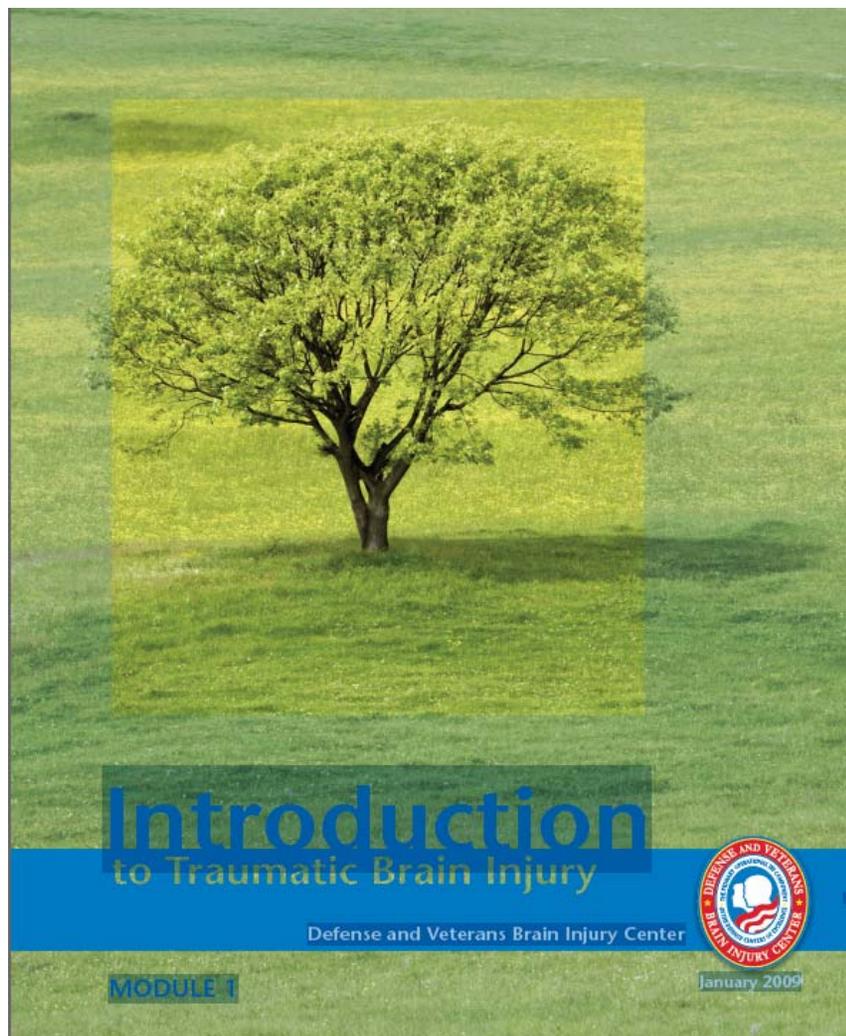


Progress

- Graphic Design – 4 separate modules each with spiral binding and 3 hole to be maintained together in one binder.
- Panel Editing and Design work group have been asked for input on logo
- Caregivers at WRAMC to review Module 1 at 8th grade and 10th grade literacy levels
- Content of all modules finalized



Progress





Progress

- CEMM reviewing all modules to assure website covers all topics of the curriculum
- Website - TBI The Journey Home
- Button on home page - The Caregivers Journey
- Will post curriculum modules as pdf on site

Traumatic Brain Injury: The Journey Home



Search:



Welcome to The Journey Home - the CEMM Traumatic Brain Injury (TBI) Web Site. This site provides an informative and sensitive exploration of Traumatic Brain Injury (TBI), including information for patients, family members, and caregivers. Topics include types and symptoms of brain injury, TBI treatment and recovery, and helpful insights about the potential long-term effects of brain injury. Animation is used to help patients clearly understand the brain, and the results of injuries to different parts of the brain. Survivors and their caregivers share courageous stories about their own experiences, providing down-to-earth facts along with inspiration and hope. [Watch Program Introduction Video Now!](#)

The Brain



The anatomy and physiology of the brain, including an interactive brain to explore

[click here to enter](#)



Mild TBI



The most common form of brain injury, also known as concussion

[click here to enter](#)



Moderate to Severe TBI



Information about treatment, recovery and long term effects for patients with more severe brain injuries and their caregivers

[click here to enter](#)



Caregiver's Journey



Traumatic brain injury in combat commonly overlaps post traumatic stress disorder

[click here to enter](#)



Personal Journeys



Personal Journeys: Real Life Stories of TBI Survivors and their Families

[click here to enter](#)





Progress

- Writers are interviewing family caregivers to include their stories in the curriculum
- Identified an existing contract with TMA to obtain consultants to conduct the focus groups



Timeline

- May 2009 Finalize curriculum, graphics
- July 2009 Multi-site focus groups, refine curriculum
- August 4-5, 2009 Panel meeting (tentative)
- August – September Revise curriculum as needed

- October 2009 Final Meeting of Family Caregiver Panel
- November 2009 Curriculum is approved by DHB
- December 2009 Dissemination begins
- December 31 Report to Congress



August 2009 Panel Meeting Agenda

- Review final print product
- Refine Marketing and Dissemination Plan
- Discuss maintenance of curriculum content



TBI Family Caregiver Panel

Questions?