



Defense Health Board Meeting

August 17, 2009



Traumatic Brain Injury Family Caregiver Panel Update

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TBI Family Caregiver Panel Chair

Lead Agency: Defense and Veterans Brain Injury Center
A component center of the Defense Centers 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, qualitative review, refinement, distribution
- Review timeline
- Outline agenda for final panel meeting (October 14 and 15, 2009)

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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 06 March 2008

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DVBIC 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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Caregiver 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



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



Modules

- Module 3 - **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 - **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

- Final work groups formed for completion of project:
 - Design & Editing
 - Multi-media
 - Qualitative Process Review
 - Dissemination
- Decision made to create a separate Mild TBI Patient Education Guide



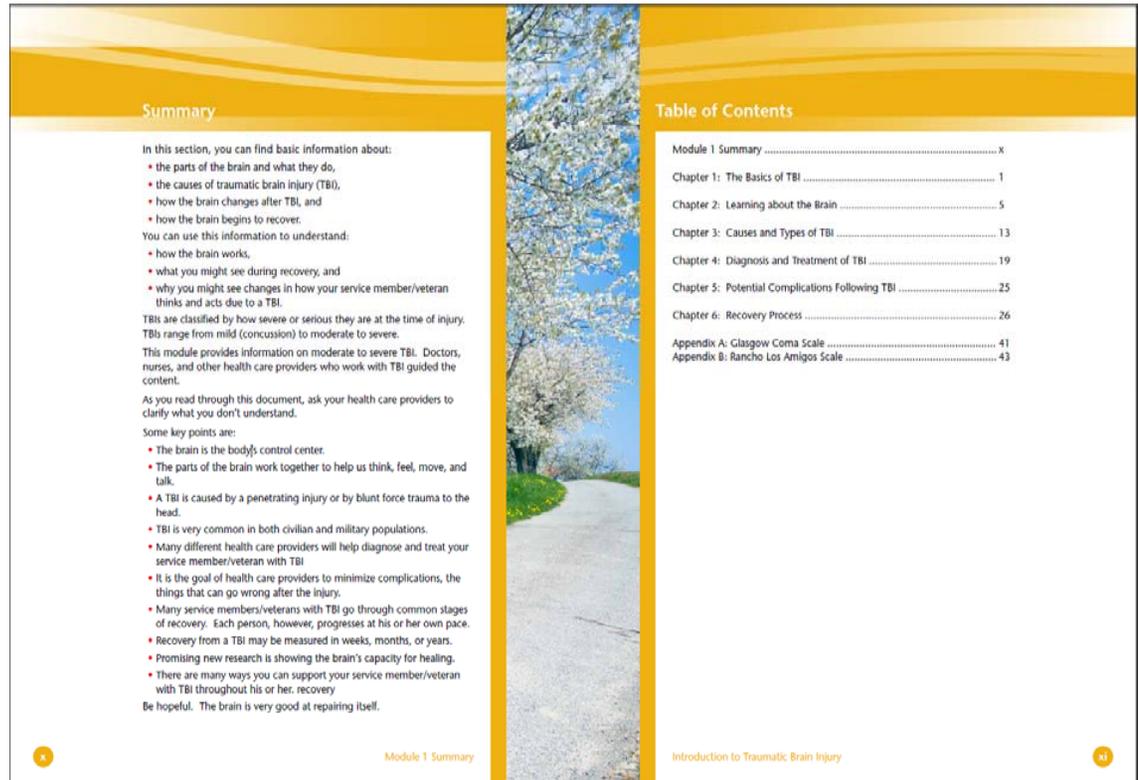
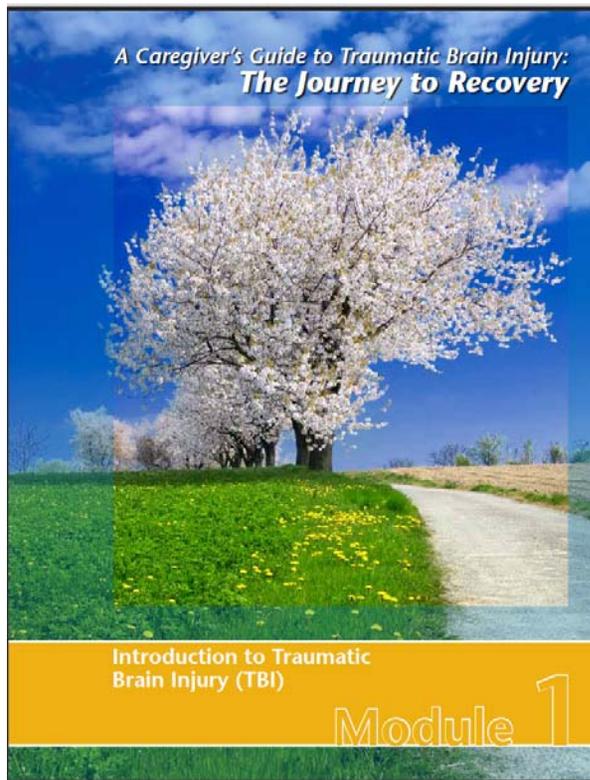
Design & Editing Update

- Final module editing including content, vignettes, graphics, layout, and packaging
- Acknowledgments completed
- Consensus for 8th grade reading level
- Workbook (similar to “Keeping it all together”) designed and finalized
- 100 copies printed and packaged for Qualitative Review Process



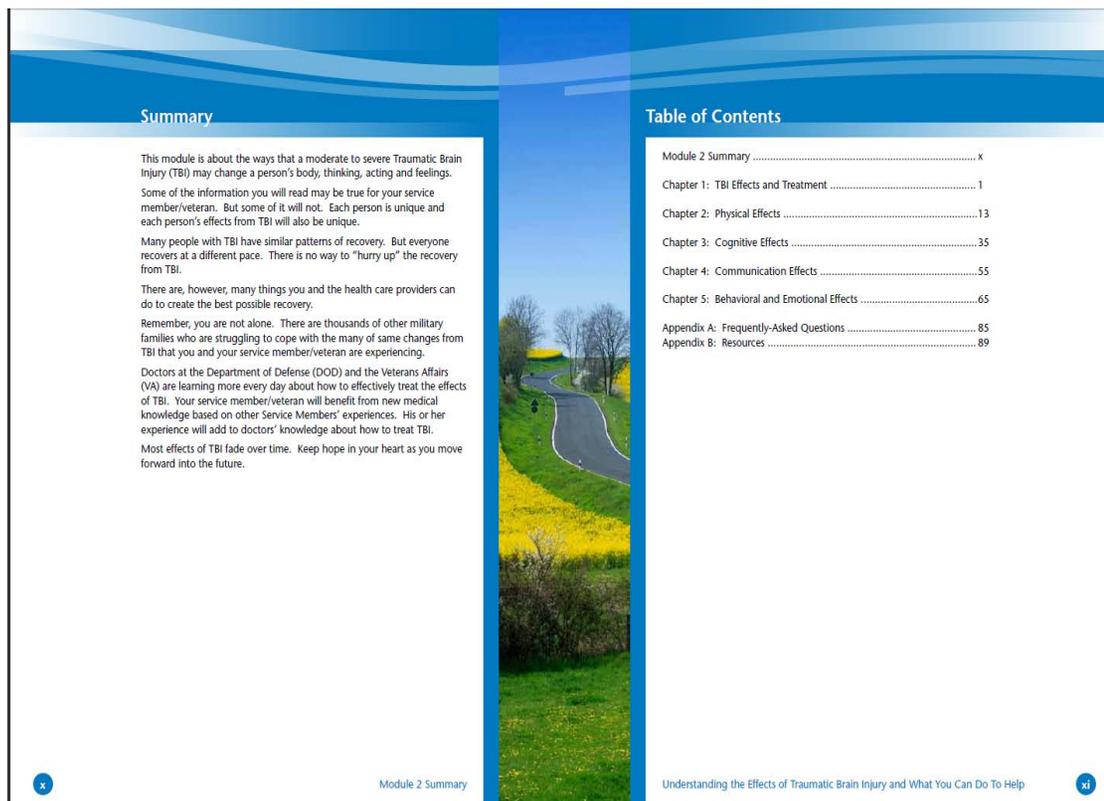
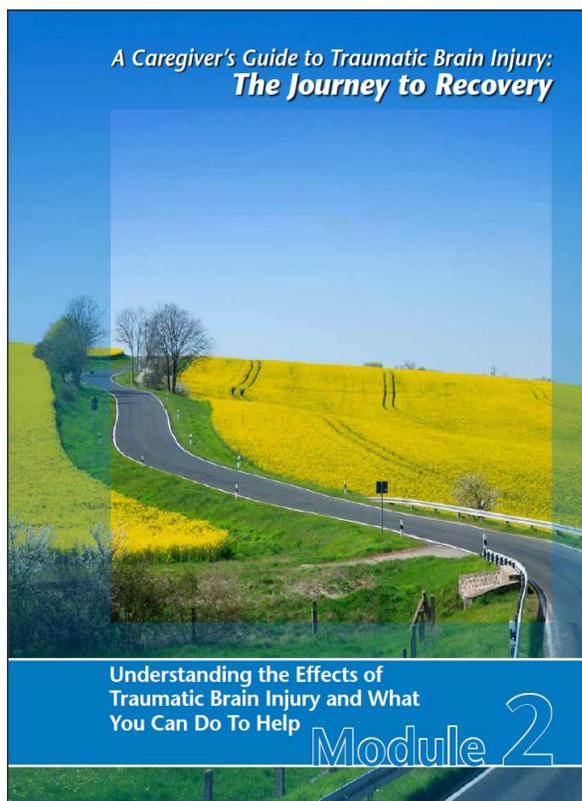


Design & Editing Update



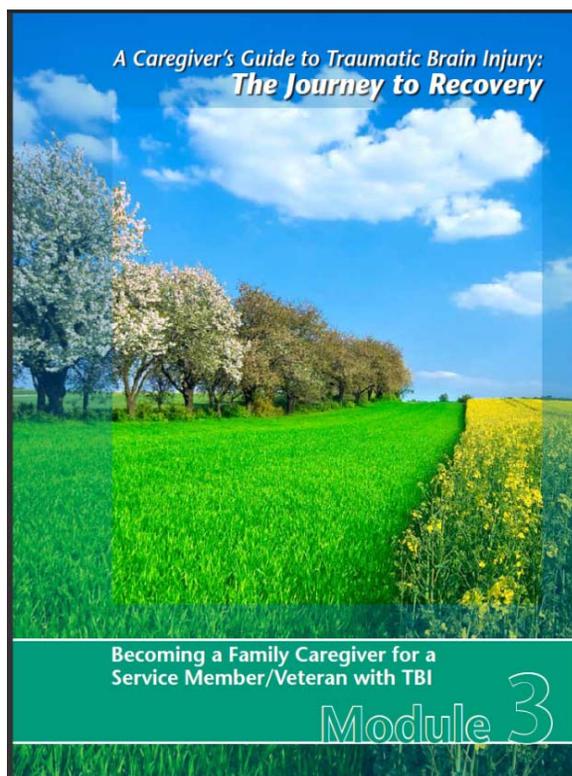


Design & Editing Update





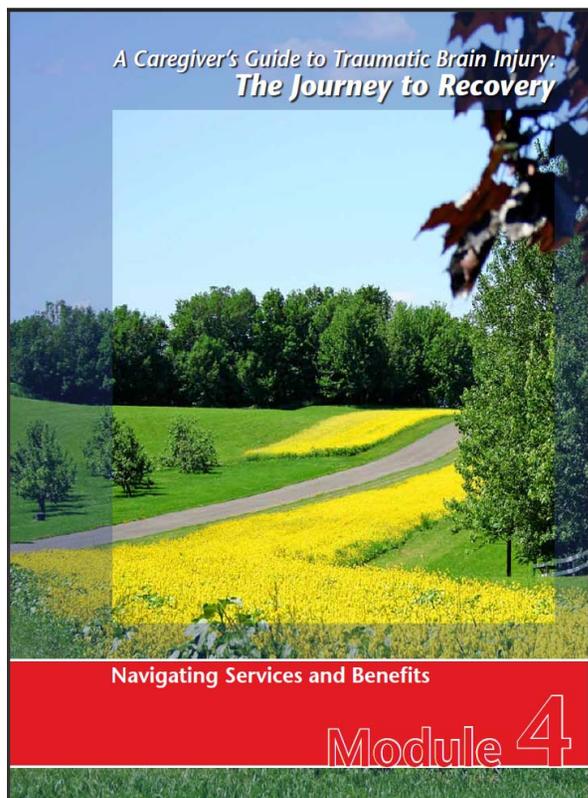
Design & Editing Update



Summary		Table of Contents	
<p>You play an important role in the recovery of your service member/veteran with TBI.</p> <p>You may be a spouse, parent, sibling, or friend. Your job as a caregiver may include being a:</p> <ul style="list-style-type: none"> • case manager • advocate • benefits coordinator, and • health care provider. <p>All of these roles may be new to you.</p> <p>This module focuses on helping you, the caregiver. It offers tips on how to get organized and get help. It also suggests ways to take care of yourself while caring for your family member.</p> <p>Some of the main ideas in this module are:</p> <ul style="list-style-type: none"> • Get to know the members of the health care team and the case managers. They can and will help you during the hospital stay, during recovery, and when your service member/veteran comes home. • Keep health care and military information about your service member/veteran in a notebook. Being organized helps you feel less stressed. • Talk about your needs and the needs of your service member/veteran to others (advocacy). • Take care of yourself first, so you can take care of your service member/veteran. • Take time and be honest when helping children and other family members cope with TBI. • Allow your friends and family to build a support network to help you. Ask for help. No one can do it alone. • Plan for some time off. Respite care and day care programs are valuable resources to you and your service member/veteran. • There are ways to balance work and caregiving through Family and Medical Leave and other means. • There are key legal issues to address to protect your family and your service member/veteran. <p>Much of the information in this module was guided by family caregivers of Service Members who suffered a TBI.</p>		<p>Module 2 Summary x</p> <p>Chapter 1: Starting Your Caregiving Journey 1</p> <p>Chapter 2: Taking Care of Your Service Member/Veteran with TBI 3</p> <p>Chapter 3: Becoming an Advocate 7</p> <p>Chapter 4: Taking Care of Yourself 15</p> <p>Chapter 5: Helping Your Children Cope with TBI 31</p> <p>Chapter 6: Addressing Family Needs 41</p> <p>Chapter 7: Transitioning to Home 49</p> <p>Chapter 8: Moving Forward 71</p> <p>Chapter 9: Addressing Everyday Issues 83</p> <p>Chapter 10: Legal Issues to Help You Plan for the Future 87</p> <p>Chapter 11: Finding Meaning in Caregiving 95</p> <p>Appendix A: Forms 99</p> <p>Appendix B: Resources 101</p> <p>References/Credits 112</p>	



Design & Editing Update



Summary

This module is about benefits and services from the Department of Defense (DoD) and the Department of Veterans' Affairs (VA). Being a member of the military brings both honor and support. You want to be sure your family member gets the support—services and benefits— that he or she deserves.

It can be hard to find your way through the maze of programs at DoD and the VA. The good news is that you are not alone. There are many caring professionals at both agencies who can guide you. Your family member will also have a Point of Contact (POC). He or she is the first person to turn to for information. (What this person is called depends on your family member's military branch.)

You also have an important role to play on your family member's behalf. **Part of being a caregiver is to be an advocate**, for both your family member and for you. You need to speak up, clearly and firmly, to communicate your and your family member's need for services and benefits. Understanding what services and benefits are available to you and your family member will help you feel more confident in advocating for them. That's what this module is all about.

The information in this module is current as of its publication. Information on services and benefits changes from time to time. Please check with your Point of Contact (POC) (see Chapter 1) for updated information. He or she can also advise you about where to look for information you need.

You can start your search with these main Web sites:

- www.tricare.mil
- www.health.mil
- www.va.gov

If your service member/veteran has passed away due to his or her military injuries incurred during active military duty, you will surely have many questions to consider in the midst of your grief. As a survivor, you are eligible for special benefits. You can learn more about survivors' benefits at <http://www.vba.va.gov>.

Module 4 Summary

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Navigating Services and Benefits



Design & Editing Update

- Ongoing coordination with CEMM to ensure design and content continuity between print and on line versions.



Design & Editing Update

- Mild TBI Patient Education Guide
- Informal survey of existing products
- Goal for ~ 20-25 page product addressing complexities of mild TBI and overlay of PTSD, depression, combat stress, etc.
 - Aug. 15, 2009 – experts finalize content
 - Aug. 20, 2009 – to HJF Graphics for layout, graphics
 - Sept. 15, 2009 – distribute to Panel members
 - Oct. 14, 2009 – panel approval of content/layout, determination of marketing & distribution plans



Multi-media Update

- CEMM to assure web site covers all curriculum topics
- “The Caregivers Journey” button on CEMM web site
- Curriculum modules to be posted as pdf’s on site

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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 the Traumatic Brain Injury introduction video.](#)

The Brain	Mild TBI	Moderate to Severe TBI	Caregiver's Journey	Personal Journeys
				
The anatomy and physiology of the brain, including an interactive brain to explore.	The most common form of brain injury, also known as concussion	Information about treatment, recovery and long term effects for patients with more severe brain injuries and their caregivers	Information on the important role caregivers play in TBI recovery and resources for caregiver support and self care strategies	Personal Journeys: Real Life Stories of TBI Survivors and their Families
click here to enter	click here to enter	click here to enter	click here to enter	click here to enter

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DHB Defense Health Board CEMM The Center of Excellence for Medical Multimedia



Multi-media Update

- CEMM Website launched June 2009
- <http://www.traumaticbraininjuryatoz.org>
- “Caregiver’s Journey” button was formatted to visually match the cover of the curriculum such that it is easily recognizable by the caregiver as complementary to the written product.
- The “Caregiver’s Journey” section of the website will continue to evolve to include additional vignettes and interactive components as we continue to work with CEMM



Interactive Multi-Media

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Traumatic Brain Injury: The Journey Home

Search:

- Program Introduction
- The-Brain
- Mild TBI
- Moderate to Severe TBI
- TBI and Post Traumatic Stress Disorder
- Caregiver's Journey
- Personal Journeys
- Resource Center

INTERACTIVE BRAIN

Introduction Anatomy Overview

MENU maximize

play audio

DESCRIPTION

LEFT & RIGHT BRAIN FUNCTION

LEFT BRAIN
In most people, the left hemisphere of the brain is dominant for language, mathematical skills, and the ability to solve problems in a sequential order. For this reason, the left hemisphere is often considered the logical or analytical brain.

RIGHT BRAIN
The right hemisphere of the brain seems to be dominant in terms of artistic ability, musical skills, face recognition, and spatial perception. Problems tend to be solved in a more comprehensive, holistic manner by the right brain.

1 SIDE VIEW 2 INSIDE VIEW 3 VISION 4 LEFT & RIGHT BRAIN FUNCTION

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SELECT AN ILLUSTRATION FOR MORE INFORMATION.

1 SIDE VIEW 2 INSIDE VIEW 3 VISION 4 LEFT & RIGHT BRAIN FUNCTION

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- The-Brain
- Mild TBI
- Moderate to Severe TBI
- TBI and Post-Traumatic Stress Disorder
- Caregiver's Journey
 - Caregiver Information
 - Specific Concerns
 - Caregiver Tips
 - Living With Brain Injury-Post Rehabilitation Recovery
- Personal Journeys
- Resource Center

Video

▶ play video

Related Information

- Glossary
- Frequently Asked Questions

Difficult behaviors may include:

- irritability
- anger
- paranoia
- confusion
- frustration
- agitation
- insomnia or other sleep problems
- mood swings

Difficult behaviors may include:

- alcohol or drug abuse
- aggression and violence
- not following instructions or rules
- social inappropriateness
- emotional outbursts
- childish behavior
- decreased self-control, called disinhibition
- inability to take responsibility or accept criticism
- thinking only of themselves
- inappropriate sexual activity

These challenges can be short term, or long-lasting, Family members of patients with TBI often find that personality changes and behavioral problems



Qualitative Process Review Update

- A contract bidding process contract bidding process resulted in the selection of Alan Newman Research, based in Richmond, VA.
- Groups homogeneous in service and heterogeneous in: geographic location, relationship to patient, severity of TBI, time since injury, and status (Active Duty, Veteran, Reserve, and Guard)
- 4 Sites: Tampa VA, FL; Fort Bragg, NC; WRAMC, Washington DC; San Diego Naval Medical Center, CA
- Goal of 50 total participants



Qualitative Process Review Update

- Focus groups initially scheduled the weeks of 20 July and 27 July
- Groups put on hold because a complaint was submitted to Tricare Management Activities and the Human Research Protections Office of the U.S. Army Medical Research and Materiel Command regarding failure to obtain IRB approval for the conduct of focus groups to obtain consumer feedback on the curriculum.
- DVBIC prepared a formal response to the complaint and on July 17, 2009, Dr. Brosch, Deputy Office of Research Protections responded that the project was not research and that their file would be closed.



Qualitative Process Review Update

- Groups scheduled: July 27-August 07, 2009
- Aug. 7, 2009 Focus groups completed
- Aug. 21, 2009 Receipt of detailed oral report from contractor
- Sep. 7, 2009 Receipt of written report from contractor August 15, 2009



Dissemination Update

- Identify audiences, end users
- Need to determine who and when the curriculum will be given to families
- Recommendations:
 - Command to receive a tri-fold tool summarizing purpose, contact information, important phone numbers and web sites.
 - Provider instruction on use prior to curriculum being provided to families
 - Need for timely and massive marketing campaign
 - Separate dissemination for mild TBI Patient Education Guide needed



October 13-14, 2009 Panel Meeting Agenda

- Final approval of curriculum Modules 1-4 and Caregiver Companion
- mTBI Patient Education Guide review and approval
- Approve marketing and distribution plan curriculum and mTBI Patient Education Guide
- Recommend plan for maintenance of curriculum content



Timeline

- July 27, 2009 Focus groups commence
- Aug. 7, 2009 Focus groups completed
- Aug. 21, 2009 Receipt of detailed oral report from contractor
- Sep. 7, 2009 Receipt of written report from contractor
- Sept. 30, 2009 Curriculum revisions complete
- Oct. 14-15, 2009 Final panel meeting & approval of curriculum
- Oct-Nov., 2009 Forward final curriculum and mTBI Patient Education Guide to DHB
- Nov. 12-13, 2009 Curriculum approval by DHB
- Dec. 1, 2009 Dissemination of curriculum begins
- Dec. 31, 2009 Final report to Congress



TBI Family Caregiver Panel

Questions?