

**Defense Health Board Meeting  
4 September 2008**



**Traumatic Brain Injury Family Caregiver Program Update**

**Col (s) Michael S. Jaffee M.D.  
National Director**

Defense and Veterans Brain Injury Center

Primary Operational TBI Component of the Defense Centers of  
Excellence

**Overview**

- Review the purpose of the TBI Family Caregiver Program
- Report on outcomes of the 17-18 June meeting of the panel
- Summarize findings from the Town Hall meeting
- Outline next steps in the project

## **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.”

## **DVBIC Role**

Provide programmatic and logistical support to ensure:

- Development of curricula according to congressional mandate
- Content accuracy
- Implementation, evaluation and ongoing support for family caregiver education

## **Tasks of the Panel**

- Conduct a review of the literature on family caregiving for persons with TBI in both military and civilian populations
- Provide guidance to health education writers on the development of consistent curricula for TBI caregiver education
- Recommend mechanisms for the dissemination of the family caregiver curricula throughout the DoD and DVA

## **17-18 June 2008 Panel Meeting**

- Purpose:
  - To appoint a Chairperson of the FCP
  - To approve a definition of family caregiver for the purpose of guiding the curriculum content
  - To develop an outline of content for the curriculum writers
  - To establish work plans
  - To hold a town hall meeting

## **Outcomes from June 2008 Meeting**

- **Chairperson:** Anne Moessner, RN, MSN, CRRN – TBI Clinical Nurse Specialist; Coordinator Mayo Clinic TBI Model System
- **Definition of Family Caregiver** – “Any family member 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.”

## **Outcomes from June 2008 Meeting**

(continued)

- **Outline of Curriculum Content** – Curriculum will be organized in 4 modules:
  - **Module 1:** TBI 101 (brain anatomy & physiology, understanding TBI and the spectrum of TBI)
  - **Module 2:** Physical, cognitive, behavioral and emotional sequelae after TBI and guidance on adaptation to clinical condition.

## Outcomes from June 2008 Meeting

- **Module 3:** Caregiver Needs, Resources and Tools
  - Outline and first draft of the written document currently prepared
  
- **Module 4:** Understanding the military and veterans' health care system & benefits programs
  - Initial draft will be a team effort between two panel individuals with multi-year experience with VA (Dr. Sharon Benedict & Gretchen Stephens, DVBIC staff, health education writers, & other panel members)
  
- **Curriculum Dissemination –**
  - Multi-media: web, print CD and other appropriate communication technologies
  - Discussion of coordination with Center of Excellence for Medical Multimedia

## Outcomes from June 2008 Meeting

(continued)

- **Credentialing:**
  - Panel members considered this issue, in response to questions raised by family caregivers regarding whether the curriculum would provide a credential in providing care of a service member/veteran with TBI.
    - Panel members felt that “certification” would imply that the individual was observed by an impartial professional in the performance of caregiving tasks or interactions.
  - Organizations such as the American Red Cross have moved away from offering certification BLS & ALS and instead provide a certificate of course completion.
  - Panel members were unanimous in their opinion that providing credentialing or certification was beyond the scope of this curricula.

## **Town Hall Meeting**

- Purpose: To allow the general public an opportunity for input into the curricula
- Held in the evening after the first meeting day of the family caregiver panel.
- Wide dissemination of meeting via list serv, broad agency announcements, electronic flyer, postings, etc.
- Web streamed
- Record remained open for comment through 30 June 08
- Website available for viewing through 17 Sept 08

## **Town Hall Meeting**

- 30 people attended the town hall in person and 7 individuals watched the town hall via webcast. 10 attendees spoke at the meeting. 4 members of the audience were survivors of TBI
- Represented organizations included:
  - Maryland BIA
  - The Quality of Life Foundation
  - VA Office of Chaplain Affairs
  - American Psychological Association
  - Mental Health Association of Montgomery County, MD
  - VA Medical Center
  - WETA
  - The Office of Senator Clinton
  - JBS International
  - TRICAE Management Activity
  - Department of HHS (Office on Disability)
  - BIAA
  - AMRPA

## **Outcomes from June 08 Panel Meeting**

(continued)

Town Hall Meeting – Input into curricula and program

- Family caregivers from prior conflicts want to mentor today's family caregivers.
- Emphasize hope for recovery from TBI.
- Provide success stories of service members from diverse backgrounds who sustained severe, moderate, and mild TBI. Family caregivers (parents and spouses) are encouraged by these models.
- Providing information on the usual course of recovery from a TBI should be a high priority in the curriculum.

## **Outcomes from June 08 Panel Meeting**

(continued)

Town Hall Meeting – Input into curricula and program

- The curriculum must provide information and tools to enable family caregivers to navigate the military/veterans health & benefits systems.
- TBI survivors want more assistance in obtaining meaningful work. They do not want to be relegated to “mail room” type activities.
- Families want strategies to prevent burn out.

## **Outcomes from June 08 Panel Meeting**

(continued)

Town Hall Meeting – Input into curricula and program

- Not everyone has a family caregiver.
- The term mild TBI creates confusion because the term mild implies that it is not a serious condition & that recovery should be quick.

## **Curriculum Work Plan**

- 2008 Summer/Fall – health education writers, panel members, & DVBIC staff will write and edit the four modules of the curriculum.
- 13-14 November 2008 – the panel will convene to approve the curriculum, select evaluation metrics, identify sites & target populations for pilot testing.

## **Work Plan**

- 2008 December – Presentation of the curriculum to the Defense Health Board
- 2009 February – Pilot testing of the curriculum at two DVBIC sites
- 2009 March – Revisions to the curriculum based on findings from pilot
- 2009 April - Wide dissemination of the curriculum
- 2009 May – Evaluation of the Curriculum
- 01 August 2009 – Final Report

## **Benefits of Curricula**

- TBI Caregiver Curricula will provide a uniform resource for caregivers through
  - Consistent and concise message
  - tools for coping and gaining assistance
  - giving hope while navigating life post TBI
- Curricula will be
  - informative and accurate
  - provide self-management skills
  - teach effective communication skills for individuals with TBI and their caregivers to communicate with providers and healthcare teams
  - be user-friendly and culturally-appropriate
  - based on real life experience