



Defense Health Board Meeting

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Traumatic Brain Injury Family Caregiver Program Update

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Presentation Objectives

- Review the creation of the TBI Family Caregiver Panel
- Review the purpose of the TBI Family Caregiver Program
- Describe the needs of TBI Family Caregivers
- Summarize highlights of the first panel meeting
- Review Curricula Development Process

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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 (continued)

- 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 with the Program

- DVBIC inherited program from USUHS
- DVBIC/DcoE to provide programmatic and logistical support to ensure
 - Development of curricula according to congressional mandate
 - Content accuracy
 - Implementation, evaluation and ongoing effort for family caregiver education

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Tasks of the Panel

- Reviewing literature and developing an evidence-base for the curricula
- Develop consistent curricula for TBI caregiver education
- Recommending mechanisms for the dissemination of the family caregiver curricula throughout the DoD and DVA

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Panel Selection

- Panel nominees were selected via the following methods:
 - utilized DVBIC contacts within TBI field
 - guidelines provided by the law
- DVBIC prepared slate of panel nominees, Ex - Officio members (2), Expert Consultants (2), and Contingency Members (3)

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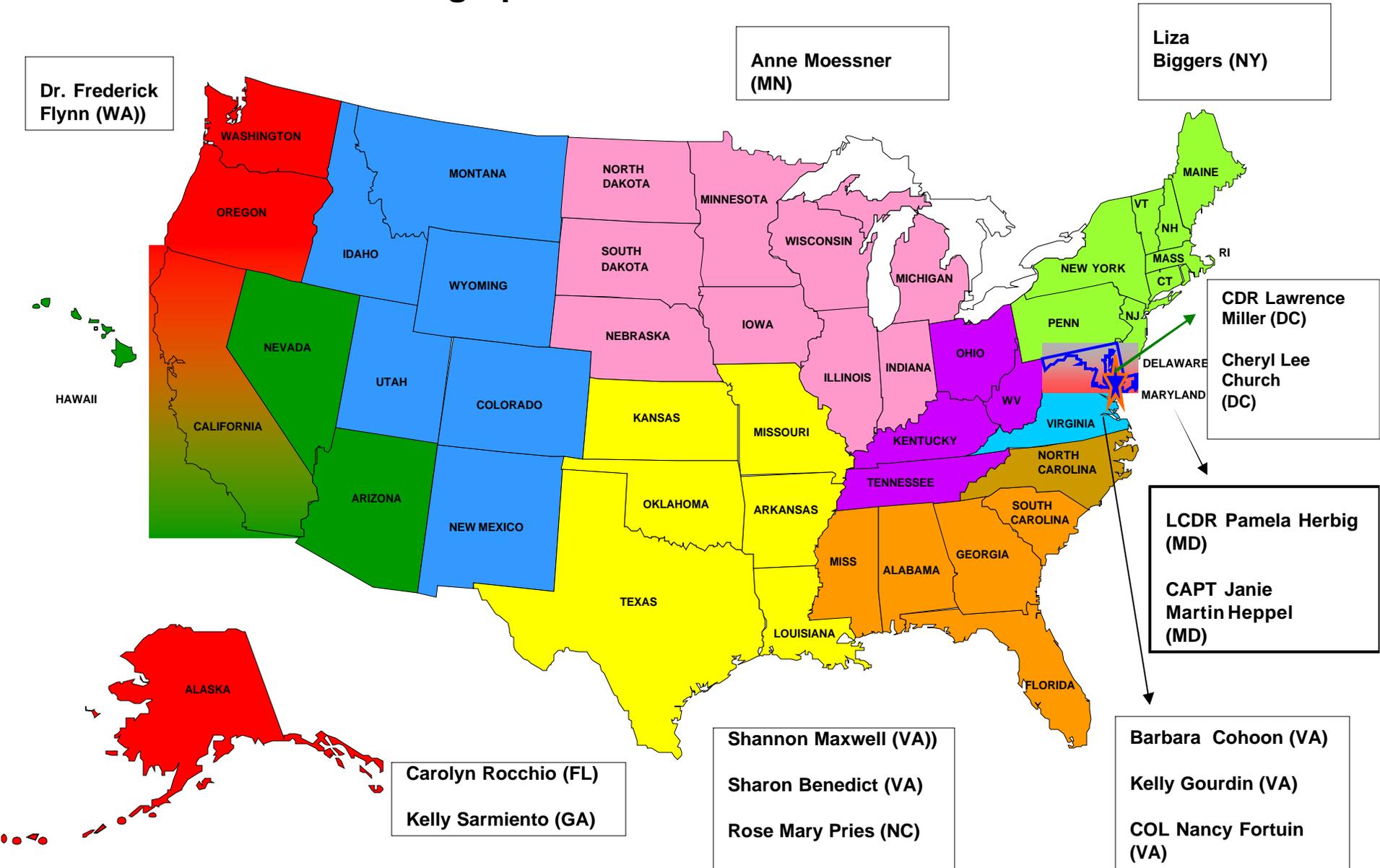


Panel Selection (continued)

- Panel nominee list forwarded for review on 26 OCT 2007
- Appointment of 15-member panel occurred on 6 MARCH 2008

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Geographical Location of Panel Members





The Need for TBI Family Caregiver Education

- Stress of care giving can be reduced through education and support (Ergh, Rapport, Coleman, & Hanks 2002).

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Panel Meetings

- First organizational meeting held 9-10 January 2008 in Silver Spring, MD
- Participants which included all 15 anticipated panelists received presentations that prepared them to be potential panel members and provided them with grounding information on the subjects of TBI and the experiences of caregivers
- Since appointments were pending meeting participants did not vote, instead they worked in consensus:
 - Established general areas of agreement
- Members discussed the opportunities and challenges faced by the panel in developing a TBI family caregiver curricula

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January 2008 Panel Meeting

OPPORTUNITIES:

- Model curricula have been developed for the family caregivers of persons with dementia and spinal cord injury
- To create and tailor a curricula to the needs of the family caregiver of a person with TBI
- Identify best practices in family caregiving support and education

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January 2008 Panel Meeting (continued)

CHALLENGES:

- Paucity of research on caregiving related to TBI
- The panel's wish to inform family caregivers of the range of treatment options even available though some are not traditionally covered by insurance (ex cognitive rehabilitation)
- Incorporate an individualized component in the curricula

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January 2008 Panel Meeting Goals of Working Groups

- Panel members broke into 4 small working groups

Expectations Group - Curricula content related to anticipating the information and resources that the TBI family caregiver will need to understand TBI and understanding the DoD/DVA medical care systems

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January 2008 Panel Meeting

Goals of Working Groups (continued)

Practical Tools Group – Curricula content providing information, skills, and tools to empower TBI family caregivers

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January 2008 Panel Meeting

Goals of the Working Groups (continued)

Curricula Focus Group - To provide appropriate materials to educate, train and provide resources to a wide spectrum of TBI family caregivers from diverse social and cultural backgrounds. Materials will address needs at each point on the continuum of care - from diagnosis to treatment and rehabilitation to reintegration to the service or community

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January 2008 Panel Meeting Goals of Working Groups (continued)

Dissemination and Format Group – To establish a variety of formats for the dissemination of the curricula so that they can be tailored to the unique needs and learning styles of the TBI family caregiver

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January 2008 Panel Meeting (continued)

Consensus Session showed the following:

- Curricula should address the continuum of severity of TBI (mild, moderate, severe, and penetrating)
- Materials must address the changing roles of TBI caregivers over time
- Utilize multiple modalities to accommodate various learning styles
- Need for a uniform definition of family caregiver that reflects a broad definition of “family”
- Curricula must contain an inter-personal component to provide an individualized guide through the TBI continuum of care

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January 2008 Panel Meeting (continued)

Initial positive steps were taken toward:

- developing a resource list of materials, programs, and individuals to add in the creation of the curricula
- developing a list of distribution channels for the completed curricula

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Panel Meetings

- Second meeting anticipated in 2008 June
 - Will occur in DC area
 - Will include town hall component (evening) where local family caregivers of people with TBI, professionals, and advocates will be invited to provide suggestions on content of curricula
 - Modalities of advertising town hall component will include announcement in Federal Register, federal and private listserves, DVBIC's/DCoE's network, and local chapters of the Brain Injury Association of America

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Characteristics of Military/Veteran TBI Caregivers

- Caregiver experience is diverse, individualized and complex
- Needs change over time
- Need reassurance and hope

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Range of Caregivers' Educational Needs

- Basic information on TBI
- Coping skills
- Problem solving
- Seeking and finding support

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Curricula Development Process

Recommendations

- Use multi-media approach - to reach broadest section of target audience possible
- Incorporate end-users' feedback as the product is developed
- Pre-train program leaders
- Recognize that needs of caregiver education may differ due to gender, race, ethnicity/cultural factors, socio-economic factors, and military rank

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Curricula Development Process Recommendations (continued)

- Evaluate efficacy of product before general release or as soon thereafter
- Plan to revise based upon evaluation results in first 1 to 2 years of product use
- Then, update the content as needed

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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

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