

March 26, 2015
2:00-5:00 p.m.
Conference call (888) 670-3525
Conference code 2922384719



Alzheimer's Disease Research Grant Advisory Board
Meeting Minutes

Alzheimer's Disease Research Grant Advisory Board:

- Ken Brummel-Smith, Ph.D., Florida State University, Chair
- Leilani Doty, Ph.D., University of Florida, Assistant Chair
- Frederick Schaerf, M.D., Ph.D., Neuropsychiatric Research Center of Southwest Florida
- Jacqueline Wiltshire, Ph.D., University of South Florida
- Amanda Smith, M.D., University of South Florida
- Mariana Dangiolo, M.D., University of Central Florida
- Ranjan Duara, M.D., Mount Sinai Medical Center
- Clinton Wright, M.D., University of Miami (absent)
- Leonard Petrucelli, Ph.D., Mayo Clinic, Jacksonville (absent)
- Neill Graff-Radford, M.D., Mayo Clinic, Jacksonville (absent)
- Todd Golde, M.D., Ph.D., University of Florida (absent)

DOH Staff:

- Sarah Hofmeister, Research Program Analyst, Public Health Research Unit

Members of the Public:

- None

A quorum was present. No votes were made during the meeting. The meeting was called to order at 2:05 p.m. Board members received all pertinent meeting materials. Board members participated via conference call and could actively and equally participate in the discussion.

I. Behavioral/Social Subcommittee

Members: Dr. Brummel-Smith, Dr. Schaerf, Dr. Smith, Dr. Wiltshire

Members were provided with suggested goals and strategies from the National Alzheimer's Project Act:

- Goal 2: Enhance Care Quality and Efficiency
- Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families

The following research priorities were also suggested to be included in Funding Opportunity Announcements:

Behavioral

- Testing of non-pharmacologic interventions for "behavioral expressions" (e.g., music, massage, Snoezellen rooms, etc.)

Social

- Applied research into different types of dementia caregiver training (e.g., The Best Friends Approach, Dementia Care Mapping, etc.)

- Alternative environmental design to promote greater independence and reduce adverse behavioral expressions (e.g., Dementia friendly housing, dementia friendly communities, dementia gardens, Eden Alternative, etc.)
- “Too much medicine” (www.bmj.com/too-much-medicine) approaches in dementia – at what point is continued treatment of co-morbid conditions unwarranted?
- Research into best methods for communicating the diagnosis to patients with dementia
- Methods of assessing surrogate decisions and their fidelity with patient wishes
- Technological interventions for assisting caregivers – app development, use of robotics

End-of-life care

- Advance care planning discussions in early dementia (e.g., ACP Decisions videos)
- Other techniques (e.g., Go Wish Cards)
- Hospice training in dementia
- Best methods of palliative symptom management in advanced dementia
- Terminal delirium
- Methods for decision-making on discontinuing treatments of co-morbid conditions in advanced dementia

Board members discussed the need for research in psychiatric care, Baker Act, and emergency room protocols. Members identified the need for more research on family and provider care. It was suggested to align research priorities with federal grant program priorities to encourage additional funding for federal grants.

II. Basic/Translational Subcommittee

Members: Dr. Golde and Dr. Petrucelli (both absent)

Subcommittee members were unable to join the call.

III. Clinical/Diagnostic Subcommittee

Members: Dr. Duara and Dr. Dangiolo

Members discussed the need to encourage collaboration between the memory disorder clinics, brain bank, and adult day care centers.

Members identified and discussed the need for a state-funded brain data registry. It was suggested to request a consortium of centers in the state to apply to create and operationalize this electronic database which will support the Minimum Data Set and ancillary functions. Collateral benefits of developing and operationalizing the data set and an electronic data base will be to standardize and improve the clinical assessment of all individuals who are evaluated at Memory Disorder Clinics as well as a common medium for providing education to health care professionals and informational material to patients.

Board members also discussed the need to develop a standardized diagnosis system to help improve and standardize diagnoses of memory disorders by healthcare professionals in the state while allowing for diversity of medical approaches and of populations Florida-wide.

IV. Research Priority Survey Question

The Assistant Chair requested the Board members identify research priorities to discuss at the April 3, 2015 meeting in Orlando to help develop the Funding Opportunity Announcement. Members were asked to identify what they perceive to be the top 2 areas/points/issues/questions in Florida needing Alzheimer’s disease research based on their expertise and experiences.

V. Public Comment

None.

The meeting was adjourned at 4:10 p.m.