

March 13, 2013

Submitted electronically to: watsonjl@nia.nih.gov

Jennifer L. Watson, Senior Public Affairs Specialist
National Institute on Aging (NIA)
31 Center Drive, Room 5C27
Bethesda, MD 20892-2292
Phone: 301-496-1752

Request for Information: Increasing Enrollment in Alzheimer's disease and Related Clinical Trials and Studies

Dear National Institute of Aging,

As the national professional association representing the interests of more than 140,000 occupational therapy practitioners and students, American Occupational Therapy Association (AOTA) is pleased to provide recommendations for actionable strategies to increase enrollment in clinical trials for Alzheimer's research. Occupational therapy enables people of all ages to live life to its fullest by promoting health and minimizing the functional effects of illness, injury, and disability, so we are cognizant of the importance of advancing Alzheimer's research.

Individuals with Alzheimer's disease and their caregivers may be hesitant to enroll in a trial because participation in the study may require transportation to a new location/facility and disrupting their daily routine. As we all know, individuals with Alzheimer's disease may be confused or anxious if their daily routine is disrupted or if they are taken to an unfamiliar environment. Therefore, AOTA recommends the following strategies to enhance participation in Alzheimer's research:

- Whenever possible, the research should be conducted in the individual's familiar environment (e.g., home). Similarly, researchers should allow scheduling flexibility, considering the individuals' routine and preferences of the caregiver.
- Whenever possible, caregivers or friends of the individual with Alzheimer's disease should be permitted to remain with the individual during the study.
- Once participants for the study are identified, researchers and their staff could introduce themselves via a DVD, internet video, or other visual modality, so that caregivers could use these resources to help prepare the individual for the study/trial. A video tour highlighting visual landmarks (e.g., from the parking to the research lab/clinic) could help orient the individual if they have to travel to an unfamiliar study's location.

- Whenever possible, the use of visual aids/cues and symbols should be encouraged to help orient the individual with Alzheimer's, especially if the individual is in a more advanced stage of the disease. For example, visual cues could be printed to show the sequence of activities/tasks or the faces of the researchers that will interact with the individual during the study's session.

AOTA supports the proposal for a centralized registry if one does not already exist. The Agency for Healthcare Research and Quality's Registry of Patient Registries (<https://patientregistry.ahrq.gov/>) does not seem to include all the registries related to Alzheimer's disease.

AOTA appreciates this opportunity to provide comment on increasing enrollment in Alzheimer's disease and related clinical trials. Please do not hesitate to contact AOTA for further information or for assistance to disseminate research opportunities and clinical trials to the community.

Respectfully submitted,



Susan Lin, ScD, OTR/L
Director of Research
American Occupational Therapy Association (AOTA)

4720 Montgomery Lane, Suite 200
Bethesda, MD 20814-3449

(301) 652-6611 x2091
slin@aota.org