

PALM BEACH COUNTY
BOARD OF COUNTY COMMISSIONERS
AGENDA ITEM SUMMARY

Meeting Date: August 14, 2018 ☐ Consent ☒ Regular
 ☐ Ordinance ☐ Public Hearing

Department: _____

Submitted By: County Library/Administration

Submitted For: County Library/Administration

I. EXECUTIVE BRIEF

Motion & Title: Staff recommends motion to approve: a request to submit a letter of participation to support Florida Atlantic University on its grant proposal to the National Institute of Health titled *“Increasing Research Participation in Alzheimer Disease Clinical Studies.”*

Summary: Florida Atlantic University is proposing as part of this grant proposal to test a novel, strategic health-literacy social messaging campaign. In collaboration with public library systems in Palm Beach and Broward Counties they will disseminate evidence-based, tailored public health messages and health education resources regarding brain health participation in clinical research in Years 1-2 and disseminating to a national sample of libraries in Year 3. Should the National Institute of Health fund the grant proposal, the Palm Beach County Library System will make available librarians for an inter-professional training program. This training will include didactic content, case studies, and role-playing simulation cases. The librarians would be raising awareness in the community about brain health and Alzheimer's disease and providing tools and consumer health resources. For this part, the Library will be compensated at \$25,000 per year for the entire three-year duration of the grant. In addition, a librarian from Palm Beach County Library System's Consumer Health Information Service will serve as an active member of the research team. This research effort will be compensated at \$15,000 per year for each of the three years of the grant. Librarians will not be recruiting older adults into research projects nor will they be substituting for medical judgment or decision-making. If the grant is awarded, the Library Department will come back to the Board to present an agreement with FAU laying out all of the terms and conditions. (Countywide) (AH)

Background and Justification: There is great interest in Public Libraries to develop targeted programs and collections to serve the needs of individuals with Alzheimer's disease. However, tailoring services and collections for persons with Alzheimer's is a challenge today, and will only become more challenging as the population of persons increases. Many librarians and library staff lack knowledge of Alzheimer's and training in serving this population, and specifically serving people with Alzheimer's in disparities populations. The Consumer Health Information Service (CHIS) is a service of the Palm Beach County Library System with a mission to contribute to the quality of life of Palm Beach County residents by improving their access to health-related information. The CHIS librarian, Mindy Rose, holds Level II certifications from the Medical Library Association's Consumer Health Information Specialization program since 2002.

Attachments: 1. Letter of Participation
2. FAU Specific Aims for the Proposal
3. Offer Letter from Dr. James Galvin, FAU Professor and Associate Dean

Recommended By:  (Douglas Crane) 8-1-19
Department Director _____ Date _____

Approved By: Todd Bonlarron (Todd Bonlarron) 8/10/18
Assistant County Administrator Date

II. FISCAL IMPACT ANALYSIS

A. Five Year Summary of Fiscal Impact:

Fiscal Years	2018	2019	2020	2021	2022
Capital Expenditures	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>
Operating Costs	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>
External Revenues	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>
Program Income (County)	<u>0</u>	<u>(40,000)</u>	<u>(40,000)</u>	<u>(40,000)</u>	<u>0</u>
In-Kind Match (County)	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>
NET FISCAL IMPACT	<u>0</u>	<u>(40,000)</u>	<u>(40,000)</u>	<u>(40,000)</u>	<u>0</u>
# ADDITIONAL FTE POSITIONS (Cumulative)	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>	<u>0</u>
Is Item Included in Current Budget?			Yes	No	
Does this item include the use of Federal funds?			Yes	No	
Budget Account No.:	Fund	Dept	Unit	Object	Object

B. Recommended Sources of Funds/Summary of Fiscal Impact:
Budget Account Information to be determined

C. Departmental Fiscal Review: Alicia Harrison
(Director, Library Finance and Facilities)

III. REVIEW COMMENTS:

A. OFMB Fiscal and/or Contract Dev. And Control Comments:

Lisa Pore 8/2/18 OFMB 8/8/18 Contract Dev. And Control

B. Legal Sufficiency:

Anne Delgant 8/9/18
Assistant County Attorney

C. Other Department Review:

Department Director



August 14, 2018

**Palm Beach County
Library System**

3650 Summit Boulevard
West Palm Beach, FL 33406-4198
(561) 233-2600
Toll Free: (888) 780-4962
www.pbclibrary.org



**Palm Beach County
Board of County
Commissioners**

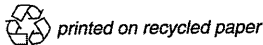
Melissa McKinlay, Mayor
Mack Bernard, Vice Mayor

Hal R. Valeche
Paulette Burdick
Dave Kerner
Steven L. Abrams
Mary Lou Berger

County Administrator

Verdenia C. Baker

*"An Equal Opportunity
Affirmative Action Employer"*



James E. Galvin, MD, MPH
Charles E. Schmidt College of Medicine
Florida Atlantic University
777 Glades Road, ME 104
Boca Raton, FL 33431

Dear Dr. Galvin,

We are delighted to write a letter of participation in your NIH grant proposal "Increasing Research Participation in Alzheimer Disease Clinical Studies". Alzheimer's disease (AD) and related dementias affect millions of Americans from all racial, ethnic and cultural backgrounds, presenting a significant public health challenge that will only increase as the US population ages.

There is great interest in Public Libraries to develop targeted programs and collections to serve the needs of individuals with AD, however, tailoring services and collections for persons with AD is a challenge today, and will only become more challenging as the population of persons with AD increases. Many librarians and library staff lack knowledge of AD and training in serving this population, and specifically serving people with AD in certain populations. The International Federation of Library Associations and Institutions' Guidelines for Library Services to Persons with Dementia recommends that library staff consult with professionals and attend relevant training workshops and conferences to learn about AD and how best to serve the needs of patients and their caregivers, family, friends, and health care professionals. The Association of Specialized and Cooperative Library Agencies (a special interest group of the American Library Association) is focused on developing standards for Public Library services targeted to AD. Unfortunately, standards have not been adopted by Public Libraries nationwide, and there is still a need for wider dissemination of knowledge of AD, and training in serving the needs of this community.

We look forward in assisting you design, implement, and analyze a novel, strategic health-literacy social messaging campaign in all 17 branches. This will involve disseminating evidence-based, tailored public health messages and health education resources regarding brain health, AD, and participation in clinical research. Additionally, we will help you develop and disseminate this exciting platform to a national sample of libraries in Year 3 of the project.

As a research collaborator in this proposal, the Palm Beach County Library System will make available to you our librarians for your inter-professional training program. This training will include didactic content, case studies, and role-playing simulation cases. Content will include providing a foundation of knowledge regarding brain health and AD, co-morbid medical conditions and their risk factors, health promotion strategies (i.e., exercise, nutrition, sleep, and social engagement), community resources, and facilitating communication between members of the community and their healthcare providers.

The Librarians will NOT be recruiting older adults into research projects nor will they be providing medical judgment or decision-making. Instead, the librarians would be raising awareness in the community about brain health and AD and providing tools and consumer health resources for interested parties to seek out more information from healthcare providers and agencies for research participation. This part of our participation will be compensated in the form of \$25,000 per year for the entire three-year duration of the grant.

In addition, one librarian from Palm Beach County Library System will serve as an active member of the research team, contributing to the study design, analysis, interpretation and dissemination of research results, and be a contributing author on research presentations, papers, and abstracts. This research effort will be compensated at \$15,000 per year for each of the three years of the grant.

We are honored to be part of this exciting research project from the ground level and look forward to a close working relationship with you and the rest of your multifaceted research team.

Sincerely,

Mayor Melissa McKinlay
Palm Beach County Board of County Commissioners

Alzheimer's disease and related dementias (collectively referred to as AD) affect millions of Americans¹ from all racial, ethnic and cultural backgrounds, presenting a significant public health challenge that will only increase as the US population ages. By 2050, the US Census Bureau estimates that over one-fifth of the US population will be 65 and older. The older adult population in the US is also becoming increasingly diverse. In 2006, 19% of adults aged 65 or older were nonwhite. By 2050, it is estimated that the proportion of elder Americans who are African American, Hispanic, or Asian American will increase to 39%.

Current treatments for AD show only modest benefits in reducing symptoms. Clinical trials are indispensable for drug approval; however, numerous trials fail to recruit the planned number of participants in a timely fashion, thus threatening trial success, raising concerns about generalizability of results, and possibly leading to disparities in disease treatment.¹⁵ Further, participation of underrepresented group (URG) older adults (low socioeconomic status, racial and ethnic minorities, rural populations) remains a significant challenge. With poor recruitment being such a widespread problem, a number of interventions have been proposed to improve recruitment with unknown effectiveness. Research in cancer clinical trials has been fruitful in identifying barriers to participation and strategies that may improve recruitment and retention.^{2,10,29,30,32} Despite the growing public awareness of AD, recruitment problems are particularly common in AD clinical trials.¹⁵

The extant literature contains studies that examined patient perception of, willingness to participate in, and self-referral to clinical trials with varied results, possibly because many of these studies were conducted in convenience samples of individuals who were already enrolled in clinical trials or in some way attached to a dementia clinic. Thus, true barriers facing investigators who have difficulty recruiting for AD trials in the general population remain unaddressed, and because of this, effective recruitment and retention strategies are lacking.

We have been at the forefront of multicultural recruitment of older adults from all backgrounds into longitudinal studies, biomarker studies, and clinical trials using rigorous but tailored recruitment strategies (see **Preliminary Studies**) developed over 2 decades of work. In 2005, we conducted a population-based survey exploring the psychosocial determinants of older adults' willingness participate in AD research to create tailored profiles and recruitment strategies. We created novel interprofessional education programming to increase physician referral to clinical research. We applied these strategies in a multicultural community study that recruited 450 older adults (40% White, 35% Hispanic, 25% Black) and increased recruitment of URG older adults into clinical research programs at 2 different NIA-funded ADRCs. These studies provided potential targets for community interventions to improve the recognition of cognitive disorders and research participation.

Our **OBJECTIVE** is to improve our understanding of patient willingness to participate in AD clinical trials gaining insight from a diverse group of respondents, incorporate community members into the research team, and create a trial-ready cohort for NIA-funded clinical research. We propose the following **SPECIFIC AIMS**:

1. Identify validated studies and conclusions about knowledge, awareness, public perceptions and attitudes towards participation in AD clinical research by conducting a scoping review of the research literature and create a compendium of known facilitators and barriers
2. Conduct a new population-based survey of 1250 White, Black, Hispanic and Asian older adults across 4 US geographic regions (Northeast, Midwest, South and West) to update our recruitment and retention materials incorporating new themes since the last survey including the NIA-AA research framework, subjective memory complaints, preclinical AD and use of biomarkers, and the use of the internet and social messaging for AD-specific clinical research to encompass beliefs, attitudes, benefits, and barriers to research participation.
3. Test a novel, strategic health-literacy social messaging campaign in collaboration with public library systems in Palm Beach and Broward Counties to disseminate evidence-based, tailored public health messages and health education resources regarding brain health, AD, participation in clinical research in Years 1-2 and disseminating to a national sample of libraries in Year 3.
4. Evaluate the effectiveness of our profile modeling, social messaging, dissemination, and community approaches.

Impact and Public Health Relevance: Our research team has been at the forefront in developing culturally-sensitive methods for detecting cognitive impairment; creating innovative culturally-relevant programming and social messaging; using population- and community-based methods to understand facilitators and barriers to participation in AD research; and successfully recruiting diverse populations into clinical trials. This application has the potential to have **sustained influence on evidence-based tailored messages** to improve strategies for AD clinical trial recruitment. Our **long-term goal** is to create a trial-ready cohort of older adults to receive NIA trial information and participate in clinical research activities, and make our tailored recruitment materials available to other investigators to assist their recruitment and retention efforts.

Attachment 3.

Dear Doug,

I am a professor and Associate Dean at the Schmidt College of Medicine at FAU with an area of clinical and research interest in Alzheimer's Disease. I am preparing a grant to the National Institutes of Health that would include working with the Palm Beach County Public Library system. I had previously had a grant from the National Library of Medicine to demonstrate the collaborative nature of medical researchers and librarians/informationists in advancing medical research and recently wrote another NLM grant that just missed getting funding. I am repackaging that NLM grant into a larger proposal.

The overarching goal of the proposal is to increase recruitment into AD clinical trials. The basis is to engage different community members and organizations into the research team and implement a variety of strategies. Here are the research aims ;

Our **OBJECTIVE** is to improve our understanding of patient willingness to participate in AD clinical trials gaining insight from a diverse group of respondents, incorporate community members into the research team, and create a trial-ready cohort for NIA-funded clinical research. We propose the following **SPECIFIC AIMS**:

1. Identify validated studies and conclusions about knowledge, awareness, public perceptions and attitudes towards participation in AD clinical research by conducting a scoping review of the research literature and create a compendium of known facilitators and barriers
2. Conduct a new population-based survey of 1600 White, Black, Hispanic and Asian older adults across 4 US geographic regions (Northeast, Midwest, South and West) to update our recruitment and retention materials incorporating new themes since the last survey including the NIA-AA research framework, subjective memory complaints, preclinical AD and use of biomarkers, and the use of the internet and social messaging for AD-specific clinical research to encompass beliefs, attitudes, benefits, and barriers to research participation.
3. **Test a novel, strategic health-literacy social messaging campaign in collaboration with public library systems in Palm Beach and Broward Counties to disseminate evidence-based, tailored public health messages and health education resources regarding brain health, AD, participation in clinical research in Years 1-2 and disseminating to a national sample of libraries in Year 3.**
4. Evaluate the effectiveness of our profile modeling, social messaging, dissemination, and community approaches.

Aim 3 proposes to partner with the Public Library system to maximize the content expertise of Librarians in the areas of brain health, cognitive aging, and Alzheimer's and serve as a public research for information-seeking. This is consistent with the NLM's goals to increase outreach to communities through their local libraries.

<https://www.nih.gov/news-events/news-releases/nihs-all-us-research-program-partners-national-library-medicine-reach-communities-through-local-libraries>

I also envision creating a team of community organizations that can help advise and shape the research, interpretation, and messaging that would include a representative from the Palm Beach County Public Library. There would be a yearly consultant fee paid to the Library for its participation.

The grant is due August 24th. If you are not familiar with the foibles of NIH, if funded the project would not start until Spring 2019 and the Aim 3 with library involvement would not occur until end of 2019 or early 2020 which would provide us ample time to work together. I would love to discuss the possibility of the Palm Beach County Public Library collaboration with you. If you did agree to participate, the only thing I would need at this point is a letter of support, which I would draft for you.

I hope you will consider my offer. I would greatly appreciate hearing your thoughts about this.

My warm regards
Jim

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