

Date: June 30th, 2016

To: MetroWest Health Foundation Board of Trustees

From: Margot LaFortune Flionis, Carolyn Hochard, Tatiana Melo, Jane Purser and Peter Wilner

Re: Alzheimer's/Dementia Pilot Project Proposal

The Problem:

The incidence of Alzheimer's Disease and related dementias (ADRD), is a rapidly growing concern not only for our country overall, but for our state and the MetroWest region as well: according to the 2012 ADRD state plan published by the Massachusetts Executive Office Of Elder Affairs, someone in the U.S. develops Alzheimer's Disease every 69 seconds and by mid-century, that figure could increase to every 33 seconds. The Alzheimer's Association of America estimated that 473,000 people age 65 and older would develop Alzheimer's Disease in the U.S. in 2015 and in that year, 1 in 9 Americans was living with the disease. Regarding the MetroWest, the MetroWest Health Foundation's (MWHF) 2014 Healthy Aging Profile For the MetroWest Region estimates that 14% (8,285) of individuals in the MetroWest area age 65 or older are living with ADRD. Simultaneously, the 2014 American Community Survey estimates that about 6.7% (25,201) of the 375,373 residents that live in the MetroWest speak English less than very well. Of those 25,201 residents, 88% (22,097) represent 10 particular languages/ language varieties and about 75% (18,957) represent one of the 4 languages/language varieties highlighted in the attached slide entitled "Top 10 Most-Spoken, Non-Native Languages/Language Varieties in the MetroWest Region," and anecdotal evidence suggests that these counts are low.

Given these statistics and the growing number of individuals that are or will be affected by ADRD, we believe that there is a need to more fully identify patients and family caregivers from all backgrounds and to bolster their ability to obtain culturally and linguistically appropriate services. As the MWHF has not yet funded initiatives that target services toward specific ethnic or linguistic populations affected by ADRD, we outline below a pilot program utilizing area professionals, students and community leaders that we believe will enable the MWHF to effectively address these issues.

Research:

Our team conducted an informal ADRD needs assessment by interviewing professionals in the MetroWest region who work directly with patients and families in our community. One individual stated that, "the caregiver tries to keep their loved one at home but may not realize how severely the social, physical and psychological effects can wear on them". Another noted, "I see one of the major issues or problems is a lack of education about dementia in the community. More extensive training is needed for the family so that they can better understand next steps and resources that are available and where to reach out for support." A third participant summarized by saying, "Dementia is out in the community at large. It transcends gender and culture, age, color and ethnicity. Dementia is the great leveler."

We then set out to determine whether elements of a framework for addressing these needs currently exist: we discovered, for example, that legislation pending in the Massachusetts legislature would require physicians and social workers to be educated and trained specifically in ADRD care in order to renew their licensure, and would implement measures that maximize resources available to patients and caregivers. (*see, for example, H 2057, H 3384, S360*). We also learned that in 2012, the Massachusetts Executive Office of Elder Affairs developed state recommendations to address ADRD -- this ongoing plan will address issues around caregiver support and early recognition and treatment, improve access to

services and information, support increased quality of service within the medical community and improve public awareness surrounding risk factors and risk education for Alzheimer's Disease.

In order to address the needs of elders and their caregivers in the MetroWest region, the MWHF, in 2015, awarded grants to several area projects that provide community support to patients and caregivers affected by ADRD. These include, for example, grants to BayPath Elder Services to assist in the development of Dementia Friendly Communities, and to the Franklin Council on Aging to offer in-home respite and companion services. While these initiatives provide much-needed tools for addressing ADRD-related issues, we believe that an important need remains unaddressed.

Based on the evidence that ADRD-related issues represent growing areas of concern in the MetroWest region and that different populations of non-native English speakers in the MetroWest region may be under-counted (as revealed by anecdotal evidence that our team collected via informal interviews), we believe that information about area resources for ADRD education may not be culturally or linguistically accessible to many patients and families in the MetroWest region affected by ADRD. According to the American Community Survey, the four most-represented languages/language varieties in the MetroWest area, in order from most to least represented, are Spanish, Portuguese, Chinese and Russian. Further, in the counties in which the MetroWest municipalities are located, there are at least 5 distinct Chinese languages spoken. To properly address these linguistic communities, it would have to be determined which specific languages are spoken in the MWHF's catchment area and what resources would be required in order to properly serve those populations. This, combined with our assessment that there are many Spanish language resources already available in the MetroWest region, leads us to recommend that the MWHF initially address the availability of educational materials regarding ADRD for the MetroWest's Russian and Portuguese-speaking populations.

A better understanding of these communities' respective cultures helps us to better serve their needs: according to sources examining ethnicity, cultural anthropology and family therapy, many Portuguese-speaking Brazilians' lives in the U.S. are shaped by typical challenges faced by first-generation immigrants, such as poor English-language skills, issues related to immigration status, and economic difficulties. Isolation, fear of deportation, and loss of social status are specific stresses that affect much of the Brazilian population in the U.S. In general, community churches are a major source of support for Brazilians. Similarly, for many Russians, there is a great deal of shame involved in divulging the family's private matters. This reluctance stems partly from Russian traditions of keeping psychological and other family issues private. When faced with ADRD, these families do not know where to turn for support and education. These examples demonstrate that there is a need in the MetroWest region to bolster the ability of ADRD patients and family caregivers, from all backgrounds to obtain culturally and linguistically appropriate social and educational support.

Foundation's Role & Community Partners:

To address these needs in culturally and linguistically appropriate ways, our team proposes that the MWHF convene a coalition of community partners, including primary care health providers, the Alzheimer's Association of MA and NH, BayPath Elder Services, Councils on Aging, senior centers, community health centers and hospitals, and community leaders from the MetroWest's non-native communities to participate in and oversee a pilot project to provide culturally and linguistically accessible outreach to the Brazilian and Russian-speaking communities in the MetroWest region. We suggest that a grant be made available to a local community partner, such as the Edward M. Kennedy Community Health Center or the community clinic at the MetroWest Medical Center, to support a Community Health Nurse who would organize an outreach effort within local Brazilian and Russian communities. The goal of this outreach pilot project would be two-fold: to disseminate culturally and linguistically appropriate

information to these communities about signs and symptoms of healthy aging versus the signs and symptoms of ADRD, and to provide information on culturally and linguistically accessible community resources for affected individuals and families.

This education and support would be implemented primarily by student clinical nurse interns from area educational institutions (e.g., Framingham State University), who would be funded by mini-grants from the MWHF. Under supervision of the Community Health Nurse, these student nurses would, using their background in health and wellness, collaborate with Brazilian and Russian community partners (such as pastors, rabbis and other community leaders) who have the linguistic and cultural capacity and relevant community ties to provide culturally and linguistically appropriate ADRD education as well as offer information about ADRD resources available in the MetroWest region. We believe that this model would allow the MWHF to meet the needs of diverse communities by connecting patients and families with resources that they would not otherwise be able to access.

How will the foundation know if its efforts are successful over time?

To assess the success of this pilot project, our team recommends that a survey of MetroWest area health care providers be conducted prior to initiating the pilot project to determine the scope of need in these communities. The survey should again be conducted 2 years after the project's implementation in order to determine how many patients and families have been contacted through the program and if the area health care providers believe the program was helpful in expanding services available to the Brazilian and Russian populations. It is hoped that this pilot project will serve as a model for reaching other underserved communities.

Risks/Pitfalls:

This project presents three primary challenges: the first is the identification of appropriate community partners who will be the liaisons between the clinical interns and the subject populations. The second is the identification of as many members of the subject populations as possible -- the circumstances under which they are living in the MetroWest region, as well as cultural and linguistic barriers, may make individuals reluctant to seek the help that they need. The third challenge is implementing the project so that it is sustainable over the long term. We believe that the model outlined above will augment the MWHF's ongoing efforts to address these challenges.