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March 23, 2015

Ms. Meryl Comer
USAgainstAlzheimer's
2 Wisconsin Circle, Suite 700
Chevy Chase, MD 20815

Glenn E. Smith, Ph.D.
Mayo Clinic
200 First St. SW
Rochester, MN 55905

Dear Ms. Comer and Dr. Smith:

On behalf of the League of United Latin American Citizens (LULAC), the nation's oldest and largest Latino civil rights organization, I am writing to support your proposal entitled "The National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network (AD-PCPRN);" submitted in response to the Patient Centered Outcomes Research Institute (PCORI) program funding announcement for Patient Powered Research Networks (PPRNS).

In my capacity as LULAC National President, I am keenly aware that Alzheimer's disease and related dementias (ADRD) are a significant health challenge to our nation. LULAC and its members are deeply concerned that the Latino community faces higher rates of the onset of Alzheimer's. Recent studies illustrate a bleak outlook for the Latino community as it ages, as recent studies have shown that individuals with diabetes have a higher risk of developing Alzheimer's. As a growing number of Latinos are overweight, obese and diabetic, ADRD is sure to have a growing impact on the Latino population

It is imperative that the ADRD population—especially those in mild stages and from under-represented groups and their caregivers—be included within the National Patient-Centered Clinical Research Network (PCORnet) of the Patient-Centered Outcomes Research Institute (PCORI). Doing so will ensure that Latinos are not excluded from important outcomes research activities supported by PCORI.

The AD-PCPRN is exquisitely designed to address this imperative. The AD-PCPRN will be co-led by patients and their caregivers. Such dual leadership is necessary given the debilitating nature of the disease, the important surrogate role in clinical research that the caregiver assumes as the patient progresses from mild to more severe levels of disease, and the negative health effects on the caregiver associated with this demanding role.

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Novel, technology-based mechanisms will be used to register and characterize patients and caregivers into the AD-PCPRN and to track their conditions over time. The AD-PCPRN will benefit from an existing novel web-based registry to recruit, characterize and retain participants, tracking patient and caregiver reported data, including primary outcomes, self-reported phenotypes, and quality of life measures.

LULAC's participation in AD-PCPRN will include, but is not limited to, a focus on outreach within the Latino community with the goal of increasing awareness of the Brain Health Registry and increasing engagement in clinical research to prevent or treat dementia. LULAC strives to address health disparities like Alzheimer's and dementia through our work in communities across the nation, and we welcome the efforts of partners like USAgainstAlzheimer's, MAYO, and the Brain Health Registry to innovate the way Latinos engage in research against the disease.

At a minimum, LULAC will help the AD-PCPRN reach both patients and their caregivers within our communities by advising on messaging and outreach strategies that are culturally competent and community focused. Both traditional and novel technology-based mechanisms will become central to bringing both patients and caregivers into the AD-PCPRN and tracking their conditions over time. The AD-PCPRN is poised to deploy novel methods, such as the latest monitoring and self-assessment technologies, to extend the ability of patients, their caregivers, families, and clinicians to become contributing citizen-scientists both within and outside clinical research settings.

On behalf of the 135,000 members of LULAC and 1,000 councils in states across the country, I reaffirm my commitment to work with the organizers of AD-PCPRN once funded. I know that with your help, we can make a positive impact in the understanding of Alzheimer's disease. Thank you again for agreeing to be a part of this important research network.

Sincerely,

Margaret Moran
LULAC National President