

Congress of the United States
Washington, DC 20515

June 18, 2012

The Honorable Kathleen G. Sebelius
Secretary, Department of Health & Human Services
Room 603 Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Sebelius:

As co-chairs of the Bipartisan Congressional Down Syndrome Caucus, we have reviewed the National Plan to Address Alzheimer's Disease. We commend you on this historic effort to fight Alzheimer's disease and related dementias and for the inclusion of Down syndrome in this National Plan. We are pleased the Plan establishes a taskforce to address the unique care challenges faced by people with younger-onset Alzheimer's disease. Additionally, we are pleased that the Plan includes steps to improve access to long-term services and supports for younger people, including those with Down syndrome.

Alzheimer's disease attacks adults with Down syndrome at a younger age and with increased frequency when compared to the general population. The pathological findings of Alzheimer's disease have been described in the brains of people with Down syndrome since the 1800s. There are genetic factors at play that, in part, explain these pathologic and clinical observations. NIH is funding Down syndrome research using natural history studies and imaging techniques to identify early markers of cognitive decline. These studies will undoubtedly help people with Down syndrome, but they will also have a broader application to those individuals in the general population who are at risk for developing Alzheimer's disease. By recognizing the specific link between Down syndrome and Alzheimer's disease, the National Plan will leverage *all* of the most current scientific data available. More importantly, millions of Americans who are at risk for Alzheimer's disease will benefit from the research that is already underway for those with Down syndrome. This is truly a win-win for the entire community.

Again, we thank you for your inclusion of Down syndrome in the National Plan, but are asking you to go a step farther. **We respectfully request that a representative from the Down syndrome research community be added to the Advisory Council on Alzheimer's Research, Care, and Services.**

Sincerely,


Rep. Cathy McMorris-Rodgers


Rep. Chris Van Hollen


Delegate Eleanor Holmes Norton


Rep. Pete Sessions

cc: Dr. Helen Lamont, HHS Office of the Assistant Secretary for Planning and Evaluation
Dr. Yvonne Maddox, Deputy Director, National Institutes of Child Health & Human Development (NICHD)
Dr. Richard Hodes, National Institute on Aging (NIA)