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March 29, 2012

Advisory Council on Alzheimer's Research, Care and Services
c/o Helen Lamont, Ph.d
HHS Office of the Assistant Secretary for Planning and Evaluation
Room 424E, Humphrey building
200 Independence Avenue, SW
Washington, DC 20201
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Dear Dr. Lamont:

I am writing to urge the Advisory Council to ensure that the population of people with Down syndrome (Ds) is specifically identified in the Draft National Plan to Address Alzheimer's Disease. Currently, this group of individuals, known to be at high risk of developing Alzheimer's and dementia, is given a fleeting reference in the Draft Plan. This omission must be rectified.

In order to better understand the Alzheimer disease process and develop early identification and other practices to treat this devastating disease which often affects individuals with DS early, research is urgently needed. Research of this type will benefit the general population as well as individuals with Down syndrome and those thousands with DS at risk for developing dementia. In addition, as a parent or family member, I am aware of the need to provide special supports for caregivers, often siblings or aging parents, who assume responsibilities for the care needs for individuals with intellectual disabilities and dementia.

Executive Director
Janet Gora

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It is also case that these individuals have special needs that may differ and require different supports than those provided to individuals in the general population. These needs have been identified by the National Task Group and Intellectual Disabilities and Dementia Practices in an action plan it issued as part of its report: "My Thinker's Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports", which has been submitted to the Council.

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Individuals with Down syndrome and their families deserve to have the need for research and population specific clinical trials identified specifically and clearly as necessary actions in the final National Plan to Address Alzheimer's Disease as well as the care challenges they face that require increased awareness, early recognition and supports.

We are working with many families who are facing this very issue and the numbers are growing. As Executive Director of one of the largest Down syndrome associations in the country, and as a member of the DSAGC Health Professional Advisory Board who also serves as a consultant for the DSAGC who specializes in helping these families, we strongly urge the Council to consider the aging families who are dealing with aging children with Down syndrome who are most likely going to end up with this painful diagnosis. It is devastating diagnosis for families who have fought so hard to provide lifelong opportunities for their loved one...and then to have those opportunities taken away because of Alzheimer's disease is tragic to watch.

Please include us in the national study.

Sincerely,

Janet Gora
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