



## **VoA Oral Comments - NAPA Advisory Council on Alzheimer's Research, Care, and Services**

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Good afternoon, my name is Jim Taylor. I am the president and CEO of Voices of Alzheimer's and this is my wife Geri who has been living with the disease for over ten years.

I am here today to express my profound concern for decades of great advances in Alzheimer's research that are being lost because FDA-approved treatments are not being made available to patients.

Despite the significant strides that are being made in understanding and potentially mitigating the disease, the lack of access to new disease modifying therapies is a tragedy for those who are currently suffering, as well as for their caregivers and families.

It is also a waste of the tremendous investment that has been made in Alzheimer's research over the years.

We all recognize that the road from promising research to available treatments is a long and difficult one, and that the process is hindered by a number of obstacles, including a lack of clinical trial participants, a lack of coordination between researchers and a lack of incentives for the private sector to invest in the development of drugs.

You have sought to address all of these, and the results have been evident in the development of multiple breakthrough treatments that have recently been launched. We in the community are tremendously grateful for your work and leadership.

However, people with Alzheimer's did not anticipate that Medicare, in determining how and when treatments are covered, would undo all the work and investment that has come before.

All of your work, and the work of so many researchers.

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Medicare is now unwaveringly focused on cost-control and cost-effectiveness rather than benefit to patients.

This year we have seen that even when Alzheimer's treatments are proven to be effective and safe, they will not be covered by Medicare for the vast majority of those entitled to the medication, and only available in a clinical trial which makes it inaccessible to **most** patients.

Additionally, the cost benefit analysis for these treatments too often has a narrow focus on specific outcomes, rather than the activities of daily living and the overall quality of life which are most important to patients.

In doing so, we have abandoned the needs and goals of patients to live well with Alzheimer's and to have more quality time with better cognitive function and independence.

Therefore, we are calling on you to help us in this fight, as you have helped the Alzheimer's community thus far – to build the body of research to demonstrate the broader impact of treatments on patient independence, quality of life and overall well-being. Take back your position as the experts on Alzheimer's treatment effectiveness and meaningfulness, from a patient-centered perspective. We need your help to put an end to the efforts of CMS to block access in order to control costs, under the pretense of evidence development.

The Alzheimer's patient community is working tirelessly to address the **discrimination** we are facing from Medicare and ensure that the great advances in Alzheimer's research, your advances, are not wasted and that treatments are available to all patients as soon as possible.

I urge the NAPA advisory committee to embrace this issue and find ways to ensure that Geri and all people living with Alzheimer's receive the care and treatment they deserve.

Thank you.