Food and Drug Administration
10903 New Hampshire Avenue
Building 31, Room 2417
Silver Spring, Maryland 20993–0002

Dear Members of the Advisory Committee,

As individuals living with early Alzheimer's disease and mild cognitive impairment, we are grateful for the Food and Drug Administration's and this committee's diligence in evaluating the safety and efficacy of desperately-needed treatments, giving us more time and precious hope.

While we understand that your primary function is to assess the scientific data related to lecanemab, our personal experience and the impact this disease has on each of us and our families should be a part of your consideration. First, you should know that many of us have participated in clinical trials or are currently in them, and we are intensely proud of those contributions. We are optimistic about research and honored to have helped advance the field for the sake of others who will one day receive a diagnosis.

Second, please know that while we fully support and hope for a cure one day, what matters to us today is simply more time. Many of us feel that our diagnoses have helped us to reorganize our priorities such that we intend to live with more purpose for as long as we can. Living purposefully means living independently. It means being present and actively enjoying the relationships we most cherish. It means being able to appreciate milestones. One of us got to see his granddaughter start high school, and he has pledged to be there when she graduates. That is the significance and promise of these treatments to us.

Finally, these new priorities include giving back. It is with a fresh perspective that we volunteer at our churches, Elks lodges, a preschool, and even a memory care unit. This is a form of coping, a form of healing, and a chance to write a new story when many of us were told that our stories were over with the diagnosis. These treatments can give us a "bonus round" during which we can give back and give more to our communities. We should have that chance. We deserve that chance.

May 25, 2023
Thank you for the opportunity to comment. Please do not hesitate to contact Laura Thornhill, Director, Regulatory Affairs, at lthornhill@alz.org or 202-638-7042 if you have questions or require additional information.

Sincerely,