March 25, 2025

Subject: Urgent Need for Alzheimer’s Caregiver Support & Respite Funding

Dear Senator Ingwersen, Representative Meyer, and members of the Joint Standing Health and Human Services Committee:

My name is John Newby, and I live in Harpswell, Maine, where I have been the full-time caregiver for my wife, Venus, for several years. I am writing to testify in support of L.D. 815, which would provide additional funding for respite care.

We have been married for 34 years, and at just 53 years old, she was diagnosed with early-onset Alzheimer’s. This disease struck without warning and has devastated our lives and our family.

From the beginning, we sought treatment through clinical trials in Boston, where Venus participated in various studies. However, when the COVID-19 pandemic hit, we faced even greater isolation and uncertainty about how to navigate this journey. I made the decision that, no matter what, I would care for Venus at home rather than placing her in a nursing facility. While this choice has allowed me to be by her side, it has also brought immense emotional and financial hardship. Her condition continues to decline—some days, she no longer knows who I am—but I remain committed to providing her with the best care possible.

One of the most difficult challenges we’ve faced is the lack of financial support for families like ours. Because Venus was so young at the time of her diagnosis and had a limited consecutive work history, she did not qualify for disability benefits or MaineCare assistance. As a result, I lost my permanent job and now rely on temporary remote work to care for her at home. Our financial stability has eroded, and we now struggle to make ends meet—often relying on a dwindling savings account and support from our local food bank.

I know that my story is not unique. Across Maine and throughout the country, countless families are enduring the same unimaginable hardship. What makes Alzheimer's particularly cruel is that it not only steals the person you love piece by piece but also takes a severe toll on caregivers—emotionally, physically, and financially.

While I cherish every moment I still have with my wife, the financial and emotional strain of this disease has been overwhelming. We need strong leaders and legislation that provide greater assistance to families like mine. We need more funding for caregivers and respite type services in addition to research funding so that we can find a cure—not years from now, but as soon as possible.

I urge you to be a voice for caregivers and families battling Alzheimer's. We cannot fight this disease alone and without you.

Sincerely,

John E. Newby
Harpswell, Maine