Written Testimony SB 748 - Favorable

Patricia Joralemon-Selko

Constituent, District 42A

Dear Chair Beidle and members of the Committee,

My name is Patricia Joralemon-Selko from District 42A, Baltimore County. I urge you to support SB748, Public Health – Alzheimer's Disease and Related Dementias – Information on Prevalence and Treatment.

This bill is particularly important to me because it will ensure that dementia-related public health outreach educates Marylanders on Alzheimer's treatment. I believe this will encourage earlier diagnoses, allow individuals to receive treatment sooner, and promote healthier lifestyle choices.

My mother silently struggled for several years with memory loss. She was terrified of Alzheimer's after witnessing her own mother endure an eight-year battle with the disease. My mother never sought help due to this fear. Unfortunately, she wasn't alone—many people fear Alzheimer's more than cancer. We tried to intervene, but the fear gripped her too tightly. She now lives in a memory care facility; I often wonder if we could have had more time with her if there had been more public awareness and if doctors were better equipped to talk to patients about their symptoms and educate their caregivers. Perhaps then, she could have stayed in her home longer. Not to mention the toll it took on my stepfather as well.

During this same time, my husband kept telling me he felt something was off with his memory. Over the course of six months, we went to three different primary care doctor appointments. In the first two, he was prescribed anti-anxiety medication for what was labeled as "anxious aging." In the second visit, the doctor directly told him, "You don't have dementia," without even conducting a cognitive assessment. After the third visit, we pushed harder and finally received a referral to a memory clinic. However, it took another six months to get an appointment.

At the clinic, he was given a cognitive assessment, which confirmed the need for further testing. Over the next five months, he underwent blood work, an MRI, and a PET scan, all of which showed that he had Mild Cognitive Impairment due to Alzheimer's. Those five months were terrifying and increased his anxiety, which in turn worsened his symptoms. There is very little support available for those going through this process. Unlike my mother, my husband was proactive in seeking early help early, as recommended for more effective intervention. However, without proper education for both primary care doctors and the general public, many individuals often wait until it's too late.

My husband and I have done a lot of research on our own, with the help of the Memory clinic, friends, and family. He has started an FDA-approved treatment, Leqembi, and we have made many lifestyle changes, which we are seeing some improvement. As it stands now, the current system creates anxiety, which worsens the disease. It doesn't have to be this way. We need more education and a centralized website for both the public and healthcare workers to easily access information about available services.

During our follow-up appointments at the memory clinic, the nurse partitioner noted down the information we found online—such as educational resources for caregivers and support groups. I give them credit for trying to find the information, too. But when we first asked the clinic, "What now? This is really hard to process!" They directed us to the Alzheimer's Association, which was wonderful. However, we needed help then, not after the disease progressed further.

If the healthcare community wants the public to seek treatment early and not ignore symptoms, they need to provide more accessible support and information for those navigating the diagnosis process. There were many times when we just wanted to give up because it was so overwhelming and scary. My husband has faced this challenge with remarkable courage, but he is not the norm, many are frozen in fear and never talk to their doctors.

Maryland has the highest estimated prevalence of Alzheimer's in the nation. However, we do not collect state-specific data on dementia prevalence that could inform our programs and policies. A diagnosis of Alzheimer's or dementia is challenging for a family regardless of the circumstances. Having access to information on treatment and services can make the situation a little more hopeful. I urge the committee to support this bill. Thank you for taking the time to read our story.

Sincerely,

Patricia Joralemon-Selko