Testimony in Support of SB 27 "Alzheimer's Disease and Dementia - Council and Coordination of Services (Dementia Services Act of 2022)."

Maryland Senate Finance Committee

February 3, 2022 FAVORABLE

TO: Chair Kelley, Vice-Chair Feldman, and members of the Finance Committee FROM: Deborah L. Halpern

My name is Deborah Halpern, and I am a resident of 5711 Mayfair Manor Drive, North Bethesda, MD. I am submitting this testimony in support of SB 27, the Dementia Services Act of 2022, which at its core creates a Director of Dementia Services Coordination at the Maryland Department of Health.

My grandmother, Ida Janis, suffered from Alzheimer's Disease for 13 years before her death in 1993. My mother, Dr. Stefanie Halpern, suffered from dementia before her untimely death from cancer in 2010.

At a very early age, I learned just how painful Alzheimer's and dementia could be for caretakers. My mother visited my grandmother in a skilled nursing facility weekly for 13 years before grandma passed away. When grandma first moved to "the home," she frequently asked why my father, Arthur, and uncle, Howard, did not visit her. My mother, a recent widow, spent her weekly visits repeating the words, "Arthur and Howard are dead." Before she could even say "cancer," my grandmother would ask the question again.

As the disease progressed, my grandmother stopped focusing on my father and uncle. One afternoon during a weekly visit, my grandmother said to my mother, "who are you?" "I'm your daughter," my mother replied.

"Well, you couldn't have been a very good daughter if I can't even remember," my grandmother said.

In 2007, I took my mother to Paris for a family Bar Mitzvah. After a day of shopping, as we were eating dinner, she looked at me and said, "when did you first come to live with me?" After I picked my jaw up off of the floor, I said, "You're my mother; I lived with you my entire childhood," and then I remembered my grandmother's comment.

My mother deteriorated very quickly after the trip to Paris, and I didn't recognize her. Nor did I want to. The highly educated, incredibly successful woman who had raised me was nowhere in sight. In her place was a woman who held dinner parties for her diseased parents and served hundreds of dollars of gourmet food per week, to her dogs, on her best china with a knife and fork. She took her 75-pound collie to the mall to buy her a dress at Nordstrom and ended up at the local police station one Christmas morning because she thought someone was trying to steal her car. It was me; I was in the process of getting her driver's license revoked.

Today, an estimated 50 million people worldwide live with Alzheimer's or other dementias, including more than 5 million Americans. In the United States alone, 16 million friends and family members provide their care.

The Dementia Services Act of 2022 would, at its core, establish and mandate funding for a full-time Director of Dementia Services Coordination at the Maryland Department of Health. The position will be responsible for coordinating services affecting Marylanders with dementia and their caregivers and families, including implementing the Maryland Alzheimer's state plan managing the Virginia I. Jones Alzheimer's Disease and Related Disorders Council; identifying and supporting the development of dementia-specific training and applying for grants to expand and improve services for Marylanders with Alzheimer's and their caregivers.

There is precedent for this position; if enacted, Maryland's point person on dementia would join similar roles in 16 other states, including Virginia and the District of Columbia. This role would work across government to aid the 110,000 Marylanders with dementia and their loved ones.

Our state spends over \$1.2 billion in Medicaid funding on this chronic disease. It is essential that we begin to build our infrastructure to help Marylanders in need. The potential for this legislation is significant in how it can help Marylanders. We can look just to the District of Columbia, where DC Health dementia coordinator Tihitina Chamiso is doing significant work, including convening a multi-stakeholder committee to build awareness about their work; redrafting the District's State Plan on Alzheimer's and Related Dementia; starting a healthy brain website, and launching a public awareness campaign about their work. Maryland can do all of this if we devote the resources and build the infrastructure to address dementia.

I respectfully urge this committee to return a favorable report on SB 27. We spend over a billion dollars on this disease, and it is time for Maryland to have a point person specifically working to end Alzheimer's and other dementia.

Thank you, Deborah L. Halpern 5711 Mayfair Manor Drive North Bethesda, MD 20852 deblhalp@gamil.com