

Date: Jan 31, 2023

To: Chair Patterson, Vice Chair Hayden, and Members of the Senate Committee on Health Care

From: Dr. Jay W. Pscheidt, 4105 Elmwood Dr., Corvallis, OR 97330



Re: SB 796, which would establish the Oregon Memory Net.

This is a letter in support of Senate Bill 796 that could establish the Oregon Memory Net (OMN). I write to you as a caregiver for my wife who was diagnosed recently with the progressive Alzheimer's-like disease known as Frontotemporal dementia (FTD). As I understand the bill, this would increase access to dementia diagnosis and care that is modeled on other states' efforts. I feel this is an important endeavor based on my personal experiences as a caregiver and professionally as a diagnostician.

The lack of coordinated help let alone the lack of treatments for memory related diseases is astounding. My first wife was diagnosed with metastatic breast cancer many years ago and the treatments to undergo were overwhelming but managed by various doctors and care teams. The contrast with this equally devastating disease diagnosis of FTD could not be greater. We did get the FTD diagnosis in a timely manner here in Corvallis but a second opinion from OHSU is still a year out due to the volume of requests. Once our neurologist gave us the diagnosis she basically washed her hands of any further appointments or help stating that there were no treatments. For FTD all they could say was eat right, get plenty of sleep and stay active – all things we already do. (VS chemotherapy, radiation, surgery, bone marrow transplant, and medications for my late wife's breast cancer.)

My mouth dropped when we talked with our neurologist about several of the typical symptoms and progression of dementia. When she was done I exclaimed that you have just described the last years of my mother's life to a tea. With 20/20 hindsight it is clear that my mother had dementia that family and physicians did not recognize. When we finally got her into assisted living it noticeably improved her health. An earlier diagnosis would have helped tremendously.

Early diagnosis is important for any disease of any living thing. I have been a professor of plant pathology with Oregon State University for several decades serving growers throughout Oregon. The diagnostic process is the same whether it is medical (for humans), veterinary (for animals) or phytopathological (for plants). There are many examples where an early diagnosis can improve the outcome and offer more management tactics. I am sure early diagnosis of memory loss diseases would be helpful for all involved.

I am finding more information and help with FTD through informal support groups that are online or in person. My son, who works as a behavior specialist for a company that manages group homes for disadvantaged people, has also helped. Between these support groups and my son I have been able to find more help caring for my wife than what we have gotten through the medical community. I recognize my advantages and believe that others who are not as connected will not have nearly the help they need to care for someone with any of these memory loss diseases. A bill such as SB 796 would clearly be a step forward for Oregon's aging population and their caregivers.