House Bill 614 - Favorable Testimony of Andi LePore, dementia caregiver

Dear Chair Pena-Melnyk,

My name is Andi LePore and my dad was diagnosed with mild to moderate Alzheimer's in the end of 2021 and I am his designated caregiver.

When I first found out about the diagnosis, I was completely overwhelmed trying to find out as much as I could about the disease and the effects on the person diagnosed. To my surprise there is not a lot of information out there to be able to get help in Maryland. This is a disease that affects more than just the person diagnosed but also the caregivers. We have to be strong and mentally prepare for the days, months and even years to come. My dad is still able to live a normal life right now, but I am trying to navigate this knowing I will eventually have to stop working to care for him.

You grow up always depending on one or both of your parents, knowing one day, they may need to depend on you. But you don't realize that they might not be able to recognize you at some point, even though you know who they are, and you know how much they love you. This will be a journey for both of us to go through together. Unfortunately, we have run into some bumps in the road. His neurologist wanted him to get into a study for people with Alzheimer's and he was not a candidate due to the fact he has regular insurance and not Medicare Part B. This saddens me as you have a person willing to help further the development of hopefully a cure one day and they are rejected due to insurance coverage. We brought home a medical device to record his brainwaves while he slept that evening and before he could even begin the study they called him and said he was not a candidate anymore for the study due to he was not deteriorated enough. This whole thing, as my dad's caregiving is confusing and I really could use help.

My father is the most selfless person I have ever met, he only wants to help and he is being denied on all fronts. I feel the disappointment in his eyes and voice when he hits a setback. There needs to be more education and research for them and us as caregivers to be able to cope with all of this for our emotions and the person diagnosed with the disease. It is very heartbreaking to see the one person in your life that has been the strongest person you know slowly disappear one moment at a time and no way to help. I have looked and the only place to get any real information is the Alzheimer's Association. We as a state need to do more to help our fellow Marylander's get educated about the disease and help caregivers with a true support system. Thank you for your time and listening to my dad and I's story.