Good Morning,

My name is Anne O'Brien. My husband Keith Frantz was diagnosed with ALS in 2018 and died in 2019. I am a register nurse and served as Richmond's State Representative for eight years, six of which I served on the House Appropriations committee. Thank you for inviting me to testify on this important bill.

ALS is considered a "rare" disease. So, it was surprising to me when Keith was diagnosed that we began to meet and learn about so many people in our area with ALS. A Williston woman who came to help us with support services at home had a 40-year-old son who had died two years earlier from ALS. We learned of a individuals in Hinesburg and in Williston, both towns border Richmond, who had ALS. A woman from Richmond, sent me a note remembering her husband who had died of ALS years ago. A friend, when she learned about Keith's diagnosis, told me that her work colleague, another Vermonter was also recently diagnosed with ALS.

While attending the ALS clinic at UVMMC, we learned about others with this diagnosis and I was surprised to hear one of the therapists comment one day on the "oddly high number of people with ALS" in our region. In addition to that, Keith himself had a friend in Plattsburg NY, who was about his age, who had died from ALS, just a year or so before him.

These are all anecdotal stories of people, and DO NOT create the basis for any conclusion except that – Vermont needs real data on this and Vermont needs an ALS registry that is based on actual diagnostic codes.

The data are important to determine the incidence of this disease in our state as well as to contribute accurately to the ALS national registry.

This data can, as you all know, inform researchers about incidence, geographic, or other common elements that could lead to better understanding what might trigger this neurodegenerative disease and then hopefully might lead to better treatment, prevention and one day a cure.

I have a few recommendations to improve the language of this bill.

1) Add the word "de-identified data" in all parts of the bill that talk about collecting confidential data.
2) Reevaluate the $500 / day fine which seems extraordinary and direct any fines collected towards those diagnosed who may need to purchase OT aids which can be expensive and not covered by insurance.
3) Evaluate whether the VITL / Electronic health records systems used by VT hospitals could be programmed to send a de- identified confidential report by diagnostic code to simplify the process and make it automatic.
4) Include a requirement to capture data from Vermont PCP's whose client is served outside the state of Vermont- as Vermonters may go to Boston, Albany or Dartmouth for their treatment and services.

In conclusion, you don't want to receive a diagnosis of ALS. It is devastating. If a small trim tab bill like this one to create a registry, can add to the knowledge and data for researchers to put together pieces of the puzzle to find clues that will lead to prevention, treatment and perhaps one day a cure this action is a very important small big thing. Thank you.