

**Verbal Testimony RE: HB0982 – Genetic Testing Protection Act of 2024**

February 15, 2024

Position: SUPPORT

Good afternoon. My name is Dr. Kuldip Dave, and I am Senior Vice President for Research at the ALS Association. I appreciate the opportunity to speak to you today in support of House Bill 982, but more importantly, in support of the more than 200 families with ALS we currently serve in the state of Maryland.

ALS is a devastating neurodegenerative disease that progressively robs people of their ability to move, speak, eat, and eventually breathe. Once this deterioration begins, there's no way to stop it, meaning that most people only live for 2 to 5 years after being diagnosed.

The discovery of more than 40 genes linked to ALS has opened the door to an era of unprecedented change in ALS care. The first genetically targeted treatment for ALS was approved just last year. And at least 10 other genetically targeted therapies are being tested in clinical trials with almost a dozen more being developed preclinically.

One such study currently underway at Johns Hopkins goes even further. It has the potential to prevent ALS from developing in people who have an ALS-linked gene mutation but no symptoms.

Imagine what it would mean if we could stop ALS before it starts. The lives and futures it would save. The financial, social, and emotional costs that would never be incurred.

A major barrier to making this a reality is that few people with ALS and their family members know their genetic status. Fear of their genetic information being used against them is one reason why.

Thus, the threat of genetic discrimination creates a serious dilemma for Marylanders – risk their physical health because they don't know their genetic status or risk their financial health because they do.

House Bill 982 will remove that threat, improving the health of Marylanders and accelerating the massively important science being done in the state.

I urge you to support it. Thank you for your time and consideration.