



To: The Honorable Members of the House Health and Government Operations Committee
Re: HB 0982 Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024)

Date: 2-13-24

Electronically Delivered Via Upload

Dedicated Representatives:

Advancements in science have allowed for an ever greater understanding of how our genes contribute to disease. For our community of people impacted by inherited Amyotrophic lateral sclerosis (ALS) and Frontal-Temporal Dementia (FTD) these mysterious and devastating diseases that result in progressive and fatal paralysis and dementia, often in the prime of life, have in some cases been pinpointed to specific changes in our genome. This knowledge has unlocked an explosion of research with great hope for advancements. Indeed, a gene-targeted therapy was recently approved for one of the many ALS-causing genes, with people in Maryland benefiting from it today.

However, the fear of genetic discrimination stalks the contemplation of research participation and disease prevention. Every day, people must make hard choices on unlocking the ability to use their genome to guide their care or remaining ignorant of their genetic makeup not to suffer potential consequences in insurance coverage. This situation is not tenable. South Carolinians deserve to access medical care related to their genome without suffering unfair discrimination. We know from Florida's example that prohibiting discrimination in insurance products based on genetic testing need not cause upheaval in the insurance market.

Matters similar to this are under consideration in South Carolina as well. At the urging of our organization, the Director of the National Institutes of Neurological Disorders and Stroke, Walter Koroshetz, MD, wrote in support of added protections from a compassionate and strategic health perspective. He was not able to be reached in time for this week's Maryland hearing deadline, but his letter to the South Carolina committee is attached and just as relevant for Maryland.

We call on the House Health and Government Operations Committee to support HB 0982 regarding Genetic Non-Discrimination Protections for Marylanders.

Sincerely

Jean Swidler
Executive Director
Genetic ALS & FTD: End the Legacy
EndtheLegacy.org



DEPARTMENT OF HEALTH & HUMAN SERVICES

National Institutes of Health
National Institute of Neurological
Disorders and Stroke

Office of the Director
Building 31, Room 8A52
31 Center Drive MSC 2540
Bethesda, Maryland 20892-2540
Office: (301) 496-3167
Fax: (301) 496-0296
Email: koroshetzw@ninds.nih.gov

February 6, 2024

Dear Ms Huffman and Representative Sandifer,

Thank you for your invitation to participate in the South Carolina hearing on the protection of genetic information and the provision of equitable insurance opportunities for persons who have inherited disease mutations. Unfortunately, I have a previous commitment to lead a scientific meeting on the NIH's research program to improve treatment of pain and opioid overuse disorder.

I have a very personal stake in this issue having cared for persons with Huntington's Disease and their families for 22 years before coming to NIH. Persons who inherit the Huntington's mutation develop fatal neurodegenerative disorder, usually in middle age. I also was the lead neurologist for the first presymptomatic testing program in Huntington's disease to provide genetic information to help at risk persons plan their lives. Persons who are at 50/50 risk for inheriting Huntington's and a host of other severe, dominantly inherited disorder face unimaginable challenges in their lives. Maintaining privacy is critical for their professional, and some aspects of their personal lives. In this vein there is tremendous anxiety and potential risk in the disclosure of their genetic status to insurance companies. Many of my more financially well-off patients would pay out of pocket for their genetic testing to avoid billing their health insurance company. These decisions are motivated by fear that the genetic test results would target them as ineligible for continued health insurance, as well as other types of insurance.

NIH research has enabled persons to undergo genetic testing to know whether they will in fact become seriously ill in the years to come and help them plan their lives. NIH research also focuses on investigating those who are gene positive but asymptomatic to learn how to prevent onset of these dominantly inherited diseases. Any actions to ensure safety, privacy and provisions to enable equitable opportunity for these persons with gene mutations to access the same insurance coverage as other Americans would be much appreciated by these folks who face so many life challenges.

Sincerely yours,

A handwritten signature in black ink that reads "Walter J. Koroshetz". The signature is fluid and cursive, with the first name "Walter" and last name "Koroshetz" clearly legible.

Walter J. Koroshetz, M.D.