

TO: The Honorable Joseline A. Pena-Melnyk, Chair
House Health and Government Operations Committee

FROM: Carolyn Applegate, MGC, CGC
Assistant Professor, Genetic Counselor
Department of Genetic Medicine

DATE: February 18, 2025

On behalf of Johns Hopkins University and Medicine, thank you for the opportunity to support **HB1007 Genetic Testing- Prohibition on Disability, Life and Long-Term Care Insurance (Genetic Testing Protection Act)**. I am a genetic counselor and Assistant Professor in the Department of Genetic Medicine.

This bill is about ensuring that all Marylanders receive timely preventative care. With recent advances in genomic technologies, genetic testing has emerged as a vital tool to provide patients, their families, and their providers with valuable information to personalize their healthcare. Genetic testing reduces the need for unnecessary tests and procedures by providing more precise information about a patient's specific health risks. Early detection and prevention can lead to significant cost savings in the long term as well as improved outcomes for the patient.

As a practicing genetic counselor, I regularly have patients who decline to receive life-saving genetic information due to a fear of being denied full coverage for life, long-term care, and disability insurance. These fears are not unfounded. A cardiology colleague had a Maryland patient share that he was denied life insurance by two separate companies after he tested positive for a mutation that increases his risk for a cardiac condition, ARVC. These positive results indicate the need for routine screening such that symptoms of ARVC can be detected early and life-saving treatments can be initiated before a devastating consequence. At the time of testing, he underwent full cardiac evaluation, and the cardiologist explicitly noted that there was "no evidence of disease." At the highest, his lifetime risk to develop ARVC is 50% though newer studies show that the risk may be as low as 6%. Additionally, there are screening and treatment guidelines that reduce the chance that the condition will ever manifest. The patient was told that the coverage denial was "due to his Hopkins records." His only care at Hopkins was the unrevealing/normal cardiac evaluation and his positive genetic test report.

Genetic conditions are often thought of as rare, but some of the most common genetic conditions affect many in the general population. Take, for example, familial hypercholesterolemia (FH), which is found in about 1 in 500 people. The average age of first hospitalization among individuals with FH is 45, two decades earlier than the

general population with hypercholesterolemia. Preventative treatments are available, but should ideally start in childhood, before cholesterol levels are high and before the necessity for life insurance becomes a concern.

Until life insurance, long term care, and disability insurances have the data to use genetic information to accurately assess risk, both as a risk factor and a mitigating factor, Marylanders need the statutory protections afforded by HB1007. This is the only way to ensure that all Marylanders can comfortably choose to receive life-saving genetic information. At Johns Hopkins, we are dedicated to providing the best medical care to our patients and their families. Therefore, we urge a favorable report on HB1007.

Sincerely,

A handwritten signature in cursive script that reads "Carolyn D. Applegate".

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