

Senate Bill 757 – Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)

POSITION: Support
February 26, 2025
Senate Finance Committee

The University of Maryland Medical System (“UMMS”) respectfully submits this letter of support to Senate Bill 757 – Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act).

UMMS provides primary, urgent, emergency and specialty care at 12 hospitals and more than 150 medical facilities across the state. The UMMS network includes academic, community and specialty hospitals that together provide 25% of all hospital-based care in Maryland. Our acute care and specialty hospitals are located in 13 counties and Baltimore City, and serve urban, suburban and rural communities.

The University of Maryland Medical Center's Neuromuscular Program provides specialty comprehensive-specialist care for patients with amyotrophic lateral sclerosis (“ALS”, or “Lou Gehrig's disease”), muscle disease, myasthenia gravis, and peripheral neuropathy. The hospital also houses an interdisciplinary ALS Clinic, managed in partnership with the ALS Association and the Muscular Dystrophy Association. Here, patients can meet with doctors, nurses, therapists and nutritionists, who collaborate to address medical issues, treat symptoms and provide resources and referrals for ongoing care. Additionally, ALS patients have access to augmentative alternative communication (AAC) devices that assists patients connect with their families and care providers.

Since 2019, UMMS has counseled hundreds of patients who have taken genetic testing panels for the purposes of diagnosis and screening for these diseases. UMMS and its neuromuscular specialists support this bill to protect the rights of patients to be informed of their genetic risks, while also protecting them against unheeded discrimination to obtain reasonable insurance policies. Patients are increasingly undergoing genetic testing due to improved affordability and increasing awareness and information regarding genetic diseases. Asymptomatic patients should not have these results be used against them when determining their eligibility for various

insurance policies. Even if a patient does carry a genetic mutation, it is not a guarantee that they will become disabled or have their lifespan shortened from the disease. Therefore, this information should not be used against the patient in a policy analysis performed by an insurance carrier.

For these reasons, the University of Maryland Medical System supports SB 757, and respectfully requests a *favorable* report on the bill.

For more information, please contact:
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