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TO: The Honorable Pamela Beidle, Chair
Members, Senate Finance Committee
The Honorable Katherine Klausmeier

FROM: Danna L. Kauffman
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James L. Madara, MD (AMA)
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RE: **SUPPORT** – Senate Bill 142 – *Genetic Testing – Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2024)*

The American Medical Association (AMA) and the Maryland State Medical Society (MedChi), the largest physician organization in Maryland, **support** Senate Bill 142. Senate Bill 142 prohibits carriers that offer life insurance, long-term care insurance, and disability insurance policies or contracts from taking certain coverage actions (e.g., denying, limiting, rejecting, increasing rates, etc.) based on whether an applicant or policy or contract holder has requested or undergone genetic testing or the results of the genetic testing.

The increasingly common use of genetic information, both inside and outside of the clinical setting, combined with the negative impact of the fear of genetic discrimination on patient care, make it essential that robust and comprehensive protections against genetic discrimination be enacted. Senate Bill 142 provides such protections in non-health insurance markets and, if enacted, would be a national model for other states to follow.

Genomic-based technologies are becoming an increasingly routine part of medical care. Every newborn, for example, undergoes a panel of genetic tests at birth to detect inherited conditions that are vitally important to treat early in life. Several clinical guidelines now include genetic testing, and the safe and effective use of many drugs requires knowledge of the patient's genotype. Genetic tests are available for risk assessment, diagnosis, and/or management of thousands of diseases. Moreover, whole-genome sequencing is gaining traction as a useful clinical tool. Genomic data is also increasingly common in non-clinical applications. Direct-to-consumer genetic testing companies analyze customers' DNA to reveal information about both medical and non-medical traits, and genealogy services analyze customers' DNA samples to deliver information on genetic ethnicity. With more frequent use of technologies that involve

analysis of patients' genomic information, the potential for misuse and discrimination grows.

Genetic discrimination and fears thereof negatively impact patient care. Knowing that their genetic information may have financial repercussions in insurance markets, some patients avoid seeking genetic counseling or refuse to undergo genetic testing, resulting in serious health implications for individuals for whom genetic testing could be beneficial. Given the rapid advancement of genomic testing available to inform diagnostic and therapeutic decision-making across a wide and growing spectrum of diseases, forgoing genetic testing when appropriate impedes optimal patient care. Even among those who do undergo genetic testing, many withhold test results from their physicians or request that genetic information be withheld from the medical record. This lack of information can have detrimental effects on future care of the patient as treating physicians unfamiliar with the patient will have no record of genetic test results. Moreover, fears of discrimination hinder the open and honest patient-physician communication that is essential in the patient-physician relationship.

The Genetic Information Nondiscrimination Act (GINA), passed by Congress in 2008, is intended to protect individuals from genetic discrimination by health insurers and employers. While GINA has afforded important protections, it left unaddressed a number of areas in which individuals may experience genetic discrimination, including in areas of disability, long-term care, and life insurance. Senate Bill 142 addresses the shortcomings of GINA by extending protections against genetic discrimination with respect to disability, long-term care, and life insurance.

Therefore, enactment of Senate Bill 142 will provide needed protection to patients who are vulnerable to genetic discrimination, help foster patient trust and engagement in cutting-edge genomic based care, and make Maryland a leader in protecting patients from genetic discrimination. The AMA and MedChi urge a favorable vote.

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