

June 18, 2019

The Honorable Trey Paradee
Chair
Senate Banking, Business & Insurance Committee
Delaware State Senate
411 Legislative Avenue
Dover, DE 19901

Re: AMA support for S.B. 144, relating to genetics based discrimination

Dear Chairman Paradee:

On behalf of the American Medical Association (AMA) and our physician and medical student members, I am writing to express our support for Senate Bill (S.B.) 144, legislation that will prohibit discrimination based on genetic information. The AMA believes that 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 at the state level. S.B. 144 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, and 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.

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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.

S.B.144 addresses the shortcomings of GINA by extending protection against genetic discrimination in the issuance and renewal of disability, long-term care, and life insurance. The AMA strongly supports these provisions.

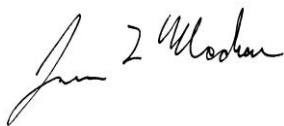
In addition, as the *AMA Code of Medical Ethics* explains, the prospect of access to and use of genetic information by third parties who have a stake in an individual's health raises ethical concerns about confidentiality and potentially inappropriate use of genetic information. Individuals who undergo genetic testing have a right to have their information kept in confidence and physicians who provide and interpret genetic tests have a professional ethical obligation to maintain the confidentiality of that information. Physicians must not release a patient's genetic information to third parties without the patient's informed consent, but the same obligation does not apply to other individuals who provide genetic testing.

S.B. 144 rightly extends confidentiality obligations to direct-to-consumer genetic testing companies by prohibiting commercial genetic testing providers from sharing genetic information with an insurer without an individual's written consent and prohibiting insurers from seeking or requiring information about an individual's genetic information for nontherapeutic purposes.

Enactment of S.B. 144 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 Delaware a leader in protecting patients from genetic discrimination. We appreciate the Committee's consideration of the AMA's position.

For additional information, please contact Annalia Michelman, Senior Legislative Attorney, Advocacy Resource Center, at annalia.michelman@ama-assn.org or (312) 464-4788.

Sincerely,

A handwritten signature in black ink, appearing to read "James L. Madara". The signature is written in a cursive style with a large initial "J" and "M".

James L. Madara, MD

cc: Medical Society of Delaware