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February 16, 2023

To: The Honorable Joseline A. Pena-Melnyk

Chair, Health and Government Operations Committee

From: Steven M. Sakamoto-Wengel

Consumer Protection Counsel for Regulation, Legislation and Policy

Heather Forsyth, Deputy Director Health Education and Advocacy Unit

Re: House Bill 155 – Genetic Testing – Prohibitions on Disability, Life and Long-Term

Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023)

(SUPPORT)

The Consumer Protection Division of the Office of the Attorney General and the Division's Health Education and Advocacy Unit (HEAU) support House Bill 155, sponsored by Delegate Kipke. House Bill 155 extends the protections of current law at Ins. Article § 27-909, which prohibits an insurer, nonprofit health plan, or health maintenance organization from using a genetic test, genetic information, or a request for genetic services to affect a health insurance policy or contact. This bill extends these prohibitions to issuers of life, disability, or long-term care coverage so the issuer may not deny or limit coverage under these contracts or policies based on genetic tests, information, or services.

We share the advocates' concerns that, if consumers fear being denied insurance based on the results of genetic testing, consumers will instead forego the testing. Genetic testing may be relevant to an individual's health care or lifestyle decisions and may be used to trace ancestry. Genetic testing is also critical to research into curing or treating diseases or developing therapeutic medicines. However, just as Maryland and the federal Genetic Information Nondiscrimination Act prohibit denying health insurance to individuals based on genetic testing, these genetic tests should not also be used to deny an individual the ability to obtain disability, life and long-term care insurance.

Maryland is not alone in offering its residents consumer protections for genetic testing. Florida recently passed a law for policies starting or renewing after January 1, 2021, which states insurers (including life, disability, and long-term care insurers), in the absence of a diagnosis of a condition related to genetic information, cannot require or ask for genetic information or use genetic test results to deny, limit, or cancel coverage or set different premiums based on genetic information. http://laws.flrules.org/2020/159. (Florida does allow a life or long-term care insurer to consider a *diagnosis* in the medical record, even if the diagnosis was made with the results from a genetic test.)

We do, however, have concerns about some of the definitions in HB 155. For example, page 3, lines 21-22 defines "Genetic Test" as having the meaning set forth in § 27-909 of the Insurance Article. That section defines "Genetic Test" as "a laboratory test of human chromosomes, genes, or gene products that is used to identify the presence or absence of inherited or congenital alterations in genetic material that are associated with disease or illness." Although we believe that the definition is broad enough to encompass direct-to-consumer (DTC) genetic tests such as 23andMe or Ancestry.com, the Division wants to ensure that discrimination based on DTC tests is prohibited as well.

Further, House Bill 155, on page 4, lines 1-5, prohibits discrimination based upon "genetic information" or a "request for genetic services" without defining those terms. Although those terms are defined in § 27-909 of the Insurance Article, the Division is concerned that applying that definition of "genetic information," which covers information obtained *for diagnostic and therapeutic purposes* at a time when the individual was asymptomatic for the disease, arguably could exclude DTC tests obtained for other purposes. Additionally, § 18-120 of the Insurance Article contains yet a different and inconsistent definition of "genetic information," expressly providing for genetic information that is *not obtained for diagnostic and therapeutic purposes*. We believe that, at a minimum, the Health and Government Operations Committee should consider using HB 155 as a vehicle for ensuring that the definitions in the Code are consistent, when intended. Moreover, § 18-120 of the Insurance Article already addresses use of genetic testing by long-term care carriers, and this bill would be inconsistent with that law. The two will need to be reconciled.

Despite those concerns, the Consumer Protection Division and HEAU believe that House Bill 155 would help to protect Maryland citizens from discrimination based upon the results of genetic testing and respectfully requests that the House Health and Government Operations Committee return a favorable report on House Bill 155.

cc: The Honorable Nicholaus R. Kipke
Members, Health and Government Operations Committee