

Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, M.D., M.P.H., Secretary

February 16, 2023

The Honorable Joseline A. Peña-Melnyk Chair, Health and Government Operations Committee Room 241, House Office Building Annapolis, Maryland 21401

RE: HB 155 - Genetic Testing – Prohibitions on Disability, Life, and Long–Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023) – Letter of Information

Dear Chair Peña-Melnyk and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of information for House Bill (HB) 155 - Genetic Testing – Prohibitions on Disability, Life, and Long–Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023). HB 155 requires that on or before April 1, 2024, MDH shall review and update materials relating to genetic testing in order to educate the public on: 1) the benefits of genetic testing; and 2) the impact of genetic testing on access to life insurance, disability insurance, and long–term care insurance policies and contracts.

In its current scope of work, MDH does not regulate genetic testing or provide educational materials on genetic testing that would be relevant to the benefits of genetic testing, its impact on access to life insurance, disability insurance, and long-term care insurance policies and contracts. The Office for Genetics and People with Special Health Care Needs (OGPSHCN) within MDH works to ensure a comprehensive, coordinated, culturally effective, and consumer-friendly system of care that meets the needs of Maryland's children and youth with special health care needs and their families. OGPSHCN achieves this mission by administering programs and providing information related to Newborn Metabolic Screening, birth defects, sickle cell disease, and congenital heart disease. As part of this work, OGPSHCN conducts surveillance on birth defects and ensures referral to genetic centers for children who screen positive for certain genetic disorders tested for at birth through Maryland's Newborn Metabolic Screening program.

Regulation and dissemination of information about genetic testing largely occurs at the federal level rather than state level. A number of federal agencies regulate and/or provide information on genetic testing, including protections offered by the Genetic Information Nondiscrimination Act (GINA) of 2008. These include the National Institutes of Health, Centers for Disease Control and Prevention, Food and Drug Administration, Centers for Medicare and Medicaid Services, and Federal Trade Commission.

I hope this information is helpful. If you would like to discuss this further, please do not hesitate to contact Megan Peters, Acting Director of Governmental Affairs at megan.peters@maryland.gov or (410) 260-3190.

Sincerely,

Laura Herrera Scott, M.D., M.P.H.

Secretary