



**House of Delegates Health and Government Operations Committee**  
**HB 982: Genetic Testing Protection Act of 2024**  
**February 15, 2024**  
**Position: Support**

The Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of the five Down syndrome organizations in Maryland as well as individuals with Down syndrome and their family members who have come together to advocate for improved quality of life for all individuals with Down syndrome throughout the state of Maryland. MDAC works in coalition with other disability and advocacy organizations across the state and supports many legislative and policy efforts.

MDAC supports HB 982, which would prohibit insurance carriers that offer, issue, or deliver life insurance policies from rejecting, denying, or limiting a life insurance, long-term care insurance, or disability insurance policy or contract based on genetic information. Currently, individuals with Down syndrome are routinely denied the opportunity to purchase life insurance, based on their genetic variation irrespective of age, health or medical history, or other factors.

Down syndrome is “one of the most common genetic variations and occurs in approximately one in every 700 live births in the United States. For most people, each cell in the body has 23 pairs of chromosomes. One chromosome in each pair comes from the mother and the other comes from the father. But sometimes, during cell division, an extra copy of the 21st chromosome is present.”<sup>1</sup> There are three types of Down syndrome: Trisomy 21 (i.e., three copies of the chromosome 21), translocation Down syndrome (i.e., part or all of a third copy of chromosome 21 is attached to a different chromosome), and mosaic Down syndrome (i.e., some cells have three copies of chromosome 21 and some have two copies).

Due largely to medical advances and shifts in societal attitudes, the life expectancy of individuals with Down syndrome has increased significantly in recent decades, with the majority living upwards of 60 or 70.<sup>2</sup> In the United States, an increasing number of adults with Down syndrome live independently, or with limited assistance from family members or the state. Some students who have Down syndrome can graduate from high school, and some attend post-secondary education.<sup>3</sup> To deny life insurance solely on the basis of their chromosomal difference is unjust. For these reasons, MDAC believes HB982 would positively impact our community and is pleased to support it.

Respectfully submitted,

Liz Zogby  
Maryland Down Syndrome Advocacy Coalition  
[katzogby@gmail.com](mailto:katzogby@gmail.com), 443-691-1755

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<sup>1</sup> National Down Syndrome Congress, “What is Down syndrome?” <https://www.ndsccenter.org/programs-resources/what-is-down-syndrome/>

<sup>2</sup> Ibid.

<sup>3</sup> Global Down Syndrome Foundation, “Misconceptions vs. Reality” <https://www.globaldownsyndrome.org/about-down-syndrome/misconceptions-vs-reality/>