



Wednesday, January 31, 2024
Maryland Senate Finance Committee
S.B. 142 – Genetic Testing Protection Act of 2024 (SUPPORT)

Chair Beidle, Vice Chair Klausmeier, and members of the Senate Finance Committee - on behalf of The Michael J. Fox Foundation for Parkinson's Research (MJFF), I write in support of **S.B. 142**, which would prohibit insurance carriers that offer life insurance, long-term care insurance, or disability insurance policies or contracts from taking certain actions relating to coverage based on whether an applicant or a policy or contract holder has requested or undergone genetic testing or the results of the genetic testing.

Founded in 2000, MJFF has been singularly dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. To date, MJFF has funded nearly \$2 billion in global Parkinson's research.

The Genetic Information Nondiscrimination Act (GINA) is a federal law that prohibits health insurers from using information learned through genetic testing, such as a gene mutation linked to neurological disorders, to deny coverage or engage in price discrimination. GINA protections, however, do not apply to life insurance, long-term care insurance, and disability insurance policies.

Currently, there are 13 states that have an extension of GINA, otherwise known as GINA 2.0, which expands protections to include life insurance, long-term care, or disability insurance. In 2008, Maryland passed H.B. 29, which prevented long-term care insurers from discriminating based on genetic information. The goal of the Genetic Testing Protection Act of 2024 is to bring life insurance and disability insurance up to the same standard and prohibit those insurers from canceling, limiting, increasing premiums, or denying coverage based on genetic information.

There are estimated to be more than 1 million Americans currently living with Parkinson's disease, with about 90,000 more diagnosed each year.¹ According to the Centers for Disease Control and Prevention, Parkinson's disease is the second most common and the fastest-growing neurological disorder worldwide.

MJFF recognizes that genetic testing can help identify changes in our DNA that may be linked to Parkinson's disease. A person's decision to learn their genetic status is a personal decision, but the results may help them make proactive health care choices and advance science closer to cures. Currently, genetic testing for Parkinson's disease is primarily for research, and not care. MJFF, however, is opposed to any genetic information being used to penalize patients seeking specific insurance coverages, including life insurance, long-term care insurance, and disability insurance.

¹ "New Study Shows the Incidence of Parkinson's in the U.S. Is Nearly 50 Percent Higher than Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 15 Dec. 2022, <https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates>.

For these reasons, MJFF strongly supports **S.B. 142**. I urge this committee to favorably vote on this important piece of legislation and look forward to seeing it move forward. If you have any questions, please do not hesitate to contact me at zhardy@michaeljfox.org or 202-638-4101, ext. 225.

Sincerely,

A handwritten signature in black ink, appearing to read 'Z Hardy', with a stylized flourish at the end.

Zach Hardy
State Government Relations Officer