

## Thursday, February 20, 2025 Maryland House Health and Government Operations Committee H.B. 1007– Genetic Testing Protection Act (FAVORABLE)

Good afternoon, Chair Pena-Melnyk, Vice Chair Cullison and members of the committee. My name is Zach Hardy, and I am a State Government Relations Manager for The Michael J. Fox Foundation for Parkinson's Research (MJFF). Thank you for the opportunity to provide testimony to the committee on **H.B. 1007**, which would bill prohibits insurance companies from using genetic testing results to influence life, long-term care, and disability insurance coverage.

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 more than \$2 billion in Parkinson's research.

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

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 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.

MJFF recognizes that genetic testing can help identify changes in our DNA that may be linked to Parkinson's disease. An individual'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. The decision of whether to undergo genetic testing should not be influenced by a fear that the results may be utilized against them in the future.

<sup>&</sup>lt;sup>1</sup> "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, <a href="https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates">https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates</a>.

For these reasons, MJFF strongly supports **H.B. 1007**. I urge this committee to support this important piece of legislation and look forward to seeing it move forward.

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