



**February 16, 2023**

**Maryland**

**House Health & Government Operations Committee**

**H.B. 155: Genetic Testing – Prohibitions on disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protections Act of 2023)**

**SUPPORT**

The Michael J. Fox Foundation for Parkinson's Research was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson's Disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with PD today.

Parkinson's disease (PD) is a chronic neurodegenerative disease or chronic motor system disorder that gradually worsens over time. There is no treatment to slow, stop, or reverse the progression, nor is there a cure. The economic burden of Parkinson's disease is \$52 billion each year for the approximately 1 million people living with Parkinson's. This estimate includes direct medical costs of \$25.4 billion, with indirect and non-medical costs of \$26.5 billion.<sup>1</sup>

Parkinson's is the second most common and fastest growing neurological disorder in the world and the number of people with Parkinson's is expected to double by 2040. In 2022, comprehensive incidence study co-funded by The Michael J. Fox Foundation and the Parkinson's Foundation found that the new incidence rate in the U.S. is 1.5 times higher at nearly 90,000 cases per year.<sup>2</sup>

### **Parkinson's and Genetic Testing**

Genetic testing can help identify changes in our DNA that may be linked to Parkinson's.<sup>3</sup> It is so important that the Foundation has been conducting a landmark study called the Parkinson's Progression Markers Initiative ([PPMI](https://www.ppmi-info.org/)) to learn more about how brain disease starts and changes and how to stop it.

PPMI follows people — with and without Parkinson's — over time to learn more about how disease starts and changes. That information can help doctors and scientists better diagnose, treat, and even prevent brain disease.

Some volunteers share data online. Others have tests and share biological samples at one of 50 participating medical centers in 12 countries. The study shares its data set — the most robust in Parkinson's research — with scientists to speed breakthroughs.

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<sup>1</sup> <https://www.lewin.com/resources/publications/economic-burden-parkinsons.html>

<sup>2</sup> <https://www.nature.com/articles/s41531-022-00410-y>

<sup>3</sup> <https://www.michaeljfox.org/what-know-about-genetic-testing>

The Michael J. Fox Foundation strongly believe that barriers to genetic testing should be broken down, and no one should face discrimination in pursuit of their health care needs.

**Support for Genetic Testing Protection Act**

The Foundation supports this legislation that addresses three areas of discrimination: life insurance, long-term care insurance, and disability insurance coverage. Federal law only protects against discrimination with regard to health insurance. The need to extend these protections in state statute can have wide sweeping positive benefits for people living with Parkinson's and their families.

Encouraging genetic testing could support earlier diagnosis. With awareness of one's genetic testing information, a person would be able to plan life decisions such as election of having children, financial and estate planning decisions, and more likelihood of joining clinical trials.

The intent of this legislation is to prevent and prohibit discrimination that our community of people living with Parkinson's have experienced. They should not be fear being denied coverage or significant rate increases based on genetic testing.

For those reasons above, on behalf of the Foundation and the patients we support, we ask for a **favorable vote on HB 155/SB 212.**

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