



**DATE:** January 31, 2024                      **COMMITTEE:** Senate Finance  
**BILL NO:** Senate Bill 142  
**BILL TITLE:** Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2024)  
**POSITION:** Support

**Kennedy Krieger Institute supports Senate Bill 142 - Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023).**

**Bill Summary:**

Senate Bill 142 prohibits life insurance, long-term care insurance and disability insurance policies from denying or limiting coverage based on genetic test results.

**Background:**

Kennedy Krieger Institute is an internationally recognized institution dedicated to improving the lives of children and adults with developmental disabilities and disorders of the brain, spinal cord and musculoskeletal system. The Institute serves over 27,000 patients per year, a significant portion of whom have a genetic basis for their disability. Kennedy Krieger currently employs seven certified genetic counselors, two board-certified medical geneticists, and numerous other physician specialists who utilize genetic testing in their care of their patients.

**Rationale:**

The rapid growth of medical genetics has affected virtually all areas of medicine. Over the past decade, advances in genomic technology and research have elucidated the genetic basis of a vast array of health conditions including neurodevelopmental disorders. Research has also identified promising pathways to targeted therapeutics. Genetic counselors are vital to translating these discoveries into clinical care and attaining the goal of precision medicine. Identifying the genetic etiology of a patient's medical or neurodevelopmental disorder. It is a standard of care for patients with neurodevelopmental disorders to have genetic testing to identify the etiology of their condition. Results of genetic testing frequently impacts medical management, prognostication, treatment, and family counseling.

Unfortunately, a barrier to uptake of genetic testing is patient/family concern about the risk of genetic discrimination. The federal Genetic Information Nondiscrimination Act (GINA) offers protections against genetic discrimination by employers and health insurance companies, but not other types of insurance. At Kennedy Krieger, we often hear from patients and families we serve that they are hesitant to proceed with genetic testing for fear that doing so would prevent them from qualifying for life, long-term care, or disability insurance in the future. Some ultimately decline genetic testing out of this concern, which negatively impacts their care. Without a genetic diagnosis, patients may not have access to disease-modifying therapeutics, clinical trial participation, and/or medically necessary treatments. Senate Bill 142 covers a critical gap in GINA, by providing protections against genetic discrimination by life, disability, and long-term care insurance. Senate Bill 142 will give patients and families affected by genetic conditions peace of mind when opting to undergo genetic testing, ultimately improving outcomes and access to treatments.

**Kennedy Krieger Institute requests a favorable report on Senate Bill 142.**