



DATE: February 8, 2023 **COMMITTEE:** Senate Finance
BILL NO: Senate Bill 212
BILL TITLE: Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023)
POSITION: Support

Kennedy Krieger Institute supports Senate Bill 212 - Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023).

Bill Summary:

Senate Bill 212 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 five certified genetic counselors who care for over 1,000 patients per year.

Genetic counselors are Master's-trained healthcare professionals who have specialized education in medical genetics and counseling to provide personalized guidance to patients regarding their genetic health. KKI's genetic counselors are vital members of the medical team, working alongside physicians, nurse practitioners, and therapists to provide comprehensive patient care. Genetic counselors play crucial roles in selection of appropriate genetic tests and interpretation of results, facilitating decision-making, as well as educating and providing emotional support to patients and their families.

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.

This legislation covers an important gap in the federal Genetic Information Nondiscrimination Act (GINA). GINA only prohibits health insurance and employers from using genetic information in coverage/employment decisions. Patients and families are often hesitant to proceed with genetic testing for fear that they wouldn't be able to get life, long-term care, or disability insurance in the future. At Kennedy Krieger, we have had families decline exome sequencing for their child out of this concern, which negatively impacts the child's care.

Kennedy Krieger Institute requests a favorable report on Senate Bill 212.