American Kidney Fund®
FIGHTING ON ALL FRONTS

April 13, 2026

The Honorable Robert Britto, Chair
The Honorable Sue Sosnowski, Ranking Member
Senate Committee on Commerce

Dear Chair Britto, Ranking Member Sosnowski and Distinguished Committee Members:

On behalf of the people we serve in Rhode Island, including the **1,926 Rhode Islanders currently living with kidney failure, we respectfully request your support for SB 3179.** Kidney disease remains a serious and growing issue in the state, where 1,162 individuals depend on dialysis to survive. This legislation would prohibit insurers from canceling, refusing to issue or renew, increasing rates, restricting coverage, or otherwise discriminating in disability, long-term care, and life insurance policies due to genetic information.

The American Kidney Fund (AKF) is the nation's leading nonprofit organization working on behalf of the 1 in 7 American adults living with kidney disease and the millions more at risk. We provide financial assistance, education, and advocacy to support patients from prevention through post-transplant living.

Individuals undergo genetic testing for a variety of reasons. Some are motivated by curiosity about their ancestry, while others pursue testing due to a family history of certain diseases or to better understand their own health risks. Millions of Americans also participate in genetic research studies—such as the NIH All of Us Research Program, Healthy Oregon Project, Healthy Nevada Project, and Nebraska Medicine's Genetic Insights Project—contributing valuable data to advance medical knowledge and public health. Although many participate in this essential research, we know that others decline to participate due to concerns about genetic discrimination. Many people who are at risk for APOL1 mediated kidney disease, a genetic marker that can indicate an increased likelihood of chronic kidney disease, are choosing not to get tested for exactly that reason.

Importantly, genetic tests conducted as part of research are generally confidential, with results often provided directly to the participant. If an individual tests positive for a mutation thought to be associated with an increased risk of disease, they must decide whether to keep this information private or share it with their healthcare provider, who can then document it in their medical record. Sharing this information and noting it in the patient's chart is essential for health insurance coverage of risk management, which may involve preventive measures such as medication, enhanced screening, or surgical intervention. It is crucial to encourage—not discourage—individuals to take proactive steps in managing their health. People should be empowered to benefit from genetic insights without fear of discrimination or penalty.

Our understanding of genetics and its role in disease continues to evolve. Even experts in the field struggle to stay abreast of the latest research, and oftentimes, must revise their understanding of how genetic mutations influence disease risk. For instance, historically, the CDH1 genetic mutation was thought to confer up to an

11921 Rockville Pike | Suite 300 | Rockville, MD 20852
301.881.3052 voice | 301.881.0898 fax | 800.638.8299 toll-free | 866.300.2900 Español
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80% risk of gastric cancer. A 2024 study, however, found the lifetime risk of gastric cancer in these mutation carriers is actually 10% or less, much lower than previous estimates.[1]

Currently, life insurers are permitted to use genetic test results in underwriting decisions with little or no transparency, a practice that would not change under SB 3179. This raises concerns about the accuracy and fairness of underwriting practices, especially as genetic research rapidly evolves. Does their data reflect the most current scientific understanding and available interventions? What assurances do consumers have? For example, 90% of Variant of Uncertain Significance (VUS) findings are ultimately reclassified as benign. As such, a VUS should never be used for any type of determination, as it is not an indication of disease risk or lack thereof. It is unclear whether and how this type of information is utilized by insurers; this ambiguity contributes to distrust and fear of discrimination.

Given our evolving understanding of the role genetics plays in disease risk and development, and the importance of incentivizing the U.S. population to contribute to science and take a more proactive approach to their health, consideration of genetic test results should be banned from use in life, disability or long term care insurance coverage, renewal, and pricing decisions. We ask that you support SB 3179 and refer the bill favorably out of the committee.

Sincerely,

Jon Hoffman

Jon Hoffman
Senior Director, State Policy and Advocacy
American Kidney Fund

[1] Germline CDH1 Variants and Lifetime Cancer Risk. JAMA. 2024 Sep 3;332(9):722-729. doi: 10.1001/jama.2024.10852. PMID: 38873722; PMCID: PMC11372503. https://pubmed.ncbi.nlm.nih.gov/38873722/