



Facing Hereditary Cancer EMPOWERED

February 4, 2021
HOUSE HEALTH AND GOVERNMENT OPERATIONS COMMITTEE
House Bill 0299 - FAVORABLE POSITION

Good afternoon. Thank you for the opportunity to comment on House Bill 299, which would establish licensure of genetic counselors in the state of Maryland.

My name is Lisa Schlager and I am the Vice President of Public for FORCE, a national nonprofit that advocates for people facing hereditary cancers. I am speaking on behalf of our national organization as well as our Maryland constituents, including myself. The majority of our members carry inherited genetic mutations that significantly increase their risk of cancer. Access to knowledgeable professionals with expertise in genetics is crucial in helping those faced with genetic testing make informed medical decisions. As such, we strongly support ensuring that Maryland residents have access to high quality care—achieved through genetic counselors licensure.

Genetics is a rapidly growing, complex field that affects virtually every facet of medicine. Quality genetic counseling services are vital as more consumers base healthcare decisions such as increased cancer screening, risk-reducing surgeries or family-building choices on genetic test results.

Most healthcare providers have little or no training in genetics. Genetic counselors, however, have advanced degrees in medical genetics and counseling. They are uniquely trained to provide information, education, advocacy, and emotional support for medical conditions that have genetic indications. They often work in tandem with oncologists, surgeons, internists and other health practitioners to provide the full spectrum of personalized medicine.

With the expansion of genetic testing, we have seen an increase in fraudulent genetic counseling and testing practices—often targeting our most vulnerable citizens. In recent years, FORCE has filed complaints against several companies and individuals for unscrupulous behavior. In the majority of

these cases, those providing “genetic counseling” had little or no training in genetics; and, most had no healthcare background. Inappropriate genetic testing or misinterpretation of results can lead to serious adverse outcomes for patients and their families

Research shows that genetic counselor licensure also serves to save the health system money. Genetic tests and the associated medical services are costly. Nearly a quarter of all genetic tests are ordered incorrectly, by clinicians who have insufficient knowledge of genetic testing.^{1,2} This includes orders for unwarranted, cost-ineffective, duplicate, or entirely unnecessary tests.^{3,1} Licensed genetic counselors have the expertise to guide appropriate patient assessment and ordering of genetic tests, thereby minimizing wasteful spending and combating health care fraud and abuse.

National guidelines recommend genetic counseling before and after genetic testing. Currently, Maryland does not legally specify who may use the title of genetic counselor. Why does our state require licensing for massage therapists and personal trainers—but not for those providing guidance on potentially life-altering medical decisions? Licensure is an important mechanism to help consumers and healthcare practitioners identify appropriately trained and qualified genetic counseling professionals. This will benefit patients and providers alike by facilitating access to the most current, evidence-based information and care.

In summary, we strongly support this legislation and urge you to endorse licensure of genetic counselors in Maryland.

¹ Miller *et al.* *Am J Med Genet A*. 2014.

² Lynch and Nouvelage. (2019 Sep 27). *Reuters*. Retrieved from: <https://www.reuters.com/article/us-usa-fraud-genetics-idUSKBN1WC1PH>

³ Berlin (2020 July). *Texas Medicine*. Retrieved from: <https://www.texmed.org/TexasMedicineDetail.aspx?id=53946>