



Facing Hereditary Cancer EMPOWERED

January 26, 2021

RE: Favorable position on SB 0034

Dear esteemed Members of the Education, Health, and Environmental Affairs Committee,

I am writing on behalf of FORCE, a national nonprofit organization that advocates for individuals and families facing hereditary cancers. The majority of our constituents carry inherited genetic mutations (i.e. BRCA1, BRCA2, ATM, CHEK2, PALB2, etc.) that significantly increase their risk of breast, ovarian, colon, pancreatic, prostate and other cancers. Access to knowledgeable healthcare professionals with expertise in genetics is crucial in helping those faced with genetic testing make informed medical decisions. As such, we strongly support the Maryland and DC Society of Genetic Counselors (MDCGC) and its commitment to ensuring that Maryland residents have access to high quality care—achieved through the licensing of genetic counselors.

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

The majority of healthcare providers have little or no training in genetics. Conversely, genetic counselors 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, gynecologists 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

One glaring example is the case of Elisha Cooke-Moore, an Oregon woman who was told that her genetic test revealed an inherited MSH1 mutation, which is associated with Lynch syndrome and a high risk of cancer. Only after Cooke-Moore underwent a hysterectomy and double mastectomy did she learn that her test results had been misinterpreted. With access to a qualified genetic expert, this calamity could have been avoided. Genetic counselor licensure serves to protect patients from this type of medical harm.

Research shows that licensure of genetic counselors 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 healthcare fraud and abuse.

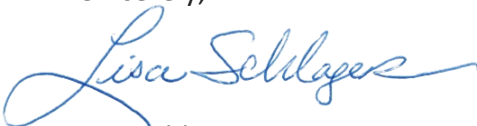
A study published in the *Journal of Oncology Practice* affirmed that counseling with a genetics expert is very important for the successful implementation of genetic testing:

“...of those who had a pre-test discussion, those with a certified counselor were more likely to recall important information about having a pedigree drawn, laws protecting against discrimination by health insurers, and issues related to life and disability insurance. Additionally, those with a certified genetics counselor were more likely to get the appropriate, guideline-recommended testing.”

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.

Sincerely,



Lisa Schlager
Vice President, Public Policy
and Maryland resident

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>