



Facing Hereditary Cancer EMPOWERED

November 17, 2020

RE: Licensing of Genetic Counselors

Dear Texas State Legislators:

I am writing on behalf of FORCE—a national nonprofit organization that advocates for families facing hereditary cancers—and our Texas constituents. The vast majority of our members carry inherited genetic mutations that significantly increase their risk of cancer. Access to trustworthy health care professionals with expertise in genetics is crucial in helping members of our community make informed medical decisions. As such, we strongly support the Texas Society of Genetic Counselors (TSGC) and its commitment to ensuring that Texans have access to high quality care genetic testing—achieved through the licensing of genetic counselors.

Genetics is a complex, rapidly growing field that affects virtually every area of medicine. Quality genetic counseling services are critical as more consumers base health care decisions such as increased cancer screening or risk-reducing surgeries on genetic test results. Unfortunately, the vast majority of health care 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 patients with information, education, counseling, advocacy, and emotional support for medical conditions that have genetic indications.

In recent years, we have filed complaints against several companies and individuals engaging in unethical or fraudulent genetic counseling and testing practices. Importantly, many of those providing “genetic counseling” had no genetics training and most had no health care background. Inappropriate genetic testing or misinterpretation of results can lead to serious negative outcomes for patients, including irreversible medical decisions such as surgery. Genetic counselor licensure serves to protect patients from medical harm.

Research shows that genetic counselor licensure also serve to save the health system money. Genetic tests and the associated health care 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 the placement of orders for unwarranted, cost-ineffective, duplicate, or entirely unnecessary tests.^{3,1} Licensed genetic counselors have the expertise to guide appropriate ordering of genetic testing, thereby minimizing wasteful spending and combating health care fraud and abuse.

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>



Facing Hereditary Cancer EMPOWERED

A study published in the *Journal of Oncology Practice* affirms 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, Texas does not legally specify who may use the title of genetic counselor. Licensure is an important mechanism to help consumers and health care providers identify appropriately trained and qualified genetic counseling professionals. This will benefit patients by facilitating access to the most current, evidence-based information and care.

Thank you for your time and consideration of this important issue.

Sincerely,

A handwritten signature in blue ink that reads "Lisa Schlager".

Lisa Schlager
Vice President, Public Policy

