

TO: The Honorable Shane E. Pendergrass, Chair
House Health and Government Operations Committee

FROM: David Valle, M.D. and Ada Hamosh, M.D., M.P.H.
McKusick – Nathans Department of Genetic Medicine
Johns Hopkins University, School of Medicine

DATE: February 2, 2021

On behalf of Johns Hopkins University School of Medicine, thank you for the opportunity to support HB0299 State Board of Physicians – Genetic Counselors – Licensing. Currently, Maryland does not legally specify who may use the title of genetic counselor. Licensure for genetic counselors is an important mechanism to help consumers identify appropriately qualified genetic counseling providers and prevent unqualified individuals from targeting vulnerable patient populations and their families. Currently, 29 states mandate licensure of genetic counselors and, as a reflection of their increasingly important roles in providing education and care for patients receiving genetic testing and/or who are known to have or suspected of having a genetic disorder, this number increases each year.

The rapid growth of medical genetics has affected virtually all areas of medicine. At the Johns Hopkins University School of Medicine Department of Genetic Medicine (DGM), we have first-hand knowledge of the specialized expertise of trained genetic counselors and the tremendous value of these counselors for physicians, patients, and families. Our genetic counselors provide significant contributions to the education necessary for understanding the genetic contribution to disease and the implications this has for an individual's health – both medical and psychological – and the health of family members. In short, genetic counselors empower providers by providing genetic services and interpretation, which is vital for the goals of individualized medicine. As precision medicine becomes increasingly important given the vast and rapidly increasing contributions of genetic research to medicine, so does the role of the genetic counselor in the continuum of care we provide our patients.

The DGM seeks to further the nation's understanding of human heredity and genetic medicine by consolidating all relevant teaching, patient care and research in human and medical genetics in Johns Hopkins to provide national and international leadership in genetic medicine. The DGM serves as a focal point for interactions between diverse investigators and healthcare providers to promote the application of genetic discoveries to human disease and genetics education to the public. We are proud that, in 1975, we were one of the first medical institutions in the country to add genetic counselors to our healthcare team. Over the ensuing years, we have successfully employed over 400 genetic counselors and through this experience have learned how valuable they are for

the delivery of state-of-the-art care for our patients. Currently, there are 30 genetic counselors working at Hopkins. They participate in the clinical specialties of genetic medicine, GYN/OB, maternal fetal medicine, fetal therapy, cardiology, neurology, ophthalmology, pulmonology, oncology, immunology, pediatrics, and plastic surgery. In these capacities, genetic counselors at Hopkins interact with more than 8,000 patients per year.

Genetic counselors are required to complete a two-year Master's degree that includes course work and in-person training in the clinic. As healthcare professionals, they provide information, education, counseling, advocacy, and the emotional support necessary for understanding the genetic contribution to a wide variety of medical conditions to patients and their families. Licensure for genetic counselors will ensure that genetic counseling providers are appropriately trained and credentialed. In the absence of licensure of genetic counselors, patients are at risk for receiving inaccurate information and/or improper care resulting from uninformed or misinformed choices regarding their medical management including the selection and interpretation of appropriate genetic testing.

With the COVID-19 pandemic and telemedicine waivers, our clinical providers were able to quickly pivot to meet the needs of our patients and effectively provide genetic counseling via telemedicine. Patients, particularly those in Western Maryland and on the Eastern Shore, experienced increased access to genetic counseling services and expressed gratitude for receiving these services without having to travel. This legislation is necessary to maintain access to genetic counseling via telemedicine while protecting patients and their families from unqualified providers. Additionally, the lack of licensure for genetic counselors in the State of Maryland meant that Maryland-based genetic counselors did not fall under Executive Orders of Maryland and other states to waive licensing requirements, with the result that many Maryland-based genetic counselors obtained licenses in other states in order to meet exemption requirements.

Licensure will formalize and strengthen the collaborative relationship of genetic counselors with treating physicians as they work within a multidisciplinary clinical setting and will improve access and timeliness to accurate and well-informed genetic information. As genetics and genomics is increasingly becoming a vital part of patient care, integration of genetic counselors at every aspect of clinical care is essential. In our opinion, absence of licensure for these highly trained professionals --our genetic counselors -- will restrict provision of greatly needed clinical genetics services to patients; a need that is ever-increasing in today's medicine.

Thus, for all these reasons, we respectfully and enthusiastically request a favorable report of HB0299.

Sincerely,



David Valle, M.D.
Henry J. Knott Professor and Director
McKusick-Nathans Department of Genetic
Medicine



Ada Hamosh, M.D., M.P.H
Dr. Frank V. Sutland Professor
Clinical Director, Department of
Genetic Medicine