



Proponent Testimony
Senate Medicaid, Health and Human Services Committee
Chair, Senator Shannon Jones
Senate Bill 23
April 17, 2013

Chairman Jones, Vice Chair Burke, Ranking Member Cafaro and members of the Senate Finance Medicaid, Health and Human Services Committee, thank you for the opportunity to testify on Senate Bill 23.

My name is Charis Eng, and the Hardis and ACS Professor and founding Chair of the Cleveland Clinic Genomic Medicine Institute. I am the founding Director of the institute's clinical component, the Center for Personalized Genetic Healthcare, and Professor and Vice Chairman of the Department of Genetics and Genome Sciences at Case Western Reserve University School of Medicine.

My research interests may be broadly characterized as clinical cancer genetics translational research and genomics-enabled healthcare. I am in the middle of a 5-year term as Editor-in-Chief of *Endocrine-Related Cancer*. I completed a 3-year term on the Board of Directors of the American Society of Human Genetics, and completed a 5-year term on the Board of Scientific Directors of the National Human Genome Research Institute. I was elected to the Institute of Medicine of the National Academies of Sciences in 2010 and served a term on DHHS Secretary's Advisory Committee of Genetics, Health and Society.

I wish to convey Cleveland Clinic's strong support of Senate Bill 23. This important legislation would allow persons adopted between 1964 and 1996 access to their birth certificates, at their request. By gaining access to their birth certificates, people will be able to obtain important information relevant to their family health history.

Family health history is an important tool used in routine clinical practice to assess health risks, inform personalized screening and early treatment options, and serves as a guide for diagnostic tests (including genetic tests). The Centers for Medicare and Medicaid Services recognize this essential component of the inpatient and outpatient clinical assessment and has incorporated

family history as a requirement for billing. In addition, the U.S. Department of Health and Human Services launched Healthy People 2020 in December 2012. The genomic objectives of Healthy People 2020 emphasize the importance of obtaining a family health history as a powerful guide for clinical and public health initiatives.

The Cleveland Clinic's Genomic Medicine Institute has been a leader in recognizing the critical role family history plays in both health and disease. In 2012, we launched a family history collection and risk assessment tool aimed to identify patients at risk for inherited predisposition to disease. This important tool, driven by information obtained from the family history, delivers clinical decision support via the electronic medical record directly to medical providers, allowing for a tailored, personalized approach to medical care.

For adopted persons born between 1964 and 1996 the ability to obtain family history information is extremely limited. These individuals, especially those now in their 40's, are of an age when family history is used to personalize health screenings, and is used to tailor early treatments for common disorders. Without a family history, medical providers are unable to proactively guide education and prevention efforts which might significantly reduce morbidity and mortality amongst adopted individuals. Additionally important, family history information flows not only from parent to child, but from child to parent. Needless to say, the potential impact of sharing family history and thereby empowering its use to guide preventive care is tremendous for generations of Ohioans.

This is the sixth bill in 24 years that has attempted to provide Ohio adoptees access to their original birth certificates. We cannot afford to wait any longer.

On behalf of Cleveland Clinic, I would like to acknowledge the important stakeholders, including the Adoption Network Cleveland, for their extensive effort to enact this important piece of legislation into law.

In closing, Cleveland Clinic would like to thank Representative Dorothy Pelanda and Representative Nickie Antonio for their support. We especially want to thank Senators Beagle and Burke for sponsoring this bill and their continued leadership in the Senate on healthcare and workforce development issues.

Members of the Committee, I thank you for the opportunity to speak on behalf of this important issue.