

SAMSON COLLEGE OF HEALTH SCIENCES DEPARTMENT OF PHYSICIAN ASSISTANT STUDIES

Proponent Testimony
Committee on Children & Youth
The Honorable Katherine M. Watson, Chair
Pennsylvania House Bill HB 162

To the Honorable Katharine M. Watson, Chair, and members of the Committee on Children & Youth, thank you for the opportunity to testify on behalf of HB 162.

My name is David R Leonard. I am the Chair of the Department of Physician Assistant Studies and Founding Director of the Graduate Professional Physician Assistant Program at University of the Sciences in Philadelphia, PA.

I have been a physician assistant for over 20 years having received my bachelor's degree in Physician Assistant Sciences in 1990. I also completed a Master's of Medical Science in 1996. Both degrees were obtained from Saint Francis University, Loretto, PA. My Doctor of Health Science degree was completed in 2010 at Nova Southeastern University in FL. My doctoral research focused on issues of adoption in healthcare and my final practicum was entitled 'Providing Quality, Competent, and Compassionate Care to Adopted Persons'.

I was adopted at the age of 14 months from the Children's Aid Society in Philadelphia and raised by my adoptive family in Western Pennsylvania. I have been in reunion with my birthmother and her sons, three half-brothers and their families for over 15 years. I am also in reunion with two half-brothers and their families on my birthfather's side of the family. My birthfather was deceased at the time of my search. Additionally, I am in reunion with several cousins in Cornwall, England.

In 2004, the Surgeon General declared Thanksgiving to be National Family History Day signifying the importance of the family history in providing quality care to patients as many diseases, both common and rare, have genetic links. It was thought that the day could be celebrated by discussing and writing down the family's health history. Obviously, for adopted persons with closed records, this kind of discussion is impossible.

The family history is an integral part of the medical history and physical exam performed on all patients. The family health history is utilized to identify and assess health risks. It is utilized to direct health screening efforts and the ordering of diagnostic tests. It may also influence treatment options.

A family history is dynamic. It is always changing. A family history given at age 25 will be very different than that given at age 60.

A family history works both ways: health information flows from parent to child and significantly, from child to parent.

Without a family history, healthcare providers are at a disadvantage when treating patients. Some people feel that genetic testing can make up for that disadvantage. Unfortunately, genetic testing, while sometimes able to predict the presence or absence of a gene or genetic code, is not always able to provide a clear picture of clinical validity and/or clinical utility.

Clinical validity refers to how well the gene or genetic code is related to the presence, absence, or risk of a certain disease. Many genetic tests do not give a definitive answer as to whether an individual will develop a given condition or not. Instead, they can only offer a risk or probability of developing disease in future.

Clinical utility refers to whether the test can provide helpful information about diagnosis, treatment, management, or prevention of a disease. The American College of Medical Genetics states that genetic tests need to be interpreted in light of personal and family history, not to their exclusion.

Take my case in point. My genetic code will tell you that I am at risk for diabetes. That's all it will tell you: at risk.

Indeed, I have been diagnosed with diabetes for several years now. At first my treatment began with oral medications. However, it was the knowledge of my family history that includes two aunts and several cousins who have or have died from major complications of the disease that has made an enormous impact in my treatment options. With this family history, I wasn't able to stay on oral medications as it was imperative that my blood sugars be kept under very tight control with the use of insulin; this in order to try and prevent or delay some of the complications experienced by my relatives. And so it was my family history, and not my genetic code, that has played a definitive role in my treatment, and indeed the quality of my healthcare: A role that the family medical history plays in the provision of quality healthcare in all persons, adopted or not.

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