

Testimony of

Bruce A. Rudolph

in support of

SB 857- AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS

February 20, 2015

Senator Gerratana, Representative Ritter, Senator Markley, Representative Srinivasan and members of the Public Health Committee. My name is Bruce Rudolph.

My wife Katherine was diagnosed with Ovarian cancer in August of 2005. She came under the care of Dr. James Hoffman at The Hospital of Central Connecticut in New Britain. Over the course of the next twenty-two months we had numerous visits to the hospital several of which were emergencies. The staff was always prepared to deliver whatever care was needed.

Katherine lost that battle in July of 2007. In June of 2008, as a result of the thoroughly professional treatment she received, I decided to make a contribution to the hospital that would be aimed at saving lives by supporting any testing that might be developed for the early detection of Ovarian cancer. I consulted with Dr. Hoffman about that notion. Unfortunately, he saw the development of such a test happening any time soon as remote. He did, however, propose another way to accomplish the same life saving goal. He proposed establishing a hereditary cancer genetics counseling service. The objective of the service would be to identify individuals who were carrying the deleterious BRCA1 and/or BRCA2 gene. The results would have a huge impact on those undergoing the testing and their families. Decisions in the future might greatly reduce the risk of contracting the disease.

In October 2009 the Katherine Ann King Rudolph Heredity Cancer Genetics Fund, which supported the hereditary cancer genetics counseling service, was established. Linda Steinmark, a biologist with certification in counseling, was tasked to establish the service at The Hospital of Central Connecticut, Hartford Hospital and St. Francis Hospital in Hartford. The service became, in Dr. Hoffman's words, a catastrophic success. It has grown to include Sara Carroll, Ann Wein and Kelly Genzlinger all certified genetic counselors. The service has come under the umbrella of Hartford Health Care Cancer Institute and has expanded to MidState Hospital in Meriden with plans to include Windham Hospital and Backus Hospital in Norwich.

I, personally, had the opportunity to experience the counseling service. Dr. Hoffman suggested that Katherine's dad be screened for the deleterious gene. He was counseled by Jennifer Stroop, a genetic counselor at the UCONN Health Center. Through this experience I learned, first hand, what it was like to hear the results of the testing. I was struck by the meaning the

results were going to have, positive or negative, for Katherine's family. The emotions involved were deep and profound.

The scope of genetic testing has also expanded from BRCA1 and BRCA2 to offer panels that can include as many as twenty-five different genes. The explosive expansion of genetic testing and the impact the results have on individuals and their families requires counselors grounded not only in the science of genetics but the skills necessary to guide this most difficult process. It is vital that the hiring process carry, as best it can, a guarantee that those entrusted with the present and future lives of patients be as qualified as possible.

I want to thank the committee members for the opportunity to support the idea of requiring a license of those who would take on the responsibility of genetic counselor.

Sincerely, Bruce A. Rudolph