

TESTIMONY PUBLIC HEALTH COMMITTEE

Monday March 17, 2014

Robin Baker, RN, BSN

RE: HB 437

My name is Robin Baker, a nurse clinical manager at Farmington Valley VNA in Simsbury CT. I want to give a personal perspective to the importance of professional standards of education and certification for genetic counselors.

In 1986 my father died of pancreatic cancer at the age of 50, soon after his twin sisters were diagnosed with colon cancer and then with uterine cancer, another sister was also diagnosed with the same cancers a number of years later. His three sisters were able to successfully battle these cancers until one of the twins died 7 years ago from a third cancer, squamous cell carcinoma of the lung (she was not a smoker). In 1988 at the age of 29 my sister (a physician) was diagnosed with the first of many cancers, we were not sure at the time that there was a genetic link until she developed a sebaceous carcinoma and the diagnosis of Muir-Torre was suggested.

In 2007 with this family history developing my physician strongly recommended that I get genetic counseling, I was fortunate enough to meet with Robin Schwartz a genetic counselor at the University of Connecticut Health Center and with her guidance and support encouraged my sister to get genetically tested first since she was the first of us five siblings to be diagnosed with cancer. My sister resides in Arizona and was tested at Slone Kettering. After her testing came back positive for Muir-Torre Syndrome I met with Robin Schwartz again and we began my testing process. Her expertise and professionalism were of the highest standards and made a very difficult process manageable.

I am happy to say that I tested negative, which also means my two sons are "safe". However in addition to my sister, two of my three brothers have also tested positive for this genetic disorder. One of who is now terminal with his third cancer at the age of 49. It is because of professional genetic counselors involved with my siblings and myself that we have been able to navigate through these very tumultuous waters. They continue to guide my siblings as they work through their diagnosis and struggle with how and when to have their children tested.

Each of my siblings has received genetic counseling from board certified counselors at the Slone Kettering Hospital/Cancer Center in Phoenix Arizona. My family is fortunate to be living near a highly respected cancer center with professionals certified to do this job. Not everyone has that opportunity. The science of genetic health is in its infancy and yet the impact of this quickly immersing knowledge has the potential to dramatically change a person's life. Knowledge is power, accurate, objective knowledge that is. There is a great deal of conflicting information that can have (not to sound to dramatic) a life or death effect on those who seek genetic counseling. It is imperative that those individuals entrusted with this responsibility have the standardize education, training and professional standards to meet the increasing need.

Thank you for the opportunity to express my support of this bill.