

SB 857 An Act Concerning Licensure for Genetic Counselors.

My name is Ellen Matloff and I live in Branford, CT. I am a certified genetic counselor and the President and CEO of My Gene Counsel, LLC. I am writing to testify in support of **SB 857 An Act Concerning Licensure for Genetic Counselors.**

Testimony of

Ellen T. Matloff

in support of

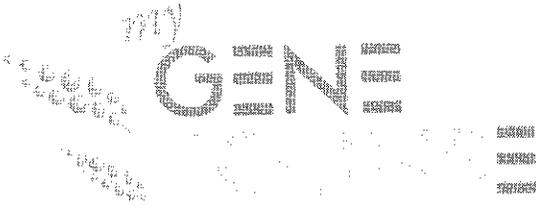
SB 857- AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS

February 20, 2015

Senator Gerratana, Representative Ritter, Senator Markley, Representative Srinivasan and members of the Public Health Committee, my name is Ellen Matloff and I am providing written testimony in strong support of Senate Bill 857- An Act Concerning Licensure for Genetic Counselors.

I am the President and CEO of My Gene Counsel, LLC. and the Founder and previous Director of the Cancer Genetic Counseling Program at Yale School of Medicine for 18 years. I was also a lead plaintiff in the 2013 Supreme Court Case regarding the BRCA gene patent ASSOCIATION FOR MOLECULAR PATHOLOGY ET AL. v. MYRIAD GENETICS, INC., ET AL. I am also the senior author on 3 published articles outlining adverse events across the United States and Canada caused when patients did not receive genetic counseling from a trained professional. These events included a patient who had her breasts removed preventively, only to learn that she did not carry a true genetic mutation, and a patient from CT with advanced ovarian cancer, whose BRCA result 1.5 years earlier had falsely been read as normal by her well-meaning physician.

Genetic counselors are graduate-trained professionals who specialize in genetic testing and interpretation of those results for patients and their families. President Obama recently announced the 'Precision Medicine' initiative, which will drive our country closer to using genetic testing in everyday medicine. As genetics moves forward it also becomes more complex, meaning it is even more critical for us to ensure that trained professionals are doing this work. This is where licensure comes in. Licensure will help to ensure that patients and consumers are protected from unqualified providers, and unregulated practices. This is very important because many of the genetic testing laboratories are 'training' clinicians, technicians, and yes, even clerical staff to order testing and send it to their



laboratories. This has resulted in grave errors and harm to patients, as we've documented in our publications. The State can prevent harm by ensuring that providers who represent themselves as genetic counselors have the appropriate training and continuing education. This could help aid in prevention of adverse events in genetic testing as we move forward. Licensure of genetic counselors, which has already been passed in many states, will remove constraints on billing for genetic counseling services, thereby allowing medical centers to hire more genetic counselors and improve patient access.

Thank you in advance for your time, effort and interest in this important issue. Please don't hesitate to contact me directly if you need any additional information or assistance.

Sincerely,

Ellen T. Matloff

Genetic Counselor

President and CEO, My Gene Counsel