

Testimony in support of SB 857- AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS

February 19, 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 a practicing Genetic Counselor in the State of Connecticut for the last 10 years. I am an author and two seminal papers that documented adverse events across the United States and Canada caused when patients did not receive genetic counseling from a trained professional. Many of them occurred in Connecticut. 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 aide 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,

Danielle Bonadies, MS
Genetic Counselor