

Testimony at House Professional Licensure Committee Hearing on House Bills 2137/2138

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Thank you for the opportunity to address an issue of persistent and pressing concern to me over my entire career of 30 years as a medical geneticist. When I was on the faculty of the Johns Hopkins School of Medicine in the mid-1980's, I testified at the State House in Annapolis on this very issue. Then the argument against licensing genetic counselors went something like, "We have enough professionals being licensed, and don't need to expand the Office of Licensing and Regulation". This came from lobbyists and legislators who agreed to license beauticians and taxidermists but not a vital and growing cadre of health professionals who had graduate degrees and board certification. I trust that we in the Commonwealth of Pennsylvania can take a more enlightened view, and follow the lead of a number of other states, including California, New York and Utah.

At least weekly, and often more often, we read in the newspaper or web, or hear on the evening newscast, about another advance in applying genetics to medicine. I checked several websites last night (listed below) and can document the following extent of the relevance of the topic today.

There are 18,841 human traits, mostly diseases, which are clearly due to variation in a specific gene. These diseases all have the potential to be heritable, meaning that more than one individual in a family can be affected.

There are 597 laboratories in the World that perform a total of 1596 gene-based tests for individual diseases. 1311 of these tests are available as 'clinical tests', which means they are performed in labs that are accredited by the FDA under the Clinical Laboratory Improvement Act (CLIA). The other 285 tests are performed only on a 'research' basis, meaning that the results cannot be reported directly to patients.

Can you imagine your primary care physician, no matter how recently and well trained, having the sophistication let alone the time to sort through this extensive list of genetic data and apply it to your particular situation?

And now the news is full of direct-to-consumer (DTC) genetic testing by a myriad of start-up and some long-established commercial laboratories (e.g., 23andMe, Navigenics, Smart Genetics deCode Genetics), which advertise extensively and solicit specimens directly from the lay population. It is well documented that the consumer is likely to be stumped by the results he or she receives. Sure, there is a result, which may or may not be accurate, but how does the consumer adequately interpret that the risk of developing Alzheimer disease has gone from the population average lifetime chance of 10% to 27%? What does that mean for his or her brother, or children? The primary care physician, who likely would have counseled against doing the test in the first place, does not want to be burdened with this sort of counseling, and frankly is not likely to have the tool box to perform it well.

There is a growing need for health professionals trained specifically in medical genetics. These professionals are of three types: M.D. Clinical Geneticists; Genetic Nurses; and Genetic Counselors.

The American Board of Medical Genetics since its inception 25 years ago has certified 1253 M.D.'s as clinical geneticists. Of this group, fewer than 105 practice full-time today. About half practice part time, as do I, in an academic setting in which we also do research and teach. The rest are administrators, retired or deceased. Surprisingly (to me) the pool of trainees is small, with only about 80 newly minted clinical geneticists every two years joining the workforce. There are 37 of us working in Pennsylvania, almost all in academic medical centers. We spend most of our clinical time diagnosing rare, genetic disorders and in some cases conducting long-term management (but not generally primary care). We struggle to make ends meet, since typically our patient visits take three hours or more (when the pre-clinic and post-clinic services are counted), we are reimbursed only for our time with the patient, and we have no revenue-generating procedures. We simply do not have the time to spend with patients performing genetic counseling.

Genetic Nurses constitute a relatively small group of R.N.'s who also have training in genetics. They should also be considered under your pending legislation.

But the focus is on Genetic Counselors, who have attained a Master's degree in genetic counseling and are certified by the American Board of Genetic Counseling, giving them the right to type 'C.G.C.' after their name, for 'certified genetic counselor'. The ABGC (and before it came into existence, the ABMG) has certified around 2500 counselors; I am certain others today will give a more specific number. We at the Hospital of the University of Pennsylvania employ 11. A similar number are employed next door at the Children's Hospital of Philadelphia. In both cases, counselors are spread over a number of departments and interact with patients in various ways. Most work with a physician, usually a clinical geneticist, to provide absolutely

essential services that the physician has no time and, I'm sorry to say, little training or expertise to do.

Others will testify to the many tasks and services that Genetic Counselors provide. Let me emphasize two points:

- I could not function as a clinical geneticist without the two counselors employed by my division;
- I cannot pay my two counselors out of clinical revenue that I generate, because I do not even cover that portion of my own effort (salary) that I devote to seeing patients.

Licensure by the Commonwealth of Pennsylvania will enable the special services provided by these highly trained individuals to be reimbursed for their services. Note that I did not say, 'bill for their services'. In fact, Genetic Counselors can submit bills for services, and there are a couple of CPT codes specifically for them. **But in the absence of licensure, insurers uniformly deny payment. Billing is an exercise in utter frustration.**

There is no question in my mind but that the demand for genetic counseling services is growing, and will continue to expand at an ever faster rate. The completion of the Human Genome Project has guaranteed this. The only way that our society will be able to provide for these important services is to pay for them, and thereby increase the numbers of counselors, the willingness of institutions, HMOs and group practices to hire them, and the sense of worth of the counselors themselves who will be able to identify a specific financial contribution to their employer.

I am pleased to be able to present these thoughts today. I am very willing to answer your questions now, in future hearings, or at anytime by contacting me directly.

Thank you.

References cited

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<http://www.geneclinics.org/>

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