Testimony for the Public Health Committee

Monday, March 17, 2014

I am Niki Lovick and I live in New Haven, CT. I am a genetic counselor at the Yale Cancer Genetic Counseling Program.

I am writing to testify on S.B. No. 437 (RAISED) AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS.

I generally support this bill and would like to express my gratitude to the committee for raising this bill on this important issue. I also support the modifications and comments on the bill that were shared with the committee chairs by our team of genetic counselors, geneticists, and other interested individuals.

There is a **nationwide movement for genetic counselor licensure** with 14 states currently issuing licenses (CA, DE, IL, IN, **MA**, NE, NM, OH, OK, PA, SD, TN, UT, WA)[1], 4 additional states that have bills passed or in rulemaking (HI, **NH**, **NJ**, ND)[1], and 7 states with bills introduced (FL, MI, MN, **NY**, **RI**, TX, WI). These include many of **our closest neighbors (in bold).**

Genetic medicine is expanding rapidly and has an influence on many medical issues throughout the lifespan (including common disease like cancer and heart disease).

- Advances in technology are decreasing the cost, increasing the availability, and increasing the complexity of genetic testing options and thus simultaneously increasing the complexity of the genetic counseling and testing process.[2-4]
- The demand for genetic counseling and testing is increasing with the increasing visibility of genetic testing through media attention (e.g. Angelina Jolie's disclosure that she carries a BRCA mutation and the Supreme Court decision to ban gene patents)

Specialized and current knowledge is critical for providing accurate genetic counseling and thus ensuring that patients reap the benefits of genetic technology.

- Genetic counselors are professionals whose training includes graduate-level training, clinical experience and mandatory continuing education in genetics. They have expertise in genetics and genetic counseling and function as an essential member of the health care team.
- Numerous studies have demonstrated that non-genetics healthcare providers have little or no formal training in genetics, have inadequate knowledge of essential genetic concepts, and have insufficient knowledge and appreciation of the complex ethical and psychosocial issues involved in genetic counseling and testing.[5-13]
- The results of these studies are especially concerning as the complexity of this process increases with advances in technology.

There is potential for harm if individuals represent themselves as genetic counselors without adequate levels of training and continuing education.

- Patients rely on the advice of genetic counselors in making significant medical decisions including major prophylactic surgeries, decisions regarding the frequency and aggressiveness of preventative screenings for fatal diseases and decisions regarding testing during pregnancies. Genetic counselors also provide services that help individuals cope with the difficult pragmatic, emotional, ethical and social implications related to genetic testing.

- Several case series have now documented numerous cases (>50) of adverse events (including many in Connecticut) that have arisen when genetic counseling and/or testing occurred without the involvement of a certified genetics professional. [14-16] These included cases that resulted in advanced cancer diagnoses, unnecessary prophylactic surgeries, unnecessary expenditure of healthcare dollars that were charged to the insurance and/or patient, and psychological distress. [14-16]

For these reasons, I support S.B. No. 437 (RAISED) AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS.

Thank you for your consideration.

Sincerely,

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References:

1. National Society of Genetic Counselors (NSGC). States Issuing Licenses for Genetic Counselors. Retrieved from: http://nsgc.org/p/cm/ld/fid=19
2. Raffan E and Semple RK. Next generation sequencing- implications for clinical practice. British Medical Bulletin 2011; 99:53-71.
3. Ku C-S, Cooper DN, Polychronakos C, et al. Exome sequencing: Dual role as a discovery and diagnostic tool. Ann Neurol 2012;71:5-14.
4. Li C. Personalized medicine- the promised land: are we there yet? Clin Genet 2011; 79:403-412.
5. Greendale K, Pyeritz RE. Empowering primary care health professionals in medical genetics: How soon? How fast? How far? Am J Med Genet 2001;106:223-232.
6. Wideroff L, Vadaparampil ST, Greene MH, et al. Hereditary breast/ovarian and colorectal cancer genetics knowledge in a national sample of US physicians. *J Med Genet* 2005; 42:749-755.
7. Doksum T, Bernhardt BA, Holtzman NA. Does knowledge about the genetics of breast cancer differ between nongeneticist physicians who do or do not discuss or order BRCA testing? *Genetics in Medicine* 2003; 5(2):99-105.
8. Suther S and Goodson P. Barriers to the provision of genetic services by primary care physicians: A systematic review of the literature. Genetics in Medicine 2003; 5(2):70-76.
9. Ready KJ, Daniels MS, Sun CC, et al. Obstetrics/Gynecology residents' knowledge of hereditary breast and ovarian cancer and Lynch syndrome. J Canc Educ 2010; 25:401-404.
10. Wilkins-Haug L, Hill L, et al. Gynecologists' training, knowledge, and experiences in genetics: A survey. Obstet Gynecol 2000;95:421-424.
11. Brandt R, Zonera A, Sabel A et al. Cancer genetics evaluation: Barriers to and improvements for referral. Genetic Testing 2008; 12(1): 9-12.
12. Lowstuter KJ, Sand S, Blazer KR, et al. Influence of genetic discrimination perceptions and knowledge on cancer genetics referral practice among clinicians. *Genetics in Medicine* 2008; 10(9):691-698.
13. O'Neill SC, Peshkin BN, Luta G, et al. Primary care providers' willingness to recommend BRCA1/2 testing to adolescents. *Familial Cancer* 2010; 9:43-50.
14. Brierley KL, Campfield D, Ducaine W, et al (2010). Errors in Delivery of Cancer Genetics Services: Implications for Practice. *Connecticut Medicine.* 74(7): 413-423.
15. Brierley K, Blouch E, Cogswell W, et al (2012). Adverse events in cancer genetic testing: medical, ethical, legal, and financial implications. *The Cancer Journal.* 18(4):303-309.
16. Bensend TA, Veach PM and Niendorf KB (2014). What's the harm? Genetic counselor perceptions of adverse effects of genetics service provision by non-genetics professionals. *Journal of Genetic Counseling.* 23(1):48-63.
17. Pollack, A (2013). FDA orders genetic testing firm to stop selling DNA analysis service. The New York Times. Retrieved from http://www.nytimes.com