

Ellen Macnamara

Genetic Counseling Student

Email interview, 4/5/2013

**What is your name?**

Ellen Macnamara

**What are you getting your degree in?**

I'm earning a Masters of Science in Genetic Counseling.

**What does a genetic counselor do?**

A genetic counselor helps people who are at risk of having a genetic disease, have a genetic disease, or are interested in testing for genetic disorders to better understand what the disease is and what it means for them as a person and as a family. We also work with families and individuals to help them adapt to genetic diagnoses or to living with a genetic disease. Genetic counselors work in a multitude of fields, however, and can be involved in clinical work (working with patients), research in genetics or the natural history of a disease, and many other "non-traditional" counseling roles.

**When do you recommend that someone get their genome sequenced?**

There isn't a perfect circumstance for getting your genome sequenced. I think it is an individual decision that depends on what information you are looking for, why you are looking for information, and what you might do with the information. The technology to sequence, and then make sense of, a genome is relatively new. Most commonly, and I believe the current best use of the technology, it is used to help diagnosis an individual who has many different problems. I think this is an important question that will require careful consideration as it becomes more widely acceptable to sequence a genome.

**What are the consequences (positive and negative) of getting your genome sequenced?**

The consequences of getting your genome sequenced are largely dependent on the reason you are having it done. In general, when a healthy person has their genome sequenced the positive outcome is that you may learn new, interesting and important information about your genetic health and the health of your relatives. The negative consequences are that you may learn a lot more than you wanted to know, or maybe not as much as you wanted to know. Sometimes people become anxious or worried about genetic test results and this can disrupt other aspects of

their life. When a person who is sick gets their genome sequenced to help make a diagnosis the positive outcome, and the one everyone is hoping for, is that you will find an answer and understand why the person is sick. It is still possible, however, that you may not find an answer, or that you will find that you are at risk of developing a certain disease, such as cancer. Genetic counselors work with many patients before having their genomes sequenced to help them think through the possible positive and negative outcomes of genome sequencing.

**What do you think the future of genetic testing will be?**

I think the future of genetic testing will be largely controversial, as people continue to debate the ethical, legal, social and moral implications of this technology. I also believe that genetic testing will become more common, both in helping sick individuals and in healthy individuals curious to learn more or prepare to have a child. The future of genetic testing is unknown but will be very interesting!

**Do you think it's a good idea for healthy people to get their genomes sequenced?**

See above answers. I think so long as a person is properly consented, ideally by a genetic counselor, it isn't a bad idea to get your genome sequenced. Again, it is a personal decision dependent on many factors. It's a decision worthy of much consideration!