

The RAMble Report - December 2021

Massey genetic counselor John Quillen, Ph.D., was the invited speaker for the final RAMble of 2021, held on December 15. With 25 people in attendance, Dr. Quillen spoke about genetic testing and counseling for hereditary cancer.

The biggest barriers to genetic testing twenty years ago, when the program was started at VCU Health, were the cost and related consequences, such as the ability to get health insurance, he shared. Because the genome had just been sequenced it was thought that soon the inherited risk of cancer could be described by a blood test. Collecting your family history wasn't considered to be that helpful at the time. A few things have changed but even as the cost has decreased, genetic testing is still not affordable by everyone. Laws have been passed that protect against health insurance discrimination but they don't apply in every situation, Dr. Quillen explained. Knowing your family health history remains an important tool even today.

Since those days the number of genes that can be tested to tell us more about our risk of cancer have increased. Unfortunately, despite this there remain many cancers and we still lack information about genetic risks.

For example, only 5-10% of breast cancers are thought to be inherited. Having a blood relative diagnosed with cancer doubles our risk of a cancer diagnosis, he explained. With about a third of the current population having someone in their family with cancer, this means many of us may be affected. Dr. Quillen warned, however, that not everyone knows if they have a relative who's been diagnosed with cancer, so the risks may be far greater. Even today, not everyone tells their family members when they have cancer and family members don't often bother to ask.

What should we know about our family health history in order to better understand our own cancer risk? This is what Dr. Quillen suggested:

- What types of cancers family members have had? If possible, get information from medical records and/or pathology reports.
- How old were they at the time of diagnosis? The majority of hereditary cancers happen in younger persons.



- What family members count? Close blood relatives count. Find out as far back as grandparents and as far out as cousins. Ask about both sides of your family.
- How should you collect this information? No best approach, but the CDC has an online tool called “Does It Run In the Family?” that is helpful.
- What if you’re estranged from your family, or adopted, or your family just won’t talk about this? Not having this information makes it hard and if you’ve been diagnosed with cancer, be a role model and share your own information with your family.
- Once you have the information, share it with your doctor, so the two of you can discuss next steps, such as meeting with a genetic counselor, testing, or a different treatment strategy.

Dr. Quillen said that while not perfect, knowing your family’s health history is the most accessible public health genetic assessment tool we have, and it’s free.

Resources:

Genetic Alliance website: familyhealthhistory.org

National Society of Genetic Counselors: www.nsgc.org

Next RAMble: Saturday, January 15, 8:30 am