

PASS IT ON

For Individuals and Families With a History of Cancer
Newsletter of the Cancer Genetic Counseling Service



UNDERSTANDING WHAT YOUR AT-HOME GENETIC TEST CAN AND CANNOT TELL YOU

BY COURTNEY ATTARD, GENETIC COUNSELOR

"It's just saliva- Discover what your DNA says about you!" You may have seen a similar advertisement while scrolling through Facebook. Did it capture your attention? That's the point, after all. Recently, there has been an explosion of these types of at-home genetic tests offered by direct-to-consumer (DTC) companies. As a genetic counselor, I am a stark advocate for increasing access to genetic information so that individuals may use that information to help inform themselves and their family of potentially elevated cancer risks. This information can be deeply empowering and can allow a person to address these cancer risks by personalizing their medical management through increased screening and sometimes life-saving surgeries. However, this information can be vastly complex and is ever changing. I often spend 30-60 minutes with a patient discussing the benefits, risks, and limitations of such a test. **For many of my patients and their families, it is much more than a saliva sample or blood test.** [continued on page 2]

IN THIS ISSUE

Understanding What Your At-Home Genetic Test Can and Cannot Tell You

GINA: Protecting Your Genetic Information

Tips For Sharing Genetic Results With Your Relatives

Of note, one DTC company has started to offer *BRCA1/2* testing for hereditary breast and ovarian cancer syndrome. This testing comes with many caveats in the fine print. **Here are three things to take into account in regards to the *BRCA1/2* testing offered by 23andMe:**

▶ *Mutations have been identified in thousands of places within the *BRCA1* and *BRCA2* genes. This test only looks for 3 very specific mutations. A negative result through this company DOES NOT rule out a mutation elsewhere in the *BRCA1* or *BRCA2* genes.*

▶ *These 3 mutations are considered Ashkenazi Jewish “founder mutations” – meaning they are typically only found in individuals with Ashkenazi Jewish ancestry. Ashkenazi Jewish describes Jews who have ancestral lineage to Eastern Europe and Russia. If you are not Ashkenazi Jewish, this result is not considered informative.*

▶ *Many other genes have been discovered to be associated with hereditary breast and ovarian cancer! While it was previously standard practice to only test people for mutations in *BRCA1/2*, we now consistently test for 40-50 genes at a time. Most patients pay \$100 or less for this testing!*

Learning about your ancestry and other fun tidbits, like whether you carry a genetic trait that makes your cheeks more likely to flush when you drink alcohol, can be really interesting and a lot of fun! But, when it comes to medical information obtained from these types of genetic tests, it is best to consult with a professional before making any major decisions. When it comes to hereditary cancer risks, a genetic counselor can offer you a more extensive and meaningful test that will likely be covered by your insurance. ■

GINA: PROTECTING YOUR GENETIC INFORMATION

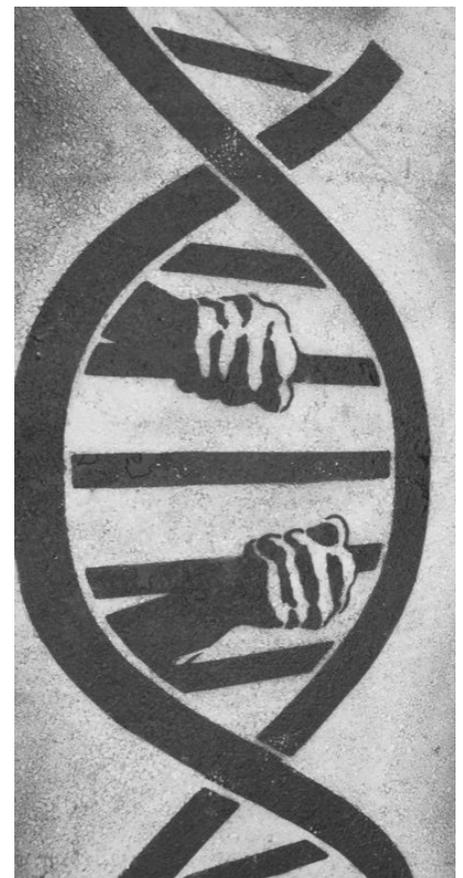
BY SARAH AUSTIN, GENETIC COUNSELING STUDENT

GINA stands for the Genetic Information Non-Discrimination Act. It was passed in 2008 and prevents health insurance companies and employers from using genetic information to discriminate against Americans. Because of GINA, it is illegal for your health insurer to use genetic information to make decisions about your insurance premiums and coverage. GINA prevents your employer from making decisions about your pay and employment status based on genetic information. GINA offers several protections, however there are some important exceptions to this law:

- GINA does not apply to life insurance, disability insurance and long-term care. Individuals seeking genetic testing may want to consider having these policies in place prior to testing.
- GINA does not protect against insurance discrimination for members of the US military or federal employees; however, these groups have their own policies in place that have similar protections.
- GINA does not apply to companies with less than 15 employees.
- GINA only pertains to genetic information discrimination. It is possible your insurance company may make decisions about your premiums or coverage based on prior health information, such as a cancer diagnosis.

If you have additional questions about GINA, you can always reach out to your genetic counselor or check out ginahelp.org for more information! ■

23andMe only tests for 3 mutations in *BRCA1/2*. Even if your result is negative, you may still have a *BRCA1/2* mutation or a mutation in another hereditary cancer gene!



TIPS FOR SHARING GENETIC INFORMATION

What Your Relatives NEED to Know

KNOWING A MUTATION IS IN THE FAMILY MAY SAVE THEIR LIFE!

KNOW WHAT INFORMATION TO SHARE

Your genetic test report! This is the MOST important document to share.

A copy of the family tree generated by the genetic counselor or doctor.

A family letter from your genetic counselor explaining the results and what it may mean for them.



WAYS TO COMMUNICATE THE RESULTS

You can inform relatives via mail, email, telephone, text message, social media or secure websites like KinTalk.org! Family reunions or holidays may be a good opportunity to share with your family as well!



REMEMBER- YOU DON'T NEED TO BE AN EXPERT!

Genetic information can be complex, but you don't need to know every detail in order to share with relatives. Direct them to a reliable online resource or a professional, like your genetic counselor!



ON BEING THE "BEARER OF BAD NEWS"

Sharing sensitive medical information can seem overwhelming and may bring up unexpected emotions. While it may feel uncomfortable, remember that this information may help your relatives prevent or detect cancer at an earlier and more treatable stage!



RESOURCES FOR FAMILY MEMBERS

Kintalk.org
 FORCE at FACINGOURRISK.ORG
LynchCancers.com
BreastCancerAlliance.org
nsgc.org/findageneticcounselor

USING KINTALK.COM TO SHARE GENETIC RESULTS

RACHEL HAGEN, GENETIC COUNSELOR

You've had genetic testing and learn that you should tell your family members. Now what? Whether you have a small or large family, getting the correct information to everyone in a short period of time can be a big job! One website that can make family communication much easier is KinTalk.

What is KinTalk?

KinTalk is a website developed by genetic counselors and physicians that provides a secure and private space to share genetic information with relatives. KinTalk also functions as a way to provide up-to-date information for a variety of hereditary cancer conditions and to connect individuals who may be going through similar experiences. KinTalk allows you to securely upload your genetic documents such as test results, clinic notes, and family information letters. KinTalk then allows you to invite relatives to view these documents by email. Only individuals that are invited via email can view your genetic information.

Whether your results are positive or negative, your relatives can benefit from access to your genetic results. By having this access, your family members can help ensure that they undergo the most appropriate genetic testing for themselves. It can also help them get the cancer screening and surveillance that they may need. It truly can be lifesaving!

Please visit KinTalk.org if you think it could be a good tool for you and your family!

