

Breast Cancer AMA Week: We're genetic counselors who help people understand their cancer risk, family health history and genetic testing options. AUA!

Breast_{Cancer}AMA¹and/ScienceAMAs¹

¹Affiliation not available

April 17, 2023

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CORRESPONDENCE:

DATE RECEIVED:
October 25, 2016

DOI:
10.15200/winn.147730.09870

ARCHIVED:
October 24, 2016

CITATION:
Breast_Cancer_AMA ,
r/Science , Breast Cancer AMA
Week: We're genetic
counselors who help people
understand their cancer risk,
family health history and
genetic testing options. AUA!,
The Winnower
3:e147730.09870 , 2016 , DOI:
[10.15200/winn.147730.09870](https://doi.org/10.15200/winn.147730.09870)

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Beyond the full-nuclear option of a double mastectomy, what can a woman do if she finds out she is at an even slightly higher risk? Is it more than just diet and exercise?

Back in the day, I was dissuaded from taking the genetics test, because if I did turn up positive for BRCA mutation that I could later be denied medical insurance coverage due to a "pre-existing condition." Is this stigma now gone with Obamacare rules?

[gnat23](#)

Hi! Mary Freivogel here, NSGC President-elect and cancer expert. Women who are at higher risk for breast cancer have several options to reduce their risk and/or detect cancer early. Mastectomy is definitely not the only option and many women choose not to pursue one. High risk women often begin screening with annual mammography at a younger age and may need to consider annual breast MRI screening in addition to mammography. Breast MRI will find things that mammography will not (and vice versa) so high risk women should consider both. Some also consider taking medication, like Tamoxifen, which can significantly reduce the risk of breast cancer in high risk women.

As for medical insurance coverage, in general, it is illegal for a gene mutation to be held against someone as "pre-existing condition" - it cannot be used to set rates or deny coverage. This is a federal law called "GINA" (genetic information non-discrimination act). You can find more information here: <http://ginahelp.org/>. Other types of insurance are a bit different (like life insurance, long term care insurance, disability insurance, etc...) and often depend on state laws. I would encourage you to find a genetic counselor in your area to learn more about your individual situation: <http://www.findageneticcounselor.com/>.

Also, remember that seeing a genetic counselor doesn't mean you have to have genetic testing. Rather, it's a way to learn about the details of the testing and make an informed choice about it. Some patients opt NOT to have testing after they meet with a genetic counselor.

Hi, and thanks for doing this AMA.

Breast cancer is a pretty big deal to me. Both my maternal grandmother and my mother are survivors to it. My question is probably pretty hard to answer, but am I at risk because both females on my

mother's side had it?

I'm only 23, but is there a way I can find out more about my own personal risk through a genetic approach?

[Admiralfox](#)

Jessica Salamone here! (My first official Reddit response. Thanks for asking!)

When we have loved ones with breast cancer, it most definitely affects how we think about the disease. The short answer, is "YES" you are at an increased risk because of your family history and "YES" you can likely find out more about your own personal risk through genetic testing. We would need to know the ages that your mother and maternal grandmother were diagnosed. A genetic cause is more likely the younger a woman is when she is diagnosed. So, if your mother and grandmother were younger than say age 50, speak to your physician about genetic counseling, possible genetic testing and ultimately your management plan. Even if they weren't young when diagnosed, still speak to your physician about appropriate breast screening modalities (including mammogram and MRI). Hope that helps. Increased risk doesn't have to mean increased fear! Knowing your risk can ultimately make you feel empowered!

Hi, and thanks for doing this AMA.

Breast cancer is a pretty big deal to me. Both my maternal grandmother and my mother are survivors to it. My question is probably pretty hard to answer, but am I at risk because both females on my mother's side had it?

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[Admiralfox](#)

If you are interested in learning more, please join us for NSGC's upcoming consumer webinar "Cancer and Family History": <http://aboutgeneticcounselors.com/Genetic-Conditions/Types-of-Cancer/Cancer-Genetics-Webinar>

Hi, I have a few questions. What is the likelihood of women who regularly feel their breasts for lumps (by regular, lets say weekly) of being successful in capturing symptoms they may have breast cancer? Is this method reliable or only for cancers nearer to the skin surface?

If someone has relatives on both their mother and fathers side who had BC, are they twice as susceptible to getting it, compared to one side of their family? Is it a single gene that had more than one avenue to you, or is it several genes with an increase in odds?

Finally, how much of a role does estrogen contribute to ones susceptibility to BC? It seems that women over 50 should get checked regularly... is the 'over 50' part related to menopause? Should, say, a 30yo woman who has surgically-induced menopause (no ovaries) factor this into her decision to take HRT?

Thank you

[Rough_Diamonds](#)

Jennifer Scalia Wilbur, Cancer Genetic Counselor, Care New England hospitals, Providence, RI Great questions! Regarding your first question about breast self exam. Our current studies do not show a clear benefit of performing routine self breast exam. The breast exam can be challenging especially in

a premenopausal women. However, if one feels comfortable with self exam and better time for self exam is after the menstrual cycle when the breast is less cystic.

Breast cancer risk should be evaluated separately if on both lineages. Familial risk can not be "combined" if both family lines are affected. Each lineage should be evaluated for a possible genetic cause and testing recommended to the appropriate person in that family line who would yield the most information regarding risk. One could have a genetic mutation coming from both their maternal AND paternal lines however that is very unusual. Combined Estrogen/Progesterin (HRT) does elevate the risk of breast cancer if taken after menopause. However if one undergoes surgical menopause it is believed to be safe to take HRT up to the natural age of menopause ~50 which is even true for our highest risk BRCA+ women.

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It's so cool you are here to talk to us about this! How much or little can I learn about cancer (and specifically breast cancer) from those direct-to-consumer tests like 23andMe? There are a lot of "services" meant to help you interpret your medical risk based on the information these consumer genetics kits, eg SNPedia/Promethease etc- but how do you think this kind of information helps or hurts the general public?

I imagine this kind of stuff is only going to become more and more common- are there aspects of lay individuals having so much information that worries you? Excites you?

[DoShitGardener](#)

Hi! Mary Freivogel here, NSGC President-elect and cancer expert. Direct-to-consumer genetic tests may be limited in what information they can offer with regards to disease risks. For example, 23andme test results do not provide information on disease risks... the FDA does not allow them to do this. If you go to their website, you can see that their results relate to ancestry, wellness, traits, and whether you are a carrier of an "autosomal recessive" genetic condition (which is most relevant to those wanting to start a family). As you mentioned, you can send the raw data from 23andme to other services for interpretation but, from my experience, these interpretations can prone to errors. Additionally, 23andme is only testing certain genes and may miss mutations in genes that place people at very high risk for cancer. Many individuals also need to consider other types of genetic tests to rule out significant disease risks. As you can see, it's pretty complicated so it's important to include an expert in your journey as you choose the proper genetic test for you, as well as to help you interpret of those test

results in a way that makes sense for you and your relatives.

Genetic information is becoming more easily accessible to consumers, which is exciting and a bit scary. I am completely supportive of individuals having access to this information as long as they have an expert resource, like a genetic counselor, to guide them in the interpretation. Genetics is very complex and misinterpretation of this information can lead to people underestimating or overestimating their risk for a disease. This could result in someone deciding to forego recommended cancer screening and being diagnosed at an advanced stage. On the other end of the spectrum, it could lead to unnecessary preventive surgery. Find a genetic counselor near you:

<http://www.findageneticcounselor.com/>.

My mother is a breast cancer survivor, so I'm already having more screenings. But my father had colon cancer. Would that play a role in me having a higher chance of getting (breast) cancer, too?

What I can I, personally, do to lower the risk of breast cancer, additionally to more frequent tests?

[Sterntalerfabrik](#)

Hi - Jennifer Scalia Wilbur here, Cancer Genetic Counselor, Care New England hospitals, Providence RI Your father having colon cancer is likely NOT increasing your risk of breast cancer. If your father had colon cancer due to a inherited genetic mutation there could be a slightly higher risk however not one that would change management beyond breast cancer family history. Also, keep in mind that the vast majority of colon cancer is NOT due to a genetic mutation and those that are we typically see diagnosed under 50 years old and have colon and other cancer family history.

Assuming your mother's breast cancer diagnosis was over 50 and without cancer family history - your physician or genetic counselor can assess your breast cancer risk by risk models to determine if you are eligible for routine breast MRI screening (in addition to your yearly mammograms) and/or could consider using a risk reducing medication such as Tamoxifen. If your mother was diagnosed with breast cancer at or under 50 you/your mother would meet guidelines to have your family history evaluated by a cancer genetic specialist/genetic counselor to understand if you/your family would benefit from hereditary breast cancer genetic testing.

Hello,

Thanks for doing this AMA!

I am currently a college student interested in knowing more about the environmental causes of breast cancer. Isn't it true that only around 10% of breast cancer cases come from genetics?

What do you guys think about how some institutes are focusing more on breast cancer prevention rather than the usual "finding a cure"?

How do you think we as a scientific community can study these environmental factors? Can the results ever be deemed credible by scientific standards if there are many different factors that influence on-genetic cases of breast cancer?

[420 swag queen](#)

Hi! Mary Freivogel, here. NSGC President-elect and cancer expert. You are correct! We always say that about 30% of breast cancer has something to do with genetics and 70% is "sporadic", meaning it does not have a genetic component. These non-genetic factors are things such as lifestyle factors, hormonal factors, environmental exposures, and chance happenings we might call "bad luck." These factors are more difficult to study because it's tough to isolate a single factor to determine what it's

particular contribution is. I know much research has been done in the past and will continue to be done in the future to better understand these non-genetic risk factors and how they interact with one another.

Personally, I am a believer in the fact that prevention is much less expensive than treating a disease. And, of course, I think most patients would choose to prevent a disease rather than undergo treatment for it. We have made some significant strides in prevention and genetics is a big key to that. The goal is to identify people who are at a higher risk based on their genetics and do things differently for them to detect cancer early or prevent it altogether. However, you are correct that we still have a long way to go in understanding all the factors that play a role in someone developing breast cancer.

There are definitely some great advantages to genetic counseling, as you all have stated. How do you feel about some of the disadvantages of genetic counseling?

I am a cancer survivor, and I experience the psychological effects that a diagnosis can have. Is there such thing as too much genetic counseling, as in digging too deep?

I would be interested in fully understanding my genome, despite the alarming information it might reveal (I am a biology teacher after all). I worry that it may negatively affect some individuals mental state. How do you consider this aspect of genetic counseling.

Thanks !

[baddann](#)

Hi! Mary Freivogel here, NSGC President-elect and cancer expert. Anonymous GC stated this very well already but genetic counseling is a very important part of a person's choice about whether or not to undergo genetic testing. Genetic counseling is about providing factual information that is relevant to someone's individual situation (meaning their personal/family history of cancer, as well as their beliefs, motivations, and personal experiences). Genetic counselors are trained to provide this information in a way that patients can understand, as well as delve into some of the psychosocial aspects of genetics. We understand that genetic testing can bring up some difficult feelings and conversations and we are uniquely equipped to guide patients through this journey. We are not psychologists and we will certainly make referrals to psychologists or other healthcare providers when necessary.

Patients with a personal history of cancer, like yourself, have unique challenges based on their experience with their diagnosis and treatment. I certainly understand your hesitancy to dig too deeply but I would like to go out on a limb and encourage you to meet with a genetic counselor, as I would venture to say that it will be a very positive experience for you, especially given your curiosity about your genetics. The genetic counselor will help you make an informed decision about genetic testing, which may certainly be that it's NOT something you want to do at this time (which is more than ok!). Although they will ask psychosocial questions related to your cancer diagnosis and genetic testing, they will not necessarily dig deeply into your thoughts and feelings, unless that seems to be indicated based on your discussion.

Hopefully this helps!

Find a genetic counselor near you: <http://www.findageneticcounselor.com/>

What are some mechanisms to reduce cancer risk? What are some lifestyle factors that can greatly influence cancer risk?

[ezzyrd](#)

Jessica Salamone here--genetic counselor at EWBC in Rochester, NY! Great question! We know that

cancer is multi-factorial which is just a fancy way of saying that it's caused by many factors! In my world, genetic risk is what I'm spending my days chatting with patients about. However, the truth is, most people do NOT carry a genetic mutation predisposing them to cancer. We can all strive to lower our risks through some simple lifestyle changes:

1) Limit your alcohol intake 2) Don't smoke! 3) Control your weight and be physically active 4) Breast-feed 5) Limit your dose of hormone-replacement therapy or avoid it altogether 6) Avoid exposure to radiation and environmental pollution

Even if you're successful in all 6 areas, it doesn't mean your risk of cancer is 0%. For those, individuals with a known cancer gene mutation, the above goals can still aid in lowering the risk but the overall risk is typically still very high and would require discussion about a management plan for screening and risk reduction through surgery.

Hope that helps!

I have BRCA1 and a long family history of breast cancer. I've had a preventative double mastectomy.

Can you speak a little on the Myriad patent case? Now that genes cannot be patented, what affect has this had on genetic counseling? Is there ways to now get second opinions?

I was able to fight and get birth control covered in my state of Wisconsin for Blue Cross Blue Shield as it is recommended as a preventative measure against ovarian cancer (though not against breast cancer). Are other states adopting this? Is this still being commonly recommended to reduce ovarian cancer risk?

[TheGreenBasket](#)

Hi! Mary Freivogel here, NSGC President-elect and cancer expert. Since the BRCA1/2 patent was overturned, there are many, many laboratories performing this type of testing (some reputable and some not-so-reputable!) and they all have different costs, insurance contracts, and financial policies. And, yes... individuals are now able to get second opinions. Interestingly, different laboratories may interpret one particular mutation in different ways so it's very important to have an expert to guide you in this process.

A genetic counselor can help you choose the right test at the right price at the right laboratory, as well as help you make the most of that genetic test by interpreting the information in a way that you can understand. Find a genetic counselor near you: <http://www.findageneticcounselor.com/>

As for birth control pills, they remain a very viable option to reduce risk of ovarian cancer. Individuals should discuss this with their physician. However, I'm not familiar with the particulars of insurance coverage of birth control pills for this indication in various states.

Do you think the benefits of genetic counseling outweigh the cons? Or would it simply be for knowledge as screening and checks would be the same for someone known to be higher risk regardless of if they had genetic counseling.

I'm wrestling with the idea of whether or not to have genetic testing done. There was no history of breast or colon cancer in my family until my father was diagnosed with stage 4 colon cancer in his 40s. Because of the age and severity, the cancer was almost certainly genetic. His insurance wouldn't pay for the test. Due to his history, I was able to convince my doctor to screen me at 30. At this early age I already had polyps. It would appear that I have the same genes as my father. My doc has advised me that if it is genetic (say lynch syndrome for example) then I am also at a greatly increased risk for

breast cancer and ovarian cancer. The colon and breast cancer we can screen for. The ovarian not so much. Part of me worries that getting the genetic testing will do nothing but make me worry over something I can't really do anything about. I will screen what I can early and regularly regardless of whether I have those specific genetic results. I'm open to opinions of others who have maybe been in my situation.

[take me to pnw](#)

Hi! Mary Freivogel here, NSGC President-elect and cancer expert. I want to emphasize that genetic counseling and genetic testing are not one in the same. Genetic counseling is the process of learning about genetic testing and making an informed choice about whether or not to undergo genetic testing. I would strongly encourage you to meet with a genetic counselor who can help answer these questions for you. <http://www.findageneticcounselor.com/>

Why does family history contribute to the likelihood of a person getting breast cancer?

[dmastergames](#)

Jessica Salamone here--genetic counselor in a high-volume radiology clinic!

This is a great question. We describe breast cancer as being multi-factorial or in simpler terms as being caused by many factors including aging, environment and genes. Your family history is the best indicator of what might be hidden within your genes. If you have a family history of breast cancer and that cancer is happening at a younger age and not in the presence of typical risk factors (ie smoking etc), then a faulty gene might be the cause. A three generation pedigree (drawing of your family history), allows someone like me to assess your likelihood of carrying a defective gene. If there's young cancer (typically under the age of 50), repetitive cancer (more people with the disease than expected) or rare cancers (maybe ovarian or pancreatic cancers), we might suspect a genetic cancer. Think about your family history against the rules of "young, repetitive or rare." If you see a pattern, speak to your physician who can refer you a genetic counselor near you. The conversation will be worth it, I promise.

Hi!

Why did you go into Genetic Counselling and how do you go into it?

I'm at a career junction and would like to know about it more!

Thanks!

[fatboy93](#)

Jessica Salamone here--Genetic Counselor in Rochester, NY. Genetic Counseling is an amazing career that is at the forefront of science right now....take for example, the number of questions we're fielding. If you love science and you love people, consider this career a great fit. More than that though, you need to be an excellent communicator in times of stress and worry. Patients need facts from an articulate messenger. Check out www.nsgc.org and www.abgc.net for more information on this amazing career. Try shadowing a local genetic counselor to see if it's a good fit for you. Good luck!

Hi there,

Thanks for doing an AMA!

I'm currently trying to wrap my head around what's happened in my family and I'm not really sure how to proceed. My mom just recently passed away from what was diagnosed as metastatic triple negative breast cancer. She was 63, Caucasian, and negative for the genetic mutations. It was 3 months and a day from diagnosis to death. She had a clean mammogram 6 months prior to diagnosis and finding a lump in her arm is what prompted the doctor visit.

My maternal grandmother also had breast cancer, but an entirely different kind. I don't know the actual diagnosis because it was over 15 years ago, but it presented at 80 and she is still doing quite well today with no relapse.

I am 26 (F). Mom got genetic testing and was found negative for all genetic mutations that they tested for (8 different ones I think?)...So what does this mean for me? I was told since she was negative I didn't need to get tested, (and as such insurance would likely not cover it...) but a lot of things feel like they are not adding up... How can I accurately assess my risk? What do I need to do to lower that risk?

Edit: to specify am female

[Zaporah](#)

Jessica Salamone, genetic counselor at EWBC in Rochester, NY. I'm so sorry to hear of your loss. 3 months and a day from diagnosis to death is overwhelming to say the least. My first thought is to find out how many genes your mom was tested for. Most clinics are testing for far more than 8 (depending on the family history). The truth is your mother's cancer wasn't caused by the genes she was tested for.....but we don't know about the other genes that she wasn't tested for. For instance, in my clinic appropriate patients are tested for between 28 and 36 genes (sometimes more). A genetic counselor can help you wade through the difficult subjects of 1) do you need testing? 2) will your insurance cover this testing? 3) what age you need to begin screening? and 4) how you can lower your risk?

I would ask your physician for a referral to a local genetic counselor. While you may not need to pursue testing, s/he can help you decide your next steps. www.nsgc.org has a "find a counselor" tab as well. Good luck!

Thanks for this AMA! My fiance and her sister are carriers of the BRCA mutation (I believe they are both BRCA2) and are having regular screenings and are aware and cautious. Both sisters are considering preventative mastectomies and oophorectomies, but both are waiting because they would like to have children first. Decisions they have made after consultations with their doctors as well as 2 trips to the national conference for BRCA carriers. What considerations should my fiance and I be concerned with in the decision to have children and their potential to be carriers of the gene mutation? Anything we can do proactively? There is no history of breast cancer in my family.

[BR0WND0G](#)

Hi - Jennifer Scalia Wilbur here - Cancer Genetic Counselor for Care New England hospitals in Providence, RI

Thank you for the question- I am very happy to hear that your fiance and her sister have taken the time to obtain so much information regarding their BRCA status so they are able to make informed choices about their options for breast and ovary cancer risk reduction going forward! I understand your concern regarding having a child who carries this BRCA mutation. First know that each child has a 50% chance NOT to have the mutation and if positive he/she may never develop cancer (seeing the risk is not 100%). Additionally, if you have a child who is BRCA+, the greatest likelihood is that screening and risk reducing options will be different by the time they are of an age where this risk is of concern.

However, there is an option for you both to consider today if interested called preimplantation genetics diagnosis (PGD) which is a process where only embryos withOUT the mutation are selected and

implanted back in the uterus. This would assure you that the mutation would not be passed on, however is not a simple process and can be very expensive (most likely NOT covered by insurance). Nevertheless, PGD is a real option for couples and we have had successful BRCA+ couples undergo PGD at our institution. If you and your fiancé would like more information about this, I would recommend meeting with a reproductive endocrinologist who will be able to review the PGD process and cost in more detail so you would be able to make an informed choice. It can be a lot to think about and a bit overwhelming so take it one step at a time - I wish you and your fiancé the very best going forward!

Please excuse me if it's the silliest question ever (if so, hope you get a good laugh), but are men also, if very rarely, affected by breast cancer? Does that mean men should have regular checks too, or the probability is negligible/zero?

[valriia](#)

Hi, Jennifer Scalia Wilbur here - Cancer Genetic Counselor, Care New England hospitals - Providence, RI Not a silly question at all.... and actually an important one.

Because male breast cancer is very rare (~0.05% general population risk), routine breast screening is not recommended. However, if male breast cancer is seen in a family, the family should be evaluated for a possible inherited genetic mutation as they meet national guidelines for counseling and testing. Male breast cancer can be caused by genetic mutations (ie BRCA1/2 gene) that would increase risk in other positive males where the national 2017 recommendations suggest their be heightened self awareness and clinical breast exam starting at 35 years old.
Good question!

Hi, thanks for doing this AMA.

I am very interested in genetics, in fact I'm currently taking a 300 level genetics course during my undergraduate degree. I have been able to get my genes sequenced, but have not got any information out of it. I only have the raw data. Do you know any good way for someone to examine and explore their own genes once they've been sequenced? I think being able to look at and explore my own genes would be the coolest thing ever.

Thanks!

[bangbangshotmyself](#)

Jessica Salamone here--genetic counselor and Genetics professor at RIT! I love your interest in genetics and specifically in your own DNA. It is the coolest thing ever. Many testing laboratories provide interpretation but I'm assuming this was not the case for your sample. The raw data can be sent to a third-party company for interpretation but in my experience there have been some problems in interpretation with this process. Companies include Promethease and SNPedia, to name a few. Some public databases exist as well. I would include a professional if possible as the whole scenario can be quite complex. Good luck with your studies!!

Thanks for the AMA! I'm debating whether I should get the testing done but not sure if insurance would cover it or if not, how expensive it is.

[bodilyfluidcatcher](#)

Hi! Mary Freivogel here, NSGC President-elect and cancer expert. The cost of cancer genetic testing

has decreased significantly over the past few years. Insurance most often covers the cost of the testing, assuming it is clinically indicated and ordered by an expert healthcare provider (such as a genetic counselor). In some cases, it's even covered as part of the Affordable Care Act with no cost-sharing to the patient.

There are many, many laboratories performing this type of testing (some reputable and some not-so-reputable!) and they all have different costs, insurance contracts, and financial policies. A genetic counselor can help you choose the right test at the right price at the right laboratory, as well as help you make the most of that genetic test by interpreting the information in a way that you can understand.

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