

03:37:57 **DR. PETERSON:** I wanted the three of us to sit down today and really go over the results in person, and just try and decide, you know, where do we go from here, and making sure that you understand what these results ultimately mean for you and your future, so...

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03:38:12 **GENETICIST:** So Barbara, you know that we... what we did is we tested for the changes in the BRACA 1 and BRACA 2 genes, and what we do is, we sequence the gene and we look for little changes in the gene that might alter the way the gene works, umm, and actually truncate the protein and actually shortens the protein so it doesn't work, and I know you've been thinking about this a long time. The result was positive. It showed that you do have a mutation in the BRACA 1 gene.

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03:37:59 No mutations were identified in BRACA 2, but there was a change found in BRACA 1, that is positive, which means that it's deleterious, which means that we know that it's linked to cancer in breast and ovarian families.

BARBARA L: Okay.

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03:38:56 **GENETICIST:** Just because you have a mutation, Barbara, that doesn't mean you're necessarily going to get cancer.

BARBARA L: Right, I know that.

03:39:02 **GENETICIST:** Okay? So just because we know that you have had breast cancer doesn't mean that you're going to have ovarian cancer. And so that's what our concern is right now. Our concern is, what can we do for you in terms of prevention and in terms of your medical management, and then of course then in terms of your extended family.

BARBARA L: Okay.

03:39:22 **DR. PETERSON:** So Barbara, what so... how are you dealing... what are you hearing right now?

03:39:28 **BARBARA L:** Well, to be perfectly honest, I kind of had a feeling it was going to be positive... I don't know, the night before that's honestly what I felt... and I guess, you know, it's always a shock to hear that, but I had to keep in mind that it's just a risk. It doesn't mean that I'm going to get it, it certainly doesn't mean that I have it.

03:39:51 But one thing that I... that kind of sat in my mind was when I first met with you...in all honesty, I don't know how to say this, but you kind of said to me, you didn't, you know, ask me, you know, how I felt, you said, "do you feel doomed?"

03:40:06 And honestly when I heard that and after I left, that's kind of what was going through my mind the whole weekend. And I understand that's not why you asked that--that specific word--but just hearing that word was kind of like... it was, you know... so that was... I don't know, I'm all over the place, but... **03:40:25** I mean it is a concern, but it's not... and you know, I want to hear what I could do to lower this of course, but I certainly know that I'm not doomed, you know I feel very positive, and I know that I don't have ovarian cancer so... that's really about it.

03:40:48 **GENETICIST:** Was it because I put the idea in your head? Was it my terminology or was it because...

03:40:55 **BARBARA L:** No, there were a lot of different things going on but I think just hearing that in the form of a question — and it was of course in the form of a question — but it just, that word, it just stuck in my head. And you know, that was... and of course I was having, on my way here I had the anxiety attack in the car, so that all played into it and, you know, that was... but it was certainly not you.

GENETICIST: No, I understand.

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03:41:21 And I think that the reason I asked you that was because I wanted you to feel — not that I can tell you how to feel — but I wanted you to feel that you weren't doomed, and that, you know, you were really approaching this whole thing in a very intellectual, intelligent way. That you were fact-finding, first of all.

03:41:37 You were making decisions based upon information you were getting. That you've already decided to have the prophylactic surgery, and that perhaps you would consider then having the prophylactic oophorectomy, because you had made that decision for the breast.

BARBARA L: Right.

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03:41:54 **GENETICIST:** when people hear that they're positive they think that they have no way out of this that they're just going to die. And I didn't want you to feel that way.

03:42:01 **BARBARA L:** Right, no I understand that. And I certainly don't feel that way.

GENETICIST: Okay.

DR. PETERSON: Did the two of you talk about prophylactic oophorectomy?

GENETICIST: Yes we did. We did.

DR. PETERSON: Is that something that you were thinking about?

03:42:14 **BARBARA L:** Yes...and probably I shouldn't even have been thinking about... I was doing too much thinking. (smiles) You know I just, you know you want to get the whole picture, and I'm a person that likes the whole picture and I want to analyze and I want to and I want to do what's right but... certainly at that point I wasn't really able. You know, nothing had absorbed, I didn't process anything over the weekend. I was just kind of all over the place.

03:42:40 **GENETICIST:** It's a lot to absorb. An awful lot to absorb, and you know especially when your emotions are so high, your anxiety was so high that day...I mean...

BARBARA L: Yeah, so that's a lot to take into consideration, but...

GENETICIST: And you cried.

BARBARA L: Yeah.

DR. PETERSON: Well,

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03:42:55 Let's start with what screening tools exist for ovarian cancer, Let me just be very honest with you up front. There are no good screening tools for ovarian cancer, which makes it very difficult when we're dealing with women who carry a mutation in BRACA 1 or BRACA 2. How do we follow a woman who is at risk —significant risk for developing ovarian cancer.

03:43:22 What we do offer women right now is that we recommend a pelvic exam by your gynecologist or your private doctor every six months. We recommend that you consider a serum blood test, a serum test, looking for a tumor marker which is called a CA-125. And that's a tumor marker for ovarian cancer, we recommend that every six months as well.

03:43:56 And then we also recommend what we call a transvaginal pelvic ultrasound, looking at the pelvic organs, specifically the ovaries and the fallopian tubes, to look for any changes that might be suggestive or suspicious for the development of a cancer.

03:44:14 Now I say all of that, but at the same time I just want you to know that our results from a scientific standpoint, when we look at what is called the "sensitivity" and "specificity," those results are not good enough to classify those measures as effective screening tools for ovarian cancer. Many of the women, when those tests are positive, don't have ovarian cancer, and many of them, when the test is negative, actually have ovarian cancer.

BARBARA L: Hm.

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03:44:46 **DR. PETERSON:** Now there is new research that's very promising for a new screening tool for ovarian cancer. That research is being primarily conducted out of NYU in Manhattan, and I have a collaborative relationship with the principal investigator, so we could consider putting you into that study if you decide that you want to follow a high-risk screening protocol for ovarian cancer. Another option would be, is there something you can do to *prevent* ovarian cancer?

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03:45:19 And the most effective tool that we have is, believe it or not, oral contraception.

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03:45:24 We know that, for instance, three years of uninterrupted use of oral contraception could probably reduce your risk of ovarian cancer by about thirty to forty percent. And that's about the best thing that we have to offer when it comes to what we call "chemo prevention" or some sort of drug or pill that you could take to perhaps prevent against ovarian cancer.

03:45:47 Of course this is all in concert with eating healthy, healthy lifestyle, you know, just making sure that you're getting proper exercise, you know, that you're eating well, and you know, living a healthy lifestyle, which we recommend for anyone to prevent illness for that matter.

03:46:09 And then ultimately on the other end of the spectrum, I guess the most effective thing that we have to prevent against ovarian cancer is to remove the ovaries.

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03:46:20 And by the way, we would remove the fallopian tubes at the same time, because they're also at increased risk for developing cancer if you have a mutation in the BRACA 1 or BRACA 2 gene. To remove the ovaries and the fallopian tubes to reduce your risk as close to zero as possible by removing, obviously by taking out the tissue that's at risk.

03:46:43 But that comes with another set of issues, as you could probably imagine. The issues around childbearing, if you're considering having children. What it means, obviously, if you're going to take out the ovaries, would be that you're no longer going to be able to bear your own children.

03:47:02 Secondly, the concept of what we call surgically induced menopause, or menopause being induced earlier than it would have been in your case, and we know that women who have surgically induced menopause tend to experience more significant menopausal symptoms than those women who naturally go into menopause. **03:47:24** So the issues surrounding that are pretty significant as well, and we get to explore that some more, depending on how you're processing all of this information eventually, and which route you would like to proceed.

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BARBARA L: Yeah.

03:47:41 **DR. PETERSON:** I guess for me, what I need to know is, what... where are you in the whole, you know, well, in this whole process of, you know, getting back this information and what your thoughts are,

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03:47:57 on what you think you'd like to do.

03:47:58 **BARBARA L:** Umm... well probably taking out the ovaries would probably be a very good idea. I'm trying... and it's hard for me, because people around me are telling me "don't get too

ahead of yourself, worry about breast cancer now and deal with this..." Although it's all, you know, it's all about me...(laughs) that didn't sound right... but, that's what it is, really.

GENETICIST: No, it is about you.

03:48:21 BARBARA L: So I'd really like to just...you know it's been a long road getting where I am now to take care of this, so then once that is on its way, then I can give a lot more thought, to...

03:48:34 DR. PETERSON: I think that's very reasonable. I think to just deal with this right now, and then when we get through this, then you'll... once we have the final results from removing the breast, and the full extent of the cancer, and what your treatment needs to be as it relates to the breast cancers, I think then your mind will be a lot more clear to then fully look at the ovarian cancer issue and decide what needs to be done at that point.

BARBARA L: Okay.

03:49:03 GENETICIST: Barbara, who have you discussed this with in your family?

BARBARA L: Ummm... my brother, my sister, sister in-law, close friends... you know, close friends at work.

GENETICIST: Mmm-hmm. Sounds like you have a very good support group.

03:49:20 BARBARA L: Yeah, I do have a very good support group. I really do. I'm very blessed. But it's a lot — it's a lot to discuss, especially with, you know, with my family.

GENETICIST: Sure.

03:49:30 BARBARA L: You know, telling them that was just very difficult... very difficult.

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03:49:35 DR. PETERSON: Did you talk to your gynecologist?

BARBARA L: Ummm, no. I tried to, but I talked to her assistant and I haven't heard back yet.

03:49:49 DR. PETERSON: Because what I'd like to do in the meantime is at least make sure that you get set up for a transvaginal pelvic ultrasound, and we should draw a serum level of the CA-125.

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03:50:03 I'll send that off prior to surgery.

BARBARA L: And what is that? Just taking blood?

DR. PETERSON: It's just a blood test

BARBARA L: More blood? Okay.

DR. PETERSON: It's just a blood test.

GENETICIST: Blood test... another blood test. (laughs)

03:50:12 DR. PETERSON: It's not as involved a blood test as the BRACA 1 and BRACA 2 testing that you had. That's a blood test that we'll get the results in a couple of days.

BARBARA L: Okay.

03:50:24 DR. PETERSON: So, any other questions? To be continued, huh? (laughs)

BARBARA L: Yeah...

03:50:31 GENETICIST: You seem to have really started to assimilate this information and to think it through, which is really great to hear. I mean, I know how devastating... I'm really... I know how devastating this was,

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03:50:45 BARBARA L: You know, why I was so upset, which is probably why I'm going to start to bawl now, is that my mother was diagnosed at this age with ovarian. So that was hard to hear, even a risk. So...

03:50:57 GENETICIST: Yeah. You know, we tend to think, "our mothers, ourselves."

DR. PETERSON: Specifically, how is your family dealing with this... individuals...

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03:51:06 BARBARA L: My brother and sister are actually doing pretty well. They have their moments. They're frustrated. You know, why you?

DR. PETERSON: Are they considering being tested?

BARBARA L: Umm, no.

03:51:18 DR. PETERSON: They've said no, or...?

BARBARA L: They haven't said no, but I kind of weaseled around the issue.

GENETICIST: Planted the seed?

03:51:26 BARBARA L: Yeah, I planted the seed. I didn't go into everything. I did tell my sister, if she wanted she could be tested. I left it at that. I didn't say it was a one in two, I think it's a one in two chance.

GENETICIST: A fifty percent chance that they're, exactly.

03:51:39 **BARBARA L:** Right, but I didn't mention that to my brother.

DR. PETERSON: Did she say no, that she didn't want to?

BARBARA L: She didn't say no. I told her it was food for thought.

DR. PETERSON: Okay, all right.

BARBARA L: So, I think once...

03:51:50 **GENETICIST:** Even if she's not tested, I mean, she really has to own the risk just by virtue of the family history, and so that... But I think that the other piece of this, which is a positive side, is she tests negative, then she's back down to that general population risk, then we know that there is no increased risk, so that there's a positive spin to this for her as well, that it's not all negative, there is a positive spin.

03:52:18 **BARBARA L:** Yeah. And I think, I mean, going through this... there are so many people that are affected by someone having cancer, so I don't, not that I don't want to push them, because you really can't push anybody to do anything, but I think it's a lot for them to have gone this far with me, so maybe in time...

GENETICIST: It's a huge decision.

BARBARA L: ...they would want to do that too.

GENETICIST: It's a huge decision.

BARBARA L: You know, it's a lot to...

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03:52:43 **DR. PETERSON:** And your brother, did you say anything to him about him?

BARBARA L: My brother... well, I talked to my brother, my brother, you know... my sister in-law. I did tell about, you know, being tested. Him I didn't get into that part of it. Out of the two, I think, well, my sister... well, out of the two I think my brother had a little... little more difficulty with this.

03:53:09 **DR. PETERSON:** Yeah, why is that, do you think?

BARBARA L: Just because... just because he looks at it... our father died of cancer, our mother died of cancer, now my sister, you know,

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03:53:20 **DR. PETERSON:** Well, the one thing I will offer to you... if they need to talk to us to get a better understanding of all of this, that's one thing that you should offer to them, because sometimes it's a little difficult when they, having to hear it from you, because

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03:53:35 it's a little bit — sometimes. I'm not saying it's always that way, but sometimes it's a little bit easier for them to at least dissociate themselves from the emotional aspect that they're going through.

03:53:44 And this might not be the appropriate time for them. I'm just saying, in the future, once you... once they've seen you make it through surgery for the breast cancer, and that you're doing well and that everything is going okay, maybe at that point when the emotions are a little less tense and the anxiety is down, it might be a more appropriate time for them to come in and have their own discussion about their risk.

03:54:09 **GENETICIST:** And the other thing we spoke about was about your mom's family.

BARBARA L: Right, I'm working on that.

GENETICIST: No, I don't expect you to make that decision today...

BARBARA L: No, no, no, I know. I spoke to my sister, actually... because we've been estranged from my mother's family for years. She has five sisters, and--

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03:54:30 **BARBARA L:** that's a whole 'nother ball of wax, but I have done some checking in to see, you know, if I can get their, their names and addresses.

03:54:40 **GENETICIST:** And like I told you, we can give you a letter that you can... you don't even have to call them. Just a letter saying, "Hi, I'm Barbara I'm your cousin." That just lets them know what's happening to you, and you're letting them know because it's important for them to know in terms of their own medical well-being, and then it's their decision of how they, what they want to do with that information.

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03:55:05 **GENETICIST:** We know that these are not simple decisions and that all this doesn't happen in a vacuum. It's not a piece of information that just falls, it has a ripple effect, and the circles, the concentric circles are just so complicated.

03:55:19 **DR. PETERSON:** Yeah, and I think that's important for you to understand also, is that while this is a test that right now is your result that you're having to deal with, one of the things that we are very clear about when it comes to this whole issue of genetic testing--just to re-emphasize what Cindy said--the results have far-reaching effects on the family. It changes the family dynamic. I mean, look, you've been estranged from your mother's family for years, and this could actually be something that might bring this family back together, or at least be in communication with each other, because the effects of the result are just very far-reaching for the entire family and the dynamics of the family.

03:56:05 **GENETICIST:** Do you have any questions at this point?

BARBARA L: No, I don't have anything.

DR. PETERSON: Set for Thursday?

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03:56:13 **GENETICIST:** You know there are questions that arise in the family. You're not quite sure what to do or who to contact or what to say, you know, we're here. We're not just dropping this information in your lap and saying "oh, go off Barbara, on your own merry way." You know, this is a continuum of care. It really does not... it continues. //

03:56:32 There's no script that anybody follows. There's no script that any family follows, because every family is different, every dynamic is different. What one sibling thinks another sibling's going to do is not always necessarily what happens.

03:56:49 There are issues of "I test positive, you test negative, why am I the--" that survivor guilt. "Why am I the positive one? Why are you the negative one? Why am I lucky and you're not?"

03:57:05 There are so many other factors to come into play, and people who just not ready to have that information-- and then like Dr. Peterson said, two years later or six months later they wake up and they say, "I'm ready." You know, I've seen patients two or three times before, sometimes, before they're ready to be tested.

03:57:20 **BARBARA L:** Really?

GENETICIST: Mmm-hmm.

03:57:21 **DR. PETERSON:** That's a thing that you need to know, that there's no particular way you or your family are supposed to feel or process this. However they are dealing with it is just fine. We're able to support them and you in whatever the decisions are,

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03:57:40 **DR. PETERSON:** Okay. Grab your bag. Let me get that for you.

BARBARA L: Thank you. I'll have to give something to Janet.

DR. PETERSON: You have something for Janet? (Laughs)

GENETICIST: Take care...

BARBARA L: Yeah, disability papers

GENETICIST: I'm going to be praying for you.

BARBARA L: Thank you Cindy. Thank you that's so sweet

GENETICIST: You probably won't remember that I actually came to see because you're going to be so drugged (laughs)

BARBARA L: Sure I will...Oh....!