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Genetic Roulette: Coping With Positive Markers for Cancer

You're listening to ReachMD XM157, The Channel for Medical Professionals. Welcome to Advances In Women's Health. Your host is Dr. Lisa Mazzullo, Assistant Professor of Obstetrics and Gynecology at Northwestern University Medical School, The Feinberg School of Medicine.

### DR. LISA MAZZULLO:

As physicians were trained to treat the ill, so what do you tell your patient who is weighing the decision of a mastectomy or treatment at 33 while she is still cancer free?

Welcome to Advances in Women's Health. Joining me is Joanna Rudnick, Director and Producer of "In the Family", a Kartemquin Film production, which discusses her battle and other patient's journeys in the decision making and ramifications of genetic testing for breast and ovarian cancer. Joanna, welcome.

### JOANNA RUDNICK:

Thank you.

### DR. LISA MAZZULLO:

This is such a wonderful project. What really led you to decide to make this film?

### JOANNA RUDNICK:

I decided to make this film because when I tested positive for this at the age of 27 for the BRCA mutation, there was really no language to talk about this to my friends at that time and to other people in my life who hadn't heard about this and there was a real stigma. Personally, I had felt there was a stigma associated with being positive for this genetic mutation and being at such a different place and my peers talking about potential removal of my breast and ovaries of such a young woman that I felt that I really needed to come out with my own story on film to make other women who are suffering with the same, very difficult, but life saving information to help them, you know, to normalize being positive for this mutation and to give them a language to talk about it.

**DR. LISA MAZZULLO:**

You know, you bring up such an excellent point. I think that this genetic education for both physicians and patients has been such a revolution in the last decade and being able to identify patients at risk for something that they don't have yet, is really opening up an entirely different medical kind of style, if you will, and really incorporating team efforts among physicians and patients, and you know, I think it is just such a great challenge on so many levels, what do you think were some of the greatest dilemmas that you faced in your diagnosis?

**JOANNA RUDNICK:**

Yeah, I think that, you know, I am still facing them, this is 6 years ago, and I am still facing these same dilemmas. I think, one of the things was just how to understand and take in the risk without feeling like the term you have heard off and probably a ticking time bomb to know that my risks were so high of developing both diseases, but to learn how to live despite having this information, and to view it as not necessarily doomsday but as life-saving information as I could take control of my own health, I could avoid getting the ovarian cancer that my mother got at the age of 43, that I did have, you know, these physicians looking out after me and that this was, in fact, life saving. So I think that was the real dilemma, how to actually take in this information and also how to define yourself and to live despite the risk and to live in those sort of what I considered to me to be these presurgery years where I have not yet decided to have these prophylactic surgeries that could actually prevent cancer. So I am in a place right now, just trying to watch myself very carefully to try to detect any potential cancers early and I think that's really sort of the dilemma as how do you go on with your life and how do you live once you know that you have this extreme risk of developing cancer and potentially developing, you know, at a young age.

**DR. LISA MAZZULLO:**

You know, I think actually we should even take this as a step back and say how do you decide to even get tested. I think as a 27-year-old with a mother who is premenopausally suffering from breast cancer, you are the perfect candidate for this type of test, but let's say you were 18 when you found that out, and what would you do with that information?, you ask. The challenge begins really with how do you decide if you get to tested out?

**JOANNA RUDNICK:**

Sure, and I think, you know, just stepping back with what happened with my family. So actually, my mother had ovarian cancer 20 years ago. I was 13 when she was diagnosed. So my mother was 20 years out of ovarian cancer and nobody in my family at that time was suffering from cancer and when I say at that time, the time that my family decided to test. My sister is a mammographer and was very aware of the BRCA mutation and also early detection for ovarian cancer and was enrolled in the study at Northwestern, the Early Ovarian Detection Program, and when they mentioned that we might be candidates for genetic testing, we were all very surprised. We did not see a typical pattern in my family. That was until we actually sat down and started doing our pedigree, our family tree with a genetic counselor and what we realized was there was a lot more breast and ovarian cancer in other generations than we had thought, but no one had actually talked about it.

**DR. LISA MAZZULLO:**

Or put it altogether for you.

**JOANNA RUDNICK:**

Yeah, we had to sit around at Thanksgiving and talk about how much breast and ovarian cancer were in the family. It was something that we didn't want to talk about. We wanted to put my mother's cancer behind us and move on. So when this all came back into our lives, you know, so long after my mother's original diagnosis, it was a bit of a shock for all of us and it was certainly a shock when my mother tested positive.

**DR. LISA MAZZULLO:**

Well, you know, I think there are a couple of things there that are obviously very important. I think the dilemma of making the decision to get tested is true, because then you are faced with all of these choices, which are really, none of them are excellent choices. They are all things about, you know, surgical interventions and medications that have side effects and, you know, I think that none of these decisions are easy for people. Do you think that there was anywhere in your journey that something was particularly helpful in helping you make the decision to get testing or what to think about in the future to do with it?

**JOANNA RUDNICK:**

Absolute, instead of just stepping back a little bit to the decision to test, at the time when, after my mother had tested positive, my older sister tested negative, and it was my turn to test, to be honest, I really did not understand the gravity of testing positive at that time. I didn't really understand that I was going to be faced with choices of whether or not to have surgery to remove my breasts and ovaries to avoid cancer, and I don't think I realized how high my risk could be if I tested positive. So even though I had seen a genetic counselor before I got my blood drawn, I think it just didn't soak in for such a young woman, what this would mean to my life, and now it's really one of the reasons also that I wanted to make the film because I felt that women should have as much information as possible going into the decision to test.

If you have just tuned in, you are listening to the *Advances in Women's Health* on ReachMD XM157, The Channel for Medical Professionals. I am Dr. Lisa Mazzullo, and Joanna Rudnick and I are discussing her experience, learning that she carried the BRCA gene and her experiences as it's gone into the research of her film, *In the Family*.

**DR. LISA MAZZULLO:**

Joanna, we were just talking about your decision making in getting testing and being somewhat unprepared for the ramifications of decision making after being BRCA positive. You said, you met with the genetic counselor. Had you gone to any other physicians for counseling in addition to that?

**JOANNA RUDNICK:**

I had not. I had one meeting with the genetic counselor. I was living in New York at that time and I drew my blood for the test on the

same day that I had met with the genetic counselor and then I came back a month later to get my test results, so I had two meetings with the genetic counselor before finding out that I carried the BRCA mutation.

**DR. LISA MAZZULLO:**

You know, as a physician I talk about this issue with patients at risk all the time, but personally don't do the genetic testing, and so I think for a lot of women now, especially as awareness has gotten greater, is that they meet with their physician, have a discussion about the risks and hopefully the ramifications that you missed initially and then meet a genetic counselor and go over the details of numbers. So I think that's actually changed and is improving.

**JOANNA RUDNICK:**

Absolutely. I agree with you and I think you also said, you know, what have I learned along the way, and along the way of making this film, which has been an incredible gift in the sense it has been a catharsis in dealing with testing positive, I have connected with the whole community of women through Facing Our Risk of Cancer Empowered, which is an online support group for women who carry the mutation and I have learned about what my options are, women have shared the reconstructions and surgeries that they had had and I've really been educated I would say, not only by my physicians who are extremely knowledgeable, and I am grateful for them, but also by the community of women who are dealing with this really unique set of issues, and it's unique in the sense that we are not part, for those of us who are what we called "previvers" in the sense that we know that we have this extreme risk of developing breast and ovarian cancer, yet we have never had cancer and are still faced with some of the issues like possibly removing breasts and ovaries, but someone who might have a disease would be faced with. More and over, that you need community and I think women have really reached out and helped each other with these unique set of choices that we also can't talk to our mothers and grandmothers about because they weren't in the same situation. This is really a generational change.

**DR. LISA MAZZULLO:**

I think that's absolutely true. I think the previver first generation after diagnosis has really revolutionized medicine in a way that we've never seen before, planning to treat people for things they don't have yet; it's anticipatory medicine, which is brand new to everybody, I think. I find it interesting that you say it's difficult to talk to your more mature family members about it. When you did decide to get testing and have gone through some of the dilemmas of decision making for treatment, have you then gone back and discussed it with them again?

**JOANNA RUDNICK:**

I have, and everyone in my family has been just incredibly supportive of this and you know my mother actually had said to me at some point she is so thrilled that I have this information and that I can be watched and I think that in a sense gives her, you know, helps her sleep at night, that she knows that so many people are watching, and at the same time she says, you know, I don't know that I would have wanted to know this, I mean, there were years for her that she was married and just having children and didn't have to think about removing her ovaries and having children quickly and you know that there was a potential disease in her future and so she has actually, you know, sort of sympathized with the dilemma that I am in and has always been supportive. No one has pushed me to make any decisions. They really wanted me to be thoughtful about the decision making process and you know there are times being a 33-year-old woman who does not have children that there is a panic where you think, okay, I need to have some children and get my ovaries out by 40 and I really have this hanging over my head, and I think that for me has been the most difficult thing is the fertility and motherhood aspects of this and how do you actually not let that sort of propel your life further or put this incredible added pressure on you, and I think that's a new set of questions also for physicians and for genetic counselors how do you counsel women to deal with that question and that inevitability that comes with knowing you are positive when you don't have children.

DR. LISA MAZZULLO:

Special thanks to our guest, Joanna Rudnick, Director And Producer of In the Family, a film that chronicles her and many patients journeys in their testing positive for BRCA and the decisions that these patients must make with their doctors.

You've been listening to Advances in Women's Health on ReachMD XM157. For questions, comments, complete program information, and on-demand podcast, please visit us at reachmd.com ([www.reachmd.com](http://www.reachmd.com)).

Thank you for listening to Advances in Women's Health, sponsored in part by Eli Lilly with your host, Dr. Lisa Mazzullo. For more details on the interviews and conversations in this week's show, or to download this segment, please go to reachmd.com forward slash women's health ([www.reachmd.com/women's health](http://www.reachmd.com/women's health)).

DOCTOR:

So, Rachel.

RACHEL:

Em, ah.

DOCTOR:

Now that you are past menopause and we have determined you have osteoporosis, I would like to start you on prescription only Evista, raloxifene-hydrochloride tablets.

RACHEL:

Why Evista?

DOCTOR:

Because it's the only medicine that reduces the risk of osteoporotic fractures and invasive breast cancer in women like you. It's important to note though that Evista does not treat breast cancer, prevent its return, or reduce the risk of all forms of breast cancer.

RACHEL:

Am I really at risk for invasive breast cancer?

DOCTOR:

Based on my risk assessment, you may be. Some risk factors for breast cancer include advancing age, family history, and personal history.

RACHEL:

So even though no one in my family has ever had breast cancer, I am still at risk for other reasons including my advancing age?

DOCTOR:

Exactly, and I think the benefits outweigh the potential risks for you. It's the one medicine that treats osteoporosis and reduces the risk of invasive breast cancer in postmenopausal women with osteoporosis. Individual results may vary, of course, but that's exciting news.

RACHEL:

Exciting? I have to take your word on that doctor.

DOCTOR:

Evista increases the risk of blood clots, it should not be used by women who have or have had blood clots in the legs, lungs, or eyes. Evista may increase the risk of dying from stroke and women at high risk for heart disease or stroke, talk to your doctor about all your medical conditions, seek care immediately. If you have leg pain or warmth, swelling of the legs, hands, or feet, chest pain, shortness of breath, or a sudden vision change. Do not use Evista if you are pregnant, nursing, or may become pregnant as it may cause fetal harm. Women with liver or kidney disease should Evista with caution. Evista should not be taken with estrogens. Side effects may include hot flashes, leg cramps, and swelling. For more information about Evista, contact your Lilly sales representative. Visit [www.evista.com](http://www.evista.com). See our ad in good housekeeping or call 1-888-44-Evista.