Mastectomies and BRCA - Are we over preparing?

According to the National Cancer Institute, a women's risk of developing breast cancer or ovarian cancer greatly increases if she inherits the mutation in the BRCA1 gene or the BRCA2 gene. In May 2014, actress Angelina Jolie underwent a preventive double mastetomy on being detected as carrying BRCA mutations. The Jolie effect has certainly increased restless genetic screening with more and more women opting for the same, but what does research indicate regarding surgical removal of breasts or mastectomies?

Is surgical removal of breast the only option for BRCA mutation carrying women? What are some of the risks involved in opting for a prophylactic mastectomy and whom would you consult prior to taking your decision?

Full Transcript:

Priya Menon : Hello, everyone, and welcome to the Cure Panel Talk Show. I am Priya Menon, Scientific Media Editor at Cure Talk, Cure Panel, joining you from India and I welcome all of you this evening to a discussion on breast cancer. This is the 36th episode of the Cure Panel Talk Show and the second time we are discussing breast cancer on this platform. Our first show on breast cancer featured Dr. Julie Gralow, and we discussed latest treatments in breast cancer advanced versus early stage. Today, we have with us an eminent breast cancer surgeon and on the panel are four breast cancer advocates and survivors.

Breast cancer is the most common cancer in women around the world. In the US alone, about 230,000 new cases are diagnosed every year. Most can be treated by just having the lump removed, but that requires radiation for weeks afterwards to kill any trace cancer cells in the breast plus frequent mammograms to watch for a recurrence. Many women don't want to worry or radiation and choose mastectomy even though they could have less drastic surgery. Mastectomy rates have been arising. In the very recent past, Amy Robach of Good Morning America announced that she had breast cancer and was opting for a double mastectomy. We do not know the details of Amy's disease leading up to her decision, but we wish her the very best.

What we are discussing today is about mastectomies and BRCA genes. According to the National Cancer Institute, a women's risk of developing breast cancer or ovarian cancer greatly increases if she inherits the mutation in the BRCA1 gene or the BRCA2 gene. Men with these mutations also have an increased risk of breast cancer, and both men and women who have harmful BRCA mutations may be at increased risk of additional types of cancer. Genetic tests can check for BRCA mutations in people with a family history. In May this year, actress Angelina Jolie underwent a preventive double mastectomy on being detected as carrying BRCA mutations. The Jolie effect has certainly increased genetic screening with more and more women opting for the same, but what does research indicate regarding surgical removal of breasts or mastectomies? Is surgical removal of breast the only option for BRCA mutation carrying women? What are some of the risks involved in opting for a prophylactic mastectomy and whom would you consult prior to taking your decision? Today we are discussing mastectomies and BRCA genes – Are we over preparing, with eminent breast cancer surgeon, Dr. Deanna Attai. Dr. Attai is a board-certified surgeon practicing in Southern California and who since 2004 has focused her career exclusively on the care of patients with benign and malignant breast conditions. She and her staff strive to provide high-quality care in a comfortable and personalized environment. Dr. Attai combines state-of-the-art diagnostic and treatment techniques with complementary therapies. Areas of expertise and interest include breast ultrasound, cryoablation, accelerated partial breast irradiation, and the role of diet and lifestyle in prevention and treatment. Dr. Attai is also on the board of the American Society of Breast Surgeons. Dr. Attai, its great to have you on the show. Welcome to the show!

Dr. Deanna Attai : Thank you so much and thank you for that lovely introduction.

Priya Menon : My co-host for the show today is breast cancer survivor and advocate, AnneMarie Ciccarella. AnneMarie is a breast cancer survivor, six years post treatment. She believes in the power of the patient voice and advocates for patient representation along the entire continuum of care. AnneMarie utilizes the power of social media to educate, engage, and empower others to be active participants in their own health matters. She is the author of the blog, Chemo Brain In The Fog. Great to have you here with us, AnneMarie, and welcome to the show.

AnneMarie : Thanks, Priya. Great to be here.

Priya Menon : Dr. Attai, what we will do right now is that we will just set up a background. I will proceed with a few questions and we will set up a background for the discussion before I hand over to AnneMarie for the panel discussion. So, my first question would be that the topic for today, I just announced is mastectomies and BRCA genes and whether we are over preparing. I presume there is no easy answer to this topic that we are discussing today, but it will be great if you could share your opinion with our audience.

Dr. Deanna Attai : I will be happy to. So, I think the first thing to talk about is that if you are diagnosed with a BRCA mutation, I think its important to realize that you do not need to make a quick decision, similar to when a patient who has been diagnosed with breast cancer, we recommend that they take some time and get their opinions and learn about all of their options. So, if you are diagnosed, generally you have three options. One is aggressive screening and usually that would include mammography, usually a digital mammogram, often times ultrasound, and the addition of MRI exams which have certainly been shown to help improve the detection rate, especially in patients who carry the BRCA gene mutation. Its important to realize that screening, even aggressive screening, is not the same as prevention. All we are trying to do is detect the disease in as early a stage as possible, that sometimes leads to better outcomes but not always.

The second option is the use of screening but also the use of a medication called tamoxifen, which is often used in breast cancer patients but has been shown to reduce the risk of developing an invasive breast cancer. Tamoxifen does certainly have some side effects and some patients are not comfortable taking that, but it can be very effective at least in terms of reducing risk.

And the third option, I think the one that most are familiar with is prophylactic mastectomy or removal of the breast before there is any evidence of breast cancer. It is important for patients to realize that you can still develop a breast cancer even after a double mastectomy. The risk is anywhere from 1% to 5%. So, even the most aggressive approach being surgery is not truly preventative, but it certainly reduces the risk significantly and then we also counsel patients on ovarian cancer screening and possible removal of the ovaries. So, these are some of the general recommendations for patients who have just been diagnosed with the BRCA testing and obviously there is a lot of consultation, a lot of discussion involved, in terms of what is the right approach for that individual patient.

Priya Menon : So, if a woman who discovers that she is BRCA positive and she comes to you, how do you monitor her progress, like you suggest mammograms and genetic counseling? When is it that you absolutely advise for a surgical removal?

Dr. Deanna Attai : You know, that’s a very difficult question because I have some patients who are BRCA gene positive, well into their 60s, who have opted for various reasons not to undergo the prophylactic surgery and they have no evidence of cancer at this point. So, I don’t think you can ever say to an individual patient that you must have your breast removed by a certain age. What we do let patients know is that their risk of cancer is much, much higher than the average population. In the average population, a woman’s risk of breast cancer is approximately 10% to 12%, whereas a woman who has a BRCA gene mutation can have a breast cancer risk over her lifetime as high as 40% to 80+%, so women need to know that they are at substantially greater risk than the average population and we do not have true prevention, but as far as the specific age or absolutely undergoing a mastectomy, there really isn’t. Ovarian treatment is a little bit different and the risk of ovarian cancer in a woman who has the BRCA gene mutation significantly increases after age 45 to 50 and the biggest problem we have with ovarian cancer is there really is no effective screening. Pelvic ultrasounds and blood tests are often used, but most cases of ovarian cancer, at least many cases of ovarian cancer are diagnosed in later stages when it is extremely difficult to treat. So, in women who have a BRCA gene mutation, we do usually recommend removal of the ovaries, but in most cases its okay to wait until after she has finished having her children and when she is closer to menopause.

Priya Menon : What would be the implications if both husband and wife are found to be carrying the BRCA mutation?

Dr. Deanna Attai : If you are a woman and both of your parents carried the BRCA gene mutation, then it would be strongly recommended that you be tested. You inherit 50% of your DNA from your mother and 50% of your DNA from your father. Now, the BRCA mutation is when during embyrology, your cell division, you inherit basically half of your mother’s DNA and half of your father’s. So, it is possible for a woman who has both of her parents with a BRCA gene mutation to not have any mutation, but they have a much higher risk and so they definitely should be tested. I think its a common misconception that its only your mother’s family history or your mother’s history that’s important and patients need to realize that you can certainly inherit BRCA gene mutations from your father, from your father’s side of the family.

Priya Menon : Thank you, Dr. Attai. With that, we will now proceed with panel discussion. I will just give a brief introduction of our panelists that we have today. We have three breast cancer survivors and advocates with us. Jennifer McCrea – She joins us from Calgary, Canada. She has a strong family history of ovarian cancer. She tested positive for BRCA1 in 2005. She was diagnosed with breast cancer at stage zero in July 2011 when she was 34 years old. Jen underwent bilateral mastectomy in August 2011, and she did not need chemo or radiation. She has since then become a runner, marathoner, and a triathlete. In June 2012, she underwent a oophorectomy and in August 2012 went in for breast reconstruction and she now advocates for breast cancer and speaks about her story and BRCA. Our next panelist is Heidi Floyd. At two months pregnant with her son, Heidi, Executive Director, Kids II Foundation and Pink Power Mom, a happily married mother of three was diagnosed with breast cancer. While undergoing treatment, she faced the challenge of balancing her guiding faith family, her own health, her son’s health, and work during an otherwise joyful time in her life. She shares personal accounts of her experiences with breast cancer survivors to deliver a compelling message of the importance of research for prevention, detection, treatment, and the cure. Next on the panel is Beverly McKee or the cancer warrior. Beverly also is an author, blogger, and inspirational speaker. She combines her clinical skills and personal experience with breast cancer to deliver the message of hope, support, and inspiration to her worldwide following through social media and speaking engagements. She is a licensed therapist by training. She connects with her followers and audiences on emotional level keeping them engaged and inspired to live the best life regardless of the challenges they face. I welcome everyone to the show. I will now hand over to my co-host, AnneMarie, to begin with the panel discussion. AnneMarie, you are live on air.

AnneMarie : Hi, everyone! Hi, Dr. Attai! Before I throw the questions over to the panel, I just wanted to let you talk a little bit about the importance of genetic counseling in some form before someone gets tested for any sort of mutation and maybe we could also bounce around a couple of thoughts about some of these self-tests that are on the market, I mean 23andme comes right off the top of my head, whereby I believe, you would be just getting information back, which means, you know, how do we decide for that information. Do you think that that's a good idea? So, having said that, I will let you talk a little bit about that and then I will bring them to the rest of the panel and to ask their questions.

Dr. Deanna Attai : Sure and I think that's a great place to start because I think its very important to stress that not every patient with a strong family history of breast cancer, first of all, not every patient will have a BRCA mutation. The BRCA mutations make up approximately 5% to 10% of all breast cancers and even though we start suspecting a BRCA mutation where there is a strong family history of breast or ovarian cancer especially at a young age, many patients will test negative. So, the first part starts with when the patient first comes in to see me, often times the patient is coming in to see a surgeon whether she has been diagnosed or is at high risk. The first part is taking a thorough family history and really figuring out which relatives were diagnosed at approximately what ages and if there are any details about their treatment. That's when we will initially bring up the subject of genetic testing and this is part of the counseling process. Its very important that patients realize and have a good understanding of all of the implications of both a positive and a negative test. Obviously, with a positive result, there are the potential surveillance and treatment options that I discussed, but patients who test negative still have to understand that they may still be at an elevated risk. Its important to realize that we have not identified all of the potential mutations and some patients may test negative for a BRCA1 or 2 mutation, but there may be something else going on in that family that we can't identify. Its imperative that any woman going through this process have access to someone who can counsel her on all of the implications of this testing, whether that be her breast surgeon and oncologist or a genetic counselor. Any of these are potentially experts in the area and its important for patients to seek them out if they are not referred. I generally and I think most genetic counselors and medical geneticists do not recommend these sort of off-the-shelf genetic tests. There is really no interpretation. There is no guidance with results and often times they are not telling you a specific genetic abnormality. They are just giving you an idea whether you are at risk for a particular disease or not, but there is no discussion about what your options are, what lifestyle changes you can make. Again, this is all part of the counseling process and I do believe very strongly that the counseling should be provided by a physician or a genetic counselor, someone who has expertise in the disease and in genetic evaluation, treatment, and management.

AnneMarie : Thank you. I think that that was very important for all of us to understand because sometimes I guess if you don't know what you are going to do with the information before you have it, it can be a little bit weedy, so with that…

Dr. Deanna Attai : That's actually an important point and just one other thing that I will bring up is there are a fair number of patients that might be high risk and choose for various reasons not to be tested and I think its important for, you know, a lot of times patients with a BRCA mutation feel that everyone should be tested and everyone should go through the surgery if positive, but its a very difficult decision often times whether or not to even be tested and this is something that has to be discussed and patients need to be counseled as well.

AnneMarie : Thank you. I am going to… Jennifer, if you are on the line, I am going to throw it to you to start the conversation with the questions that you have.

Jennifer McCrea : Can you hear me?

AnneMarie : Yes, we can.

Jennifer McCrea : Okay. Good afternoon, everybody. I am just wondering because I am in Canada and you guys are mainly in the US, what are the current screening guidelines for BRCA cancer gene mutation carriers specifically, like how often do you recommend that they have the mammogram and the MRI, etc?

Dr. Deanna Attai : Well, most of the guidelines that I follow and that a lot of people follow are the NCCN or the National Comprehensive Cancer Network Guidelines and what I did put on the blog site were the guidelines for screening and for testing. In patients who have tested positive for a BRCA mutation, generally its recommended that starting at age 18, what we call breast awareness, we used to call it breast self-exam, but we have moved away from that time. A clinical breast exam every 6 to 12 months starting at age 25, clinical breast exam means an examination by the physician. Annual mammogram and breast MRI starting at age 25, although we often don't use mammograms in very young women because of the concerns of cumulative radiation exposure and in addition the density of the breast tissue sometimes makes the mammograms less sensitive. So, in younger, in very young women, we may use more a combination of MRI and ultrasound and then as part of the evaluation is the discussion of risk-reducing mastectomy, discussing the potential benefits of salpingo-oophorectomy, but along with this needs to be a lot of consultation as far as the limitations of prophylactic surgery, discussion as far as the patient's reproductive desires, does she want to have more children, does she want to maintain the possibility for breast feeding, and along with this counseling also is addressing the very many psychosocial and quality of life aspects. In patients who do not choose to undergo the salpingo-oophorectomy, then its recommended to at least consider transvaginal ultrasound and potentially CA-125, although like I said before, ovarian cancer sometimes is very, very sneaky and even with these tests, you can have ovarian cancer, but those are the general guidelines and like I said, this comes from the National Comprehensive Cancer Network recommendations and these are posted on the site.

Jennifer McCrea : Okay. So, its, for example, you would have your MRI in February of 2013 and then six months later have a mammogram or do you or how do they recommend they have them both at the same time?

Dr. Deanna Attai : Generally, we do them six months apart…although sometimes just based on timing, it works that they get everything once a year, but most often I think we are doing it, the imaging six months apart and again these patients should all be evaluated by their physician every six months as well for clinical breast exam.

Jennifer McCrea : So, that's basically how they have it in Canada. Can I share a little bit of my story and explain why people with the BRCA cancer gene mutation need to know that the screening may not always catch what's going on.

Dr. Deanna Attai : Right. That's actually what I touched on earlier is that screening is not 100%. Mammogram, ultrasound, and MRI can all miss breast cancers, there's no question about that.

Jennifer McCrea : Is there any scientific data that they have reviewed with cancers and BRCA mutation carriers that you can talk about the fact of how aggressive these cancers are because in my case my cancer jumped from stage zero to stage I in a matter of three weeks. So, the six months in between the screenings, a lot of bad can come in those six months.

Dr. Deanna Attai : Well, if you don't mind, let me just ask you a question. (Uhmm…) When you said that you initially had a stage 0 and six months later it was stage I, how is that stage 0 diagnosed?

Jennifer McCrea : It was… I had a breast MRI in May of 2011 and so then there was a little line that wasn't there on my previous MRI and in July, they did a breast biopsy and then it was on July 18th that it was diagnosed as stage zero.

Dr. Deanna Attai : And this breast biopsy was a needle biopsy. Correct?

Jennifer McCrea : Yes. Yes.

Dr. Deanna Attai : Yeah. And then what happened from there?

Jennifer McCrea : And then I had a bilateral mastectomy on August 11th and from the pathology report from the tissues in my breast, it was showing that my breast cancer had went from DCIS to invasive cancer, stage I, grade 3.

Dr. Deanna Attai : Okay. Well, I think I might be able to shed some light on that because generally breast cancers don't progress that quickly, although there are small percentages and that do. When we make a diagnosis by needle biopsy, we are obviously not removing the entire lesion. We are taking a small sample just so we can get an idea what's going on and then come up with a treatment plan. About 20% of the time when you find DCIS on a needle biopsy, you will find invasive cancer at the time of the surgery and this is even if the surgery is done one week later. So, its not that the cancer necessarily progressed. Its that on the needle biopsy, the pathologist only has a very small amount of tissue to evaluate. They are not getting the whole picture and I give the analogy that a needle biopsy is like taking one piece of a jigsaw puzzle and that piece is green and you are then as the pathologist trying to figure out is that a little speck of green carpet, is it a green lawn, is it a green painting and sometimes its not until you have the entire puzzle put together or in this situation of pathology it might not be until the pathologist has the entire area to evaluate where they can actually see the full extent of disease and that's probably the most common explanation for the situation that you experienced.

Jennifer McCrea : Okay. Thank you.

AnneMarie : All right. Heidi, are you around?

Heidi Floyd : I am here. Hello!

AnneMarie : All right. You are up. You have a couple of questions here.

Heidi Floyd : Oh, okay. I am ready to jump right in with my questions.

AnneMarie : I want you to jump right in because Priya did all these good intros. So, you can just keep the conversation moving.

Heidi Floyd : Sure. Perfect! Okay. So, I am one of those women who tested for BRAC1 and 2 and was found not to have either; however, my family history, every woman older than me, has passed away from breast cancer. So, we know that there is a family history and they have taken my tumor for study. Hopefully, they will be able to utilize it to detect a new genetic mutation and use it to help other women. When I was diagnosed, I was pregnant as it had been mentioned earlier and so I didn't really push very hard and I was so happy that I was able to find an oncologist who was able to treat me while I was pregnant because the first one would not. So, I had to go get a second opinion. I was so happy that he was willing to treat me while pregnant that I didn't really push hard for a complete mastectomy even though it was one of those things _____.

AnneMarie : What happened to Heidi?

Dr. Deanna Attai : I think we might have lost Heidi.

Priya Menon : Heidi, she is online. Heidi, you are live? Or maybe you could just move on to the next person until I get Heidi back.

AnneMarie : Sure. We could. We can move on to Beverly maybe if Heidi is not there. Beverly!

Beverly McKee : I am here.

AnneMarie : Okay. Beverly, you are going to jump in and we are going to let Heidi come back to finishing her story and her question in a second, so we will move on to what you have to say.

Beverly McKee : All right. Thank you, Dr. Attai, for talking to all of us today. I know you have a lot of patients, so I appreciate that you are taking your time out to educate all of us on this.

Dr. Deanna Attai : My pleasure.

Beverly McKee : And I want to just touch a little bit on the psychosocial impact of BRCA testing. I am a therapist by training and I talk to a lot of people across the nation about their journey through breast cancer and I think its important before people go out and get tested just to understand that there are lot of psychological impacts of knowing that you have a BRCA mutation or if you test negative that there are still some impacts from that and so I kind of want to just have that conversation with you.

Dr. Deanna Attai : Sure. I had mentioned it very briefly earlier, but this absolutely needs to be discussed and again there are many patients with a strong family history or even a known BRCA mutation where they may not want to be tested or they get their test results and for example, I have a young woman in my practice whose sister was recently diagnosed with breast cancer in her 20s. My patient came to me and was tested and the patient's sister had a BRCA mutation. So, my patient came to me asking for testing and we went through all of the issues that we usually do and she tested negative and she came back later saying she felt so incredibly guilty because her sister was diagnosed at stage III and is going through chemotherapy. She felt so guilty that she wasn't going through the same thing, not that she wanted to, but she felt that that actually pushed them a little bit farther apart than she had even anticipated. So, again, these are sometimes some of the issues that come up in patients whether they are deciding to be tested. I have patients who, for example, get tested and are found to be positive and they are absolutely devastated that they might have passed something wrong to their daughters. So, all of these issues need to be discussed and like we said earlier, this is why the counseling before doing any testing is so very important.

Beverly McKee : I can certainly relate to that because my sister tested negative while I was dealing with my stage III breast cancer and she felt guilty and didn't want to tell me that she tested negative. Then, of course, I was thrilled to know that she had tested negative. It was a big relief for me and I have two young boys and there's a lot of guilt knowing that I tested positive for BRCA2 and knowing that I might have passed it on to them even so there's nothing I can do about it. Its very frightening.

Dr. Deanna Attai : Right and I think again one of the things that we do in the counseling process and I am sure you are familiar with this as well, is remind women that they really don't have anything to be guilty about. We often say you can't take your parents, you can't take your genes. It is what it is and I think stressing the fact that you now at least have this information and then its up to the individual to decide what they want to do with this information. I think that's the best approach to take, but that's obviously a lot easier said than done.

Beverly McKee : That's very true.

Dr. Deanna Attai : And you know one thing I wanted to touch on very briefly that I hear a lot from people is that they are worried about being discriminated against by their health insurance or by their employer if they were to test positive. I just wanted to mention The Genetic Information Non-discrimination Act of 2008 had actually dealt to protect people who have had genetic testing. You cannot be denied by your insurance if you test positive and I think that's important for people to know.

That's absolutely important but what also is important to know is that applies to health insurance, but it doesn't necessarily apply to life insurance and some other types of insurance as well, but you are absolutely right. There is federal protection as far as genetic discrimination and that's something that patients need to be aware of. I still have some patients coming in and asking if they could just be tested anonymously or if I get tested on a cash basis, will my insurance find out? I don't ever recommend that because if you fail to disclose certain conditions to your insurance, just by contract that could be grounds for termination. Now they cannot terminate you just because you do test positive for BRCA mutation and if anyone finds themselves in that situation, they need to talk to their insurance company and pull up this federal legislation because that's basically against federal law.

Beverly McKee : Okay. Thank you for answering my question.

Dr. Deanna Attai : My pleasure.

AnneMarie : I think Heidi is back on the line. Heidi, are you there?

Heidi Floyd : I am. Can you hear me?

AnneMarie : Yes, we hear you.

Priya Menon : Yes, we can hear you. Okay.

Heidi Floyd : I just did my whole thing and I was wondering why it was so quiet. So, I was _____.

Dr. Deanna Attai : I think we left off right after you were diagnosed and you found your second oncologist and you opted to have the lumpectomy.

Heidi Floyd : Yep, I did and that was not… I felt very strongly that I should have a full mastectomy at that time, but I had been recommended to go the preservation route and again I was so happy to have this oncologist that I didn't want to just push away and keep pushing. I was so happy that I could do what I could do. So, in spite of the fact that I was tested for the BRCA gene and found none, I did have the partial and then five years later, a new tumor kind of took me down the full mastectomy journey and reconstruction and I was wondering is the pendulum kind of swinging back to at least encourage discussions between oncologist and breast surgeon and patient to maybe discuss complete mastectomies or are we still on the let's preserve everything we can even if its something that just helps the patient to have a peace of mind?

Dr. Deanna Attai : Okay. So, first, I have a question or two for you and then we have got plenty to say on this topic. When you had your lumpectomy, were you pregnant at the time?

Heidi Floyd : I was, yeah.

Dr. Deanna Attai : Okay. That might be one of the reasons that they recommended the lumpectomy, only because in any woman that's pregnant, we want to try to minimize their exposure to general anesthesia. It is generally considered safe after the first trimester, but you know, you just never know and a lumpectomy is usually a shorter surgery and a little bit less involved, so often times there's less exposure to general anesthesia. I have operated on patients that were pregnant and will often times recommend a lumpectomy and then depending on where they are in their pregnancy before they start their radiation, they may or may not decide to have a mastectomy. And then my other question for you before we go into the lumpectomy-mastectomy discussion is your new cancer, was it in the same spot or in a different area of that breast?

Heidi Floyd : Ummm… Same spot. As a matter of fact, my oncologist found it because to me all of my scar tissue felt like lumps, everything. So, it was really hard for me to do self-exams. So, it was right in the same area, but they did find and I know I am probably going to say it incorrectly, the cellular development on the other breast.

Dr. Deanna Attai : Okay. Then you might have had what's called atypical hyperplasia or some abnormal cell growth on the other side. So, to get to the issue of lumpectomy versus mastectomy, really before the 1970s or 80s, mastectomy was our only option and any woman who felt the lump essentially went from the surgeon's office to the operating room. They would remove the lump and do a frozen section and if it was positive for cancer, that woman had their breast removed and I still remember as an early medical student, I am old enough to remember this, consenting patients for a breast biopsy, possible mastectomy. At the time, we didn't have any other options as far as surgery. There were no lumpectomies. The studies hadn't been done to prove the safety of that procedure. So, around the late 70s and early 80s, some large studies were published suggesting or showing that if you perform a lumpectomy followed by radiation, that those women lived just as long as the women undergoing a mastectomy and because mastectomies were such aggressive treatment and often times were done for very, very early stage disease, both patients and physicians really embraced this because we no longer had to remove an entire breast, we knew that that woman was not going to live any longer if she has her breasts removed and so really from the 80s up until about the mid 2000s, breast conservation or lumpectomy was really considered the standard of care for early-stage breast cancer. The pendulum has sort of swung back the other way and this sometimes has some physicians scratching their heads because just when we have really now 25+ years of data showing the safety of lumpectomy with radiation, women are coming in asking for bilateral mastectomies.

Often times for stage zero or stage I breast cancer and I think there are a lot of issues with this. First of all, I will say that it is always, always, always going to be the woman’s choice. I am not the one that has to live with the decision, she is, but it is very important that women realize some or understand some basic facts and one is that the survival is no different. There is a risk of recurrence, whether its a local recurrence or something called a new primary, in other words a cancer developing in the breast after a lumpectomy and radiation. Depending on the type of cancer that you have and depending on your treatment, that risk can range anywhere from 5% to 15% over the rest of your lifetime. Another way to say that is you may have an 85% or 80% to 95% chance of not developing another breast cancer. Its also what we are more recognizing is that if you have a lumpectomy and radiation and you develop a recurrence, it can be a little bit more difficult to do the reconstructive surgery because the radiation obviously causes some tissue damage and it can sometimes limit our options as far as the reconstruction and I think sometimes some women just feel that they only want to go through this once and they want to just put it behind them, but the important points to counter that are that you can still develop a breast cancer even after mastectomy, although the likelihood is much, much lower and there are some real and very significant potential complications from undergoing a bilateral mastectomy and reconstruction and I think sometimes when we have celebrities or public figures coming out, you know, often times they don’t come out and talk about their treatment until after its all finished and we just see them back on camera or back on the red carpet and they look fantastic. That’s sometimes not what we have rich woman’s experience is in terms of going through the bilateral mastectomy and reconstruction. So, these are all of the things that we discuss with the patient. I can say as a woman and as a breast surgeon, I know the science, but I also completely understand when a woman’s gone through her imaging, had a diagnosis, had an MRI. We sometimes do additional biopsies and then I often get asked well, if we treat this breast cancer, what do we do next year.

I say, well, we start the process of imaging all over again. What’s to say if there’s nothing that, you know, could be there next year and my answer is the same. We just don’t know and so, I think a very balanced discussion about the risks and benefits of both approaches and the limitations of both approaches is extremely important and I always tell patients, “I don’t want you to make this decision while you are sitting in my office. You may have come in saying this is what I want, but hear me out, go home and think about it, talk to your family, and then at the end of the day I am comfortable doing what you want as long as I know you have made an informed decision and are not necessarily just doing a knee-jerk reaction of remove both of my breasts.

Heidi Floyd : Wow! Wonderful! Thank you.

Dr. Deanna Attai : Does that answer your questions in a very long winded way.

Heidi Floyd : It did. No, it does. I speak to so many women who have that exact question, what should they do and I always say basically what you just said, its your decision but talk to your doctor. If you trust your doctor, pour your heart out and they will kind of guide you if you have got a great doc like you.

Dr. Deanna Attai : And a good followup point to make is that if you are not having these conversations with your physician, then maybe you need to get another opinion. Because these conversations should definitely happen. I think they are very, very important because one thing to realize about a bilateral mastectomy, it is a 100% irreversible procedure. Plastic surgeons can do a lot to make them look and feel much more natural, but we can never actually put your breast back and I think that we all know that, but that is actually a point that I stress that if you are not sure what you want to do, then let's do a lumpectomy, let's get a full pathology and then we never want to do more than one surgery, but if you are not sure, let's not burn any bridges by going right to a mastectomy.

Heidi Floyd : Yes. Yes. Perfect. Thank you.

Dr. Deanna Attai : You are welcome.

AnneMarie : I was sitting here listening and remembering how it took me, I am going to say 5 minutes to go from the 0 to 95% certainty in my own case as to what the right decision was for me, which was a bilateral mastectomy, but there were a number of reasons why I made that choice and they were all based on science even though I really wasn't an advocate back then. You know, I knew I was in a high-risk category. My mom had premenopausal breast cancer. I was premenopausal and I also had invasive lobular which tends to, you know, unlike stem cells there is a chance that there is something going on in the other breast and its also the "sneaky cancer," so I kind of went down that path, but still I found my _____ and I agonized over that 5%, well, maybe I…, but at the end of the day, you know, I kind of like emotionally detached and said these are the facts. And I am going to throw it back to Jen for another question, but talk a little bit about what happens once you have had breast cancer and they see something on, you know, an imaging test down the road. Do you get that? You are in a high-risk category, so we can't just, you know, that watchful waiting and scanxiety and all of those wonderful words that we hear.

Dr. Deanna Attai : Right. Yeah, its one of those things where if you do find something on subsequent imaging, it may be something completely benign, but we can't ignore it. Now, it doesn't mean that we are taking women back to the operating room. We have much less invasive techniques in terms of needle biopsies and that is almost always the initial recommendation. What women also have to realize is that MRIs, while they can be very sensitive for detecting breast cancer, can have as high as a 20% false positive rate, which means out of a 100 women going in for an MRI, I am going to call 20 of them back, saying we see something that looks suspicious, we are going to work that up and it turns out to be nothing at all. So, that does bring up the whole scanxiety issue and things like that, but we basically have to take each new situation as it comes and start from the beginning, not make any assumptions based on the prior history but certainly keep that prior history in mind so we don't delay treatment for anything.

AnneMarie : Thank you and, Jen, if you are on the line and you have something else you would like to ask here. I am going to pass it back to you.

Jennifer McCrea : Okay. So, the one thing that I know for sure is that a woman that has a preventative bilateral mastectomy due to their BRCA cancer gene mutation will have much better results in the end than a woman like myself that got cancer anyways and had to have a bilateral mastectomy. For Dr. Attai, what other options might you guys be having that you could recommend to me, a woman dealing with postmastectomy and reconstructive scars?

Dr. Deanna Attai : Okay. So, first of all, I can tell you just from my experience and from the literature that patients even with early stage breast cancer can have excellent cosmetic results. We are more often performing nipple-spearing mastectomies. We may perform the mastectomy through what's called an inframammary incision, which means the scar in the bra lines sometimes its not visible. You know its certainly not a normal close and things like that. We can sometimes make the incisions fairly small around the nipple or around the areola. Any surgery, whether its done prophylactically or whether its done for cancer has the potential for scarring. And you are correct in that if the surgery is being done for cancer sometimes we are a little bit more limited in terms of where we make our incisions. We can't always be as creative as we would like to be because of the location of the tumor, but even a prophylactic mastectomy, patients can still sometimes have scarring. Some patients develop what's called a keloid scar, which is a very thick gray scar and you may not… I am sorry?

Jennifer McCrea : That’s what I have, yeah.

Dr. Deanna Attai : Okay. So, but that could develop whether you have this entirely as a preventative procedure or in your case it developed after a mastectomy for cancer. Chemo is just one of the things that we all dread because you can’t always predict. Some ethnic groups, Asian and African-American patients in particular, have a higher rate of keloid formation, but I have seen keloids in the most fairer-skinned patients and you may have had surgery in other areas of your body with no keloid formation and then you have a breast surgery and you may keloid, but its very difficult. Sometimes injections of a steroid material can help. There are some topical agents that can sometimes be effective and more often plastic surgeons are using various laser treatments to help minimize or at least flatten out some of those scars. But, its a difficult problem and unfortunately that’s the reality with any type of surgery anywhere in the body.

Dr. Deanna Attai : Okay. I might just get a tattoo right across my chest that says (laughter) “Yes, they are fake. My real ones tried to kill me,” that’s what I think I might just do and you know _____(laughter).

Dr. Deanna Attai : I have a fair number of patients, whether they have had a lumpectomy or a mastectomy, they would opt to have their scars tattooed (yeah) and I have seen of the most beautiful, amazing tattoos and what the patients tell is they just wanted to bring some beauty back. So that is… Its certainly an option. Its certainly not for everyone, but that is a fairly common situation.

Jennifer McCrea : Yeah. Okay. Thank you.

AnneMarie : That was actually very good. I liked that tattoo conversation got brought up because it was something that was done in New York City in October by a tattoo artist. Heidi, are you still on the line or did you…

Heidi Floyd : I am here yet.

AnneMarie : I can see also that Heidi is tweeting like crazy.

Heidi Floyd : I can speak now, almost over.

AnneMarie : And if this goes on, I can’t multi-task like that, not when I am having, in the middle of the conversation. (laughter) I have to say stay away from Twitter or you will end up having, you know, dead air here. I won’t be here. Heidi, is there something else that you would like to discuss with Dr. Attai?

Heidi Floyd : I do. Yep. I was actually on Twitter trying to scroll through because I had just found a website that gives you a bunch of ideas and images for tattoos, for breast cancer patients specifically. If I can find it, I will try to throw it up, I’ll re-post it, but it was amazing. So, my question is…

Dr. Deanna Attai : Yeah, I will say also tattoo artists are getting much, much better and…I haven’t had any patients go through this particular procedure yet, but there is something called 3D tattooing for nipple reconstruction with differences in shading techniques and things like that and at least from the pictures that I have seen they are absolutely amazing. So…

Heidi Floyd : Well, I will let you know because that’s on task for me in my January or February (laughter). I am serious, you know, mine has faded and its time and that’s exactly the route I am going, so we may do a little show and tell on Twitter. Maybe I will, you know, _____ (laughter) _____ tattoo photos.

My question is when I started speaking and meeting a lot, a lot of people. Like I said, I have interacted with just thousands of women. There seemed to have been at one time a marker. People would say how long are you out? How far have you been removed from, you know, surgery, chemotherapy, things like that and then if someone would say, “Oh, I am 6 years.” They would do an indication of, “Oh, you hit the five-year magic marker like all of a sudden, you are completely scot-free. You have no more worries in the world.” And in that frustrates me and I wanted to know if there is some sort of, like where that came from and it is still there because I have so many dear, wonderful friends who are 10, 15 years out and they are finding it now and of course, my own recurrence happened right on my five years. So, is that something that has dissipated now or is it still out there?

Dr. Deanna Attai : Yeah. There is still sometimes that misconception that either at 5 years or 10 years, you are safe. Way back before there was immediate reconstruction and right when reconstruction was first coming out, patients never got immediate reconstruction. They had the mastectomy. They were told to wait five years before getting reconstruction. We know that the risk of recurrence, the risk of local recurrence, in other words, in the breast or in the chest wall, is highest within the first few years after the surgery and it does tend to decrease over time, although there is always a risk for a whole new breast cancer developing and so we used to tell patients, “Oh, you are five years, don’t worry about it.” Five years is sort of just the tip of the iceberg and unfortunately with breast cancer, there is no time when you can truly be considered safe.

It also comes down to what is your stage of disease but probably more important what is your tumor biology? Is this an estrogen-progesterone positive cancer with a low proliferative rate or is it a triple negative or a HER2-positive cancer that’s more aggressive. The more aggressive cancers are more likely to recur early, which makes sense because these are more rapidly growing. What we are seeing a lot of now is patients with slow-growing disease, estrogen-progesterone positive that are 10 to 15, even 20 years out from their treatment and are developing either recurrences or metastatic lesions. This is why some of the recent data on prolonged endocrine therapy, so generally tamoxifen was recommended for five years. There are some studies now showing that the survival has improved with 10 years of treatment. That’s why some of these studies, even though there’s a lot of side effects from the medication, are so exciting because we know that these cancers can sometimes just essentially go into hiding. They are very slow growing. They may have taken 10 to 15 years to develop in the first place and you treat the main cancer, but there may be cells that have gotten into the blood stream and are just kind of floating around for lack of a better term and it gets to a point where years later they find their other little cancer friends and they all meet up and decide that your liver or your bone seems like a nice place to take hold. We can hopefully stem that a little bit with either newer agents or with in some cases prolonged treatment, but again unfortunately we can’t ever say that you are completely out of the woods. Its one of these things that time will tell, so it is always important to keep in touch with your body, be aware of any new symptoms and certainly report that to your physician. Again, as we have talked about before, there is no way to prevent a recurrence or to completely prevent a metastasis, but there are certain things that we can all do to help reduce our risk of not only cancer but of heart disease and other things in terms of lifestyle and activity and getting plenty of sleep, AnneMarie, and… (laughter). You knew I would bring that up…

AnneMarie : Yes, I did. I have a little note here, hash tag redpolice. But, so, yeah, it is a difficult thing and you know, we obviously want to tell our patients that you are going to be okay, that’s just our nature. We want everything to be okay, especially after the very difficult treatment that women go through, but the reality is with cancer as with a lot of other diseases, you just have to be, you just have to be vigilant.

Heidi Floyd : Yeah. I find the difficulty in educating other people because (yeah) there are so many people that have a tendency to say, “Oh, you had cancer, but that was like four months ago. You are fine, right?” I mean, do you have any idea? This will go on until I am gone. I mean…

AnneMarie : You know what ? Heidi, that’s so funny because I think what we are going to do is after this call, we are going to get Priya to set up a conversation just on that topic. Ah! There is tons of that. I want to just give Beverly a chance to see if she has one, you know, one final thought that she might want to throw out there and then, you know, we will be getting ready to wrap up shortly, so, Beverly, if there is something else, please do.

Beverly McKee : Sure. Umm… Dr. Attai, I just wanted to ask about the BRCA3 and 4 mutations and the research into that and how do you anticipate that will change the future of our cancer treatment?

Dr. Deanna Attai : I think we are going to find going forward obviously there is a lot of research now on other mutations because we know it doesn’t stop at BRCA1 and BRCA2, but there are many more mutations that are being evaluated and I think we are going to have a whole panel of genetic abnormalities that can be linked to breast cancer. One thing that’s really an interesting area of research but also a very frustrating area for patients is a situation called the variants of uncertain significance. You may undergo a BRCA test and a lot of patients think its always going to be either yes or no. There are several hundred mutations, probably even more that have been identified and there are even more out there that we just don’t have a test for, but there are mutations that can be detected where we don’t know what they mean and those are called the variants of uncertain significance.

Beverly McKee : And I am going to chip in to interrupt you right there and say yay, maybe because that happened on both of mine. BRCA1 and BRCA2 returned VUS. So, now you can explain.

Dr. Deanna Attai : So, the issue is you had an abnormality, but it doesn’t fit any of the known mutations that are linked to an increased risk of breasts or ovarian cancer. As more testing is done, companies develop larger databases where we can start sorting out what are these variants and do they mean anything and I have some patients that were tested several years ago that had a variant of uncertain significance and I will get a letter back saying we have gathered more information and we have determined now that that is not a deleterious mutation or on the other hand, it is a deleterious mutation. So, just because you get a variant of uncertain significant result, don’t assume that you are at higher risk. Again, we have to take that into the context of your whole family history because as we do more testing and as we gather more information, a lot of these variants will turn out to be of absolutely no consequence whatsoever. So, I think that’s important and that’s something that we will be learning a lot more about, especially now since there are many more companies that are performing BRCA testing. We are going to have a lot of these patients with the variants of uncertain significance and the more appropriate patients get tested, the more information we can get in these databases so that we have less uncertainty as far as our recommendations in counseling.

And I know that this is the decade of big data, that’s what I just keep hearing everywhere I turn and the data is coming out of our bodies and its kind of important that we all participate if, you know, I mean I know I am going to probably send my results to, I don’t know, I think I am going to… Andrea, I apologize if you listen to this that I not remembering, its free, the date that there is an initiative going on right now for everyone to get their data into one place so that, you know, if there are common themes running through, it can be, you know, more easily identified. Nothing is easy _____.

And this goes to the importance of not using some of these off-the-shelf tests (umm…) because there is no central repository. There is no real collection of the data and evaluation of the data and you may not really learn anything about yourself and you are certainly not going to learn anything about yourself in the context of other patients who may be at similar risk or have similar condition. So, again, that’s a push for go through the proper channel, get the counseling, get the appropriate testing because we can then start gathering some of this data and hopefully get more answers and more guidance for patients.

And that’s the importance of information and education so that we can make the best possible choices for each of us and I think that that kind of is what we were hoping to glean from this whole conversation, everyone coming at it with their own experiences so that Dr. Attai could put the expert analysis to let us understand why its so important to understand that we are doing things for the right reason and the right reason is the reason that works for each of us as long as we are doing it with proper education behind us. So, Priya…

Beverly McKee : I agree a 100%.

AnneMarie : If you want to come back on the line, Priya, and add anything to the conversation, I think that would be a good idea.

Priya Menon : Thank you, AnneMarie. Thank you so much. I think we just never realized how 60 minutes flew past. Dr. Attai, as you said, having mastectomy for breast cancer is not a guarantee that the cancer won't come back and I think that having a prophylactic mastectomy will not ensure that cancer won't develop. I think that's a clear message that we can send out from our panel today. Would you like to send out any other message, doctor?

Dr. Deanna Attai : Again, I think to stress that if you are diagnosed with a BRCA mutation, just like if you are newly diagnosed with the breast cancer, please take the time to get your information, get extra opinions if you need. Its a very important decision and these are very difficult decisions. AnneMarie, you said you agonized over your's. Honestly, women should agonize over this decision. Its not as easy as just do I want the red shoes or the blue shoes. Its a life-changing decision. So, get the information you need. If you don't feel you have that from your current medical team, that's also a reason to get another opinion, but you want to have as much information as you need to make a decision that you are most comfortable with.

AnneMarie : And don't be afraid to get second opinion because the best doctors will encourage you and if you are with the doctor that takes offence with the fact that you are saying you want a second opinion, in my opinion that's not the doctor that you want to go to because I know, Dr. Attai for example, would be encouraging you to go out there and get even if you need a third opinion if you get two conflicting opinions and you have to get the third person to kind of break the tie, she would be the first one standing there, saying go, saying go, do it. So, you know the doctors…

Dr. Deanna Attai : AnneMarie, are you in my consultation room?

AnneMarie : Its much the same when you are in my house making show of sleeping at the right time. (laughter).

Dr. Deanna Attai : There, you got me.

AnneMarie : But, no, I think that its important for women to understand or for any patient to understand that any doctor that discourages us from, you know, getting a second opinion, you should take a long, hard look at that physician and wonder, you know, why, what's the problem with, you know, going to get another opinion. I would be leery of anybody that didn't feel that, you know, that was something I felt strongly about. In any event, I don't get the last word. I think Priya and Dr. Attai do. So, I am going to be quiet and say thank you to everyone. Its been wonderful, so…

Priya Menon : Thank you. Thank you, AnneMarie. Thank you, Dr. Attai. It was actually a pleasure to have you amidst us today. It was a wonderful discussion. AnneMarie, Heidi, Jennifer, and Beverly, thank you so much. I thank the audience for your support and we look forward to having all of you join us for the next Cure Panel Talk Show and we are going to discuss multiple myeloma with Mayo Clinic Expert, Dr. Chanan Khan. We will be discussing monoclonal antibody therapies in myeloma. For more details of upcoming shows, please visit curepanel.carefeed.net or email me Priya@trialx.com. The link for today's show will be sent via email to all participants. Thank you so much.