“Breast Cancer Survivors: What You Need To Know About Recent Developments In Genetics”

National Teleconference Transcript
October 29, 2013

Presented by:

SHARSHERET
Your Jewish Community Facing Breast Cancer

This program is supported by the Cooperative Agreement DP11-1111 from the Centers for Disease Control and Prevention.

I. Introduction

Mike: Good evening everyone, and welcome to tonight's program. At this time, all lines are in a listen-only mode. However, later in the program you will have the opportunity to register to ask questions. Tonight's conference is being recorded, and at this time it is my pleasure to turn the conference over to Ms. Shera Dubitsky. Please go ahead.

Shera: Thank you, Mike. Good evening everyone. My name is Shera Dubitsky and I am the clinical supervisor at Sharsheret. We would like to welcome you to tonight's national teleconference entitled "Breast Cancer Survivors, What You Need to Know About Recent Developments in Genetics." This has been a banner year in the world of breast cancer genetics. Angelina Jolie announced to the world that she tested BRCA positive and opted to undergo a prophylactic bilateral mastectomy. The Supreme Court ruled against Myriad's patent on the BRCA gene, enabling other labs to test high risk individuals and their families for hereditary cancers. Finally, there are new testing panels that are changing the way we are identifying genetic mutations that may predispose one to a cancer diagnosis.

As a result of this trifecta, Sharsheret has been busy fielding questions that are triggered by these events. We have been fielding calls from women and their families who are interested in learning more about genetic counseling and testing and from women who tested BRCA negative and are wondering if they should undergo further testing. We hear you loud and clear and that is why we chose to address the recent developments in genetics this evening.

As an organization with an expertise in Jewish families, we feel compelled to raise awareness about hereditary cancer because one in 40 individuals of Ashkenazi Jewish descent carry the BRCA mutation. Our goal tonight is to answer the many medical, legal, financial, and emotional questions and concerns that have been posed to us over the past year. Tonight's teleconference is part of our survivorship series. We are committed to presenting topics that are on the forefront of the minds of breast cancer survivors.

In addition to these teleconferences, our survivorship program, which is called Thriving Again, offers conversations with Sharsheret's genetic counselor, peer support, and a free personalized survivorship kit. If you haven't already received your personalized Thriving Again survivorship kit, send us an email right now to info@sharsheret.org with your name and contact number and we'll be in touch with you tomorrow. I would like to

thank our panel of experts for joining us this evening and following their presentation there will be an opportunity for questions and answers. Without further ado, I would like to introduce our first speaker.

Danielle Singer is a graduate of Brandeis University with an MS in genetic counseling. She has many professional affiliations including the National Society of Genetic Counselors and serves as a secretary for the Human Genetics Association of New Jersey. Prior to joining Sharsheret, she worked as a genetic counselor at the Yale Cancer Center where she counseled individuals and families about hereditary cancer risks. As part of Sharsheret's genetic program, Danielle provides supportive counseling, information, and resources regarding hereditary breast cancer and ovarian cancer to women diagnosed or at high risk of developing breast cancer and ovarian cancer and their families, including men. Tonight, Danielle will be speaking about developments in genetics research. Danielle, the floor is yours.

II. Recent Developments in Genetics

Danielle: Thank you, Shera. I am delighted to be on this teleconference tonight to speak to you about the new developments in the field of cancer genetics and to introduce you to Sharsheret's Genetics for Life program and everything it has to offer. You may be wondering why you should revisit the topic of genetics as a breast cancer survivor, especially if you have already had genetic testing.

As new developments are made, you may want to consider additional testing. This testing may clarify risks for other cancers, such as ovarian cancer, and importantly has relevance for risks of family members. As the field of genetics changes, women who have had genetic testing years ago are calling Sharsheret to learn more and to inquire whether further counseling and testing is necessary. Some are calling for help managing the overwhelming decisions that come along with a positive genetic test result. Perhaps most importantly, women are calling Sharsheret to discuss what genetics means for their own lives, health, and for their families.

Before I delve into what is new in the world of cancer genetics, I would like to just provide a context for some of those listening tonight, although many of you may have already heard this information before, been through the genetic counseling process, or even had genetic testing. As a reminder, we know that 90% of cancer diagnoses are actually sporadic and only about 5% to 10% of them are hereditary. Two genes, BRCA1 and BRCA2, are responsible for the majority of hereditary breast cancer.

BRCA1 and BRCA2 are genes that we all carry and every single one of us has two copies, one from mom and one from dad. The job of these genes is to protect our bodies against breast and ovarian cancer, so these genes are important for our bodies to function. Two copies should be there and two copies should be working. However, sometimes we find individuals who carry what is called a mutation in one of these genes. A mutation is similar to a spelling error. If we think of a gene as a long sentence that our body reads through, and there is a typo in a single letter, it will impair the body's ability to read through the gene properly. Therefore, if there is a mutation, there is less protection against these cancers, thereby producing an increased risk for breast and ovarian cancer.

BRCA1 and BRCA2 are long genes. There are many places within the gene where mutations can exist. However, we know that one in 40 Ashkenazi Jews or Jews of Eastern European descent carries one of three very specific mutations found in specific places in these genes. Often, when an individual of Ashkenazi Jewish descent pursues BRCA genetic testing, the testing will begin with just those three mutations. If that person is negative, often testing will proceed to what we call sequencing. Sequencing is essentially a read through of the entire BRCA1 and BRCA2 genes, letter by letter, looking for spelling errors or mutations.

Recently, there have been many changes and updates in the field of cancer genetics and the technologies which are used in genetic testing. The first update I'd like to discuss is called BART, which stands for BRCA Rearrangement Test. BART is essentially another way of looking at BRCA. Instead of scanning the gene letter by letter to look for mutations or typos, BART is a different technology which looks for chunks of the gene which may have been deleted of rearranged. This test became available in 2006, so if you had genetic testing prior to 2006 and tested negative it may be worth recontacting your genetic counselor or genetics professional to discuss whether you might consider rearrangement testing.

Another technology which is now widely being integrated into clinical practice are cancer genes panels. Technology now allows for testing of multiple genes at the same time, between 10 and 50 or even more. As scientists learn more about hereditary cancer, other genes besides BRCA1 and BRCA2 are being identified which can be associated with an increased risk for breast cancer. These panels can now test for mutations in any gene that has ever been proven to have even a slight association with an increased risk for breast cancer. Other panels exist for other types of cancers.

Sometimes the more testing that is done the more chances there are for ambiguity. It is possible for someone to undergo a panel test and

unexpectedly discover they carry a gene mutation associated with a hereditary colon cancer syndrome, despite their breast cancer history. It is also possible to be told a mutation was found in a gene that may be associated with an increased risk for breast cancer, but not a lot is not known about this gene. This can be distressing and confusing for people to hear information from this type of test that they were not expecting to hear. It can also make it very difficult to guide medical management for genes that we know little about.

Other considerations to think about are costs, insurance coverage, risks for other cancers, and how this information will affect your medical management, your emotional well being, and risks to other family members. These panels, however, can prove extremely useful in cases where personal and family history are unclear or when previous genetic testing does not provide an answer. Genetic counselors and providers are sometimes baffled when an individual has a strong family history of breast and/or ovarian cancer and genetic testing for BRCA is negative.

Doing panel testing has the potential to clarify risks and discover the cause of cancer in the family. Panel testing can also be useful when limited family history is known to suggest one hereditary cancer syndrome over a different one associated with breast cancer. For example, it can be challenging to track family history for individuals who have lost family members in the Holocaust or for individuals who have been adopted. As scientists learn more about these genes, there is great potential for these panels to be expanded or revised to discover new causes of hereditary cancer or to clarify personal and family hereditary cancer risk.

Recently, I attended the National Society of Genetic Counselors conference in California. There was a lot of buzz about these cancer gene panels at the conference. As breast cancer survivors, if you have already seen a genetic counselor or had genetic testing, is it worth pursuing a panel? Depending on your specific set of circumstances and family history, it might be. I strongly recommend checking with your genetic counselor or me at Sharsheret to discuss if this or any additional testing would be appropriate for you.

How does Sharsheret address these recent developments and important concerns and questions that Jewish women and their families have? Sharsheret's Genetics for Life program provides resources, information, and individualized genetic counseling to Jewish women and families facing a cancer diagnosis or at risk due to their strong family history of breast cancer or ovarian cancer. Additionally, Sharsheret educates and informs health care professionals about the specific concerns of Jewish

women and Jewish families, including their increased risk for hereditary breast and ovarian cancer.

Through our genetic counselor hotline, you can call to speak with a genetic counselor, namely me. This hotline is an opportunity for individuals to connect to Sharsheret to receive free tailored and confidential individual support and to have questions answered about genetics, family history, and genetic counseling. Our peer support network connects women one-on-one with others who are at increased risk or have been through a similar experience. Family conference calls are a unique feature of the program. This feature allows women to conference with family, partners, or friends to discuss any genetics-related concerns with the assistance of a genetic counselor. I have spoken with families about communicating genetic information, strategies for testing, medical decision making, and much more.

We also distribute our culturally-relevant book, “Your Jewish Genes,” which addresses frequently asked questions about breast cancer and ovarian cancer genetics and share personal stories of women relating to genetics. Our “Have The Talk” campaign is a national cancer genetics campaign which encourages college students and young men and women to begin critical family conversations about their medical history. Participants pledge to “have the talk” and can use an online pedigree to record their family cancer history and access Sharsheret’s culturally-relevant resources and the Genetics for Life program to discuss their personal issues and concerns. Lastly, our health seminars, teleconferences, and webinars, like this one, are presented nationwide to educate Jewish women and men about the importance of understanding family medical history and to address genetics-related concerns.

After this teleconference, I highly encourage you to call Sharsheret and discuss any questions or concerns you have with me and get connected with our Genetics for Life program if you have not done so already. I look forward to connecting with each and every one of you.

Shera: Thank you, Danielle. As you were speaking I was thinking that several years ago Sharsheret hosted a teleconference on genetics and we focused on the BRCA gene, so it’s exciting to see how much the field of genetics has now expanded and we at Sharsheret continue to be committed to keeping up with all these new testing options.

Our next expert is Dr. Karen Hurley. Dr. Hurley is a licensed clinical psychologist specializing in hereditary cancer risk. After completing a post doctoral research fellowship in behavioral oncology at the Mt. Sinai School of Medicine, she spent eight years on faculty at Memorial Sloan-Kettering

Cancer Center providing services for high risk patients and conducting research on patient decision-making about prophylactic surgery and other psychosocial issues relevant to familial cancer. She is now in private practice in New York City with adjunct faculty appointments at Memorial Sloan-Kettering and Teacher's College Columbia University. She frequently presents lectures, teleconferences, and workshops to United States and international audiences, including patient groups, professional societies, and health care professionals . Dr. Hurley is a member of several national advisory boards, and tonight she will be discussing decision-making and communicating with your family. Dr. Hurley.

III. Communicating with Family Members

Dr. Hurley: Thank you so much for having me. I've admired the work of Sharsheret for many years, and I was delighted to get the invitation to talk tonight. I will discuss briefly some of the things that makes being a BRCA carrier emotionally challenging. Of all the different issues that people come to me with, probably the most wrenching can be dealing with the risk to children and how to talk with children - whether it's your adult child, young child or teenager. It doesn't matter. There's something about the risk of passing gene mutations from one generation to the next that becomes highly poignant. People will often ask me, "How do I tell my child about my risk?"

There are really two levels to that question. On one level, people will be looking for the right words, is there some way to say this that's going to make it okay for my child. Another level to the question is, how do I go through with this? How do I deal with the emotional challenge of sitting down and having this conversation? I'd like to speak to both levels.

I think one of the hardest things about BRCA mutations is their random nature. As Danielle pointed out, if you're a carrier, you have a 50-50 risk of passing the mutation on to someone else. As far as we know, at least from the science, there's nothing that predicts who's going to inherit the mutation and who doesn't. It's a 50-50 flip each time. That's from the science point of view.

From the spiritual point of view, people may have beliefs about the nature of suffering or why a certain person faces challenges or has a certain life path. Regardless of your belief about how this happens, it comes to a point where you run against the limit of human understanding for this situation and you can't see into the future about how this is going to turn out. Am I going to get cancer or not? Is my child going to get cancer or not? If I have the surgery will that take care of the risk or not? These are all challenging things to think about.

Another way that I express this is, if you think about cancer as the C word, the thing that's hard to talk about. I actually think the real C word in all of this is "control." Because what happens is when you can't control passing on this mutation, you start to recognize the limits of not just controlling the effects of cancer in your life, but really controlling what happens to people you love in general. Control has a negative connotation, as in "control freak." In reality, this urge to control and protect comes from the deepest part of our nature. It comes from that mammalian part of us, the mother lion, who will do anything and everything to protect her cub.

When people are in the grips of that feeling, they're reaching for something that will satisfy it, but it may not necessarily make longitudinal sense. It may not match what the genetic counselor is telling you or what your physician is telling you. For example, people can feel guilty about having passed on the mutation. You may logically know that you yourself did not choose to pass this on and the fact is if you could have stopped it you would have. However, that helpless feeling of not being able to protect is so difficult to stomach that some people would rather take the responsibility and say, "I did this," rather than the scarier position of, "I can't protect the people I love completely."

Another thing that happens is people feel guilty that they have ruined someone else's life, that they're harming them in some way and have ideas that what makes them a good parent is keeping bad things from happening to their child, or keeping the child from having bad feelings. This could extend to relatives, too. Trying to control other people's experiences can become very challenging.

Another way that people try to exert control is through silence - by not telling, by withholding information, by waiting until the right time or until the child is older or waiting for an adult daughter until after she gets out of college so that she has a good idyllic time away. Although your intentions may be good, it can backfire and isolate people from each other. Even though you're trying your best to cover what's happening, people can sense it anyway. People can overhear a conversation. A child might overhear half of a conversation, or just sense that someone's going to a medical appointment more often or sense that people stop talking when someone comes in the room. From that standpoint, I've seen sometimes that people will decide to delay disclosure, and then the person that they were trying to protect actually gets mad and feels like their trust has been violated. What else are you keeping from me?

It is important to have this conversation to maintain a connection because this is a lifetime condition. The risk doesn't change. You can do things about the risk and you can monitor it, but the genes stay the same.

Therefore, what you really want to focus on, rather than focusing on trying to control your relative's experience and feelings, is building up trust and giving people the opportunity to step up, to be helpful, to surprise you with the level of support that they can offer.

Another piece of advice I often suggest is to think about the advice you get on the airplane. Put your mask on first before you try to help someone else when they say the oxygen level is low. If you're feeling upset and you're thinking about how you are going to manage your child's experience, what you may not be facing is the extent to which you had that painful feeling of feeling guilty, feeling anxious, feeling helpless, feeling out of control. It's really important to acknowledge those feelings in yourself and tend to them. Talk with somebody, identify someone who can be of good support to you, and then you can turn around and make decisions about how to have a conversation with your child or with your relative.

Each person can contribute to that by listening to each other, being present for each other, and exercising good coping skills to deal with your own feelings. That helps you be more present for each other and it opens up space for conversation.

The other thing I wanted to point out, and again, just speaks to what makes this such a challenge, is that when we're talking about hereditary risks, cancer genetics, and mitigating risks, it does ironically put mortality on the table. Even with all the progress that we've made about cancer, we have this association in our heads about mortality. It's such a scary thought. One of the ways that we soothe that thought is to think of the next generation. Who's going to carry on? The hereditary risk goes straight to the heart of that defense, that protection, because the thing that's helping you feel better about this feeling that you're facing is also threatened.

What I want to say in closing is what I have learned over the years from sitting with many, many people who have gone through genetic testing, talked through the issues with their family, and made their decisions about whether or not to have preventive surgery. Facing cancer and facing cancer risks forces you to think about things that most people don't want to think about, the things that we've put our blinders on to protect ourselves from. We're all subject to random events, not just mutations. Without exception, we're all subject to hard times and to mortality. What talking about risks does, and what talking about cancer does, brings this to the forefront. What I've seen is that people are their most individual when they are facing cancer and cancer risk.

This is just the “other facts of life.” What we have in this challenge is also the opportunity to think about what do we want our legacy to be? It’s so easy to focus on that single mutation as a legacy, but really we have so much more to offer. There’s so much that we are passing from one generation to the next. It’s not only research or genetic materials, but it’s also how we face the challenge. Our children and our relatives are learning from us. What do we have to teach about facing uncertainty and facing hard times? That is the true gift that we have to give to each other. I will stop there. Thank you very much for your attention.

Shera: Dr. Hurley, thank you so much for your insights. I think that this highlights why it’s so important to make sure that you’re having conversations with a genetic counselor to go over some of these issues. Sometimes people often think about genetic testing and they are focused on the actual testing itself and they forget that there’s a whole genetic counseling piece that they can benefit from. How to communicate with your family members is certainly one of the things that the genetic counselor can discuss with you. I do want to encourage all of you to take what Dr. Hurley has shared with us this evening and give Danielle a call in the Sharsheret office if you would like to speak about your particular family situation.

Our final speaker this evening is Anya Prince. Anya is a staff attorney for the Cancer Legal Resource Center. Ms. Prince leads outreach efforts to provide education about the legal rights surrounding genetic testing, provides legal services and resources to those experiencing cancer-related legal issues, and is involved with regulations and proposed legislation to improve genetic testing laws.

IV. Insurance and Legal Perspectives

Anya: My name is Anya and I'm a staff attorney at the Cancer Legal Resource Center. Just to give you a general overview of our organization, we provide free legal information and resources to cancer patients, survivors, and health care professionals in the field. I had a fellowship and now am a staff attorney there to expand our resources to people with genetic predispositions to cancer. I've done a lot of work with some of the legal concerns that crop up with genetic predisposition to cancer.

I want to take a short minute to talk about the differences between somebody who has already been diagnosed with cancer versus somebody who has not been diagnosed but has a predisposition or a family history of cancer. There are different regulations that apply. Once somebody has already been diagnosed, there are laws such as Health Care Reform and the American With Disabilities Act that protect people who have a history of cancer or a diagnosis of cancer.

What I'll talk about today are those laws that protect the family members who have not been diagnosed and their family history and genetic information. One of the main laws in this area is the Genetic Information Nondiscrimination Act, which is often called GINA. GINA prohibits genetic discrimination in both health insurance and employment. It is really narrow in the sense that it does not cover all employers or all health insurance companies. It's really important to check if you would fall under that law.

In the area of employment, it covers state and local governments or private employers with 15 or more employees. It stops those employers from using genetic information to discriminate, so they can't fire somebody or refuse to hire or pay somebody less because of a family history or a genetic test result. On the employment side, it does not cover Federal employees or people who work for small businesses with fewer than 15 employees. This doesn't necessarily mean that you're not covered at all if you work for the Federal government or if you work for a small business. There are other protections at the state level or in the Federal government. It's important to just make sure that you know where the protections lie.

In the health insurance arena, GINA gives similar protection. It prohibits the health insurance companies from denying somebody insurance or charging somebody a higher premium based on genetic information. Now again, this is a really important area where having already had the cancer diagnosis is going to be different than just the genetic information or genetic test results. Health insurance companies, until January 2014, can look at the medical information, and, in some situations, the medical diagnosis, but not the genetic information. After January 2014, with health care reform implementation, health insurance companies will not be able to take into consideration either the genetic information or any other medical information, so there's going to be broader protection.

Health care insurance companies and employers are also prohibited from collecting or purchasing any genetic information, or requesting or requiring that somebody give them that information, unless they fall under a specific subcategory or exception. This is an area where it's really important to keep in mind the definition of “genetic information.”

GINA defines genetic information to include not just a genetic test result, a BRCA test, but also family medical history and the use of genetic services such as speaking to a genetic counselor, or participation in genetic research. That's really comforting to know that talking to a genetic counselor or calling Sharsheret to talk about some of these concerns is protected genetic information. In and of itself, an employer can't ask you

about or a health insurance company can't necessarily gain access to that information.

”Family members” is also very broadly defined in GINA. The genetic information includes the medical history of family members and that includes up to four generations removed, your fourth degree relatives. That's not only your great-great-great-grandparent, but also your grandparents' relatives going back down the line, so your cousin twice removed. It really is quite broad, which helps to protect somebody from learning or guessing from your relatives that you have a genetic predisposition to cancer.

Unfortunately, even with these protections, there have been some specific cases of genetic discrimination that we've either seen at the CLRC or in the news. The EEOC, the Equal Employment Opportunity Commission, is in charge of enforcing the employment protections of GINA. They have been taking some cases and litigating them when employers have violated GINA. Often that's coming up in the context of asking about family medical history in a wellness program or in a medical questionnaire.

There have been a couple of stories in the news of cases that settled before going to trial. For example, a woman in Connecticut said that she had been fired when her employer found out about her genetic information. Since no cases have been litigated all the way through, we don't have any case law that helps us to understand how courts are going to deal with this in the future.

In the health insurance arena, the enforcement provisions are slightly different. If you feel like you've been discriminated against, you need to contact the state's Department of Insurance. The process in each state is going to look a little bit different. In my experience, the number one thing is to appeal, appeal, appeal directly to the insurance company. In some situations, the charges have resulted in increased premiums because of somebody's genetic information. In some cases, unfortunately, I've seen insurance denials based on a person choosing to have a prophylactic mastectomy.

Again, in January 2014, many of these issues will be moot. Insurance companies will not be able to use any medical information, and so they will be much less likely to violate these regulations. I think some of the violations that I've seen have been insurance companies just not properly training all of their staff about GINA. I think that there is going to be a lot of progress once health care reform is fully implemented. It will also protect many survivors from having a denial based on a preexisting condition of

your cancer diagnosis. It will allow for much more movement with insurance.

One of the major gaps in GINA is that it does not cover life insurance, long-term care insurance, or disability insurance. These are areas where I get a lot of calls because people are concerned, naturally, about wanting to make sure that their family is covered. If you know that you have family history, a genetic predisposition or tested positive for BRCA, it's natural to want to go and get disability insurance or life insurance. Unfortunately, there are still gaps in this area where companies across the country can take into account genetic information. It's a difficult area because many people start to question whether or not to get tested. When it comes to balancing whether or not to get tested, because of those insurance concerns, I do think there are concerns to be aware of, but I don't think it necessarily precludes testing. I think that's a choice between doctors and genetic counselors and family members. Taking that genetic test isn't necessarily going to give the insurance company that much more information than they already had, but it sure will give your family a lot of extra medical information and the ability to take those preventive measures that you feel comfortable with.

What you have to do in this area is look to the state law. Some states, and increasingly more of them, have begun to pass laws in this area that protect against the use of genetic information within these companies. Unfortunately, very few states ban the use of genetic information outright. What they do is regulate how those companies can use genetic information. California has the strongest protections at this point. They ban life, long term care, and disability insurance companies from denying somebody or discriminating against somebody based on their genetic predisposition.

Unfortunately, there may be ways where the insurance company can still charge a higher premium for somebody because they're "more risky" due to their family history. This can happen even in the state with the strongest protection. Many other states that do have protections also permit what's called "fair discrimination." Fair discrimination means that if there's higher medical risk, then the insurance company is allowed to charge higher premiums. As an advocate in this area, I don't see it as fair, but unfortunately that's the way that the law is written.

I also want to briefly talk about some of the other issues that have come up in this arena. As was mentioned in the beginning of the program, one of the big events this year was the Supreme Court decision in the Myriad case. Myriad Genetics had a patent on the BRCA gene, which means that they could stop any other entity within the United States from doing the

genetic test in clinical practice or for monetary gain and, in some situations, stop research on this gene as well.

The ACLU and a couple of other actors filed a suit against Myriad Genetics claiming that the patents were unconstitutional. This case went all the way to the Supreme Court. The ACLU and others argued that DNA is a product of nature and, therefore, not legally patentable. The Supreme Court, in a huge decision that was a unanimous decision, said that it's true that certain types of DNA are in fact unpatentable. They did leave open a small category where a type of DNA called cDNA is patentable.

In patent law, products of nature are not allowed to be patented. For example, you can't patent a tree because it grew in nature. The ACLU argued that patenting a gene was like patenting a tree leaf. If you snap a leaf off the tree, it is still a product of nature. Therefore, they argued, when Myriad Genetics took out the BRCA gene, it's still a product of nature because they simply removed a part from the whole.

Myriad Genetics disagreed and stated, "No, it's not like a tree leaf. It's more like a baseball bat." You can make a baseball bat out of a tree. When you do this, you're manipulating that product of nature so much it becomes a patentable process. The Supreme Court fell right in the middle and said that cDNA, which is a type of DNA where you're creating more, is patentable because you're taking out more of the parts and manipulating it enough to pull it out of the product of nature category. However, general DNA, just isolated DNA, is not patentable. What this means is that Myriad Genetics cannot be the exclusive company that test the BRCA gene. Other companies are now offering the BRCA gene testing and, hopefully, that means that there will be more data out there. As a result, some of those ambiguous genes that Danielle was talking about hopefully will get enough data so that we start to understand those in the medical community.

I also briefly want to mention, and I can take some questions on this later if people do have questions, one of the other areas that I do get a lot of questions about - how to get insurance coverage or genetic counseling for those preventive measures (a prophylactic mastectomy or maybe a mammogram for that) that you might want to take once finding out that there's a BRCA gene [mutation].

With health care reform, there are a lot of changes that have come about which requires health insurance companies to cover genetic counseling, specifically for the BRCA gene. As part of that, they also have to cover the entire cost of testing itself. However, this is only for people for whom it's medically required. Somebody with no family history whatsoever probably

can't get this. This doesn't apply to all insurance companies, but it does apparently to some.

Another piece that has to be covered free of cost for many people over the age of 40 are mammograms. However, they only have to cover a preventive mammography. If somebody has already been diagnosed with breast cancer and maybe has been in remission for years when they go to get a mammography often times it's coded on the medical side as diagnostic because it tells the radiologist to look for something different. Therefore, because of that coding, the insurance company doesn't have to treat it like a preventive mammography, and therefore they don't have to cover it absolutely free of cost. They will still cover it, mostly likely, but not absolutely free of cost.

When working with insurance companies, it's very essential to never take no for an answer. Give our organization a call or go on our website. We have a lot of information about insurance appeals. It's really important to push back in these arenas, especially in the case of genetic testing and preventive services. Due to the fact that these are so new, often times the insurance companies haven't quite gotten the protocol down and it's a good area to push back to. I think in all of this if you feel like you're being discriminated against or anybody in your family is or if there's been a denial or an increased premium in any of those life, long-term care, it's always really important to try to push back and to go through the appeal. I'll stop there, but I'm happy to take questions at the end and thank you so much.

Shera: Anya, thank you for your takeaway about advocating for yourself. I think that's probably the most important thing. You're right, we will certainly encourage our callers to call the Cancer Legal Resource Center. Also, here at Sharsheret, those are things that we can also help you with as well and make sure you get to the right resource.

V. Questions and Answers

Shera: While the questions are coming in, we did receive several questions prior to the teleconference that I'm going to go ahead and present to our speakers. Anya, a lot of things that you were discussing related to people who are at risk. Can you also, perhaps briefly, talk about how this applies to women who have already been diagnosed or is there a difference?

Anya: Sure. The important thing to keep in mind is with GINA, genetic information in and of itself is always going to be protected. Disease that manifest from that genetics is going to be protected by different laws. Once you've already developed cancer or had a diagnosis, other laws are

going to apply. Employers are still not allowed to take into account your cancer diagnosis and discriminate in those arenas under the Americans With Disabilities Act, so there are protections similar to GINA for those individuals who have been diagnosed.

Similarly, in the life, long-term care, and disability insurance arenas, there are also fewer protections for somebody who has already had a cancer diagnosis. It's not impossible to get life insurance or disability insurance after a cancer diagnosis, but it does depend on how long ago you were diagnosed, what stage of diagnosis you're at, and other factors.

With health care reform, there are a lot of changes as I mentioned for survivors. I think personally that one of the biggest things is that beginning January 1st of this upcoming year, no health insurance company is going to be able to deny somebody coverage based on a preexisting condition. They also are not allowed to charge a higher premium for anybody who has any medical condition. This will change the field drastically because after you've had a cancer diagnosis for so many of us health insurance is tied to your employment. Even if you want to take time off work as you go through cancer treatments it might be hard, but after health care reform goes into effect, that may be more of a possibility for people.

Shera: Great, thank you. Danielle, it seems that there's a lot of information coming quickly about the panels. How do you know which panel to order and from which company? Does some testing tell you information that other tests don't? How do you know which is best for you?

Danielle: That's actually a great question that I receive all the time. The short answer is that genetic counselors are still figuring that out. There are many, many companies that are offering different types of testing, so even just in the realm of hereditary breast cancer some companies go through a certain process to decide what genes to include on their panel. Other companies go through a different process to decide what genes are included on their panel, and so I think it's a decision that genetic counselors and medical providers are really looking at, and determining, how to evaluate these technologies for their patients because we are very protective of our patients and we want to make sure that they are getting the full testing that is appropriate for them and at the cost that is appropriate for them as well. Basically, there are many, many things to think about such as cost, insurance coverage, which genes are included on the panel, what is the turnaround time, how quickly do the results come back, does the lab have financial assistance available, etc. Really the short answer is that we are still evaluating it and it's an exploding field.

Shera: Thank you, Danielle. Dr. Hurley, you focused a lot about speaking to your own children about the genetic risks, and we're getting some questions actually about other family members who are not necessarily a woman's own children. One woman said it turns out that she doesn't have any children of her own, but her sister has. Also, we received a question about the men and sons in the family, and I was wondering if you had any particular insights about these other family members?

Dr. Hurley: These are both really important issues. For each nuclear family unit, the parent is the gatekeeper, if you will, of information. A common conflict is from one who is a breast cancer survivor and is a mutation carrier. She wants to give the information to her nieces but her sister doesn't want to deal with it, doesn't want to get tested, and is trying again to control the information.

The situations become very complex. A couple of guidelines, is number one, especially if you feel someone is angry or in denial, instead of going head-to-head with them about taking that denial away, it's more important to start emphasizing with them where that denial comes from. Denial is a defensive maneuver, signaling that underneath that person is either sad, fearful, feeling helpless, and they're grasping at denial as a way to deal with that. That can cool the situation down enough so you get to that place where you're listening to each other again.

The other thing is that there's more and more information out there about BRCA, especially now that Angelina Jolie has come out. More people, young women and teens, have access to this information. The information is out there, so sometimes the children are coming to the parent with questions. Again, I think it's important for people to listen to what the child is telling you about what they want to know or not know. It is important to trust that the information will get to them one way or another, especially as the awareness is raised more. If you're becoming concerned about a 25-year-old niece who doesn't know that she should be tested, the fact that she knows that maybe you're a breast cancer survivor will more easily trigger that question in her mind than it may have done even five years ago.

Let me talk a little bit about men and sons. There's a lot of research going on and Danielle can speak more about this and what the risks are to men who are carriers. There are some elevated risks of cancers depending on whether it's BRCA1 or BRCA2 mutation. In general, the overall risk of cancer is less to the men. It's especially hard for fathers who may have passed on a mutation to a daughter. It is something that doesn't affect them so much, but greatly affects the women that they love.

Everything that I said about helplessness goes triple for them because they would want to take that on for themselves if they could. I've seen some men reacting with incredible feelings of guilt about this. They have a hard time standing by. In our culture, men are socialized to be doers and like to have something to do. Watching a loved one go through a surgery and there's nothing for them to do is difficult. They don't even know where to channel their feelings, having different ways to address them with the male relatives, whether that's simply acknowledging your feelings, giving them tasks to do, letting them take the job of the researcher, or showing them what they can do to support the family so that they can fill a role and not just be in that place of standing by.

Shera: Anya, we are hearing from several women actually that they're a little hesitant to undergo genetic testing because they're worried that it may jeopardize their disability benefits through their employers. Have you ever had this experience? If so, how would you recommend handling it?

Anya: Sure. It's definitely a concern that does come up. As I mentioned, the disability insurance companies may have access to just family history, and so the actual test itself may not give any additional information to them but give a lot of additional information to you. Additionally, when it comes to employer disability insurance, often times group disability insurance looks less into your medical background than if you were just purchasing an individual disability insurance plan. It may be easier to get disability insurance through an employer, though they still may be able to take some preexisting conditions into account.

It can be difficult, but it is an area for consideration. Often times, what some people will do is try to get the disability insurance prior to testing and try to secure the disability insurance, and then they can decide whether to keep it or not after they get the test results back. If you do apply for disability insurance and are denied because of genetic information, as I said, definitely appeal, even contact our organization and we have information about how to appeal those cases.

The final thing I would say in terms of disability insurance is that there are federal disability insurance programs through the Social Security Administration. These will not take genetic information or medical history into account because they're federal programs. There are five states that have short-term disability insurance programs that also will not take genetic information into account. Even if you are unable to get private insurance, there may still be ways to get disability insurance through state and federal programs.

Shera: Thank you. Danielle, is there ever a reason to be retested given these new developments in genetic testing?

Danielle: I think the answer to that really depends on your personal and family history. If somebody was tested, like I said, before these developments became available and tested negative and they still have a strong family history of cancer, that can be frustrating to be left with. I think that really is a personal decision, but also because these developments are so new it's something that you might want to ask you genetic counselor. I would recommend for people to stay in touch with their genetic counselor or they're welcome to call me here at Sharsheret to discuss their personal and family history, and we can talk about which testing might be appropriate, if any.

Shera: Anya, we have a question here that is asking the difference between a state law versus a federal law and how does that affect coverage?

Anya: Those state and federal laws can protect an individual and help them to get access to health insurance or disability insurance. In the arena of health insurance, usually federal law is going to be the most helpful. Somebody might have both a state law and federal law available to them as a protection, but it's just important to know that you're protected globally. Usually in the health insurance arena, the federal laws are going to be the most protective.

In the life, long-term care, and disability insurance arenas there are no Federal laws related to genetics yet. There's some talk about trying to get a Federal law, but there's just nothing available right now. In those cases, you have to look to state law for protection.

Shera: We have a couple of questions about Medicare coverage. One question is, will Medicare cover tests for adult nieces and nephews? How do you find that information? The second part to that question is, is there a way to appeal when Medicare is not covering?

Anya: Medicare has very specific coverage rules for BRCA. It has to do with somebody's specific family history and diagnosis. It's very difficult to get Medicare coverage for somebody who does not have a cancer diagnosis at all. If somebody has been diagnosed with cancer and there's the family history, then generally somebody can get Medicare coverage. Genetic counselors can see what the Medicare rules are in their area. Unfortunately, with Medicare it can be hard to cover.

I haven't looked up the rules of other companies that are now starting to cover BRCA. If somebody is uninsured or underinsured, it may be

possible to get coverage through Myriad. They have patient support where they will lower the cost, but if you have insurance, sometimes you can't get that. New companies that are just starting out could be something to look into.

Shera: Thank you. Dr. Hurley, a question came in about the burden of responsibility in terms of communicating. This woman, and I would imagine many women or men actually on the call tonight, feel that it is important to share information for the health of their family members, but their family members don't want to receive the information. What is the responsibility on that man or woman who wants to communicate the information?

Dr. Hurley: I can speak to more the emotional responsibility in terms of to what extent there is an ethical responsibility. You would need to talk with the genetic counselor or the physician who is helping with the testing to clarify that. Just on the emotional basis, getting through to people, just thinking about the fact that this is information that could help you protect your health and to connect them with a genetic counselor so that the burden of communicating all of the ins and outs of risk management, which can be pretty complex, getting across that basic message but that there are ways that this can work for you. People are fearful of the idea of getting surgery, or they're fearful of having to step up their surveillance, or fearful of the guilt that they might have passed on a mutation to their children.

At a certain point you can put it in front of them, but then they do have to take it. Sometimes it's very painful to have, again, that helpless feeling that you've done everything you can. It's almost like, think about if somebody's out in the ocean, you throw them a lifesaver and your job is to aim well. Their job is to grab it. If you think about what in the message will aim well, and then at a certain point their free will takes over. All you can do is be with them and love them even in this state of denial.

Shera: Thank you. That's actually very helpful. Danielle, we received a question about using genes to identify targeted treatment. How does that fit into tonight's discussion?

Danielle: You bring up a great point which is that there is a difference between tumor testing and germ line genetic testing. I think that that's a question that a lot of people are getting confused about as the technology is advancing so rapidly and as genetics becomes such a big part of medicine and how cancers are being treated. Some of you, for example, may have heard of Oncotype DX. That's just one example of where oncologists and surgeons are ordering genetic testing of a tumor to classify the tumor and to figure out how that tumor is best going to respond to certain treatments.

That type of genetic testing is very different than the type of genetic testing that we are talking about which is hereditary cancer genetic testing.

When I say genetic testing what I'm really talking about is the type of genetic testing that we're trying to identify. For example, if there is something going on in the family causing hereditary cancer to be running through the family. Most genetic counselors that are working in cancer settings are really dealing with that piece of things. If there are specific questions about treatment or Oncotype DX or tumor testing, that's really what's more being done in the process of treating breast cancer and how it will best respond to certain treatments.

VI. Conclusion

Shera: The final question for the evening is does Sharsheret have resources for patients that cannot afford genetic testing? Also, are there any resources for men in the family who have tested BRCA positive? The answer to that is yes, yes, yes. Absolutely call Sharsheret for resources and we can get resources out to you and we can steer you to particular organizations that will address your particular needs. Yes, give us a call and we'd be more than happy to get those resources out to you.

I would like to thank all of our speakers and to all of you for joining us for this productive discussion. Sharsheret's survivorship program, Thriving Again, was made possible with grants from the federal Center for Disease Control and Prevention. I would also like to thank Sharon Stahl, Shasheret's Thriving Again program coordinator, for all her time and hard work in making this evening's program such a success.

Please remember to reach out to Sharsheret's genetic counselor, Danielle Singer, who can answer your questions and offer you a peer supporter who had to perhaps consider the difficult decisions that you are facing. Again, if you have not yet received your personalized Thriving Again survivorship kit, send us an email to info@sharsheret.org with your name and contact number and we will be in touch with you tomorrow. Sharsheret also offers a financial tool kit to learn how to successfully navigate these often complicated issues of health insurance that were discussed this evening, in addition to disability rights and financial planning. Please visit us online at www.sharsheret.org or call us in the office at 866-474-2774. We are here, as you need us, when you need us. Have a great evening.

VII. Speaker's Biographies

Shera Dubitsky, M.Ed., MA, is the Clinical supervisor at Sharsheret. She is a graduate of Columbia University and a doctoral candidate of Adelphi University Institute of Advanced Psychological Studies. Shera supports and connects newly diagnosed young women and those at high risk of developing breast cancer or ovarian cancer with suitable peer supporters, advances and develops programs addressing the unique needs of the young women and families of Sharsheret, counsels individual members of the Embrace program, and facilitates its monthly support group teleconferences.

Karen E. Hurley, Ph.D., is a licensed clinical psychologist specializing in hereditary cancer risk. Dr. Hurley is in private practice in New York City, with adjunct faculty appointments at Memorial Sloan-Kettering Cancer Center (MSKCC) and Teacher's College-Columbia University. She has provided psychotherapy and consultations to over 375 individuals, couples, and families with BRCA, familial breast cancer and ovarian cancer, Lynch syndrome, and other forms of hereditary cancer.

Dr. Hurley earned her A.B. in Psychology from Bryn Mawr College and her Ph.D. in Clinical Psychology from Temple University. After completing her post-doctoral research fellowship in behavioral oncology at the Mount Sinai School of Medicine, Dr. Hurley spent eight years on faculty at MSKCC providing services for high risk patients and conducting NCI-funded research on patient decision-making about prophylactic surgery and other psychosocial issues relevant to familial cancer. Dr. Hurley is a member of several national advisory boards, including FORCE, Bright Pink, and the Cancer Support Community's Breast Cancer M.A.P. Program/Cancer Experience Registry.

Anya Prince, Esq., is a Staff Attorney at the Cancer Legal Resource Center. In her present position, Ms. Prince leads outreach efforts to provide education about the legal rights surrounding genetic testing, legal services, and resources to those experiencing cancer-related legal issues. She also comments on regulations and proposed legislation to improve genetic testing laws.

A graduate of the University of California, Los Angeles, with a B.A. in Political Science, Ms. Prince went on to earn her J.D. and M.P.P. from Georgetown University Law Center. Ms. Prince is a member of the State Bar of California.

Danielle Singer, MS, CGC, is a Genetic Counselor at Sharsheret. She is a graduate of Brandeis University with an MS in Genetic Counseling. She has many professional affiliations including the National Society of Genetic Counselors, and serves as the secretary for the Human Genetics Association

of New Jersey. Prior to joining Sharsheret, she worked as a Genetic Counselor at the Yale Cancer Center, where she counseled individuals and families about hereditary cancer risk. As part of Sharsheret's genetics program, Danielle provides supportive counseling, information, and resources regarding hereditary breast cancer and ovarian cancer to women diagnosed or at high risk of developing breast cancer and ovarian cancer and their families.

VIII. About Sharsheret

Sharsheret, is a national not-for-profit organization supporting young women and their families, of all Jewish backgrounds, facing breast cancer at every stage—before, during, and after diagnosis. Our mission is to offer a community of support to women diagnosed with breast cancer or at increased genetic risk, by fostering culturally-relevant individualized connections with networks of peers, health professionals, and related resources.

Since Sharsheret's founding in 2001, we have responded to more than 25,000 cancer inquiries, involved more than 1,750 peer supporters, and presented over 250 educational programs nationwide. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment. We also provide educational resources, offer specialized support to those facing ovarian cancer or at high risk of developing cancer, and create programs for women and families to improve their quality of life.

All Sharsheret's programs are open to all women and men and Sharsheret is the beneficiary of funding from the federal government.

Sharsheret offers the following national programs:

- *Peer Support Network,* connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- *Embrace*, supporting women living with advanced breast cancer
- *Genetics for Life,* addressing hereditary breast and ovarian cancer
- *Busy Box,* for young parents facing breast cancer
- *Best Face Forward,* addressing the cosmetic side effects of treatment
- *Family Focus*, providing resources and support for caregivers and family members
- *Sharsheret Supports,* developing local support groups and programs
- *Ovarian Cancer Program,* tailored resources and support for young Jewish women and families facing ovarian cancer
- *Thriving Again,* providing individualized support, education, and survivorship

IX. Disclaimer

The information contained in this document is presented in summary form only and is intended to provide broad understanding and knowledge of the topics. The information should not be considered complete and should not be used in place of a visit, call, consultation, or advice of your physician or other health care professional. The document does not recommend the self-management of health problems. Should you have any health care related questions, please call or see your physician or other health care provider promptly. You should never disregard medical advice or delay in seeking it because of something you have read here.

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