

The Jewish Family Facing Breast Cancer: You Are Not Alone

**Conference Transcript
Beth Israel Medical Center
New York City
Tuesday, June 12, 2007**

Presented By:



Linking Young Jewish Women in Their Fight Against Breast Cancer

Conference Sponsor:



For more information about Sharsheret, please call toll-free (866) 474-2774 or visit www.sharsheret.org.

Table of Contents

I.	Introduction	3
II.	Presentation by Susan Gross, M.D.	6
III.	Presentation by Marc Silver	17
IV.	Presentation by Shera Dubitsky, M.Ed., M.A.	26
V.	Question and Answer Session	32
X.	Symposium Conclusion	34
X.	Speakers' Bios	35
XI.	About Sharsheret	36
XII.	Disclaimer	37

I. Introduction

Cindy Turkeltaub: Ladies and gentlemen, I would like to welcome everybody. I'm Cindy Turkeltaub. I'm the Coordinator of Social Work in the Cancer Centers of Beth Israel and St. Luke's Roosevelt, and on behalf of Beth Israel and Continuum Cancer Centers of New York, I'd like to welcome everybody, and I'd also like to take the opportunity to welcome Eillene Leistner, the Executive Director of Sharsheret.

Eillene Leistner: Thank you, Cindy, and welcome, everyone. I'd like to ask you please to find seats and also to please turn off your cell phones if you have them. We are taping this for people who cannot be here and who are unable to attend.

Again, I'd like to thank you so much for joining Sharsheret at our symposium, *The Jewish Family Facing Breast Cancer: You Are Not Alone*. As Cindy mentioned, my name is Eillene Leistner, and I am the new Executive Director of Sharsheret.

I'd like to begin again by thanking those who have made this important event possible. A generous grant from the Greater New York City Affiliate of Susan G. Komen For The Cure has enabled us to present this important symposium. I would like to introduce Andrea Mayfield. Andrea is the Program Associate at the Greater New York City Affiliate of Susan G. Komen For the Cure, who is with us. I thank you. Thank you so much to Beth Israel Medical Center, who opened their doors to Sharsheret once again, and particularly to Cindy Turkeltaub for her assistance in coordinating the details of tonight's event. Sharsheret's staff and volunteers have worked tirelessly, and in particular, I'd like to recognize Elana Silber, our Director of Operations, and Ellen Kleinhaus, our Program Coordinator, who helped to coordinate this evening's symposium.

The ripple effect of a breast cancer diagnosis impacts the heart of the family and its extended members. From the time family members hear that a wife, daughter, sister, aunt, or mother has been diagnosed, they may be overwhelmed with a rush of anxious feelings. They may also feel deluged with the flood of information available from the medical team, the internet, spiritual resources, and the community at large.

Some of you with us today may be facing a new diagnosis of breast cancer or are in the midst of treatment or even a few years beyond diagnosis. Some of you may be otherwise healthy but face the risk of breast cancer, nonetheless, perhaps with a significant family history of cancer. And many of you may have the same questions that we have heard from families that are calling Sharsheret for support. What do we need to know about breast cancer genetics and its impact on the Jewish family? How can I better support the woman I love as she journeys through breast cancer diagnosis and treatment? What impact will a

breast cancer diagnosis have on all of the members of our family? And how can Sharsheret help? Our speakers tonight have volunteered their time to address these important questions and more. We will hear brief presentations from each speaker and then take questions from our audience.

In the information packets you received, you will find an index card. Please jot down any questions you may have on the index cards during the presentations, and after the speakers present, volunteers will circulate the room to collect these cards.

Before we begin, I would like to highlight Sharsheret as an available and valuable resource for those of you participating this evening. Sharsheret was founded in 2001 to support young Jewish women facing breast cancer.

We now offer three core programs:

1. The Link Program connects women across the country in one-to-one conversations with peer supporters who share the same backgrounds and concerns.
2. Quality of Life Programs designed to enhance the quality of life for younger women living with breast cancer with initiatives like the Busy Box for parents of young children and Best Face Forward to address the cosmetic side effects of treatment.

We recently launched Embrace, a support program for women living with advanced breast cancer, and Empower, a support program for single women with breast cancer.

3. Finally, the Education and Outreach Program educates women, their families, communities, and health care professionals about the issues impacting young Jewish women and their families facing breast cancer with symposia like this one.

Since our inception, we have received over 10,000 phone calls from women affected by breast cancer, their family members, and the health care professionals, and during these past five years, the subject of the Jewish family facing a breast cancer diagnosis has been a critical topic of discussion at Sharsheret. Our goal tonight is to answer many of your questions and provide you with information to support you and your family facing breast cancer. As with each of our medical symposia, this is the first of what is certain to be an ongoing conversation, and we encourage you to stay involved as the Sharsheret, the chain, continues to grow in the years ahead.

It is now my pleasure to introduce Dr. Susan Gross. Dr. Gross is Co-Director of

the Division of Reproductive Genetics, Department of Obstetrics and Gynecology and Women's Health at Montefiore Medical Center and Albert Einstein College of Medicine and an Associate Professor in Obstetrics and Gynecology and Pediatrics. Dr. Gross has served on national committees for both the American College of Medical Genetics as well as the American College of Obstetricians and Gynecologists. She also serves as a vice-chair for the Ethics Committee for clinical research at Einstein. As Medical Director of the Molecular Genetics Laboratory at Jacobi Medical Center, she is embarking on the establishment of a clinical molecular genetics facility that will provide accessible state-of-the-art genetic testing for the underserved in New York City through the Health and Hospital Corporation, the City's public health hospital network. Please join me in welcoming Dr. Gross.

II. Presentation by Susan Gross, M.D.

Dr. Susan Gross: I really just want to say thank you, and thank you for the very unnecessary gift. Being here for me is more than a gift. To be associated with such an outstanding organization, I'm honored to be here tonight, and I thank you for asking me.

My background is actually obstetrics and gynecology, as you heard. I'm also a geneticist. We at Einstein in the Bronx were one of the first hospitals to take on the challenge of genetics and breast cancer, and that happened because I'm based in a women's department of health. On top of that, the heritage of Einstein was that it was a Jewish university hospital and medical center. Everything kind of meshed and came together.

What I'm going to speak to you about today is the risk for hereditary breast cancer and the role of family history. What I want to drive home to you today is that family history is very important whenever we talk to couples and we talk to individuals, but there is a difference between the impact of having a family history of breast cancer and carrying a mutation in a gene associated with hereditary breast cancer. It's very confusing, and I have a limited time; I'm going to do my best to impart that knowledge to you.

The other issue I want to bring up is that we are talking much more so tonight about the nuclear family, our immediate relatives, but, again, there are issues here specific to Jews and genetics, and what you're going to see tonight is we're actually one family. One of the beautiful things that touched me so much about Sharsheret from its inception was this concept that all Jews are responsible for each other. I can't imagine a more important value and certainly not a more important issue that's confronting us today.

So let's get started. First of all, I'm going to give you a run-through on basic genetics, really just a handful of slides. I always tell my medical students that this is it. Frankly, if you understand the next few slides coming up, you get genetics. And the beauty of it is, to my mind anyway, it's the simplicity that makes it such a magnificent system.

This slide that you see up here, first of all, this is your slide paid for by taxpayer dollars. This is on the Web. It's a Human Genome Project slide. In fact, we have copyright issues with slides, but the Human Genome Project wants people to use their slides and get the word out. Every cell in our body has chromosomes, which are basically just the way we package our genes, and the genes are on strands of DNA. Now, the reason you need chromosomes is that if we didn't have this packaging, these strings would just be all over the place and it would be very hard for the cell to make use of them. The way I explain it to my patients and my students is that chromosomes are like a string of pearls. We

have 46 in every cell in our body, and the pearls, those are the genes, and that's it. That's really all there is to genetics.

The amazing thing is that there are four molecules. We call them base pairs. They're identified by four letters -- C, G, T, and A. But it's that sequence of letters, only four, that determine the entire genetic code. This I took off the website. Again, this is a public website paid for by our tax dollars. The breast cancer gene, which I'll be speaking about shortly, what scientists seek when they get on to the website is the series of letters. The Human Genome Project is done. The breast cancer sequence genes are done. What we're trying to make sense of is how they work and what do they do, and that's been part of the frustration.

I was at the meeting when it was announced that they had found the breast cancer genes. It was back in the '90s. It was a standing-room-only crowd, and people literally had tears in their eyes because they saw the start of the next era of medicine. I wish we had a cure. I wish we had preventative measures that we can dream about that would only target cancer cells that could cure so easily. We're not there quite yet, but this sequence, you know, it's in there. It's in there somewhere.

Now, basic genetics, part two, the chromosome. As I said, 46 chromosomes, and they come in pairs. All the women are two Xs. The guys here would have one X and one Y, so not all of us look identical, but this is what we look like under a microscope. You rub any slide, and I can make a picture like this. And, again, amongst humans, this is what we look like.

Now, again, one chromosome from Mom, one chromosome from Dad. That's the trick to all this. Thankfully, our chromosomes come in pairs. If we have a gene on the chromosome we got from Dad that's not working so great, but if we got the gene from Mom and that's working well, usually we make enough protein to stay healthy.

The breast cancer genes are BRCA1 and BRCA2. BRCA1 is on chromosome 17, and the gene sits at that particular spot on 17. You cannot see the gene. You have to do molecular testing to see those letters in order. However, this is where it sits. The breast cancer gene two sits on chromosome 13 and sits in that particular spot. Again, thankfully, most of us have two copies, not a problem. Some of us, however, have a change in the gene. That makes the gene not function well. Again, the way I try to describe it and describe it to others, it's kind of like the brakes on the car, and if the rear brakes are not working so well, you know, this car's still going to be okay. The problem is, what happens if the front brakes go out? Also, you appreciate that if one copy is not working so well -- let's say this copy you inherited from your dad, and it's not working quite right, you have a 50/50 chance of passing it along to the next generation.

The way sporadic cancers work, most cancers aren't inherited via these genes. Most of them are very much related to many genes working in combination possibly or you could potentially be affecting some very powerful genes. But, what has to happen is you have damage somehow as cells divide both copies, and statistically, for any people who are math mavens in the audience, that's a little bit harder to do.

If you are born already that, let's say, BRCA2. You have one gene not working well but the other gene is. If that cell divides, then you only need to knock out one copy to potentially have a problem. That is basically the inheritance pattern and model for breast cancer genes.

One of the other things that's very important is that with the breast cancer genes, is in the general population, you can have many of those letters knocked out, missing, switched, or changed because it's a long sequence of base pairs of those molecules. You can have one gene but many mutations in the same gene, and that's just the way genetics is. It's one of the things we have learned that in most cases, it's very seldom that it's one change and one gene that causes one disease. Usually, there are many changes that might take place. That's in the general population.

When you look at families -- how do geneticists look at families? We have a shorthand code, and this is the family tree. It's the pedigree. I'm going to teach you about that now, too, for those not familiar. Round are women; squares are men. People have different mnemonics. Mine was always Mother Earth to remember the circles. What we do when we see families is we ask questions and we listen. We actually go back at least three generations, because of that pattern that I described to you: 50/50 chance you might pass it along. (Here would be a grandmother.) Here would be a woman with breast cancer; 50/50 chance that she's going to pass it to her kids. There are some families who have all boys or all girls, so it's not always 50/50, but in the general population, 50/50. She passed along the gene to three of her offspring. One actually developed cancer, but the other two didn't. Then they passed along that same copy that had the problem, and for example, this father passed it to this son. Neither of them had breast cancer. You can have breast cancer in males. It's much more rare. But that's why they never had a problem. But then they had a daughter. Or, in this case, you had a woman who was a carrier, did not get breast cancer, but she had offspring that did. This is called classic autosomal dominance. It shows all the important features, 50/50 that you can pass something along and it appears to skip generations. The other thing that is so important is everybody thinks breast cancer, ovarian cancer, women.

What I want you to go home today and remember is that it takes two people to make a baby. We are blessed with inheritance from both sides of our family, and

you have to know what's going on in the father's line, as well. There is a lot of misinformation out there. I'm embarrassed to say there are many doctors who will tell women [as] they're getting family history, "Well, I don't care about the father's side." If they'd just ask about the father's side! That's something that you now know, which, again, with many physicians, it's taking a while to get the information out.

Now, this is a very important slide, and this slide has to do with the title and topic of what I'm discussing today. Family history is important. It does increase your risk. If you look back in the family history and have relatives who have had cancer, it does increase your risk. But you have to remember a term that you see all the time in *The New York Times*, relative risk. What happens is you'll see an article that says for example, late age of birth the first child, early menarche, benign breast disease. You hear this bantered about all the time, and you read the headline, *doubles your risk*. Well, I mean that scares me, double the risk. But what was the risk to begin with? And that's what you have to always take into account. Yes, all these things might actually increase your risk. But look what happens if you're actually carrying a mutation. This risk factor becomes greatly amplified. It is in a different category altogether. That's really kind of a take-home message from what I really want to discuss with you today. You should go home with an understanding that family history has a role to play that is not hereditary. It's a very, very different, very different thing.

Now, what are risks? Just to give you some numbers, again, if you go to the books, papers, they might differ a little bit, but by the age of 70, breast cancer is very, very common. Your risk of breast cancer is 7%. It doesn't matter what you do. It might even be a little bit higher. Some people are concerned that it might be going up somewhat. I'm not an epidemiologist, so I'm not going to speak to that specifically, but 7%. Ovarian cancer is, thank God, less common. It's the 1% in the general population. Unfortunately, it often gets picked up later. Breast cancer, we have mammography, we have screening, you can do breast self-examination. Ovarian cancer, unfortunately, not the same.

If you are carrying one of those mutations, one of those genes, you can see the risk goes up significantly and in a very big way, and this is if you are just healthy, doing everything right. But if you just can get a sense of the order of magnitude how significant this is.

Hereditary cancer where you have breast cancer, ovarian cancer, and you go ahead and you screen and you look at the genes, you're only going to pick up a problem in those genes about 10% of the time. The vast majority of cancer is not passed from generation to generation. This makes up a smaller category, and that's very, very important.

If you're thinking this might be something that's really passed along in the family,

these are the features your doctors should be looking for, and again, if you look at this, it's common sense. It troubles me, but I have to say that often I have patients who self-refer, that they know that the cancer was diagnosed early. They have so many relatives or they have ovarian and breast together or they've had a tumor in one breast, a tumor in another breast. Common sense. Again, people know it. They have a sense that this might be something of significance. The early age of diagnosis is, of course, a tie-in for Sharsheret's mission in terms of younger women, and that is the tie-in there specifically to heritable forms of breast/ovarian [cancers].

Population genetics, I'm going to repeat myself, in the general population, hundreds of mutations have been identified in the breast cancer gene where they do the series of letters, they compare it to what I just showed you, and they don't match up. Hundreds. But in Jews, there's a difference. In our population and of Ashkenazi Jews, of which I am part of that group as well, only three mutations account for over 90% of the changes. Not hundreds, three. The other important piece of information is one in 40 will carry one of these three mutations. Those are the numbers that are specific to Ashkenazi Jewish population.

Just briefly, to give you all you actually need to know about population genetics, what's going on, Jews are not bad, defective genes, at all but because of our history and because of the way we would marry and our social and religious conventions, we end up with something called founder mutations. That is a high frequency of a specific gene mutation in a population founded by a small ancestral group. This is how it works:

You start off in an area, geographic area, of an original population, and let's say one fellow has that mutation. Let's say it's like one in 100. No big deal, same as the rest of the population. Okay, here comes Jewish history. Unfortunately, this happened in two ways that our population would shrink. One is that we were told you got 24 hours to move, and people would literally just pick up with their families, and it's been our story, unfortunately, for so many thousands of years. We picked up and we moved. If by chance, this person left with that particular group, now this carrier rate is not one in 100. It's actually much more frequent. Let's make up a number, now it's one in 20. Now he has bunch of kids, these people have a bunch of kids, and now you can see what happened generations later. You need a bottleneck, and then you need a population expansion. Also, unfortunately, the other way it happened is you didn't move. Yeah, an [extermination] happened, and that was another way that our numbers would shrink. It's the tale of our history, but it is what it is and has certain benefits.

In Jews, it's very easy to screen for these mutations. If I have a woman in the Bronx who is of Hispanic origin, she's looking at a \$3,000 test to sequence every letter that I just showed you. If you come and you're of Ashkenazi Jewish extraction, I only have to look at three, and that accounts for over 90, maybe

even higher, of the potential changes.

Audience Participant: What is the cost for running the Ashkenazi test?

Dr. Susan Gross: That's a very interesting question because, honestly, to run just three mutations, anybody who does any lab and any research knows that that shouldn't be particularly expensive. There is one company called Myriad Genetics, who holds the patent, and you have to go through them, by and large, and it comes out to a few hundred dollars.

Audience Participant: I think it's \$450.

Dr. Susan Gross: Yes. To wrap up the talk, what happens is the other thing about Jewish community is our thirst for knowledge and that we want information and that we want to know and that we want to take what life throws at us to see what we can do with it to make things better, and to do that, you really need a very basic, strong understanding of what is actually out there.

We also are very good at offering ourselves up to these study subjects so that that is one of the other reasons we have a lot of studies done on Ashkenazi Jews. We're not afraid of the health care system. We actively participate in the health care system. If there's a chance of doing research that we can benefit others, Jews really, they pick up the ball and carry it, by and large. So many wonderful people and families participated in this study by Mary-Claire King, who published in *Science* in October 2003. We had colleagues all over the Greater New York area that participated.

Ashkenazi Jewish women diagnosed with breast cancer from 1996 through 2000 and molecular analysis for those three ancient breast cancer mutations were looked for, and other related important questions were asked, and this is really the bottom line for tonight's talk. There was a lot of very important data in that paper, but this is what was found. Any woman of Jewish Ashkenazi heritage with breast cancer has approximately a 10% chance of carrying the mutation. You don't need an extensive family history. And that was the real kicker from the study.

For many people, for example, I'm a child of Holocaust survivors, there is no family tree. That has been an issue for a very long time, and again, it depends what physician you're seeing who would have enough sense to even engage in the conversation. There are no aunts, no uncles, no cousins. They just aren't there. However, even in the context of having that capability, you don't need to have a lot of relatives, and just having breast cancer in and of itself carries approximately a 10% chance. If you are older at the time of diagnosis, it's somewhat less. Yes, if you have more relatives, that would certainly bump up your risk. If it's somebody who has breast cancer and ovarian cancer, again,

puts up your risk.

Beautiful, elegant work out of Israel and in the States, as well as in Canada and other countries, ovarian cancer in the family seems to increase your risk, as well. Even before this study, if we had a Jewish woman with ovarian cancer, this issue of possible mutation came up.

To wrap up, what am I telling you today? I want you to leave here not with, oh, we're all going to go get tested. I want you to leave here with an understanding that there's a specialty called genetic counseling. There are wonderful people I work with who are trained to talk to people. I've been a patient. I've had family members who are patients. You're always thinking, how do you become a doctor but you don't know how to talk to people? It's unfortunately the way medicine sometimes is. These people are trained experts in genetics and to educate. The issue here is getting people to experts to be able to talk about the issues, to get a proper education, and the way we do it, by the way, is we construct those pedigrees, and there are algorithms, mathematical algorithms, that will tell you what is the risk of you having mutations. Then you make the decision. That's the most important thing. It's about choice, education, and autonomy in decision-making, and education, education, education. It can affect care and management if you are diagnosed with breast cancer, and there are preventative measures for people in the family who don't have breast cancer and who should not get breast cancer and at least that the knowledge is available, it's out there, and to give people choice, not only individual, but the reason I love genetics, actually, is it's family. It always means that you are actually talking, thinking about family, which is the point of today's talk.

I'm going to finish with this slide, as well. I have a real hard time with all the genetics that comes out, it's in the papers all the time, it's in the *Science Times*, this idea that we're all our genes. That's who and what we are. And I absolutely love this quote. It's from the Talmud about how can you tell if somebody's Jewish, and it is not by your genes, and it's actually even not by inheritance, because there are people who have converted into Judaism. But this idea that it's a nation distinguished by three characteristics: merciful, bashful, and perform acts of kindness.

What more can one say? At the end of the day what this is all about is to take knowledge, not be afraid of it, but to use it to do good deeds and to save lives. It certainly represents what Sharsheret is about. I'm happy to take some questions, and thank you so much again for having me.

Audience Participant: What about Jews of Sephardi descent?

Dr. Susan Gross: Excellent question related to Sephardi Jews. If you take a look at Iraqi Jews, for example, breast cancer in Iraqi Jews, generally what

happens currently is that they would fall more into the category of how we deal with patients who are not of Ashkenazi heritage. This question had come up before the presentation. I even called around to colleagues, and most people do what we do. Some will start with just the mutation testing. Some will just then go on to sequencing. In our practice, I haven't had anybody of Sephardi heritage come up with those mutations. Having said that, the world is changing very quickly. First of all, Ashkenazi Jews are marrying Sephardi Jews. There was once upon a time that that was considered a great shanda, and thank God, we are no longer in that place and people have much more mixed backgrounds. So that's an actually wonderful question. They don't have these particular mutations, they just don't come up in the same frequency like we see in Ashkenazi Jews, and many of them will end up the full sequence. After you've looked at these three, you can look at that whole series of letters.

Eillene Leistner: We have a few more questions, so if I may read them.

What is the purpose of genetic testing if one tests negative for BRCA1 and 2, are there genes that cannot be tested, making the woman at high risk?

And, also, discuss the new genetic test done after Ashkenazi and comprehensive genetic test.

Dr. Susan Gross: Okay, I'm not sure about the second part. The first part is very important, and again, it's beyond the scope of the talk, so I left those slides out. But this is how it works. It depends who's being tested in the family. If, for example, there's a woman who comes and she tests positive for one of those mutations, that makes the situation much simpler because in that family, each individual will decide if they want to be tested. You know what to test for.

If I showed you that family and let's say the woman that was at the top was tested, she was a carrier for a specific mutation, then all the children, let's say, go for testing. If you're negative, you don't have that mutation, you really go down to population risk, which is not zero, and this is another problem. People think, "Okay, I'm negative. My mom was positive. I'm negative. I'm not going to get breast cancer." Absolutely not the case. You still have to take preventative measures.

The other problem comes when you go for testing, it's negative, which is probably much more related to this. And then, again, what is important is take a look at the family history. If you still have a strong family history, early age of onset, then in that sense, you look at this, and you say, "There's something else going on."

Mary-Claire King, for example, and other researchers have been very interested, and particularly in these families, to try to answer that question, maybe there's

another gene. We just don't know it yet. That's work that's done around the world. What the important thing is, again, is just to make sure that you get the right follow-up and the right care in that setting.

We do have another situation. For example, if somebody gets breast cancer, they're an older woman with really negative history, there's nothing going on. It probably is just not a heritable cancer, and it probably is, what I was mentioning, those sporadic cancers that happen in 90% of the cases, much more likely. It can get complicated, and that's why we have specialists who are really there to talk to people.

Eillene Leistner: Here's another one. If I have the BRCA2 gene, does that mean that one or both of my sons will absolutely have the gene?

Dr. Susan Gross: You have two copies, you can't keep passing all your genetic material. You can only pass one copy. It's a 50/50 chance. You may pass the copy that has the change, or you might pass the copy that doesn't have the change. It's 50/50 if you have the gene that you're going to pass it along.

In the old days, not that long ago, people were afraid of testing because they didn't know about insurance and if there would be coverage, and there's a lot of issues. Now that there are actually preventative measures and it might change your management, that's not so much the issue. It very much is the dynamic in the family and how people feel about testing and very much so how they're going to tell their children. Dealing with people, talking to people, how you deal with in the family dynamic that you're thinking much more about the rest of the day is much more important. It really truly is. It's a talk for another time, and you're going to hear insight on that topic, as well, later in the evening.

Eillene Leistner: We just have a few more. A question about the percentage of successful reproduction for survivors, obstacles to overcome. Have scientists experimented with exonuclease to attack the gene?

Dr. Susan Gross: There are reproductive issues, just in terms of passing along the gene, that women do talk about and that there have been different technologies that have been offered. It's controversial, to say the least, as to how we deal with those problems.

Presently, in terms of treatments and therapies, whether or not there is gene presence, oncologists will, by and large, take a look at the other factors and put it all together in terms of deciding the best therapy.

However, it is worthwhile to know if you are diagnosed with breast cancer and you're a Jewish woman and certainly, certainly if you see family history or you're a younger woman with breast cancer, whether or not you have lumpectomy

versus mastectomy, your surgeon may very well want to know that, and you will want to know that before making decisions. There are issues about reconstruction and when you do it. It is becoming more and more a part of care at the very outset.

Eillene Leistner: How old must a woman be to have genetic counseling and testing? Can teenagers be tested? Who in a family affected by cancer would be the best candidate for testing?

Dr. Susan Gross: I'll answer the last question first. It is always best for what I explained before is if whoever is the person in the family with the cancer. That is the right person to test if it's possible. Sometimes we can't. Families are spread out, and sometimes it's difficult to do, but that's ideal because if we find a positive mutation in that case, then it's just so much easier to direct what you're going to do subsequently.

In terms of age, the pediatric community is pretty clear, and I'm in 100% agreement, you don't do genetic testing on kids unless it's something that's going to be lifesaving. There are other genetic disorders that as a geneticist, I really want to know because I can do something to save a child's life if we find out early enough. This isn't that. Even in terms of the earliest time that you might have early onset even with the breast cancer mutations, it's not going to be in teenagers. This highlights what I said before, that genetics is easy. It's four molecules in a certain order. That's not the difficult part. The difficult part is the family dynamic. You're talking to specialists in the field. When is the best time? Different people respond to this differently. You have to know your kids. I'm a mother, too. You want to protect your kids. That's number one. It doesn't matter who you are, where you are, Jewish, not Jewish. It's the maternal instinct to protect your child. What we do is we really have to work with genetic counselors. But also, there are people who are psychologists, therapists, and others who have real expertise in how you deal with these issues. But teenage years, it's too early. It's not going to make a difference.

However, you might want earlier surveillance, and in your 30s might actually be too late. It's a difficult issue. The issues of marriage, telling future spouses, I think that people on the panel really are the ones who do so much important work in that area.

Eillene Leistner: Thank you so much, Dr. Gross. You've answered all our questions and informed us of something that enlightened us to quite a bit about our genetic make-up here.

I'd like to now move on to introducing Marc Silver, who is the author of *Breast Cancer Husband: How to Help Your Wife (and Yourself) Through Diagnosis, Treatment and Beyond*, which was named one of the top 10 self-help books of

2004 by *Library Journal*. His wife, Marsha, was diagnosed with breast cancer in 2001, and after undergoing surgery, chemotherapy, and radiation, she is in good health. Silver is an editor at *National Geographic Magazine*. He has also been interviewed about his book on *CNN*, the *Weekend Today Show*, and *NPR's Morning Edition* and contributed stories on cancer to the *Washington Post*, *Health Magazine*, *U.S. News and World Report*, and *Cure Magazine*. Marc has spoken about breast cancer husbands across the country and in Santiago, Chile. This year, he was named a Yoplait champion for his efforts and he is a great believer in the breast cancer husband's motto, "Shut up and listen."

III. Presentation by Marc Silver

Marc Silver: It's a great privilege to be a part of this incredible program. I'm very grateful that there is a group like Sharsheret as the husband of a Jewish woman and the father of two Jewish daughters. Thank you for all your good work.

When I was invited to speak here, I thought, I should say something Jewish before I start my husband program, so first I thought I could talk about when my wife was diagnosed in 2001. It was a month before my younger daughter's bat mitzvah. It was the time of the High Holy Days. It was a really hectic time in our lives anyway. We would sit in doctors' offices waiting to see doctors, practicing our Torah portions for the bat mitzvah. I think people thought we were crazy, yet it sure beat watching *The Price is Right*, I will say that. Doing these kind of Jewish things, my wife would have chemo on Fridays, we'd have Shabbat dinner afterwards, it just gave us some sense of normalcy and connected us to the life we had before breast cancer. It really helped us get through this experience. But then I also thought I should talk about my mother-in-law, my wife's dear mother, a Jewish mother. And we love her very much. She died of pancreatic cancer two years ago, and Jan was a very special breed of Jewish mother. She knew it all, and she wanted to help out, but she didn't want to work too hard to help.

When Marsha was diagnosed, Jan would call her. She lived in Boston. We live in Washington, D.C. Jan would call her, and she would say to Marsha, "I know why you got breast cancer. It's because you work too hard, you skip breakfast, and you don't eat enough for lunch." And this made Marsha feel really not so great, I must tell you. Fortunately, medical science does not back up Jan's theories. In retrospect, what we think she was trying to say to us is she didn't want to feel like it was her fault in some way that she, as a mother, had failed her daughter, so she was casting blame at her daughter instead.

Later in the experience, when we were going through chemo, Jan wanted to come down to stay with us for a week and help out, which was a great idea, but I felt like, man, if she comes down here and starts to saying to Marsha, "And it's your fault," that would not be very helpful at all. I secretly called Jan one night when Marsha wasn't home, and I told her we'd love to have her come down, but she couldn't tell Marsha that anything she ate, did, saw, or thought about had caused breast cancer. We both cried on the phone. It was a very moving conversation. Jan came down, and she was really a great help to us. It was really great having her there. And that's one thing guys have to understand: welcome in everybody who wants to help. Don't say no.

One night we wanted Jan to make her famous kasha varnishkas for dinner, and

Jan was like, "Kasha varnishkas, it's too many pots out, too many dishes to do." But she made it anyway, and it was delicious. Then she went back home to Boston and a couple weeks later, I came home from work one day, and Jan had called Marsha, and she had a new theory about breast cancer. Jan had a friend Eleanor in Florida (everybody's got a friend in Florida) and her friend had read an article that said exercise causes breast cancer, which, of course, defies everything we know about exercise. Furthermore, Marsha's mother had figured out what type of exercise caused Marsha's breast cancer. Marsha mows our lawn. We have a small lawn, and she uses a push mower. And Jan decided that when Marsha pushed the mower, the vibrations traveled up her arms into her armpit and into her breast and caused the cancer. At first I was so angry and also, because then, whose fault is it? It's not really Marsha's fault; it's my fault because I should be mowing the lawn. I was really going to call Jan up and say, "How could you say that?" and then we both just started laughing, and we laughed for like 20 minutes because it was so preposterous, and in the end, I should've called Jan and told her thank you for the good laugh." To her dying day, she would call up every Sunday, and I'd answer the phone, and she would go, "Marc, is Marsha mowing the lawn?" Since she had usually already finished, I would just say no, and I wasn't lying. But anyway, that was the Jan story.

Actually, I talked about these kind of dynamics with some of the people I interviewed for the book, and one thing is that a lot of people will come up to you, when your wife has breast cancer, and they have all their different theories about what caused it. It was deodorant, and it was this, and it was that. I think that it's really important for the husband and the wife both to be able to say, "It's just not helpful for us to hear that right now." If people still persist telling you this stuff, one psychologist suggested singing *Yellow Submarine* in your head while they're talking. I think *Hava Nagila* would work well, too.

The other thing that was interesting is that when I called my mother-in-law in secret, I was wondering was that a good idea, and a lot of people said to me, "You know what? It's much better to say to your wife, "You know what? I'm going to call your mom and talk about this." Because, otherwise, her mom will call her up and say, "Guess who I heard from today." I did learn a lot in researching the book.

On the other hand, when I started out as a breast cancer husband in 2001, I really was that clueless guy. I didn't know anything about what I was supposed to do, about how to help, and all my instincts were wrong.

My wife had gone for a call-back mammogram and called me at work on a Friday in August to tell me that it looked like she had breast cancer, and my reaction, as she likes to remind me, was, "Ew, that doesn't sound good." After we talked about what would happen next, when we could see the doctor, which would be the following Tuesday, because of Labor Day, I signed off, and I said, "See you

tonight, honey." Marsha later told me she thought she'd called the wrong husband. I did eventually stop playing the denial game and became a better breast cancer husband. But, back in those dark days when it seemed like cancer and chemo were ruling our lives, I wished they had some kind of a book to help me out, and I couldn't find one, so I wrote one for all the clueless guys like me.

In doing this book, I didn't want it to be just my story, so I talked to over 100 different couples who'd gone through breast cancer together. They told me great stories, I remember, and they made me understand what had happened to me. I used to go out for a drive sometimes, and a song would come on the radio, and it would make me cry, and I thought I was losing my mind. I talked to lots of guys who cried in the car. One guy told me that every time Barry Manilow came on singing, *I Can't Live Without You*, he'd burst out crying like a baby, and he hates Barry Manilow. So, strange things happen for sure.

The one thing I learned, too, is that there are not a lot of rules that apply in every marriage. Every marriage is different. Some marriages bust up because of breast cancer, some grow stronger, and some there's just a lot of stress and tension because cancer really does add a lot of stress to any relationship. But some things always work, flowers. A friend of mine at work who had breast cancer said to me [that] her husband had flowers waiting for her every night after a chemo treatment. I followed orders and my wife would love it, and she would go, "How much did you pay for those flowers?" She's from Boston and is very frugal, and I'd never tell her. But it was a way of bringing a little romance and joy back into our house at a time when cancer was sort of lurking in every corner.

I did find about nine things that husbands tend to do wrong, though. There are certain things all of us guys have in common, and our time is really tight tonight, so I'm going to race through. I'm going to dare to tell New Yorkers what to do. I'm going to talk really fast so I cover everything, and if I'm running too long, someone should just give me the time signal.

Bad response number one, *I know what you need.* A lot of guys feel that way, and you know what? You don't. It's not about you. It's about your wife and her needs, and her needs can change from week to week, from day to day, from hour to hour, which is very confusing.

How do you find out what your wife needs? We mentioned earlier the breast cancer husband motto, "Shut up and listen." I know we're the people of the book, but if people don't want to read my book, I have a button. You could just kind of wear this, and it would be a good reminder. It's very hard. Guys don't like to ask for directions, but sometimes you have to swallow your pride and really just ask your wife, "What do you need from me?" One thing you can do is offer something like a backrub. It's very simple. You know, you can carry it out, and it's probably something that will make your wife feel better.

Sometimes you do think you know better than your wife. I thought I knew that my wife should stay home during chemo treatments and just relax and watch TV. She's a schoolteacher, and it's so stressful to go in. But she kept saying to me, "You know what? When I stay home, I worry more about the cancer than if I go in to work." She also felt like cancer had taken so much from her that she didn't want to let it take away her job, as well. She would drag herself into work, and I would feel bad, but I realized that was her decision and I had to respect it. Other women I interviewed had the opposite reaction. They had very stressful jobs. They just said, "I'm taking a leave," after diagnosis and didn't go back. It's very hard for guys. We just have to sort of grit our teeth and ask what are we supposed to do to support our wives and hope that they'll tell us.

It's tough, too, because husbands really do think they know it all. This one woman was telling me that her husband was a great guy, and he got a leave from his work in November. She was diagnosed in November, and his boss said, "Stay home for the rest of the year and take care of your wife." He decided to be the perfect caregiver. His wife's doctor said she should avoid crowds during chemo, so he analyzed the traffic patterns at all the local supermarkets. He decided the only time she could go shopping was on Wednesday afternoon. She couldn't go to Shoppers Food Warehouse, where you have to bag your own groceries. I think after two weeks, she sent him back to work.

There are always going to be tensions, and I asked one doctor what you can say. He said, "You know what? Give your wife a hug. Tell her you love her. And if you're frustrated about something, say, 'Honey, I'm frustrated, too, but let's not fight,' and then you've got to just shut up and listen."

Bad response number two, the doctor's office. A lot of women really say to their husbands, "You don't have to come with me. Go to work. It's okay. I'm fine." I just did say you shut up and listen your wife, but this is one case when maybe you shouldn't listen to your wife. There are some women I talked to who genuinely did not want their husbands in the room with them, in the waiting room, or in the doctor's office. One woman said her husband used to cry in the doctor's office, and it touched her profoundly, but it wasn't helpful at all. Another woman said her sister was a nurse, so she took her sister along, and her husband was grateful to be able to continue his work schedule.

I think you have to ask yourself, "Why is she saying this to me? Is it because she really doesn't want me there, or does she just feel guilty imposing?" My wife, Marsha, would always say, "You don't have to come." And I would say, "You know what? I'm going to come, too." Sitting next to her in the doctor's office is what really kind of shocked me out of my denial and made me understand what was going to happen to us in the next months ahead. I saw that I could play an important role because Marsha would come out of the doctor's office and she

would have forgotten half of what the doctor told her. I was like, "Man, I would remember everything if it were me." What I found out in researching the book is [that] it's very, very common for patients with a critical disease to just not absorb the information. They're in shock, they're stunned, and they're getting all this information about procedures and options and new treatments, and it's all very overwhelming. And there was even a study in the Netherlands that found that patients forget 40 to 80% of what a doctor tells them if they have a critical disease.

The husband's job then can be to help out, to take notes, or to tape-record the visit. It made me feel great to have a job to do, at last, something I could help out with, and it really is a tremendous benefit to have a record of what the doctor was telling you. You kind of change the balance of power, too. You give your wife someone to support her as she asks the questions that she needs to ask to make her decisions about treatment.

It can even be a little bit of fun. One night we went to a hospital for a CAT scan because Marsha was having shortness of breath, and she really did say to me, "You know what, Marc? Stay home." I was very tempted, and I said, "Oh, what the heck. I'll come." We got there at seven. We got home around midnight. We waited and waited and waited. We read magazines that weren't very interesting in the waiting room. I'm sure they have better ones here. Of course, the CAT scan showed nothing, but as we walked up the front steps to our house, I squeezed Marsha's hand and said, "See honey, you can't say we never go out anymore." So, brownie points.

Bad response number three, *I'm running the medical show.* I just remember feeling so strongly, that it was my job to find the doctors and decide on the treatment and say to Marsha, "Here's what you need to do to treat your cancer." You know what? It's not your job. I came to understand that Marsha had to make decisions that were the right decisions for her. She had to pick her doctors, the doctors who gave her a sense of confidence and who could carry her through the treatments, and she had to decide on a treatment plan that made sense to her. You know what? It's always complicated. All of us who have been through breast cancer know there are many, many decisions. There's not always a right answer. I heard of one woman who had a bumper sticker on her car saying, "Honk if you think I should get a mastectomy." I think it's probably better to ask your husband. Marsha did ask me sometimes, and it's very helpful to have an echo or a foil, someone who will say, "Yeah, I like that doctor, too." Or, "Gee, I'm not so sure about that."

But then sometimes she didn't follow my advice and I'd feel really bad, and one psychiatrist I interviewed for the book helped me understand. She just said, "You know what? Think of yourself at work. You always go to your boss and say, 'I've got a great idea.'" The boss goes, "Huh, that is a good idea." But then the boss

does what the boss wants to do, and your wife is the boss.

Bad response number four, *Cheer up, honey.* I thought it was my job to cheer my wife up all the time, and if I said the right thing, it would kind of snap her out of any depression or bad feelings that she had, and then I would be a hero. But that kind of behavior can really backfire. Actually, on Yom Kippur night, right before services start, we had gone to a doctor that day. It turned out my wife had bilateral breast cancer, a tumor in each breast. The doctor had suggested a double mastectomy. It was very hard for Marsha to cope with, and she just looked sadder than I'd ever seen her in her life. We were sitting there together, and I said, "You know, honey. It doesn't matter to me. I'll love you with or without your breasts." I thought I was being such a sensitive guy. She turned to me and said, "How would you feel if they were going to cut off your penis?" And I tried very hard not to take it personally, but I did learn to try to not be the cheerleader all the time. Sometimes all the patient wants to do is say how much it sucks, and all she wants her husband to say is, "Yup, it really does suck."

And there are actually studies that show that. There are studies that looked at groups of women who have gone through treatment for breast cancer. This doctor I talked to had looked at two different groups. One group of women let all of their emotions out, and if they were feeling crummy, they said they were feeling crummy. Another group kept all their emotions bottled up and tried to be positive. The women that let it all out actually fared better with the stress of treatment and did a bit better than predicted from their initial prognosis.

Bad response number five, *Stop crying about being bald.* It drove me crazy because Marsha, she'll say she doesn't have the best hair, she'll admit it, was just obsessed with losing her hair to chemo, and she couldn't let go of it. I just wanted to say to her, you've got to stop fixating on that because it just doesn't matter. What I came to understand from talking to people for the book is that for women, losing their hair was often harder than losing a breast to surgery. They look in the mirror, their bald hair staring back, and it meant they were a cancer patient, they were on chemo, and everything is different than it was before. What do you say to your wife when she is bald? One woman, said one Sunday morning after a couple of chemo sessions, well, I guess after one chemo session, her hair was starting to fall off. Her husband was making pancakes. She went in the bathroom, shaved her head with a Lady Gillette and said to him, "What do you think?" He looked up and said, "You look beautiful to me." I think that's a beautiful answer. Someone just told me, too, "You know what? It's not so bad to go through the months without hair." One woman I met said that she and her husband and some friends had gone out for dinner. She had her wig on, and at the table next to them, another couple was there, and the woman was going, "I'm having such a bad hair day. I'm having such a bad hair day." The cancer lady took her wig and threw it on her head and said, "You think you're having a bad hair day!"

Bad response number six, I had my slides translated for Chile, and they sounded so good in Spanish. This is the sex slide. *Sex is taking a holiday.* I mean a lot of guys really think, and women, that when breast cancer comes on, that's the end of your sex life for nine months or more. The rejoinder is, "Not so fast, Mr. Celibate."

There's nothing wrong with coming on to your wife, even in the middle of the chemo months. Just be gentle, and if she's not interested, "too bad for you," as my wife would put it. We were actually very lucky. My wife's oncologist said very simply to us, during chemotherapy it's possible to maintain intimacy. A little light bulb went off in our heads, and we were very grateful to Astroglide, one of the many lubricants that can come in handy. Dr. Susan Love was on TV recently, and she was saying, "Just having a jar of something called Astroglide by your bed, it's just a thrill, even if nothing happens."

Sometimes nothing does happen. I mean chemotherapy and other treatments do take a toll on your sex life for sure, but the thing that was stressed to me and that I think we understood as we went through this is, that even if your wife is not in the mood, if the husband pulls back entirely, that's really tough. It's the loss of touch that's a huge, huge loss. Sometimes what your wife needs is a hug or a cuddle or a foot massage. It kind of keeps you connected to your wife at a time that's very difficult and very stressful.

What does the husband crave through all this? One guy said to me, "You know what? I wanted sex twice a week before cancer, I want sex twice a week now, but my wife's going through chemo, and I can't have sex with my wife, so what do I do?" It is true that the sex desires for the guy are pretty much the same.

Bad response number seven, *I can do it all and I don't need a break.* A lot of guys feel that way. It's like the macho thing. I don't even want to take time to do anything I enjoy, and you've just got to. You've got to have some down time. I think if you ask your wife's permission first, that's really important. If you need some time to shoot baskets, go for a bike ride, it helps you recharge your battery. It makes you a better caregiver when you come back.

The converse problem is for women. I don't know if this is a Jewish woman problem. I think it's all women. Some women try to do it all and look like everything's fine, and "I can keep up everything at home and my job and not miss a beat." Then the husband thinks, "Oh, everything's fine, so I'm just going to go to work." Women have said to me sometimes they were very hurt that their husband didn't support them more, and sometimes it was because the husband felt like, "Oh, my wife's handling it all." It is a really tough dance. I think you have to just be really honest with each other and talk about what you can do, and the husband just has to be there and offer to help whenever he can.

Bad response number eight, *Cancer is no laughing matter.* It turns out there's a study of 150 breast cancer couples, and joking around, lightening it up a bit, reduced the woman's stress. It is a tough crowd, though. You're playing a very tough room. These are some sample cancer jokes from real husbands. The second joke was mine about the beauty parlor, and Marsha kind of grimaced and then she grinned because she was thinking the same thing. As I said, you're playing a very tough room. You have to be very sensitive to your wife's feelings.

One woman said if her husband teased her about being bald, that would've been going too far. Then I met this one guy. He was a retired military officer. He said when he saw his wife's bald head and sunken eyes from chemo, he'd say to her, "Honey, I have the urge to go bowling." He said she thought that was very funny. I thought he was a little bit deluded. I called his wife up and said, "Did you really laugh at that?" And you know what? She said she really did. It was so outrageous, it made her grin.

And wrapping up, **Bad response number nine, *When treatment ends, don't worry, be happy.*** I think for a lot of guys, that's the natural reaction. It's like you've gone through nine months or whatever period of time, the surgery, chemotherapy, radiation, and you're just ready to put it all behind you and move forward and say to your wife, "Here are the car keys. You can drive the carpool now. And, could you pick my shirts up at the drycleaner on the way back?"

What guys need to realize is that after all this treatment, it might just catch up to your wife at that point, that she's been through this incredibly stressful experience. She may be suffering from chemo drain. She may be absolutely exhausted. She may have a dent in her breasts or other reminders. She may have lost her breast. She may carry these physical reminders of her experience with her. Some women said it was much harder after treatment ended. They liked having these doctors looking at them all the time and taking care of them, and it's kind of hard to be cast out and told to come back in six months or a year. It was very hard for my wife, I know.

You also get a new normal. What can I say? You have all the same worries as before, but sometimes people do change their lives and kind of learn what's important to them. Maybe they don't get bent out of shape by a little problem. Maybe they spend money a little bit more freely. I called one couple to interview them, and I heard drums playing in the background. I said to the woman, "Oh, is that your teenage son playing drums?" She said, "No, it's my husband. He always wanted a drum set, and after cancer, he decided he was going to go out and get it." He loved playing the drums, and she loved it when he stopped.

But, it is hard. It's a hard time to be in this new normal period. My wife and I had a whole round of metastatic disease scares this past spring and winter, and we're

going to get some biopsy information in a couple of weeks. We're hopeful that it's nothing, but there are a lot of uncertainties that you just have to live with. That was very hard for Marsha. She wanted to feel like she was going to be scanned and tested every two minutes, and the doctor just said, "You know what? It doesn't make a difference. If it's metastatic disease, if they find it by symptoms, it doesn't give you any better chance than if they find it earlier by a scan."

Her doctor did say something very helpful to us. She said, "If you've never had a recurrence, if you worry about a recurrence all the time and you don't have a recurrence, you've wasted all that time worrying. If you do have a recurrence, you still wasted all that time worrying." We try to live by those words. It's kind of tough. But when I backslide, I think about a story from the Bible. In the story of Sarah and Abraham, Abraham is kind of upset because Sarah wanted to cast out Hagar and her son. What did the Lord say to Abraham? In His infinite wisdom, He said, "Whatever Sarah tells you, do as she does, as she says," and, so, I do shut up and listen.

Thank you.

Eillene Leistner: Marc hit on so many sensitive and amazing points, and again, I'd like to give him another round of applause. I think he was fabulous. Thank you so much.

I'd like to introduce Shera Dubitsky. Shera is Sharsheret's Link Program Coordinator, and she has served as a Psychology Resident and Fellow at the Bronx Psychiatric Center of the Albert Einstein School of Medicine and an Associate Psychologist for the Jewish Board of Family and Children's Services. She has also worked as a Researcher at Memorial Sloan Kettering Cancer Center. As Sharsheret's Link Program Coordinator, Ms. Dubitsky assists newly diagnosed women and those at high risk of developing breast cancer and their families and provides supportive counseling to women living with metastatic breast cancer. She also assists in the advancement and development of programs addressing the needs of the women of Sharsheret. I just want to also say that she addresses everything with a wonderful sense of humor. So, please, Shera, come up here.

IV. Presentation by Shera Dubitsky, M.Ed., M.A.

Shera Dubitsky: Thank you. I want to say that I'm going to perhaps repeat some of the information that Marc offered, but it really is worth repeating and sinking in, even for myself. I really enjoyed your presentation, Marc, and I want to thank you for that.

When I first began to draft this presentation, I was contemplating a more sophisticated, theory-laden approach outlining the impact of cancer on a family member. If you're here today, you already know that the disease exists within one person, but it psychologically resides within the family group. Also, many of you know firsthand that the physical demands, the role changes, the emotional stress, and interrelationships are often the most difficult adjustments that a family member must confront. I certainly don't need to point out that a family's world turns upside down each step of the way. First, with the diagnosis, and just when that has a moment to sink in, you're dealing with perhaps surgery and treatment, and certainly survivorship does not come without its side effects for both the women and her family. I was thinking, what then can I offer? Most of what I've learned about the experience of living with breast cancer comes from the women and families of Sharsheret. As a Link in Sharsheret's chain, I, therefore, want to pass along their hard-earned wisdom. Also, my mom was diagnosed at the age of 41, and I was 13, and so the rest of what I know about families and breast cancer comes from my own personal experience.

Other than cancer and the treatment of cancer having the greatest impact on a family, I believe that the next most important variable in how a family functions during and post-trauma is communication. I intend to briefly outline some of the challenges in communication and offer some strategies that may promote a more comfortable space for family members to support one another. The common ground among family members is the emotional impact of the cancer diagnosis. Like the patient, family members experience sadness and fear and anxiety, and they, too, are overachievers when it comes to imagining worst-case scenarios. Family members also struggle with the "how" and "why" did this happen, both concretely and spiritually. I'm also hearing parents who are calling in to Sharsheret, and they're saying, "Why my daughter? Why couldn't it have been me?" We also are hearing other family members say, "Well, you know, I keep thinking, does this increase my own risk of developing breast cancer? Then they actually feel guilty about having this thought and having it compete with their concern for their loved ones.

Women have also expressed feelings about being identified as cancer patients even sometimes well beyond having had cancer. One woman stated that she fears that when people think of her, their first association is with cancer even though she herself is post-treatment and is also well accomplished in other areas

of her life. What she said to me is that she feels as if, "cancer is an accessory that I carry around where people feel free to share their unsolicited opinions." You know what? This is true for family members, as well. How often are family members perhaps going to the shul or going to local shops or going to their children's school, and they're faced with well-intentioned people who are asking questions and wanting to share their well wishes at a time when maybe they want to be more reflective or perhaps want some distance or may be well beyond cancer?

Generally, it's really hard to change how someone is feeling, and if you continue to try to change how somebody is feeling, what happens is either they artificially suppress the feelings or, more commonly, they create further frustration and higher emotions. It just takes a lot of energy to avoid your emotional life. Another Sharsheret caller shared with me, and she said, "I feel like coping with cancer is similar to experiencing a car skidding in the winter. As it's happening, I feel like it's slow motion, and my instinct is to push on the brakes. But I remember from driver's ed that the best response is to go with the skid. Attempting to put on the brake only increases my chances of crashing." Women often come up with different metaphors, but I believe the message is the same, and that is, that it's important to allow yourself the emotional experience so that you can really move beyond it.

Now, that being said, how you manage and communicate your emotion differs from individual to individual based on several variables, including one's personality, whether you're the patient versus the family member, and your position in the family, whether you're the parent, sibling, husband, or child.

I'd like to talk about some of the challenges that we're seeing in communication. First of all, it's important to know that when people experience trauma, they often become caricatures of themselves. In other words, people become a more extreme version of themselves. If your natural baseline is to be a worrier, then this heightens. If you tend to be a doer, then you quickly move into action mode. If your baseline is to be controlling, well, then you're in a lot of trouble because this is, unfortunately, a disease where you may lose a lot of control. Therefore, if your baseline is to be controlling, you may experience increased frustration and stress. The bottom line is this, that coping with cancer magnifies a person's personality and, therefore, it may reveal some longstanding problems in a relationship that even predate the cancer.

Some communication hazards that we're seeing is that people are either providing too much information, or they're censoring information, or they're withdrawing, or not respecting different views. People often offer unsolicited advice, I think, as Marc was sharing about Jan, and this can be overwhelming. Living in an age of information is a wonderful thing when it's sought out. However, when too much information is thrust upon a person, it can feel

overwhelming.

As we heard Marc say, out of concern for loved ones, sometimes people can behave as if they're award-winning oncologists. What are we hearing? People are saying, "Well, why are you doing that? You know it causes this. Why don't you try this? My friend's mother tried it, and it worked." This is the more recent popular one, "You know, I read online." Also, clichés become popular. This quote from a woman is probably one of my favorite things that I heard, "When people find out I'm dealing with breast cancer, they often try to comfort me by saying that no one knows when their time will come. After all, they could get hit by a bus tomorrow. What I want to know is, why is it always a bus? Are thousands of women dying every year because they're stepping out in front of a bus? If so, why aren't we hearing about it on the news? I demand to know more about these absent-minded women and these murderous bus drivers."

A journalist, Sidney Harris, once said, "When I hear people sigh, "You know, life is hard," I'm always tempted to say, "Well, compared to what?" A country singer, Nanci Griffith, sings a song that's titled *If Wishes Were Changes*. It would be great if wishes were changes, but wishing something doesn't necessarily make it so. When a person is feeling sad, fearful, or anxious, cheerleading or blanket optimism causes some people actually to retreat into themselves because they don't feel like they have an emotionally safe place to share their fears and concerns. It is important to remain hopeful. Some people also don't want answers or solutions; they just want to feel heard.

At a *Living Beyond Breast Cancer* workshop, Lora Rhodes had noted that sometimes people get into the trap of saying, "Well, we're communicating," but really, what are they talking about? They're talking about blood results, and they're talking about appointments and what did this doctor say. But they're not necessarily talking about how they're feeling. In some families, we're seeing that there's a conspiracy of silence, where everyone is aware that the family members are having feelings and emotions but no one really knows how to talk about it. An end result is that family members are often bearing the emotional pain alone.

Families, particularly parents, inherently want to protect their child, regardless of age, and they want to keep their child safe. A woman may censor information because she can't tolerate her family's reaction, and as a result of this censored and edited information, family members want to seek more information by barraging and overwhelming the woman or other family members with questions. In some instances, family members aren't being told anything, and they may not even know that their loved one has cancer, and that certainly raises a whole other set of dynamics that are beyond the scope of this symposium.

I'd like to just briefly talk about communicating with young children just for a moment. With the onset of an illness, children must assimilate new information

into the family system based on what's being communicated, whether it's directly or indirectly. Consequently, when a parent becomes ill, there's also an increase in interactions with other family members and with people outside of the family, and this can sometimes cause a strain on a child's interpersonal relationships.

Research has shown that good communication that is age appropriate is really the child's best defense against inaccurate or frightening stories that they may hear about cancer or their parent's condition. On the flip side, it's also the way for parents to recognize and to respond to their children's needs in a healthier way. Failure to be honest with the child can profoundly diminish the child's trust, and when the parents hide the truth, what they're communicating to the kid is that this is just too awful to face. When, maybe on the contrary, what we'd like to teach the children is, "I have confidence that no matter what's happening, we're going to deal with the emotional, the spiritual, and the physical changes that may arise." This is a lesson and a tool and a resource that these children can perhaps access for the rest of their lives. I can tell you that this is true even 30 years later. It's a resource that I continue to rely on.

For valuable insights into meeting the needs of young children, I recommend visiting the Sharsheret website and downloading the transcript from a previous symposium entitled *How Do We Care for Our Children?*

Finally, I'd like to address some of the unique concerns that Jewish women and their families are facing, what they're facing in addition to what Dr. Gross has already talked about.

Family members may be in spiritually different places. We're hearing questions about, What's God's role in the event? Is there room for teshuva, for repentance, for atonement? Is this a bracha, a gift, or a curse? Differing beliefs and practices can sometimes cause rifts in a family.

The good news is that the Jewish community is like an extended family. The bad news is that the Jewish community is like an extended family. They can be wonderfully supportive and resourceful, but like any other member of a Jewish family, they can also be overbearing and intrusive. Let's talk about some strategies for family members to offer and receive support. As we talked about earlier, each member of the family copes differently, so it's important to be respectful of differing needs and perspectives in the spiritual beliefs and practices. We all know that relationships are in constant flux, and it's very fluid. If you take that and you combine it with the changes that you'll find from step to step in terms of managing cancer and the side effects of cancer, it's certainly reasonable that family members can frequently just be out of sync because there are all these changes going on. It's important that each woman, family, and friend constantly adjust their coping and communication strategies and skills to move along with these changes.

How to communicate? In addition to communicating within the family, I encourage family members to seek support systems outside a family network, such as Sharsheret, to alleviate the burden and stress on the already emotionally laden family. I also strongly recommend that you take good care of yourselves. It's hard to be supportive when you're running on empty.

- Let the woman take the lead in the conversation, as Marc also pointed out. It's tempting to always put a positive spin on things, but it doesn't always necessarily feel supportive.
- Be a good listener so that the person doesn't feel isolated.
- Some women appreciate unsolicited information, some women don't. It's always important to check in and see what she prefers.
- Many women have expressed the desire to just hang out with loved ones without an agenda because sometimes talking about life besides cancer can feel uplifting.
- It's tempting, but don't try to fix every problem because every problem may not have a solution. If you attempt to control decision-making, it may only serve to put pressure on the woman, and by backing off, it somehow gives the woman the opportunity to explore her options and to choose what she feels is best for her.
- Try not to assume you know what the woman needs, again, Marc point out, just as it would not be useful for people to assume what each of the family members may need. It's a shame, for example, to give her something that she may not need, and even worse yet, that she may be going without something that she could find very useful.
- For the family, it's important to clarify the logistics that they will find helpful. Find out what are the childcare needs, transportation, meals cooked. Also, relief care-giving for the primary caregiver is really important so they can do something for him or herself. Find out specifically what they need.
- It's also important not to bite off more than you can chew because not following through on a promise can make her feel worse and make the family feel worse. It probably would make you feel pretty bad, as well.
- For everybody in the family, I strongly encourage setting boundaries with other family members, extended family, and with community.

Some helpful communication strategies for the woman who's living with breast cancer:

- Remember it doesn't matter how old you are, that you're still somebody's child and you just need to remind them that you have indeed grown up and that it's just overwhelming and it takes a lot of energy to work on image management, always putting a positive attitude in the spin just to protect your family and friends.

- It's important to acknowledge that everyone is probably experiencing fears and feelings, and you can't take away their anxiety, and I think that the best that you can do is to talk openly and honestly. A statement that just may be helpful to say to your family is, "I know that you don't like to see me in pain, but this is something I have to do my way."
- Don't assume that people know what you need. It's important to give them concrete ways that they can be helpful. I have to say that I have found, in fact, that if you give them things to do, they may actually feel less inclined to be intrusive. That's something that I'm getting a lot of feedback from women.
- As I mentioned earlier, personalities become magnified, and certainly by this point in your lives, you should have a good sense of the strengths and weaknesses of your family, so delegate wisely and demonstrate a good learning curve. If you find yourself saying, "You know, I said 100 times to him," or "I asked her 100 times," you should probably be better off asking yourself, "At what point am I going to realize that this is not effective and that perhaps I should either change my expectations or re-delegate more wisely?"

How can Sharsheret help? We have a program called *Ask Sharsheret*, where we invite family members and friends to call the office and speak with the Sharsheret staff asking questions or sharing some concerns. We can offer you some valuable resources and some organizations that may be more specific to your needs. We also have a Family Focus packet that we can send out to family members, and in there are some articles, some information, but it also includes some organizations that may meet your specific needs; for example, mothers supporting daughters, programs for husbands.

Also, there's a great online Web page called *Care Pages*. I think that for the woman and for the family, repeating the story and repeating every test result and repeating what the doctors say can feel overwhelming. You can actually go to *Care Pages* and a family member can post onto this website, and everybody can read and respond to it. There's also another website called *Lotsa Helping Hands*, where you can actually coordinate care-giving needs online so that you're not busy and taking up time with phone calls and playing phone tag.

We also have an online Forum on www.sharsheret.org where we invite family members and friends to post questions and engage in an online dialogue.

I invite you to invite us to your community not only to discuss breast health but to educate the community on how to be supportive when a woman and her family are living with breast cancer.

In conclusion, I'd like to share one more quote from a Sharsheret caller, and what she said was, "I have incredible family and friends who truly care for me. Maybe this is an opportunity to take a second look at the people around me." I encourage you all to seize this opportunity.

V. Question and Answer Session

Eillene Leistner: Thank you so much, Shera. Ladies and gentlemen, we've had a really fascinating and, I hope, helpful symposium.

I wanted to thank, again, Cindy Turkeltaub. As the Coordinator of Social Work Services and the Cancer Centers of Beth Israel and St. Luke's Roosevelt Hospitals, you provide individual, family, and group counseling to cancer patients and their families, and coordinates a wellness support group in many community outreach programs. Ms. Turkeltaub also serves as a consultant at Chai Lifeline and the Jacob Perlow Hospice of New York.

Are there any closing questions for our speakers?

Unidentified Speaker: Are there any support groups for husbands?

Marc Silver: Yes, it's funny. There's a joke in the breast cancer world that husbands would love. Breast cancer husbands would love to come to a support group if it never met and when they got there they didn't have to say anything.

What I found in the book is that guys just poured out all their feelings to me, and I think there is this sort of just awful aloneness that you're suffering because I think many men don't confide in other guys what they're feeling. They confide in their wife. Suddenly they're in a situation where they feel like, "I can't tell her what I'm feeling because I'm frightened, and I don't want her to feel like I'm not going to be there for her." It is a really tough place. I think that if there were a support group when you're going through the months of treatment and you're dealing with so much stress, just being your wife's caregiver and working your job and doing more stuff around the home, how could you find the time to go to a meeting, and when would it be, like before work, after work? So it is tough.

I think the Internet's a great resource. I've seen some great threads on BreastCancer.org, where guys have posted a problem they're having, and other people, women and men, have weighed in. Maybe that's one way to kind of bring us in and let us know there's a place to unburden ourselves and hear what others have to say about what we're going through. One of the reasons I wrote the book, too, is that I felt so alone. I just wanted you to know that we're all out there. We're all going through this together. There is no effective way, I think, of connecting us all, but I think any small steps that are taken are great steps.

You're in a very hard place, and I think I'm a selfish guy, so I knew I needed to do the things I needed to do. I needed to go jogging. I needed to ride my bike or go out for a walk even if my wife couldn't do it. I think some guys tend to suck it up and they feel like, "I can't even take the time to give myself those kind of moments."

I'd interviewed Steve and Cokie Roberts for the book, and people would call Steve Roberts up and say, "What can I do to help Cokie?" He would say to play tennis with him, and that was his way. Actually, Cokie said that she gave him permission to confide all his feelings, all his fears and thoughts in a guy friend or some other friend. It's like she said, "It's okay with me if you want to say anything you're feeling to your friends." I think that was a nice thing to do, too, because you may feel disloyal. If I'm afraid my wife is going to die and I say that, am I being a bad husband? Someone said to me, "Women have more practice just talking all those things out with their women friends, and guys just don't," because we're guys, I guess. It's sort of changing your behavior, but I think just a couple can work together maybe to encourage that.

What helped me a lot is that husbands of other breast cancer women I knew, a cousin's husband would call me up sometimes and say, "Marc, how are you doing?" It made me feel, it was great. It was my time to tell him how I was doing. He reached out to me, and it wasn't like I was taking away from my wife and all the terrible things she was going through, but, it did give me a way to let some of those feelings out, and it's very, very helpful. Also, crying in the car is really great because it's cathartic and you feel better afterwards. I cry to Ray Charles, actually. I have better taste.

X. Symposium Conclusion

Eillene Leistner: Thank you so much.

As we wrap up this evening, I wanted to also mention that Marc Silver has copies of his book and he'd be happy to share them with you, sell them to you, sign them, and autograph them. I encourage you to talk to him after the event, after our symposium.

I think this was terrific, and as we wrap up, I wanted to thank again all of our speakers for generously offering their time and expertise this evening. I'd like to also thank our sponsors once again for bringing us together, the Greater New York City Affiliate of Susan G. Komen For The Cure for this grant that made this symposium possible and for Beth Israel Medical Center.

I'm going to ask you all to please complete your evaluation forms. Your feedback is important to us. It helps us design future Sharsheret events.

Thank you all to everyone here for coming. I wanted to also just say, for more information, since we were founded, we have supported hundreds of Jewish women and their families across the country facing breast cancer. Tonight we address your questions and concerns, and a written transcript of this event will be posted on Sharsheret's website, www.sharsheret.org, in just a few weeks.

We look forward to continuing this important conversation about the impact of breast cancer on the Jewish woman and her family and hope to share new research and information with you in the years ahead.

Thank you again and good night.

X. Speakers' Bios

Shera Dubitsky, M.Ed., M.A. is Sharsheret's Link Program Coordinator. Ms. Dubitsky served as a Psychology Resident and Fellow at the Bronx Psychiatric Center of the Albert Einstein School of Medicine, and an Associate Psychologist for the Jewish Board of Family and Children's Services. She has also worked as a Researcher at Memorial Sloan-Kettering Cancer Center. As Sharsheret's Link Program Coordinator, Ms. Dubitsky assists women newly diagnosed and at high risk of developing breast cancer, and provides supportive counseling to women living with metastatic breast cancer. She also assists in the advancement and development of programs addressing the needs of the women of Sharsheret.

Susan Gross, MD, is Co-Director of the Division of Reproductive Genetics, Department of Obstetrics & Gynecology and Women's Health at Montefiore Medical Center and Albert Einstein College of Medicine and an associate professor in Obstetrics & Gynecology and Pediatrics. Dr. Gross has served on national committees for both the American College of Medical Genetics as well as the American College of Obstetricians and Gynecologists. She also serves as a vice-chair for the ethics committee for clinical research at Einstein. As medical director of the molecular genetics laboratory at Jacobi Medical Center, she is embarking on the establishment of a clinical molecular genetics facility that will provide accessible, state-of-the-art genetic testing for the underserved in New York City through the Health and Hospital Corporation, the city's public health hospital network.

Marc Silver is the author of *Breast Cancer Husband: How to Help Your Wife (And Yourself) Through Diagnosis, Treatment, and Beyond*, named one of the top ten self-help books of 2004 by Library Journal. His wife, Marsha, was diagnosed with breast cancer in 2001. After undergoing surgery, chemotherapy, and radiation, she is in good health. Silver is an editor at *National Geographic Magazine*. He has been interviewed about his book on CNN, the Weekend Today Show, and NPR's Morning Edition, and contributed stories on cancer to the *Washington Post*, *Health* magazine, *U.S. News & World Report*, and *Cure* magazine. He has spoken on "Breast Cancer Husbands" across the country and in Santiago, Chile. This year, he was named a Yoplait Champion for his efforts. He is a great believer in the breast cancer husband's motto: "Shut up and listen."

Cindy Turkeltaub, CSW is the coordinator of social work services in the Cancer Centers of Beth Israel and St. Luke's-Roosevelt Hospitals. Ms. Turkeltaub provides individual, family, and group counseling to cancer patients and their families and coordinates a wellness support group and many community outreach programs. Ms. Turkeltaub also serves as a consultant to ChaiLifeline and the Jacob Perlow Hospice of New York.

XI. About Sharsheret

Sharsheret is a national not-for-profit organization linking young Jewish women in their fight against breast cancer. Sharsheret (Hebrew for chain) pairs young women facing breast cancer with volunteers who can share their experiences, both personal and medical.

Sharsheret's programs respond to the needs of the women we serve and include:

- **The Link Program**, a peer support network connecting young women newly diagnosed or at high risk of developing breast cancer with others who share similar diagnoses and experiences.
- **Education and Outreach Programs**, including health care symposia addressing the concerns of young women facing breast cancer. Recent events addressed the subjects of breast cancer and fertility, parenting through breast cancer, breast cancer genetics, and surviving breast cancer. Transcripts of all symposia are available on Sharsheret's website, www.sharsheret.org.
- **Quality of Life Programs**, including the Busy Box for young parents facing breast cancer, Best Face Forward to address the cosmetic side effects of treatment, and Embrace, a support program for young women living with advanced breast cancer.

For more information about participating in Sharsheret's programs, please call toll-free (866) 474-2774. All phone calls are confidential.

Sharsheret is grateful for the generous support of:

The Greater New York City Affiliate of Susan G. Komen For The Cure

XII. 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.

The information contained in this document is compiled from a variety of sources ("Information Providers"). Neither Sharsheret, nor any Information Providers shall be responsible for information provided herein under any theory of liability or indemnity. Sharsheret and Information Providers make no warranty as to the reliability, accuracy, timeliness, usefulness or completeness of the information.

Sharsheret and Information Providers cannot and do not warrant against human and machine errors, omissions, delays, interruptions or losses, including loss of data. Sharsheret and Information Providers cannot and do not guarantee or warrant that files available for downloading from this website will be free of infection, viruses or other code that manifest contaminating or destructive properties. You access such materials at your own risk. Sharsheret and Information Providers have no control over and accept no responsibility whatsoever for such materials.