

Breast Cancer and the Next Generation: Caring for Our Children

National Teleconference Transcript
Wednesday, November 4, 2009

Presented By

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Your Jewish Community Facing Breast Cancer

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I. Introduction
Shera Dubitsky, MEd, MA Clinical Supervisor

Shera Dubitsky: Thank you for joining us this evening for Sharsheret's national teleconference, Breast Cancer and the Next Generation: Caring for Our Children.

My name is Shera Dubitsky and I am the Clinical Supervisor at Sharsheret. I will soon have the pleasure of introducing tonight's speakers, all of whom will share their insights into what has become an important subject for those touched by breast cancer.

I frequently hear women saying, "Somehow I've managed breast cancer to the best of my ability, but my greatest worry is for the emotional and physical well being of my children." Our goal this evening is to address the concerns you may be having for your children, from toddlers to young adults. There will be a question and answer period following the presentation.

We intend to offer some suggestions and guidance that may be helpful in meeting the needs of your children. In addition to this teleconference, I encourage you to contact Sharsheret for further support and resources. I will give you that contact information at the end of the teleconference.

I also strongly encourage you to complete the evaluation form. We will be emailing you a form that you can complete online, or you can complete the evaluation form found in your teleconference packet. Our programs are driven and inspired by the feedback from our Sharsheret callers. It's important that we continue to be able to tailor our programs based on your needs.

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The inspiration for this teleconference came on the heels of receiving a beautiful email from Ally Cooper, and we thought that there was no better way to introduce this teleconference. Ally, a Sharsheret volunteer, first got involved with Sharsheret in the spring of 2009 to honor the memory of her mother who passed away from breast cancer. By sharing her experiences, Ally hopes to offer her insight as part of the support system that Sharsheret provides to women everywhere. Ally, the floor is yours.

II. When My Mom Had Breast Cancer Ally Cooper, Sharsheret Volunteer

Ally Cooper: Thank you so much, Shera. As a Jewish woman with a family history of breast cancer, I know all too well the lasting impact that a parent's breast cancer diagnosis can have on a child and on a family. My grandmother, my mother's mother, passed away from breast cancer when my mother was a young child. My mother was diagnosed with breast cancer when she was 42. I lost my mother to breast cancer when I was eight years-old, almost 20 years ago.

When she was first diagnosed, I was seven and my younger sister Sarah was five. Because we were so young at the time, my mom didn't think that Sarah and I needed to fully understand how sick she was or what was really going on. We were her little girls and she wanted to make sure that we had a happy childhood. She thought it was best that we didn't think about scary things like breast cancer or death.

It was very important to my mother to keep things as normal as possible around our house. Her doctor appointments and treatment sessions were always scheduled during school hours or when we had after school play dates. If my mom happened to be particularly weak or tired one day, my father would tell us that mom needed to catch up on sleep, and keep us distracted so she could rest.

Thinking back now, the only change we noticed around the house was a physical one, that mom suddenly had very short hair. As a result of chemotherapy, my mom had lost most of her hair and what she didn't lose, was very thin and short. She went out and bought a curly wig, which I remember being a bit scared of since it made her look like a completely different person. She also bought some scarves and hats.

When we asked her about her new look, she told us that she thought it might be fun to try a new hairstyle. Sarah and I may have told her we weren't such fans of the curly wig, because I don't really remember her wearing it all that often. Most of my memories of my mother at the time are of her wearing floppy straw hats. I think those are the ones she found easiest and most comfortable to wear, and they also happened to fit her personal fashion sense perfectly.

While my mom was able to be at home with the family for most of the duration of her cancer, there were a few short hospital stays and times when we went to visit her there. Even in the hospital, where the stage was set to sit the two of us down and tell us what was going on, my mother's illness was never discussed in detail.

Somewhere in the back of our minds, we must have known that clearly something was wrong.

It had to be serious if she needed to spend nights in the hospital. But when we would get there, she was the mommy we knew and recognized. She asked about our days, wanting to know what we learned in school and making sure that all of our homework was done before we had come over. We loved talking with her and telling her every detail about our day and about our friends. We would go on and on, dancing and playing around the hospital room until it was time to leave. I think that we thought as long as we had time with her, whether it was spent in our home or in the hospital, everything was okay. Soon enough, she was back in our apartment with us and we just assumed she was slowly getting better.

My father came home on a Shabbat morning and told us that mommy had died. I remember being surprised and caught off guard that I hadn't realized she was so sick and that the end had been near. I was upset that I hadn't been at the hospital with them, hadn't been able to say goodbye in person and tell her that I loved her and I would never forget her. But when you're eight years old, how do you know when someone is really sick and close to death? It shouldn't be something you'd be able to recognize easily.

I can't fault my mother and father for the way they handled the communication around my mother's illness. I can't imagine what it must have been like for her to receive such a grim diagnosis, and then to come home and look at her two little girls, who she knew she wouldn't be able to see grow up. A mother's first instinct is to

protect her children. I understand my parents wanting to shield my sister and me from a disease that was about to change our family forever.

As an adult and as I look back on the past objectively, I am sorry for not knowing more details and not realizing that the time I had left with my mother was limited. It is both a scary and difficult thing to admit to your children that not only are you sick, but that you're scared, when it's you that your children look to as the biggest source for comfort and courage.

What should a mother recently diagnosed with cancer share with her children? As much as I appreciate my parents trying to protect me from all of the pain they were going through, I wish my sister and I could have been involved more so that looking back on that time as adults, we would feel as if we had been included.

Even if we didn't know all the details, it would have been okay to tell us that mommy was sick and we should spend as much time as possible with her. This way we could have cherished the moments we spent with her during her final months, knowing that they would be her last. I believe that one's family is the strongest support system and if you don't let them in, you may miss out on one of the best kinds of support available.

Having a family history of breast cancer and being as some would call "a patient in waiting," I know the importance of meeting with my high risk doctors regularly and learning whatever I can about early detection and possible procedures. While I try to be well-educated and able to put on the bravest of faces, especially when discussing

all of this with my husband, I often find some of the information frightening and overwhelming.

Sharsheret offers a support system that not only enables, but encourages families to open the lines of communication and to feel comfortable discussing different issues. Had an organization like Sharsheret been around at the time of their diagnoses, my mother and grandmother could have benefited tremendously from the support the organization provides. Had they both had an opportunity to talk with other women who currently are going through or had previously gone through treatment, they may have been more comfortable discussing their illness and the details with their families.

Becoming part of the community of support may have inspired them to take full advantage of the time that they had left and to live each day to its fullest surrounded by those that they loved the most.

Shera Dubitsky: Thank you, Ally. You have certainly set a beautiful tone for tonight's discussion.

Our next speaker is Toni Cabat. Toni is well-accomplished and highly esteemed in the world of psychosocial oncology and it would truly take days to read all of her accomplishments. I will share with you some of the highlights of Toni's career.

Toni is the Director of Family Services and Organizational Development at Chai Lifeline. She came to Chai Lifeline from Memorial Sloan-Kettering Cancer Center where she was the Assistant Director of Social Work. Toni oversees many vital

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psychosocial programs such as counseling centers throughout the Greater New York City region, teleconference support groups and information lines, graduate and undergraduate field training and is the Project Director for the Greater New York City Affiliate of Susan G. Komen for the Cure Grant, meeting the needs of Orthodox Jewish women living with breast cancer. She was the recipient of the Eleanor Clark Award for innovative programs and patient care.

Sharsheret has partnered with Chai Lifeline in the past and we are proud of the working relationship that we share. Toni, the floor is yours.

III. How Do I Talk to a Young Child About My Breast Cancer Diagnosis? Toni Cabat, DSW, LCSW

Toni Cabat: Thank you so much, Shera. Ally, it was an inspiration to hear from you.

I think Shera shared with you that I have much professional experience in dealing with families where cancer is an unwelcome guest. Mostly, we're going to rely upon the literature. There is much literature out there today and I'll be highlighting some books that may be useful both for children and parents.

Similar to Ally, I had my own personal experience that I think adds to this and probably was the impetus now that I look back, of why I got into this field. My own mother was also diagnosed with cancer when I was 12. My experience may be somewhat different than Ally's. I realize now, that many of the opportunities were not there many years ago. I'm much older than Ally, I won't say how much,

but I am a grandmother myself so you can imagine it was many years ago that I experienced a mom with cancer.

What we're going to talk about today is integrating cancer into your family. As I said, many folks have described it as an unwelcome guest. No one invited it, no one's really happy to have it as a part of the family. But the reality is once a member of the family is diagnosed, and oftentimes if it's the mom, it affects the entire family and it must be contended with.

It really doesn't go away so easily, and I think that today's conference is about how to address it. For each mom and for each family, it means understanding your own style, your own tradition, your own culture, your own structure, your own rules, your own emotional makeup, your own history, and your own strength.

No one can say to you from the outside, "This is what you should do and this is how you can do it," because you're on the inside. All of us, when it's not our family, are outside. Your extended family is outside, your friends are outside. Those of us that are professionals in the field, we're on the outside.

You really need to understand your own family style, take what I'm talking about tonight, and see how you can adapt it to your own family and to your own ability to communicate certain things or find other family members that can help communicate it. The approach that most of us are taking today is much more of a family-centered approach, whether it is in education, in mental health, and definitely in terms of oncology, when cancer unfortunately comes and visits your family.

There's a wonderful book that I've relied upon. It's a book by Wendy Schlessel Harpham. The name of the book is *When a Parent Has Cancer*. Wendy herself was a physician. When she was 36 years old she was diagnosed with a form of non-Hodgkins lymphoma. Her own children were two, four, and six. As a result of the experience, she decided to write about herself and her diagnosis and what it's like being diagnosed with cancer.

One day while she was waiting for a reporter to come to interview her about her book, her seven year-old asked if she could be interviewed. The mom took a cue from there and said to her daughter that the reporter was coming to talk to her, but she thought that would be a great idea if she and her daughter would talk. The mother would talk to her daughter through interviewing the daughter about what it's like for a child in the family when a mom has cancer. As a result of it, the book comes with a little compendium and it's called *Becky's Worry Cup*. It's basically the outcome of her talking to her own child about what it's like for the daughter to have a mom with cancer and her concerns and her worries.

From Wendy's book and Becky's book, we learn many, many things. In talking to the children, it has to be on an age-appropriate level. It's very different, even for two sisters in a family as Ally talked about, if one is three and one is ten. It's a different conversation if I was twelve as opposed to three. Maybe my mom wouldn't have said the same kinds of things to me.

What you say to a child depends upon their own age level and even two and three year-olds may have different levels of sophistication: the language, the logic, their own pre-conceived notions, their own experiences, their ideas, including their own fears, hopes, and their faith. What you're telling a child, how much you're talking to a child about your own diagnosis or what it means to the family, again, has a lot to do with the age of the child and a child's abilities. All the information has to be age-appropriate.

What Wendy tells us in her book when she's talking about information, is giving us the courage to talk about it. What we do is look inside and find courage to face the future honestly, with hope and love. Information has to be delivered with love and hope and, again, in an age-appropriate fashion.

What I wanted to do is talk about some books. I've mentioned Wendy's book, which I think is useful for a parent, a compendium which you could use with a child as young as eight and up. Another book I want to mention is *How to Help Children Through a Parent's Serious Illness*. That's by Kathleen McCue and it was written in 1994. Again, these are two parent-oriented books. You need some language when talking to the children, and some of these books will give you that language.

For younger children, more like three to eight, there's a wonderful book, *In Mommy's Garden: A Book to Help Explain Cancer to Young Children*. Many of these books can be found on the Internet. The author on that one is Neyal Ammary. In this book, everything is colorful, with great pictures, but not such big words, so it's good for younger children. She compares the weeds in the

garden to cancer and the flowers to the healthy cells and uses that analogy to explain to the children what cancer is like and what mommy is doing in terms of the garden.

Another wonderful book that Shera suggested is *Butterfly Kisses and Wishes on Wings* by Ellen McVicker and Nancy Hersch. Again, the language is very simple and the pictures are beautiful and explains what is going on to younger children.

A book that was written a little while ago, is *Mira's Month* by Deborah Weinstein-Stern in 1994. I think it could be used for an older child, and again, can give some of the language. In that book, the mom goes off and is in a hospital for a while. That's the month that the child checks off and talks about how she contends with it and how she uses it.

A very wonderful website if people are not familiar with it, is Kids Konnected, www.kidskonnected.org, in which you have many opportunities for older kids if they want to talk online and also for parents to get some language.

The key concepts that you're going to be conveying to the child are:

- Openness
- What is going on in whatever language is age-appropriate
- The information and facts
- Hopefulness and love
- Identification of the positive and negative feelings
- The experiences of the child
- Understanding the child's fundamental needs.

I think I'll talk a little bit about some of the personal experience that I can remember. I was 12, many years before cancer was even a word that was spoken. Oftentimes patients weren't even given that word as part of their diagnosis. But I think my mother, without some of the benefits of the education that I had, had a very clear instinct that a child needed to know that their needs were being met.

She was clear and said, "I'm going to the hospital." She would be away a while. At that point, children weren't even able to visit. Ally was talking about going to the hospital and playing around; I went back many years and remembered children weren't even allowed up to the hospital. I remember she reassured me that I'd be brought by my dad. I could see her from a window and I could wave. I think she was assuring me that she'll be there for me. I could see it very concretely, and I can remember that visit.

She also assured me if I needed anything and she wasn't available, to be in touch with my aunt. I was very close with my mother's older sister, and my aunt was going to be there for me. She made it very, very clear. I knew the phone number, I knew the address. It was like, don't worry. There's a backup.

I even remember her saying, "If Mommy doesn't get better, you know you can call your aunt. You know your aunt will be there for you." Again, this was meeting my fundamental needs, my concrete needs. Who was going to take care of me? If I needed something, who can I call, because Daddy was going to be busy visiting Mommy?

The third thing she did was a very, very concrete thing. At that time I didn't understand it. Now looking back, I understand it a lot more. She gave me a small sum of money. I still to this day can't remember how much. I keep saying it was \$20, but that sounds like a lot of money for back then. To me it seemed like a large sum of money, but it was probably a small sum of money. She said, "Listen, if there's anything you need while I'm not here and if Daddy's busy, you can go right around the corner to the store and pick up ice cream or anything you want." And she left me in charge of this money.

All of these things were taking care of my fundamental needs. I knew where to go. I knew I wasn't alone, there was someone a phone call away. I knew I'd get to see her, and I knew I could be in charge of this little sum of money, which I think in many ways shaped my life and made me a very responsible person.

We can talk about some of the benefits that come out of this. I was reassured I was going to be cared for and I knew who was available in her absence. Sometimes moms can't do all of this and they can't say all of this. What happens if you're overwhelmed and you can't handle all of this? Are there other people that can help explain some things to your child? A spouse? Other family members? Health care professionals? Sometimes parents say that the health care professional should talk with the children, but we want a family member. I don't think it's a really great idea for a social worker to be telling a kid, "This is what's wrong with mom, this is why you won't see her." Many times, mom or dad can use the strength and some of the language of all those professionals.

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Some parents have said, “They haven’t asked. If they don’t ask, I’m not going to say anything.” I think most of us say, “Take some initiative; start to tell them something that’s age appropriate.” Use the resources: Sharsheret, many of the websites, the books.

It is best to tell them in a quiet place, one child at a time. Again, keep things simple, direct, and maybe not tell everything all at once. I know some parents try to give the children so much information that it’s a little bit of an overload. They go back to a simple question like, “Why aren’t you better? When are you coming home?”

Many of us struggle with the question, “Do we use the word ‘cancer’?” Each person needs to deal with this in their own family structure. Some families are very open, very comfortable, and very able. Some families are not as comfortable and many of us encourage you to try and see what your level of comfort is and find other words.

You need to prepare yourself before you start talking to them, for the questions they’ll ask. “When will you get better? Will you get better? Can I get cancer? How did you get cancer? What if Daddy gets cancer? Will you be able to come to my baseball game?” These are the very basic questions that any discussion that’s opened will oftentimes lead to. Sometimes if you prepare yourself when you get the question, you’ll be in better shape to learn to handle it.

I think lessons can be learned from this. Can any good come from this? I think that’s an important part. Sometimes the children learn

that their mom is not going to look well. Ally talked about the sparse hair and the funny wig. That's maybe a time for a lesson about what people outside see, but inside she is the same mom. She may have been bald and puffy. Maybe, there was a weight change and she's tired. Inside, she is the same mom and they need to learn some of those lessons, understanding about the change of a health status and also how to deal with stress, worry and, uncertainty.

I mentioned to you the companion book that comes with Wendy Harpham's book, *When a Parent Has Cancer*. It's called *Becky's Worry Cup*, recognizing that her daughter had worries and addressing how could she help the daughter deal with the worries. Again, she establishes the routine of a worry cup.

The lesson is change and adaptation. Change will happen to all of us in all families with the mother's illness. As with any change in family, how do we adapt and what is the lesson of flexibility? I remember one of the best things I learned from my Abnormal Psychology professor, was that the sign of mental health was flexibility.

It's good that children have a routine: go to bed at the same time, get up at the same time, brush their teeth, and take their bath. But they need to learn the balance of flexibility too. When Mommy isn't feeling well, we can take a later bath, we could have somebody else help us with our homework. From this, many times children will be empowered. How can they help themselves? How can they help the family?

Don't put too much on their plate, but maybe it's time that they can set the table. Maybe they can be involved in preparing a meal, so that they can be part of the new family structure. Children are resilient. Family priorities may have to change; your priorities may have to change.

One thing I often talk to mothers about is what can you give away? They say, "What do you mean?" You're so used to doing the cooking, the cleaning, the laundry, and the many different activities in the household. If you couldn't do one of them and maybe someone else could do it or some service could do it, what would it be so that you could keep your energy bank account? So that you can save your energy for maybe something you could do with the children or something they could help with.

Something else that is important is never to speak about them in front of them or within earshot. Many times people say, "Oh, they don't hear." Then oftentimes you'll know that the kids heard everything. One mom submitted a question that she didn't want to tell her 11 year-old daughter about the drainage bottles or this or that, but the child saw them from the corner of her eye and started asking questions.

Another thing you can do, if you can't be there, is to set up a substitute ritual or routine. If you can't be there for nighttime, what you can do is set up a tape recording and go through the ritual and the child can follow along. Or they could write a letter to you every day, if you're in the hospital. Or video the play you can't attend and show it to other family members. Or maybe use a computer hookup for long distance communication if you have to be out of

town for a while for treatment. Turn some of these obstacles into opportunities.

I go back to my experience again. Remember the small sum of money that mom gave me, I was very proud when she came back home. I set up what now I know as a spreadsheet. I showed her what I spent, what I spent it on, and how much more I had to give back to her when she returned. That lesson stays with me today. I manage money very, very well and never was afraid of it. I think it came from that very, very simple experience and the obstacle became the opportunity.

Also, find a place where cancer doesn't invade. Remember I said it becomes the unwelcome guest? But is there an island in the house where cancer does not exist? Maybe it's the kitchen, the dining room, the place where cancer doesn't take over your world and their world. A time when we're not talking about illness, when we're talking about other things that are going on in the family.

In my final conclusion, I'd like to talk about what happens if there are some disappointments. If a child says, "I thought you'd be over this, I thought you'd be better." Or the child themselves, starts to show some physical symptoms, perhaps they're not feeling well. Or there's regressive behavior, they're acting more childlike, they forgot their toilet training. They're blaming themselves, "It's my fault that you're sick." They're showing unusual fears or anxieties. They become aggressive, they withdraw, and they become quiet. They have sleeping or eating difficulties.

You need to assess whether these are short-term or is it stress? Can you verbalize some things for them; help them along with this, provide some reassurance? Or at this point do they need some intervention, someone to assess if this is very temporary?

The more you can verbalize their disappointment, their anger, their loss, and their sadness, and balance it with hopefulness and appreciation for what they're going through, it may be able to help them. We've talked about finding the silver lining. What can they get from this? What can they learn? What have they grown from?

Some famous children books, for example that have nothing to do with cancer that many parents have used in helping their children grow up are *The Little Engine That Could* or the famous *Wizard of Oz* and the lion of courage. Many of you can probably cite many biblical figures that faced adversity. How can they deal with this kind of adversity?

Be conscious of all times to use, wherever you can and however you can, the laughter, the distraction, again, that Island of No Cancer. Play is a very therapeutic tool. Kids love to play and they express themselves through play.

Make use of the many books out there. Many of the resources available will give you some of the language and some of the words to use in talking with children. Make use of the professional health workers: social workers, psychologists, Rabbis, and communal leaders. A book that was well known a while ago and helps reframing it emphasizes, "It takes a village to raise children, not just one parent." Using all of these resources in helping to discuss your

diagnosis in the family with young children will be helpful. Thank you.

Shera Dubitsky: Toni, thank you. We're particularly grateful for how much important information you were able to provide to us in such a small amount of time.

IV. How Can I Help My Teenager During My Cancer Treatment? Shera Dubitsky, MEd, MA

Shera Dubitsky: At this point, I will now introduce myself. I am Sharsheret's Clinical Supervisor. I have 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 Services. I have worked as a researcher at Memorial Sloan-Kettering Cancer Center, and as Sharsheret's Clinical Supervisor, I assist women newly-diagnosed and at high risk of developing breast cancer, in addition to providing supportive counseling for women living with metastatic breast cancer.

The way I see this evening unfolding, I feel like we're putting on layers. By all of us sharing our experiences, we're adding layers. I really want to add on to what Ally and Toni have already shared.

June 26, 1978, I'll always remember that date. It was my parent's anniversary and we were all gathered at my aunt's house to celebrate. After the meal, all of the kids dispersed and then we were summoned back to the table. I was 13 years-old at the time and my parents stood and announced that they had some difficult news to share. My mom said that she had just been diagnosed with breast cancer and that was all I heard. Apparently, I missed the part about it spreading to the other parts of the body, because just the words "breast cancer" sent me into a fog.

I didn't exactly know what cancer was and in those days no one voiced the words "cancer." There was no internet, no Oprah Winfrey, no Susan G. Komen, and most unfortunately, no Sharsheret.

I remember looking around the table for clues on how to respond to this and everybody responded so differently. My aunt was crying. My grandfather remained silent and still. My parents continued talking and they assured us that they were going to fight this with everything they had.

All of us kids just sat and watched except for my 10 year-old brother. I don't know what it was, maybe a lack of fear, lack of reservations, perhaps simply a lack of knowledge, he was the first one to speak up. Innocently he said, "Well, what's that?" To be honest, I don't remember what my mom said. I do remember that as she spoke, her initial bravado softened and she became teary. That was very hard to watch. Subsequently, I learned that my 41 year-old mom had been diagnosed with Stage IV breast cancer. My parents traveled all over the world for second, third, and fourth

opinions, yet the opinions didn't differ. The consensus was that my mom had little time left.

My parents were very open with us about the cancer, about treatment, and about their feelings. I often wonder if maybe they were too open. But then again, I also think that my brain only processed what it could. My defenses protected me by only taking in as much information as my psyche could tolerate. In hindsight, I am better able to understand the dynamics within my family. Unconsciously, we each assumed a different role in the family that represented all the emotions that we were experiencing collectively.

Let me elaborate, because I think that this is important. As we experience trauma, we become a more extreme version of ourselves, a magnified version, and in some cases, a caricature of ourselves. If someone is a doer, then they move into hyper-action mode. If someone is by nature a worrier, then that becomes heightened.

My dad was a pulpit Rabbi in a conservative synagogue. His baseline was to be public and rely on his congregants for logistical and emotional support. There certainly were no private moments. My mom, the Rebbetzin, also a public figure, wanted more privacy and primarily wanted support from her family and close friends.

My 16 year-old brother never used emotional language. He never discussed conflict or struggles and just went about his life studying, sports, and friends. My 10 year-old brother had no filter and he would say what everyone was thinking but would never dare say aloud.

I was the emotional one. Perhaps because I was the only girl, a middle child, I carried the emotions for the family. It was really the perfect storm. Having just turned 13, my hormones were stirring up and I had just started middle school. And now my mom, my role model, my only trace of estrogen in the house, was fighting for her life.

Collectively, we were all these things. I think we all wanted to shout it out to the world to solicit help from every possible source out there. Collectively, we needed a boundary and some privacy. I think all of us wanted to go on with our lives as if this wasn't really happening. I think we all wanted the freedom to say what we were thinking without emotional repercussions. And I'd like to believe that we all felt angry and scared, worried for my mom's well-being, as well as our own. We each took ownership of these different aspects of coping and, together as a family, we lived with advanced breast cancer.

There were times that I felt angry that we were all reacting and coping so differently, but now 25 years later, I think by each taking a piece, we gave each other a gift. We couldn't be all of these things. We would be too overwhelmed, we would have just imploded. We needed someone to be the calm one, another to be the worrier, and another to remind us that we needed to normalize our lives.

I am grateful to my younger brother for soliciting information that I would never have had the courage to seek out. Now, I'm ambivalent about having been the one to carry the emotions. I had so much anger, but I felt tremendous guilt when I expressed these feelings. I remember worrying that my emotions would be the

cause of emotional pain for my parents, as if somehow that pain didn't already exist within them.

I appreciated that my parents shared information directly and openly. There were maybe one or two times that I overheard my parents speaking to one another or with someone else, and I was pained by what I had heard, as Toni had mentioned. Now that I have my own kids, I'm reminded how somehow kids manage to hear everything and they manage to see the things that we're trying to hide.

25 years ago, there was no internet, and no Googling. The downside of this is that we were very limited as to the information that was available to us. Another downside is that well-intentioned people often shared anecdotal information that was either irrelevant or just outright wrong and heightening our anxiety.

The advantage of not having internet was that the information my parents shared with us was tailored to the unique set of variables pertaining to my mom.

Today, our children have access to the internet and we speak more openly about breast cancer. But again, this also has its pros and cons. I highly recommend that when speaking with your teenage children, you need to remember that you are setting the emotional tone for how the family will face cancer. You may want to remind them that they may hear or read about a lot of information regarding breast cancer, but that there exists a unique set of variables that are relevant to your cancer.

I appreciated that my parents offered us the option to go speak with the oncologist. I felt reassured that we were really in good hands after speaking to the oncologist, because somehow it was one thing hearing it from my parents, but there was a different level of validity when we heard information directly from the medical team.

My spontaneous memories of my teenage years revolved more around my social life than my mom's cancer. My parents managed to create a new normal in the household. We went to school, engaged in after school activities, were involved in the synagogue, and we went to camp just like all the other kids.

Every week a different person took my mom to chemo treatments and this was also normal and routine, for us, at least. Sometimes I would go with my mom and her friend and I remember the waiting room where everyone was so happy to see her and this, by the way, was not normal to me but not for the reasons that you would think.

My mom had my, then, eight year-old cousin draw a placard that she wore as an old-fashioned sandwich board to her treatments which included a word of profanity not appropriate for this presentation. Attached to this board were colorful helium balloons, enough to seemingly lift my mom off the ground. One day there was a new nurse on the shift. Upon seeing my mom, the nurse called the psychiatric unit to see if a patient had escaped. This vision still makes me laugh even 25 years later.

What I remember most from my visits to treatment was not the hospital, but the lunches that followed. It was a ladies day out and I felt so included. Now, I'm not suggesting that you have to bring

your kids to treatment or doctor's appointments. My point is that parents - my parents, at least, kept to the routine. I now understand that every household has their own routine and that one seemed normal for us. By establishing a routine it normalized my experience and I felt safe, emotionally, and well taken care of.

I don't want to mislead you because things weren't always calm and routine. Things got loud and chaotic at times. We had sibling rivalry, fights with parents, squabbles with friends, and problems in school. I suspect that it was difficult for my parents to know how much of our behaviors were connected to our feelings about my mom having cancer and how much of it was typical teenage behavior.

Teenagers, by their very essence, are unpredictable. I suppose that this becomes exaggerated when facing difficult and painful challenges. I remember one time my mom asking me directly, "Are you reacting this way because you're worried about me?" I just couldn't answer that. How does a teenager know what's typical or what's a reaction to cancer?

It's difficult to know the ingredients that contribute to one's behaviors. When we see a cake we know that it contains milk, flour, eggs, sugar, salt, and so on. What we don't know when we are presented with a cake is how much of these ingredients were used. It's the same when coping with cancer. We know that there are many contributing factor and ingredients. How much of it is typical teenage behavior versus a response to cancer remains an unknown. We should just assume that all these ingredients found in this cake are called "teenagers coping with a parent with cancer."

As I give my teenage years more thought, I think I was ambivalent about my level of independence. On the one hand, it is developmentally appropriate for teenagers to separate from their parents and spend more time with their peers. I did this, but at a cost. I remember worrying about my mom, thinking that maybe I should stay closer to home. My parents discouraged this as much as possible, encouraging me to partake in the typical teenage activities.

I don't remember talking about my mom's illness at any great length with my friends. Throughout the six years that my mom lived with cancer, I can only recall two distinct conversations I had with a peer about what was going on with my mom. It's hard to remember if this was due to my wanting to maintain privacy or if I just didn't think my peers would be able to relate to what I was going through.

I think, on some level, that my brothers and I responded differently because of our difference in gender. Adolescence is a time when our bodies are changing. As I was developing breasts, a time when most girls are feeling good about development, I remember wondering if my breasts would someday cause me to have a serious illness. As I developed breasts, my mom was losing hers. As much as I wanted to be like my mom, I remember having a conversation with her about finding the differences. I think we were both secretly happy that I began menstruating at a later age than she. Perhaps if there were enough differences somehow I would, maybe, dodge the bullet of ever having breast cancer. My brothers didn't struggle with this issue, though they certainly had their own unique concerns.

In retrospect, I wish my parents had a better sense of the areas that were appropriate for me to help in the care giving and those that weren't. Certainly it felt important for me to help in the house and to assist my parents with certain tasks. However, there were areas that were just not appropriate for me to be helping my mom and that boundary was sometimes blurred. I advise parents to be cognizant of these boundaries and to not expect their teenage children to take on too many added responsibilities.

I just want to briefly expand on the issue of boundaries. Concerned people in our lives perceive teenagers as being old enough to field questions or share thoughts about a parent's illness. I remember feeling put off and uncomfortable when I would be at the synagogue or in town and people would approach me with questions. First of all, I just wanted to go about my normal routine. I also think that I was more fragile than I appeared even though outwardly, it seemed as if I was a confident, outgoing teenager. I suggest mom's try to encourage friends and families not to use their children as conduits for information.

When I look back on my adolescence, I appreciate that my parents didn't focus on the big events or the big ticket items. My parents understood that quality time, hanging out, and just simply spending time together, was all we needed. My spontaneous memories of that time in my life are not the Bar and Bat Mitzvahs and were not the times we spent on vacation. My spontaneous memories were that I started my day with my mom cuddling with me. I remember when I came home she always sat with me and asked me about my day. I remember family dinners and hanging out with her on her bed. It was the day-to-day interactions that were the milestones.

So what are the takeaways? Remember that you are the expert when it comes to each of your children. Each child will have a different reaction and will have different needs.

Encourage your teens to talk about their feelings, but realize they may find it easier to speak with friends or teachers or Rabbis or they may prefer to handle it privately. Talk about the changes in the household and let them know what to expect, but that you will try to keep things as routine as possible.

Remind them that their emotional and physical needs remain a priority. Encourage them to maintain activities and friendships. Set appropriate limits regarding care-taking and don't rely on them to take on too many added responsibilities.

As much as you can, try to encourage friends and family not to use your children as conduits for information. Offer them resources or access to your medical team if they seem to have questions or concerns.

Toni spoke about this and I want to emphasize it. If you see that they are exhibiting significant changes in mood, appetite, sleep habits, socialization, or school performance, you may want to consider counseling.

In the information packet that we sent out, there is a wonderful guide called *When Your Parent has Cancer: A Guide for Teens*. I encourage you to look at that. Also, I invite you to look on the Sharsheret website, www.sharsheret.org, for the transcript, *How Do We Care For Our Children?*

I would also consider journaling or documenting your life. I wish I had my mom's own words when it comes to her life from her childhood to my childhood. Regardless of where you are in your journey, whether recently diagnosed or whether you are post-treatment with no evidence of disease, I invite you also to look at the transcript, *Take It From Me: My Experience in My Own Words*, for tips on getting your stories and thoughts down for your children.

At some point, it may seem like cancer ends. For most women today, it comes when a woman is said to have no more evidence of disease. For other women like my mom, it came when she passed away.

Many people in our support systems want to just move on as if cancer is over. We are changed forever because we have been touched by cancer. Fears of recurrence or fears that family members may be diagnosed with cancer are strong. The lingering impact lasts for years, both in the positive and negative aspects. It's important to remember that this is true for your children as well.

Whenever I see a new doctor and they take down my family history, I'm reminded. Whenever I read something about cancer or hear about someone with cancer, I'm reminded. When I have to go for routine exams or screenings, I'm reminded.

Whenever I'm faced with challenges, I remember the gift that my parents gave me. I remember to stare challenges straight in the eyes and decide that they will not break me. I remember to rely on resources and support systems to help me through the journey. I don't have to go it alone. I remember to laugh even during life's scariest moments. I remember to embrace the every day moments

and to not live for the big milestones. It's 25 years later, and it still touches me. But my brothers and I, we're okay and I wanted you all to know that this outcome exists.

It's now my pleasure to introduce Niecee Singer Schonberger, Sharsheret's Genetics Program Coordinator. Niecee graduated from Sarah Lawrence College with a Master's of Science in Human Genetics. She has provided genetic counseling in all aspects of genetics, and for the past ten years, has focused on breast cancer genetics. She is a founding member of the National Society of Genetic Counselors and a past president of the Human Genetics Association of New Jersey.

Niecee provides supportive counseling, information, and resources regarding hereditary breast cancer to women diagnosed and at high risk of developing breast cancer. Niecee approaches each interaction with expertise, warmth, and patience as women have shared their deep concerns around hereditary breast cancer, genetic testing, and its implications. Niecee, I now hand the floor over to you.

V. What Can I Do to Ensure My Young Adult Daughter About Her Risk of Developing Breast Cancer?
Niecee Singer Schonberger, MS, CGC

Niecee Singer Schonberger: Thank you, Shera. And thank all of you for these personal stories that are so insightful and helpful. My discussion tonight will be less personal but framed by a scenario in which a woman has been diagnosed with breast cancer, had genetic testing, and is found to carry a mutation in a BRCA gene. The dilemma then is if or when to discuss this with her 18 year-old daughter, whose risk now of carrying a mutation is 50 percent. Of course, there's also a 50 percent chance of her not carrying the mutation.

For many years, the prevailing wisdom in the genetics community has been that one does not test minors if no medical interventions are indicated. In 2003, the American Society of Clinical Oncology stated, "Where no risk reduction strategies are available and the probability of developing a malignancy during childhood is very low, for instance, with hereditary breast and ovarian cancer, testing should not be offered."

But it's not that clear-cut today and guiding an 18 year-old after your diagnosis of breast cancer and a positive mutation result, can be fraught with uncertainty and misgivings. The question as to what and when to tell her, and how to advise her, can be overwhelming. There have been numerous studies performed over the years to look at the best way to address these very questions, but despite professional guidelines recommending against testing minors, there is ongoing debate over the testing of minors for the BRCA mutations and other adult onset genetic disorders.

The debate is, essentially, over the rights of the parents to have information that can optimize the ongoing health care of their children against the rights of the children to have their best interest protected and to make their own decisions about whether they'll actually want the information when they become adults.

As we heard just a little while ago, children and older adolescents have access to the internet now where they can learn everything they want to know about genetic testing and certainly the media and TV cover the subject almost daily. So they know a lot more and are more comfortable with genetic testing than adolescents did in previous years when these guidelines were put forth.

Studies on the subject of when to tell are divided and offer, unfortunately, no good advice to parents facing this dilemma. In a 2007 study, it was found that only a minority of children had problems with understanding the implications of the information and a similar minority had negative results to the disclosure of the cancer and the test results.

We'd all agree, of course, that a parent shouldn't burden a child with her own problems or test her daughter in order to reassure herself. However, open communication leads to less guilt and less secrecy. One study showed that if the parent shares the worry with her daughter, there's less depression on the part of both of them, in addition to positive adjustment for both. I'm going to give you some of the potential risks and benefits of sharing the information and encouraging or not encouraging your daughter to test at this age.

Against testing at age 18 is the fact that there is no medical indication or timely benefit to knowing if she's a carrier. There are

no risk reduction options recommended until age 25, when clinical breast exams and mammography would begin.

Also, an 18 year-old may be too immature to deal with the information or make an informed decision as to whether or not to undergo testing. Having her parents know her genetic status violates her right to confidentiality, which may cause her a great deal of distress. It should be recognized that she'll benefit from having the opportunity to participate in the decision-making process when she's old enough to do so, but may not understand the implications for her future if she tests as a minor.

Having a mutation means that the risk for ovarian cancer is increased as well as the risk for breast cancer. Since there's no reliable screening tool at this time to detect ovarian cancer at an early stage, the recommendation is removal of the ovaries once child-bearing is completed. A mutation carrier would be advised to have her children earlier rather than later.

Also, depending on which gene is involved, there may be risks for other cancers, as well. Facing these possibilities can cause an 18 year-old increased anxiety and dread of the future. Knowing that she carries a mutation that predisposes her to cancer will become part of her self-concept as she matures. As an adult, she may even decide that she doesn't want to know her mutation status and she's entitled to have the option of making that decision for herself.

On the other hand, in support of informing and/or testing at this age is the idea that this may foster preventative behaviors early, change her early health habits, teach her about breast self-exams, and informed child-bearing decisions. Also, knowing can bring relief

from uncertainty and allow her and the family to make informed choices for the future, including plans for health care, career, and reproduction.

Many 18 year-olds are mature enough to handle the information and to make their own informed consent to either test or not to test. After considering these potential risks and benefits, most experts have still concluded that predictive testing of minors for adult-onset diseases is not appropriate unless specific medical interventions are recommended prior to adulthood or the request is voluntary and comes from a competent and informed adolescent.

The determination to delay testing until adulthood is also based on the speculative nature of the psychological benefits and harms. Parents have to respect the child's right to dissent to testing despite their own urge to know.

Obviously, there are no right or wrong answers to this dilemma, only a caution to weigh the pros and cons in light of what you know about your daughter, her level of maturity, and her desire to hear the information. If she tests and is negative, that's amazingly reassuring and her risk of developing breast or ovarian cancer in her lifetime is the same as anyone else in the general population.

But if she tests positive, the burden of that knowledge can change the way she sees herself and her future. It could also bring her relief from uncertainty and so your discussion with her, if you decide to have that discussion, has to be cognizant of the implications of the knowledge you're offering as well as her desire or lack of desire to know.

There's plenty of time now for your questions and comments so please let us know your thoughts on any aspect of the teleconference and Shera, Toni, Ally, and I will be happy to answer your questions. Thank you.

Shera Dubitsky: Niecee, thank you for taking such complicated information and sharing it in such a manageable and understandable manner.

VI. Question and Answer Session

Moderated by Shera Dubitsky, MEd, MA

Shera Dubitsky: We are now going to open the floor for questions and answers.

We received several questions prior to the teleconference. An 11 year-old daughter asked her mom, "When is this all going to be over and when are you going to be 100 percent better?" The mother's question is, "I don't even know the answer to that, so how do I begin to respond to her?" Toni, can you take that question?

Toni Cabat: Sure. It's the million dollar question that not only her daughter has, but that we all have. Sometimes part of it is the honesty. We talked about the open communication and the trust. The honesty may be being able to say, "I'm going through it with the doctors. Everything I know from the doctors I will share with you as much as appropriate and possible." You may not know at what point you're 100 percent better and when it's going to be all over. But as you go along, the process you'll share with her.

I think it's the disappointment that a child is sharing and that we all share. That it's not going along the road that we wanted and hoped for. That everything would be fine. Any one of us going into any medical procedure is all hopeful that we will be coming out of it feeling pretty good. A day or two or three or four afterwards, you realize that the recuperation process is taking longer than you anticipated. If you're sharing that with her and being there for her, it will help her a little bit along the way. There's no certainty and it may be just letting her know that you're there with her during that uncertainty is reassuring.

Shera Dubitsky: Thank you, Toni. Niecee, a question came in for you. “You spoke a lot about 18 year-olds. My daughter is 14 and she is very concerned that she will be at risk for developing cancer. Any suggestions about how I should address this with her?”

Niecee Schonberger: The first thing you have to do is to begin with what she already knows. As I said, there’s so much information out there. It’s important to know what she already knows about cancer and about the inheritance of cancer. Also, find out what her questions are before you start. Don’t just give her a lot of information because, as Shera said, you can answer too many questions that are not pertinent to what she’s really asking.

In terms of the inheritance of it and the possibility of it, I would even start with saying that most breast cancers are not inherited. If she’s concerned about her own risks, that’s the truth. 90 to 95 percent of breast cancers are not inherited and so that could be reassuring for her.

What Shera suggested about having her go with you, if she is mature enough to handle that, to a visit with the oncologist or to participate in your treatments can also be very reassuring for her.

I don’t think that going into the genetic testing aspect is really appropriate for a 14 year-old but if she knows about it, then I think you do have to discuss it with her.

Shera Dubitsky: Thank you, Niecee. Another question came in. “My kids are six, eight, and nine and I worry about what they will think about going to doctors or about illness in general. Ally, do you feel tainted by your mom’s experience?”

Ally Cooper: It's important to address the ages of the kids. Like Toni alluded to before, you know your children and you know what is age-appropriate. What you would necessarily share with the six year-old about doctor's visits might not be the same way you would present it to your nine year-old.

We really weren't brought to doctors visits or included in that conversation. I don't know how much my younger sister would have benefitted from something like that. I think if I had heard a little bit about it that was age-appropriate, I would have felt better about it. I also think your kids are following your lead. If you go into the doctor's office with a brave face and you discuss what's going on at whatever level is appropriate, they'll follow your lead. If they think you're being brave and informing them, they'll feel just as brave and secure about it.

Shera Dubitsky: Toni, do you have anything you want to add to that?

Toni Cabat: Niecee alluded to sometimes seeing the silver lining in the cloud and taking the opportunity for teaching and learning moments. None of us approach going to the doctor's visit with great glee, but know it's something that we need to do. In the long run, the doctor's visit, if it uncovers something, will bring us to the treatment quickly. That's the piece that needs to be conveyed to the child. Recognizing the apprehension, recognizing that it's not something anyone wants to do, because none of these procedures sound like fun.

At the same time, we do believe in keeping our health up and improving our health. For that reason we feel that we're proactive. Compare it to something less intrusive and less invasive but on the

same principle as brushing your teeth. Very few kids really want to get up there and go brush their teeth. They learn pretty quickly that this is helpful in the long run because they will need less dental care. It makes it part of the routine and participating in it gives you some level of control. But I'm not sure about their involvement, again, in going to the oncologist unless they're very age appropriate and need more information from that visit.

Shera Dubitsky: Great. Toni, we have a line of questions for you. "How do I discuss a mastectomy with an 11 year-old child?"

Toni Cabat: Now again, it goes back to some of the things that Niecee said. What have you told the child about what you're going for? Does she understand about the bad cancer cells and how they can be harmful to you? Also, when you have something bad that has to be removed, how does it be removed? Going from the simple, let's say the bump on your hand that needs to be removed, the mole or whatever, to a more intimate body part such as the breast. It is something that will not only help you, but also save your life from that bad cancer cells spreading throughout your body.

It's taking it from the simple notion of why something is being removed, to the more complex notion of a part of your body that is being removed. Again, follow the child's needs and don't jump into many complicated explanations. Unless the child, at that point, asks the questions. If she thought to ask, then you have to be prepared to tell her.

Shera Dubitsky: That would probably be true for this next question which is, "How do I address questions about recurrence with my four year-old?"

Toni Cabat: We've got lot of young ones today. Again, what does a four year-old know about recurrence? It's the same question at any age, that mommy has been sick and could mommy get sick again? In all honesty, you can't say yes or no because you don't really know. It goes back to that first question about the uncertainty.

It would be very nice if we all could say, whether it is to our children or even to ourselves, that something will never come back again. Everything is going to be fine. We know that we all live with a certain amount of uncertainty in the real world, because we don't know that answer.

We explain to the child that we're hoping that something doesn't come back again. Just like the bad cold that the child may have had or the chickenpox or the flu or something else like that but we know that sometimes it does come back and just like we had medication, treatment, help the first time, we'll have medication, help, and treatment the second time. Again, stay age appropriate since it's a four year-old.

Shera Dubitsky: I'll field this next one. The question is, "How does one deal with the emotional aspect? What about unexpressed fears and crying?"

I would have to say that what's true for you as the parent is true for the kids as well. One of the things that I'm sure many of you experienced when you've called me at Sharsheret, on the first phone call, was that when you would become teary or start to cry and then feel apologetic about it, my response to that is, "I'm glad to hear you're taking an emotional hit, because that seems like the rational response to such an irrational situation."

I actually think that it's healthy for your children to see you crying about this and hearing words like, "I'm scared too, but I want you to know that I'm being as responsible as I can be in terms of my doctors, in terms of the treatments that I'm pursuing, and that I'm very confident about my treatment team. Even so, it can feel scary at times."

It's important to be able to model for them that the whole range of emotional experiences is important because at the end of the day, it will validate their own emotional experiences.

Shera Dubitsky: Toni, you're back on again. A question came in about the parent trying to filter information based on what they think would be protective to their children. There have been occasions where either the child has seen something or has overheard something and has confronted the parent on that. The question is, "How do you know if you're filtering properly?"

Toni Cabat: That's another million dollar question. The best way of knowing is that the child feels comfortable enough to come back with the question and ask you again, "Mommy you said this, but I see that." What does it mean? It means that you've established an openness about the communication. As you said Shera, you can't tell all the kids at different ages all the things. They may sometimes feel a little overexposed if they got too many details.

It's natural for a parent to try to filter some things based on what's age-appropriate and understanding their child. If the child comes back and says, "What about that?" or "I heard that" or "I saw this," then you have to keep those wonderful lines of open communication that you already started. Really congratulate the

child for coming back and asking some more and maybe taking that deep breath and going to the next level of explanation.

Remember I said when you start the conversation you have to think through some of those questions that they might ask like, “Can I get it? How did you get it? Can it happen to somebody else? Are you going to die?” It’s the same thing, you filtered, and maybe appropriately so, and then the child sees something, hears something, and you need to be able to answer. As long as the child hears that you’re being open and you’re helping them with as much information that you have and feel that they can handle, they’re comfortable coming back to you. Then you’ve been very, very successful with it.

Shera Dubitsky: Thank you, Toni. A question came in for me that we had mentioned some books for teens that are technologically advanced. The question is, “What websites would be helpful in a Jewish vein as opposed to just Googling?”

As we all know our kids may just end up Googling, but what I’ve recommended to moms in the past is to actually make a list of websites that you have felt comfortable with. For example, Kids Konnected is a great website to go to. Some of the reliable websites for breast cancer that I always go to are, for example, Breast Canger.org and I plug in my questions there. I would encourage your teen to do those searches with you so that you’re sure they are putting in the proper information.

The other thing that is important is that we have a program called *Family Focus*, which includes the “Ask Sharsheret Helpline”. I certainly would encourage you to either have your teens call me

directly or you can call me and ask for specific information in terms of how to present this to your teens.

VII. Teleconference Conclusion Closing Remarks

Shera Dubitsky: As we wrap up this evening, I'd like to thank all the speakers for their wisdom and warmth in discussing the emotional and physical well-being of the children whose lives have been touched by breast cancer.

Please be sure to complete the evaluation forms you've received in your information packet or online. Your feedback is very, very important to us. Again, I encourage you to reach out to Sharsheret for further support and resources. The phone number is 866-474-2774 or you can even email me directly at sdubitsky@sharsheret.org.

If there are further questions, you can certainly send me an email or call me directly and I will make sure that the questions get to the appropriate presenter from this evening. They have agreed to respond to those questions. Additionally, if you have not received the information packet, please feel free to contact Sharsheret and we can certainly get that out to you.

I want to thank you all for joining us this evening. Facing breast cancer is a frightening experience unto itself and the lasting impact it can have on children is deep and emotional for the many reasons that we discussed tonight.

I believe our speakers have offered guidance and insight into how to make this journey for and with your children a more meaningful experience. It's the Jewish imperative, u'shmartem et nafshotechem, to care for ourselves, our collective selves, and, most importantly, our children today and in the future. Good night.

VIII. Speaker Bios

Ally Cooper, a Sharsheret volunteer, first got involved with Sharsheret in the spring of 2009 to honor the memory of her mother who passed away from breast cancer. By sharing her experiences, Ally hopes to offer insight to others as part of the support system that Sharsheret provides to women everywhere. Ally received her Bachelor's degree from Boston University and currently works in Human Resources for Aegis Media in Manhattan.

Toni Cabat, DSW, LCSW is the Director of Family Services and Organizational Development at Chai Lifeline since 1996. She came to Chai Lifeline from Memorial Sloan-Kettering Cancer Center where she was the Assistant Director of Social Work. Toni oversees many vital psycho-social programs, such as counseling centers throughout the greater NYC region, teleconference support groups and information lines, graduate and undergraduate field training and is the Project Director for a Greater NY Komen for the Cure grant meeting the needs of Orthodox Jewish women living with breast cancer. As a representative of Chai Lifeline, she is an affiliate of many local and national organizations including the Childhood Cancer Alliance. She has been an active member of several professional associations, including APOSW, NASW and SSWLHC, Metropolitan Chapter. She was the recipient of the Eleanor Clark Award for innovative programs in patient care in 2003 from the National SSWLHC. She has served as a consultant to several health care organizations and has presented at numerous professional conferences throughout her career on program innovations in HIV/AIDS and pediatric and adult oncology.

Shera Dubitsky, MEd, MA is Sharsheret's Clinical Supervisor. 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

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Children's Services. She has also worked as a Researcher at Memorial Sloan-Kettering Cancer Center. As Sharsheret's Clinical Supervisor, 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.

Niecee Singer Schonberger, M.S., C.G.C. is Sharsheret's Genetics Program Coordinator. Ms. Schonberger graduated from Sarah Lawrence College with a Master of Science in Human Genetics. She has provided genetic counseling in all aspects of genetics, for the past 10 years, has focused on cancer genetics. She is a founding member of the National Society of Genetic Counselors and a past president of the Human Genetics Association of New Jersey. Ms. Schonberger provides supportive counseling, information, and resources regarding hereditary breast cancer to women diagnosed and at high risk of developing breast cancer.

IX. About Sharsheret

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

Sharsheret has developed the following programs in response to the needs of young Jewish women facing breast cancer.

The Link Program

- *Peer Support Network*, connecting women newly diagnosed or at high risk of developing breast cancer with others who share similar diagnoses and experiences;
- *Embrace*, supporting women living with advanced breast cancer;
- *Genetics for Life*, focusing on hereditary breast cancer;
- *Family Focus*, providing resources and answering questions of caregivers and family members.

Education and Outreach Programs

- *Health Care Symposia* on issues unique to younger women facing breast cancer;
- *Sharsheret Supports*, a national model for local support groups;
- *Sharsheret on Campus*, outreach to college students;
- *Facing Breast Cancer as a Jewish Woman* educational resource booklet series;
- *National Volunteer Program* sharing Sharsheret's mission through representatives and programs across the country.

Quality of Life Programs

- *Busy Box*, for young parents facing breast cancer;
- *Best Face Forward* to address the cosmetic side effects of treatment.

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X. Disclaimer

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