

Young Survival Coalition
Young Perspectives Teleconference
“My Mommy Has Breast Cancer”
September 20, 2004

MATT: Good evening, everyone, and welcome to tonight's teleconference. All sites have been placed into the program in a listen-only mode. There will be an opportunity for polling and questions and answers later in the program. Instructions for participating in these events will be given at that time. I would now like to turn the conference over to your moderator, Randi Rosenberg. Good ahead, please.

Introduction

RANDI ROSENBERG: Thank you, Matt. Good evening, everyone, and welcome to tonight's installment of the Young Survival Coalition's Young Perspectives Teleconference Series. Thank you all for joining us. Tonight's conference is entitled "My Mommy Has Breast Cancer." My name is Randi Rosenberg, and I'm the President of the Young Survival Coalition. As most of you already know, the YSC is the only international non-profit dedicated solely to the issues surrounding breast cancer and young women. Miraculously, I'm also a new mom, and that's six years after being diagnosed and treated for breast cancer at the age of 32. I'll be your moderator for tonight's call.

So ... "My Mommy Has Breast Cancer." How to communicate with your children when you're diagnosed with breast cancer, what to say, when to say it, and most importantly understanding how they might experience your cancer are issues that are of great interest to all of YSC's constituency. Almost 20 percent of young women registered on our web site have at least one child, many have more than one, and others undoubtedly hope to in the future. So tonight we'll try to answer as many of your concerns and questions as possible. For those of you who have not been on our calls before, the purpose of our Young Perspectives Series is to provide you with a variety of viewpoints on the issues that mean the most to young women.

Tonight we have a panel of three wonderful women who will share their different views on facing breast cancer as a medical professional, a parent, and also as a child whose mom battled breast cancer. Each has graciously given of their time to be with us tonight. Dr. Wendy Harpham, Sharilyn Jones and Emily Spivack, founder of Shop Well With You. Tonight before we hear from Dr. Harpham I'd like to provide you with a few of the logistics of tonight's call. First and foremost, tonight's call is being recorded and a transcript will be made available on YSC's web site, which, of course, is www.youngsurvival.org. It usually takes between two or three weeks for that transcript to be completed. So keep your eyes peeled and we'll send out information.

The format of the call is as follows: we'll start the call with a presentation by each one of our panelists. Each presenter will impart his knowledge and experiences to you. Many of you had submitted questions in advance of the call, and we've tried to incorporate as many of these as possible into the presentations. And after each panelist has spoken we'll then open up the lines for your questions. And in order to make sure we get to as many questions as possible we'll ask you to please try and be as brief as possible when you have the podium.

Finally, the call is operator-assisted, so when we open the lines for questions Matt will give you instructions on how to ask those questions to make sure that all of our panelists can hear them. And if we should run out of time and there are still questions remaining, we invite you to submit those questions to us at info@youngsurvival.org, and we'll certainly do our best to get an answer for you. We also have through the wonders of technology the opportunity to do polling questions to get an idea about your experiences and we'll ask a few questions to learn a little bit about you, our audience, and Matt, if I can ask you to give brief instructions and go through our first polling question please.

MATT: This is the conference operator. We will begin polling our audience at this time. After I read the question we kindly ask that you press the digit that corresponds with the best answer. Please stand by. *Polling question number one. If you are a breast cancer survivor please indicate how old you were when first diagnosed. Twenty years of age or younger please press one. Twenty-one to 25 please press the digit two. Twenty-six to 30, please press*

three. Thirty-one to 35, please press four. Over 35, please press five. We'll pause a moment to get our results.

Panelist One: Dr. Wendy Harpham

RANDI ROSENBERG: Very good. Thank you, Matt. So without further ado I would like to introduce you to our first panelist this evening, Dr. Wendy Harpham. Dr. Harpham is a Doctor of Internal Medicine, a best-selling author, long-term cancer survivor and also a mother of three. And after years of caring for patients in her practice she was diagnosed with lymphoma. Her children were one, three and five years old at the time. While undergoing numerous courses of treatment she wrote award-winning books including "When a Parent Has Cancer: A Guide to Caring for your Children," which will be released in paperback tomorrow, September 21st, as a matter of fact. She lectures widely to lay and professional audiences and also participates as a patient advocate at both the local and national levels. Her work has been recognized with the Writer's Award from the National Coalition for Cancer Survivorship, and she's also received the 2000 Governor's Award for Health from then Governor George Bush for which she was inducted into the Texas Women's Hall of Fame. Very impressive, Wendy. Thank you so much for joining us, and I'd like to turn it over to you.

DR. WENDY HARPAM: Thank you for having me. You asked me to participate in this teleconference because, as you said, I'm a physician who writes about cancer survivorship. But it's mostly because of my experiences as a mother going through repeated courses of cancer. You said when my children were one, three and five years old I was diagnosed with a widespread indolent non-Hodgkin's lymphoma, which is a type of cancer with no known cures. Over the next eight years my cancer did respond to each course of treatment only to recur again and again until my eighth and last course of treatment in 1998 put my cancer into a remission that continued and has continued to the present. Well, since for so many years I didn't get well and I didn't die my family was stuck dealing with cancer. I had to continue to learn about what was happening with my kids and find new and better ways to help them. The challenges were many and so were the rewards.

I'm very happy to tell you that my children are now 15, 17 and 19 years old. The oldest has been launched to college. My family has grown closer and my children stronger through my illness. Now, I realize every family is unique. And many families are very different than mine. But I've also had the opportunity through my public speaking to hear hundreds of family stories as I've traveled across America.

Since there is no one right way to raise kids, let alone raise kids when Mommy has breast cancer, what I'm going to do is share just a few of the insights and advice that I present in my book set, "When a Parent Has Cancer" and the children's book, "Becky and the Worry Cup" as well as a book I wrote for younger children called "The Hope Tree: Kids Talk about Breast Cancer." (*Book set can be ordered at: Harpham.nt3.npsis.com/news!.htm*)

When Mommy has cancer the crux of the problem is this: How can someone be a good Mommy when her own needs are so great?

My basic tip is to establish and maintain open lines of communication about the illness and all of the associated fallout. Basically ongoing dialogue prevents and minimizes misinformation, misunderstandings and unresolved painful emotions. Good communication with the parents is the children's best defense against inaccurate or frightening stories they hear about cancer or the parent's condition, and good communication is the only way for parents to recognize and respond to their children's needs in healthy ways.

I realized that even if my husband, Ted, and I had said nothing my children would have sensed that something major had happened at home and they tried to understand what was going on and find ways to cope. I emphasize open communication but I have one caveat -- that is that open communication allows parents to meet the children's needs *if and only if* the parents are always honest. This is the one area of dealing with children where I believe there **is** a right and a wrong way. Parents must, without exception, tell the truth in order to establish and maintain a bond of trust.

I meet many families who want to keep Mommy's illness a secret or they want to avoid the word "cancer." And no matter how honorable their motivation and intention, when parents hide the truth they are sending their children the message, "This is too awful; I don't

think you can handle this." And conversely, telling the truth says "I have confidence that we can handle this." What better way to instill confidence in a child?

If you ask my daughter, my oldest daughter, who was five when I was diagnosed, and she's now 19 off at college, what helped her most through my illness and when times were rough, without hesitation she'll tell you it's that I always tell her the truth. She never has to waste energy wondering if she knows what's going on or trying to figure out what's going on. And if you ask *me*, now 49, what helps me most in raising my teenagers, it's that I know that they are truthful. Even when they know I won't like what I hear.

Telling the truth sounds simple but it's very complicated by the challenge of figuring out just how much to say. When I finished my first round of chemotherapy and my four-year-old middle child Jessica said, "Mommy, now that the cancer is gone, can it come back?" a truthful answer would have been "Yes." Clearly that bluntness would not have helped her deal with her fear. Exactly how much to say is determined by how much that child must know in order to deal with his or her world. And how much does each child *want* to know?

Jessica needed to know the obvious fact that my cancer was not cured. It was in remission. And yes it was possible to come back. And then I could couch that in support and hope that I'm doing well now, things look good and if it comes back we'll deal with it. But we're not dealing with it now.

Life with cancer and with children can seem very overwhelming. I mean, ask any parent who doesn't have cancer about raising kids and it can be overwhelming. So to make it simpler when I was going through my treatments I narrowed it down to my children's three fundamental needs.

One, my children needed satisfaction of physical and emotional needs. So they needed meals and diapers and someone to say good night to them at night.

Two, my children needed to understand what was going on in their world around them. They needed to understand it on their level. So they needed to understand why I was bald or why I wasn't working.

And third, children need reassurance that they will be cared for no matter what happens with their mom and dad, and that it's okay to be concerned about their own needs.

No matter what is happening I make sure that these three needs are met, and I emphasize that I don't necessarily have to be the one who *meets* the needs, I just have to make sure the children's needs are met.

One thing that helps children is preparing them for changes that are coming their way. And you can hear from my advice that it's all founded on truth. If I'm telling them the truth then it becomes easier to prepare them for changes that are coming their way. And children, like adults, crave predictability. So the physical changes are a start. In our house before I even lost any of my hair we went to the mall, we bought headgear, hats and scarves and turbans, and then we played dress-up in the family room. Throughout the courses of my treatment we would talk through plans of what would happen, and what we expected to happen and how we'd deal with it.

Now, of course, things are going to come up that you don't expect. And you can teach children that they can live with the uncertainty. "I can't predict everything that's going to happen, kids. But I guarantee you that we will keep you informed and we'll help you through." I emphasize that parents can't take too much for granted. I've heard stories of children who, when the parent got through treatment, the mom got through chemo and everything was great. And the scalp hair started to grow back, the child thought that meant the cancer was growing back. So when I say to prepare children for changes, it's really for all changes, good or bad.

The other thing is that less concrete changes are important, too, such as when a mom is tired or irritable. I remember when I continued to need a nap during my first remission and my daughter wondered, well, Mom told me her cancer's gone, but she never napped before she had cancer. She napped when she had cancer. She's still napping. Is her cancer really gone? And I had to explain to her that my body was using energy to heal from the treatments and that napping was normal for months after finishing chemotherapy. This open communication saved my daughter from a lot of unnecessary worry.

And that brings me to another challenge of raising children when Mommy has breast cancer. Educating, guiding, reassuring your children is not a one-time chore. You can't

say, well, I told them it ... whatever the question is. I told them the cancer could come back and then you clapped your hands together and then said, okay, I told them about recurrence. Educating, guiding and reassuring your children is an ongoing process throughout treatment and recovery. I know this happened to me, and many moms or dads will say that people are worried, people are telling them they're telling their kids too much. Too little information can be at least as damaging as too much. And if anything I think it's better to err on the side of too much information, because children just naturally protect themselves from information overload. They really only hear or process what they're ready for at the time. So my simple rule of thumb is: Tell the children enough, not everything. What do your children need to know to deal with their world?

Underlying all of the parent's words and actions must be the sense that they don't feel sorry for their children. Pity is poison to children, and I saw this as an internist with my patients who had illnesses as youngsters. If they were raised in an environment where they weren't pitied they grew up self-reliant and with good self-respect despite their physical changes or problems, whereas children who are pitied don't have self-respect. And if the parents don't feel pity the children will less likely feel sorry for themselves. Not pitying them sends a message of confidence that they can deal with it.

If anything, one of the shining silver linings of my illness has been what I've been able to teach my children through my unwanted illness. When my children work around my limits, my energy limits, whatever it is, they are learning flexibility. When my children respect my special needs they're learning tolerance. When they tend to my needs they're learning compassion. When my children wait for me because I'm slower or I need more time they're learning patience. When my children see me as whole, whether I'm bald, whether I'm limping, whether I've got bandages, they are learning self-love. When my children pick up the slack they're learning teamwork. When my children have to fend for themselves because I'm not available they're learning self-sufficiency. When they have to deal with my cancer recurrences, my setbacks and my conditions, they are learning perseverance and resilience. Even when the family is unable to conjure a tangible positive outcome children receive the gift of appreciating

their resiliency. They learn that they can survive discomfort and loss. They can survive hard times.

Someone e-mailed a question about this, and that is that one of the hardest tasks is how do you help children when a mom is told her prognosis is months to maybe a year. Unless you are physically on your deathbed, right now even though your prognosis might be six months to a year, you are fully alive and able to raise your kids. For a child, six months to a year is a pretty long time and they can do a lot of learning and growing and loving in that time. In your own mind you need to remember that your prognosis is not a prediction. It tells you what is likely to happen. It tells you what happens to most people in your medical situation. It does not tell you what's going to happen to you.

In 1993 my prognosis after my second recurrence was two years. That was the most likely outcome for me. But obviously that is not what happened with me. So you can tell your children the truth couched in hope, support and love. You can tell your children that your cancer is not doing very well right now. But your doctors, your nurses, everyone is doing everything they can to try to get you better ... and that you'll keep the kids informed.

If they ask you if you're dying you can tell them the truth. You are not dying now. You're doing everything you can to live as long as you can. Most people with your type of cancer do get sicker and die of their cancer in a year or so, but some people don't and you're hoping to be one that doesn't. You'll keep them informed. They will be cared for no matter what happens to you, and you're not dying now. Let's focus on living. By not denying the truth you can be their ally in helping them prepare for and deal with whatever happens. You can't guarantee your children that you're going to survive. What you can guarantee is that you'll do everything you can to get better, and they will feel your love and they will be cared for and they can be happy no matter what happens.

This brings me to another insight. Shaping my children's perception of reality complements, not replaces, dealing with their emotional responses. A conversation such as about whether you're dying or not or whether you're going to lose your hair or not can be very emotional. Even when you present it in a hopeful and loving way, even when you use perfect

words and phrases and hugs, cancer-related stresses and changes can be expected to cause the children a host of unpleasant emotions. And I'll share with you that this was one of the most painful parts of my own survivorship.

I could deal with the bone marrow biopsies, I could deal with the surgeries and the chemotherapy. It was so hard to see my children's anger and frustration and sadness. But I also knew that their emotions were not the problem. They were the signal of a problem, be it fear or worry, separation anxiety, or their emotions were the response to a problem. When I had my first recurrence and my second recurrence my oldest in particular, she was furious. And she had every right to be.

Giving her a safe place to have and express her normal reaction, one, it allowed me to know what was going on; two, it taught her that her emotions were normal because I didn't stifle them; and, three, we could use them to help her move through her anger and fear to coping tools that would help her deal with the situation the way it was. I had to reassure her that her anger was not hurting me. It wasn't going to make my cancer get worse. I also reassured her that her anger, as long as she didn't stay angry but she used her anger to deal with it, could help her.

Cancer is very serious but the family does not have to be serious all the time. The pain and the loss are sad, but the family does not have to feel sad all the time. Sometimes joys are related to the illness. We made lots of jokes in my house. We tried to find ways to laugh at the problems. I remember one time I had again a bunch of bruises from IVs and I still had some bandages from recent surgery and when I got up to leave the room I bumped into the corner of a chair and I said, oh, no, my body isn't perfect anymore. And it was perfect. We were rolling with laughter. And it was a way to acknowledge how terrible it was about the physical losses and the changes, but it also made us feel a bit empowered to laugh at something that was pretty sad. And it's been kind of a joke ever since. Oh, no, I'm not perfect anymore.

Every family has their own kind of style or blend of humor. When appropriate try to use humor. We like to say in my house, "A no hair day is better than a bad hair day," or "No nodes is good nodes."

Well, even when parents have done a great job educating and reassuring their children, keeping the lines of communication open, problems can arise as children's needs fluctuate. One child who never seems to mind being left out of the crisis may suddenly demand total inclusion. It helped me to realize that my approach to each child may need to change over time. So I had to keep asking myself what does this child need now.

An unexpected challenge that kind of surprises a lot of families is when children process events out of synchrony with the rest of the family. I'll share a story about my son William who was one year old when I was first diagnosed. When he was seven there was this whole flurry of media exposure surrounding the release of the book set, and he came home from school one day and just was irritable and uncooperative, just not himself. And it took me about 30 minutes to pull out what was wrong.

In school that morning when he walked into the classroom one of the kids had yelled out, "Hey, William, I saw your picture in the newspaper." And the teacher then said, "Hey, Will, why was your picture in the paper?" And my son stood tall and responded proudly, "My mommy wrote a book that helps people," after which another child in the class blurted out, "Because his mom had cancer." Will finished his story to me in tears and I said, "Why did that upset you? You know that I've had cancer. You know I'm in remission now. I'm doing great." His big brown eyes looked in mine as a tear wove its way down his cheek and he said, "It's so sad that you were so sick."

My son William, seven years old, had every reason to be sad. Although we'd known for years that I had had cancer he was only then first old enough to understand the implication of what he knew. Children can know things long before they really understand them. Consequently children are often out of synchrony with their parents, needing to work through issues that are long past at a time when parents really would rather have it put behind them.

A number of participants e-mailed with concerns and questions about their children who were too young or weren't even born when the mom went through breast cancer. So what do they say to these kids? When do they bring it up? How do they talk about it? Whether I'm talking about cancer or hurricanes, terrorism or AIDS, what helps my children most

is the truth couched in love and support. If your children know about your cancer history it doesn't become this big mystery or secret that takes energy to maintain. By telling your history, you establish a bond of trust and don't risk them losing trust in you by possibly finding out from someone else.

If you're hesitating to say anything because you don't want your children to feel the same unpleasant emotions you feel when you talk about it, be it fear or stigma or loss of self-esteem, it helps to remember this: Your children are experiencing things differently than you. So though you may be sad or anxious when you talk about your breast cancer history, it may not bother your children at all. How you present it affects how they perceive it. And someone even sent an e-mail wondering if she should tell her prepubescent children she had a mastectomy and reconstruction.

You've told them stories of taking them home from the hospital, what your favorite color is, what you're allergic to. And telling them that you've had cancer is just something about you. You can teach them cancer is bad, you can teach them good things come out of bad experiences. Not the least of which is you got through your cancer. And I'd say how you present it affects how they perceive it. Put a positive spin on the facts. Instead of presenting it as something you're ashamed of or how awful it is that you lost your breast, you can focus on the fact that you lost your breast but have pride in your resilience that you got through it, gratitude that your treatments not only got you better but because of the reconstruction, hey, you can wear a bathing suit again. Nobody can even tell.

I mentioned earlier -- secrets are hard to keep. And if you're found out you now have a breach in trust that can be hard to repair. By telling the truth you are always their ally. Lastly you can teach your children that you're living with challenges instead of hiding them. What a wonderful lesson for your children. One other question I got in, before I close, is how to tell a child that your type of cancer runs in families. Let's say you're BRCA1 or 2 positive. It is not so much what you tell them as how you tell them. I sound like a broken record, don't I? Tell the truth couched in love and support.

If they ask if they can get it, does it run in families ... I mean, they're going to hear stories on the television, in ads with all the Race for the Cures and everything. If your cancer runs in families focus on the benefit of knowing so that you can take steps to prevent it. Remind them that risk is not fate. And even cancers that run in families usually don't occur until adulthood. By the time your children are adults and at risk there is every reason to believe we'll have newer and better means of detection and treatment for them.

Lastly, you know, I could go on and on and on about the best way to address this or that under this circumstance or that. Knowing what to do and doing it in real life are two completely different things. Intelligent, well-intentioned, loving parents make mistakes and handle situations poorly. Many times you just don't have the time, energy or patience to deal with your children's needs in an ideal way. I can't tell you how many mistakes and times I just didn't handle things well with my kids. The mantra that helped me through my bad days was this: the best I could do was the best I could do. And the best is good enough.

When I responded poorly I apologized. I explained. I asked forgiveness and they forgave. The greatest gift we can give our children is not protection from the world but the confidence and tools to cope and grow with all that life has to offer.

And now I think we're going to switch to Sharilyn.

RANDI ROSENBERG: Wow, Wendy. Thank you so much. This is Randi again. What a great way to end your very informative conversation. And I noticed in your talk that you incorporated so many of the questions that our audience had submitted prior to the call, so thank you for finding a way to answer everybody's questions and concerns. And I think the one underscoring point that came through as I was listening were sort of three "Hs:" honesty, humor and hopefulness. And if you incorporate those three into your situation, whatever it may be, you stand the best chance for helping your children.

DR. WENDY HARPAM: That's right.

RANDI ROSENBERG: That's terrific. Wendy, thank you again so much. And before we introduce Sharilyn, our next panelist, we wanted to get an idea of the age range of

your children when you were diagnosed. *So for those of you who are breast cancer survivors how old was your oldest or only child when you were diagnosed? And Matt, if I could ask you to come on and read the choices for our audience, please.*

MATT: Yes, of course. Once again please press the digit that corresponds with the best answer. This is polling question number two. We want to get an age range of your children when you were diagnosed. How old was your oldest child when you were diagnosed with breast cancer? Newborn to three years of age, please press the digit one. Four to six, please press digit two. Seven to ten, please press three. Eleven to 15, please press four. Over 15, please press five. And if you are currently pregnant please press six.

RANDI ROSENBERG: Great, Matt. Let's give a few minutes for people to respond to that question, and then perhaps you can read the second part of that question.

MATT: Stand by for the second part of that question.

RANDI ROSENBERG: I can read it for you. For those of you who have more than one child, please indicate the age of your youngest at the time of your diagnosis. So the first question was your oldest child and this question now is your youngest. If your child was newborn to three years of age, please press one. If your child was between four and six years, press two. Between seven and ten years, press three. Eleven to 15 years old, press four. And if your child was over 15 when you were diagnosed, please press five. Again, that's your youngest. All right, thank you.

Panelist Two: Sharilyn Jones

Now, our next panelist is Sharilyn Jones. Sharilyn is a young breast cancer survivor, a member of the Young Survival Coalition and mom and she'll share with you a little bit about her experience. I'll tell you a little bit about Sharilyn. She was diagnosed with breast cancer at the age of 36 in 2001. Her children were both under five years old at the time. Her son was three and a half and her daughter was one and a half, and they're now seven and five. Sharilyn is a part-time advocate and of course a full-time mom. And when Sharilyn was first diagnosed there was really no history of breast cancer in her family. Her treatment consisted of a

lumpectomy, chemotherapy, radiation and an oophorectomy. Two years after her diagnosis she had a double mastectomy and reconstruction when she learned she had a BRCA mutation.

Sharilyn, I'd love to turn it over to you and share your story with us.

SHARILYN JONES: Thank you, Randi. And thank all of you on the call for letting me join you tonight. I'm going to share some of my experiences and stories over the last three and a half years on this journey. I am not an expert but I do believe that as parents we know our children better than anyone. And I know that counts for something. Like Randi said, both of my children were very young when I was diagnosed, but they both immediately knew there was something going on in our household before I or my husband said anything to them. What I learned very quickly, which we all know, which has nothing to do with breast cancer, is that each child is different. I did have a conversation with my son about my cancer. I always used the word "cancer" with him and I tried to relate cancer to something he could understand.

I talked about cancer, at least in my breast, like a rock that was growing, that was making me sick and unhealthy and if I didn't take it out it could make me sicker. And he seemed to understand that concept. I also explained to him that I would have to take some very strong medicine that would make me sick, make my hair fall out, it would make me unable to take care of him by myself full-time. But as I told him this, I stayed in my role as his mother and knowing that I would share only as much that I know that he could process.

My daughter was very young at the time, she was one and a half. So she was much too young to understand these details, but not too young to see that there was a lot going on and that I was changing and there was lots of stuff happening in our household. In fact, after my first chemotherapy treatment my son went with me to have my hair shaved at the home of my hairstylist. And he had been in her house running around with the dogs when she was shaving my hair off, and he looked up at me once my hair was all gone and said, "Hmm, you like Uncle Wally," which is one of my brothers. And I did look like Uncle Wally. And then he went back to playing with the dog. I was fine with it. I had prepared myself for it and I was okay. I was in a place that was safe for me to have it done, I was with someone who cared about me and knew me for a long time. So that was just my son following my cues, and he was fine with it.

My daughter, on the other hand, did not like seeing me without a wig on my head. She didn't even like seeing me with a hat or a scarf. I had to have the wig on my head. As soon as I woke up she would run and get my wig if I didn't put it on. But we still had a lot of fun, and that's where the humor is important. In dealing with her attitude I would ... whenever I would brush her hair I would say, "Oh, Mia, I love your hair, it's so long." And I would say "Can I have it?" And she would protect her head but grab at one little piece and say, "Here, just one piece," you know, like she was giving me one piece of hair. So I still tried to infuse that humor in there that her hair was beautiful and I loved her hair. But it also made me feel good that even though I had no hair and she had this long, beautiful hair she still wanted me to have some of her hair ... but only one piece.

But another important part of my journey and what made the road easier for me was getting help. And I know that when we're diagnosed so many people come out and want to help us, and I really did take everybody's offers. I was also lucky enough to have someone who had been helping me part-time in my home with my kids before I was diagnosed who came -- I know this is not always the case with everybody, but my husband and I thought it would be worth it for us -- who came to work for us full-time while I was in treatment. And my kids had already known her for their whole lives.

And they always had someone ... I couldn't be the person that could take care of them all the time. But they had someone there who knew them, who loved them, who would take care of all those needs that we talked about earlier that small children need, and I couldn't always be the one to make their food or wash their clothes or bathe them, but I could sit with them while they ate, or help them pick out their clothes for the day or rest while they were being bathed and have enough energy to put them to bed myself.

Another part of the journey for both me and my children was to find other young mothers and children of similar ages who were experiencing what we were experiencing in our family. As my treatments went on the kids got pretty used to the routine of my good days and bad days, and I think that's what Wendy talks about, a new normal. This became our new normal. And they got in the groove, too, and they knew when I was feeling well and not. But

my son, who was approaching four by that time, approached me and asked if there were other kids in his school who were bald or whose moms had cancer, and I had decided that it was time to tell him a little bit more, because he had come forth with me with that.

And I had made friends with a couple of other gals who had kids, and we had already done outings with those families. So when I told them that some other kids that he knew, that their mother was also bald and was going through treatment like I was, that comforted him to know that other people were ... other kids were experiencing this. And we had started to do more outings with those families and those kids. And one of those outings included a bowling event that was sponsored by the nurses at our local hospital, which was for children of cancer patients.

And I dropped off my son with other children there. When I picked him up he was very happy and got in the car and was talking and talking and talking. And I asked him how his day was and he said, "Mom, did you know that lots of kids have moms *and* dads who get cancer?" And I said, "Yes, I do." And he said that ... and this was a turning point for our family. He told me that, "Sometimes, Mom, you just have to trust and pray." And to this day I'm so grateful. I know that's important for ... we feel so isolated when we're going through this. And you have to work but it's worth it. You have to find the resources in your community that are going to help you and your family and especially your children deal with this. You can't do it by yourself.

I also think it's important to remember that our kids pick up a lot more than you tell them and process it in their own ways, and I know Wendy just spoke on that. But when my hair began to grow back I wanted to keep it short for a while. And I liked how easy it was and stylish it was. And my husband liked it, too. So my son had overhead us talking and he was not very happy about it. I asked him, you know, "Aren't you happy my hair is growing back? I'm getting better; I'm done with the treatment now." And he said, "Yes." But he wanted me to grow my hair back long. He said, "Never cut it. Grow it back long and never get sick again." He equated the short hair with being sick and still to this day whenever I want to go get a haircut he's like, "Just a little bit." No, he doesn't like that.

What also helped us was the indirect exposure to breast cancer and other families. And when I mean indirect I mean by events out in the community, conversations, other people, just an awareness, like what we do as advocates. One of the things we all do here as a family is go to the Komen Race every year. And my children look forward to it every year. They love the energy of the day. They love running in the children's races. And they love seeing other young survivors. They love to go on stage with mom as do other kids when young moms are there, go on stage with them.

However, I won't make this all glossy because I know that that exposure does have consequences. A couple of years ago I did lose a friend and the race was dedicated to her. And her children happened to be at that race that year. And my children had met them on a few other occasions and knew that their mother had died and died because of breast cancer. And there was a moment that we honored her and her children during the race that day. And when we left that day my kids had a conversation in the car that was very hard to listen to when they were asking me why do some mothers have to die from breast cancer. Why can't they keep living with their children?

And it's not a question that's easily answered. They also knew that these children were now living with their aunt and uncle. And they knew that that aunt and uncle were also their godparents. Well, my children related this to what they knew, and they have different godparents. And I heard them discussing in the back seat, well, if something happens to our mom, you have to go live with Marta and Uncle David and I get to go live with Uncle W. So it breaks my heart to listen to them in their own world trying to figure out what would happen to them. And of course that's when you do step in and have to reassure them that, no, you will be taken care of. We don't have to worry about Mommy right now. Mommy is doing great. I'm feeling healthy and strong and Daddy's doing great. Daddy's healthy and Daddy's here.

This year my son at the Race for the Cure got to run with the bigger kids and had a great time. And at the end of the race he finished with the middle of the pack. And as we were going to get a drink he seemed kind of quiet and a little bit down. And I said, "Jacob, you did a great job. Didn't you have fun? What's wrong?" He said, "Yeah, but I wanted to win the race

for you." And I said, "Jake, you did great. Everybody did great. Everybody's a winner. We're all here for the same reason." And he just looked at me and said, "Mom, I thought whoever won the race means that their mom would never have to get breast cancer again."

So again that was a heartbreaker. And I know that's a big part of the child's mind and that male competition and winning coming out of him. But that's his reality and that's when you have to explain that that's not how it works. But that was a part of him I realized that he's out there and he's wanting to do that for me. And in his young life I realize that breast cancer has always been a part of his life. He's always been old enough and has a memory back to when I went through treatment, even at three and a half years old, and he's seven now. And it breaks my heart but that's his reality, too. It's not a part of our everyday lives but it is a part of our lives.

In Florida we have a breast cancer license plate. And recently we were in a parking lot and my son saw a license plate, a breast cancer plate, on a car and an older woman getting out of the car, parked right next to us. He went up to her and said, "My mother's a survivor, too." And the lady was, wow. How many seven-year-old boys go up and say this to an older woman? In one way I'm very proud that my son is aware and so sensitive, but in another way I never invited this into our lives and it's really hard knowing that this is part of his reality.

Something else I wanted to point out that I talked about earlier is how children follow our cues, and we should always try to follow theirs. We think that we're the ones that always have to set the tone, but they need to set the tone sometimes, too. And I got reminded of that quite a bit going through treatment and still do. When I had my initial surgery my son knew that I had surgery on my breast and under my arm, and for a long time I couldn't pick him up and he could not lie all over me and cuddle like we used to. He had to be sensitive to areas of my body.

And up until that time he had always slept in his own bed, but during my treatment he began coming into our room in the middle of the night and getting in bed with us. And this was when I was in active treatment. He would come into our room and get in bed and he would sleep in bed next to me and he'd put his hand on my bald head and he would rub my skin there just like ... it made me think of the times when he was an infant and I would nurse and

he would just have to rest his hands on my breast and rub my breast. And as soon as you move him he doesn't want to move his hand.

Well, he was the same. I would go to take his hand off my head and he wouldn't want to move that little hand. And I realized that it was his way of communicating love to me and that he still needed to be able to touch me in that intimate mother/child way that he had. And he himself had found a way to still have that bond, and it wasn't even something that I ... that had come into my realm that he was still looking for and still needed.

I want to end my few minutes here with my little bit of wisdom on my experiences with breast cancer and my children. When I was diagnosed, just like any parent who's diagnosed with cancer, our greatest concern is our children. We fear that we will not be around to raise them, which is a real fear, and watch them grow up. And for me this fear was very scary and very debilitating. The only way I figured out how to deal with it was to be honest with my feelings, to share with my children how much they're loved. To listen to them, to let them know that our loved ones and our prayers can heal us. I mean that in a spiritual sense in terms of easing our burdens and to be honest about our place in the universe. I know that's different for all of us.

I let them know in great and small ways every day that they are each unique and they are loved little beings and I am always here and always will be here in great and small ways, when I'm gone, too. For all of us, our children are our future and they experience us as we experienced our own parents and families. And my wish is to pass on the story of my life to my children and hopefully one day they also pass those on to their children, because I think ultimately that's what we all would like to say at the end of our lives is that our loved ones and our children, they knew us and they loved us and they cherish our stories and will continue to.

Breast cancer is a scary thing for so many families and so many young women, unfortunately. But it is not without its gifts. And that's not an easy thing to say and an easy place to get to, but for me personally I have gotten to that place and I hope to stay in that place. So I thank you for allowing me to share some of my stories with you tonight, and I look forward to hearing Emily.

RANDI ROSENBERG: Sharilyn, I can't thank you enough for sharing so many of those intimate stories about your family. And we also hope you stay in that place for a very, very long time. So thank you for sharing all of that. It was extremely moving. One of the things that you mentioned that really stuck with me was the idea of sort of it takes a village, and finding peers within your community, people in similar circumstances with children of similar ages who can relate to what you're going through. And certainly in addition to community resources the Young Survival Coalition has many of those networking resources as well. So we invite anyone who's seeking out peers for peer-to-peer networking or support during these challenging times, we invite you to be in touch so we can try to put you in touch with others. Thanks again, Sharilyn.

Panelist Three: Emily Spivack

Now I'd like to turn the panel over to our final presenter. Last but certainly not least is Emily Spivack. And Emily is the Founder and Executive Director of Shop Well With You, which is a national not-for-profit organization that helps women with a history of cancer improve their body image and their quality of life by using clothing as a means towards wellness. And through education, outreach, personalized services, Shop Well With You focuses on the woman, not the cancer, in order to provide support and promote survivorship. Now, Emily's perspective that she brings to us tonight is that of a child who went through her mother's diagnosis of cancer. Emily was ten, 16, 18 and then 20 years old during the four times that her mother was diagnosed with cancer. And she was inspired to start Shop Well With You after she observed the positive impact of clothing upon her mother's well-being and self-image. Emily helped her mother move beyond each of her cancer diagnoses by finding clothing that made her feel comfortable, that helped her lift her spirits, improve her body image during and after her cancer treatments. And the great news is that Emily's mom is currently 56 years old, healthy and refers to herself as a victor. Emily, that's a great way to introduce you and please, we'd love to hear your experiences from your perspective.

EMILY SPIVACK: Thanks, Randi. Well, I thought I would just go through each time my mother was diagnosed with cancer, because I feel like each of those times was a different part of the time when I was growing up, and I had a different reaction or my memory of my reactions and those responses differs through each diagnosis. As you said, the first time that my mother was diagnosed I was ten years old. So that was about 16 years ago. And I really have bits and pieces of my memories from that time. I actually was speaking with my mother recently prior to this and just chatting with her about what she recalled and some of my responses to her diagnosis.

The first time that she was diagnosed she had a lumpectomy and she had radiation treatment. My mother and father decided to tell me and my sister ... my sister is four years younger, so she was six at the time ... and they met with our pediatrician ahead of time and discussed with him what he thought the best way to present the information to us would be. They decided to tell us in a casual setting instead of sitting us down in a very formal way.

They sat us down, we were at dinner one night, and my mother told me that she had cancer and that her treatment was going to make her feel tired and that we might have to help her around the house a little bit more and that she might need us there a little bit more. And she may be a little bit tired. And my response when she first told me was ... and she still sort of can't believe that my response to this was ... I said, "Mom, will you lose your breasts?" And my mom to this day has no idea how I knew that at all, because she had a lumpectomy. And there had been ... although actually both of my grandmothers did have breast cancer... there had really been no conversation about breast cancer until that point in time.

So, I wanted to be as involved with my mother as I could during that time. I think what my parents really wanted to do was to maintain as much normalcy as possible. I think that what was said earlier, what Wendy said about telling your children as much as they need to know in order to deal with their own world really hit home with me. I think they told me just at that time as much I needed to know. I didn't need to know all of the scientific terminology. I didn't need to know the percentage of survival, etcetera, etcetera. I wanted to know that she was going to be there. I wanted to know that she would be able to come to my soccer games, that she

would be able to sit with me and help me with my homework. She and my father really worked to keep everything as normal as possible.

When she was first diagnosed it was in 1988, so things were quite different then. She was 40 years old and there was very very little support out there for a woman. That was considered very young at the time. There was very little support for her. I knew no one who had had cancer or whose mother had had cancer. So I really didn't know so much about what to do with that information. I spoke about it with my family and spoke about it with my sister.

I do have a very vivid memory, though, of helping my mother ... she had limited mobility in her arm. And helping her put on her sweatshirt or helping her walk the wall with her exercises to regain mobility. I remember helping her with those exercises and really feeling like I could be a part of the process of helping her get better.

The second time that she was diagnosed she had a recurrence when I was 16. And this time she had a TRAM flap and she had chemotherapy. She did get a wig but her hair actually didn't fall out, it just thinned quite a bit. And at that point I was older. They still were very careful in what they told me. They told me the truth. But again it was as much as they could tell me that would maintain some level of normalcy in my life and my sister's life. I went with my mother and helped her find comfy clothing before the surgery.

I had a number of questions I would ask her. I went to visit her in the hospital. I remember before going to the hospital I had talked to my dad and asked him what could I do for her for this visit. And my sister and I decided to make her some arts and crafts. We made her a pin that she was able to wear in the hospital. I think it said, you know, "We Love You, Mom." And she carried it with her through her different treatments.

And what was really interesting and challenging that summer is I had had plans ... my family had made plans and I had made plans to go to Spain. I didn't want to go. I didn't want to leave my mom. And they really wanted me to maintain the normalcy, to keep going with things that had been planned. So, we worked out a deal where my father would fax me ... and this was before ... I guess it was before really people were e-mailing. So the best way to get in touch was he would fax me every other day and just kind of give me an update on what was

going on so that I could feel clued-in and feel like I had some control over the situation. I also spent a lot of time at that point talking with my sister a lot, who was 12 years old and who was at home during the time and who was very scared and had a lot of anger. We were just very open about our feelings together.

The third time she was diagnosed I was 18, and this time she had thyroid cancer. When she was diagnosed it was just sort of an unbelievable moment in my family. We couldn't believe that she had been diagnosed with cancer again. This time I wanted as many details as possible. I was in college. I helped my mother find scarves to disguise the scar on her neck and clothing that was comfortable for her and just wanted her to just try to be there as much as I could for her and try ... I really wanted to make an effort to be as grown up and ... it was hard sometimes to ... I wanted her to be able to open up to me as much as she could but it was hard being the child but also wanting to be the mature child who could listen and try to help my mother.

And all throughout these times I should also mention that my father was amazing, and also my grandparents were amazing, and they were able to take me out when my mom needed some time, and they were able to also just serve as support for my mother.

The fourth time that my mother was diagnosed I was 20 years old, and I was in college and she was diagnosed with breast cancer, and it was a different breast cancer. It was an occult form in her armpit.

At this point what was really interesting is I did feel like more people could relate. It was a number of years later. It was ten years later. More people's mothers had been diagnosed with breast cancer. People were just talking about it more. I think ten years before that people really weren't talking about cancer all that much. And I just felt like I could finally find more people that I could speak with that I could relate to. At the same time, it was difficult because I still had not met anyone whose mother had had cancer four times. And that was really hard for me.

But there were moments that ... I know that there have been many mentions about humor. And there were moments, just humorous moments throughout, stories that stick out. We

were at a department store and I was with my mother and she was wearing ... she wound up really wearing her wig infrequently and she just wore hats and scarves. And I think we were at a make-up counter ...or we were walking away and a guy came up to her and she was wearing a hat. And I think she sort of had that chemo glow and just started flirting with her.

And I just couldn't believe it. I mean, here's my mother, and she's, I don't know, in her late 40s, early 50s, or I guess she was exactly ... she was 50 at that point. And this man was flirting with her and I was totally mortified, embarrassed. But it was also just so amazing to me to see her reaction and it was just ... it just sort of, I think, helped her feel like she was ... that she could move beyond this cancer diagnosis. And there were many many incidences that helped her feel as though she would move beyond the diagnosis.

Also at that point ... my mother when I was younger was very careful to make sure that I didn't see the scars and the drains and the ports. But at this point she was much more forward with me and I had more questions and wanted to see what she looked like. And she was much more willing to show me and we also, again, made jokes about ... I had joked with her that I wanted to get a tattoo. And she said, well, I beat you to it. Because her nipple was tattooed after having her reconstruction. And I would help her find a bathing suit. And sort of many mother/daughter activities, things that we did but that were just sort of ... had altered a bit and probably a bit more meaningful as well just because I had been working with her and living with her as she was going through these bouts.

I think that there are a number of things that came out of this ... these experiences. And I think, as Wendy said, at an early age I believe that I learned how to be flexible and how to be tolerant and how to be compassionate and I learned patience and self-sufficiency, and perseverance, all of these things that Wendy had mentioned ... I learned. I was able to really build bonds with my family and with my sister.

I think that as I was going through school one of the things that came out of this experience was that I was sitting in the classroom and just after working with my mother through all of these different bouts I really felt like I wanted to do something, and I felt like when I was in college the time was just going by very quickly. I felt like I really just wanted to not be sitting

in the classroom talking about different theories, but I wanted to be out there doing something. Right after my mother had been diagnosed for the fourth time I decided to take some time off.

I moved to New York City and I worked at a not-for-profit organization called Dress for Success, which helps women get back into the work force by providing them with work-appropriate clothing. When I went back to school I had all of these ideas floating around in my head. I wrote a business plan to start Shop Well With You. It was inspired by my experience with my mother, and motivated by thousands of women who are trying to move beyond their cancer diagnosis and move beyond just being known by their cancer diagnosis to being known as a mother, as a sister, as a friend, as a professional.

So now my mother is healthy. I still feel, even now that I'm older and much more aware of what's going on and am now seeing many more people around me who are being diagnosed but also who are surviving and who are living full lives ... there is still that sort of scary feeling I have that something could happen to her. But at this point I've really grown up learning the importance of taking advantage of every day and not letting opportunities pass you by. And you really don't know how ... or I feel as though I don't know how my life will turn out. I know that I'm at a high risk. As a result I take one day at a time and really enjoy the time that I can spend with my mother and share with her the achievements that have been built from Shop Well With You and just feel like I've learned so much from the challenges that I faced working with my mother. That's my input. Thanks for having me.

RANDI ROSENBERG: That's incredible input, Emily. And I think that not only did you learn from that experience but you went on to form this organization that's really helping so many women. Would you mind giving us the URL for Shop Well With You?

EMILY SPIVACK: Oh, sure, yes. It's www.shopwellwithyou.org. It's a free service, we're a not-for-profit, and we help women use everyday garments to help them move beyond their cancer diagnosis. We provide women with one-on-one assistance. We work with women nationwide, and we also have a web site with a ton of resources on it, whether it's

specific camisoles with prostheses in them or bathing suits with pockets or hats, head coverings. We just are basically an information hub for women who are looking for body image resources.

RANDI ROSENBERG: And it's a wonderful organization. I think the take-away message here for our callers and particularly those who have young kids is that your cancer experience may even inspire your kids some day, like Emily, to go out and start an organization that can impact so many other women's lives. So Emily, thanks again for being with us and sharing that perspective with us. It's really incredible the stuff that you've done watching your mom over the years. Now it is just about 12 minutes after the hour, and we're supposed to end our call at 9:30. So indeed we have gone a little bit longer than we had hoped to allow for questions. But we're going to open the floor for as many questions as possible, and for those of you who wish to stay on a little bit past 9:30, depending on how many questions we have, I would imagine that our panelists would welcome the opportunity to answer more of your questions. So, Matt, if you wouldn't mind providing instructions to the callers on how they can queue their questions.

Question and Answer Session

MATT: Of course. To ask a question please press star one on your touch-tone phone. We'll take the questions in the order they are received. If you'd like to remove yourself from the queue, you may do so by pressing the pound key. So once again at this time if you do have a question please press star one on your touch-tone phone. (Overlap)

DR. WENDY HARPHAM: Randi, this is Dr. Harpham. Can I address a question that came this afternoon?

RANDI ROSENBERG: Sure. Then we'll open the floor, Matt, as soon as we have Wendy's answer to this question.

DR. WENDY HARPHAM: I think it's such an important question. How do you know if your child is in trouble? Are you doing okay helping your children through your illness? When you have concerns about if your children are okay, get help. Get professional help. Emily

mentioned that she spoke with her ... mentioned that she spoke with her pediatrician. Family doctors, internists, pediatricians can help you. There are counselors and social workers, child life specialists who can help you. It is better to sound a false alarm. You're worried about your child and you find out that you and your kids actually are doing just fine. It's better to sound a false alarm than to hesitate to ask for help and let small problems become big ones. Thanks.

RANDI ROSENBERG: Thank you, Wendy. That is an important question. And now I think Matt had provided the directions for dialing in with your questions. Matt, do we have any questions in the queue?

MATT: Yes, we are standing by with about three questions in the queue.

RANDI ROSENBERG: Very good.

MATT: We'll take our first question from the site Racine, Wisconsin. Good ahead, please.

Question 1: *Yes, I was just calling because my question is really about the fact that I haven't received any hair since I have been on recovery, and that's been about three years now. And this has had a huge impact on my kids, because I think that we go for this whole hair thing, it's interesting to hear from the conversations how people interpret the hair issue. And without having it back I think my kids have kind of thought that I'm still sick. And I've reassured and we've talked about it and we've gone through it over and over again but I still feel like there's this nagging sense of, if you're never going to get hair are you really really really getting well. And at this point in time I am doing well, and I'm doing fine. But I'm not even sure where to go with this, because I've tried different ways, and I don't know if it's up to somebody else now to refer it to say if I should hand it off to somebody else and say ... I don't know, give them another person to say that it's still okay.*

DR. WENDY HARPHAM: This is Dr. Harpham. It's not a common problem, which makes it harder to deal with. If you can point to all these other women who never got their hair back after chemo it would seem more normal. It would be easier to convince them or make it seem true that you're perfectly healthy. So I think acknowledging the challenge, acknowledging that it's hard to accept the truth is a first step. And I think giving them time.

Letting them be where they are, as long as they are functioning well, meaning if they have some concern about are you really well, but they're eating well, they're sleeping well, they're doing okay in school, they're relating well. Then even if it's a concern out there it's not interfering with their growing. It's not interfering with them moving forward.

MATT: We'll take our next question from the site of Culver City, California. Go ahead, please.

Question 2: *Hi. I'm concerned about my daughter who's eight. She was six when I was diagnosed and lately she's just gotten super clingy and doesn't want to leave my side. And we've talked about it, and it's kind of come up that she's afraid I'm just going to up and die on her. She'll be on a sleepover or something and she'll come back and I'm dead or something like that. And we've talked about how that's not how cancer works but that doesn't seem to help her fears. I'm afraid for her because I see her missing opportunities and missing the fun things that little kids do that she's too afraid to do because of me and has kind of got this weird dynamic going on. And I really need some direction here. We did actually get some counseling last spring for another issue with her, which was her fits of rage and just anger. Those have actually subsided and gotten better but now it's kind of "transmorphed" into a clinginess. So any words of wisdom or direction would be really helpful.*

DR. WENDY HARPAM: This is Dr. Harpham again. The bad news is it sounds like she's having a hard time. But the good news is she's communicating to you that she's having a hard time. Clinginess is a message to you, "I need something." And the other good news is that you're obviously very responsive and you want to do the right thing. You got help for her before, but just like if a pipe in your house is leaking, you get the plumber and he fixes the leak, if it starts leaking again you get the plumber again. So it sounds like it would be a good time to get some professional input into what's happening with your daughter. The other thing is I mentioned this idea that my son was seven when he first was upset about my diagnosis from years earlier. As your daughter gets older she's going to reprocess what she knows with her new equipment that comes with being older intellectually and emotionally. So getting a tune-up or

getting a re-evaluation by a child life specialist or a child counselor may help you know what you're doing right and maybe how to help respond to her needs so that she is okay with what's happening.

RANDI ROSENBERG: Great. Any of our other panelists want to add from their perspectives?

EMILY SPIVACK: This is Emily. I know that my sister also became very fearful and did not want to leave my mother's side. And they actually went and sought some professional assistance working with her and slowly but surely they were ... it was right around the time when people were going away to sleep-away camp. And so she slowly ... I think she was about ten at the time. And they had her go away to sleep-away camp for a week and then it was two weeks and then it was three weeks. And she just actually ... she's in the midst of college and she just went away for three months. And my parents are just like amazed and thrilled. So I think that there's a process that she did go through. But it sounds quite similar.

DR. WENDY HARPHAM: And I emphasize this idea, acknowledging that it's hard. Saying to your daughter, I see this is hard for you. That's okay. Let's figure out what to do.

RANDI ROSENBERG: And to underscore Emily's point as well, it is a process. And time will have its way of healing her and what she's going through and for you and your family as well.

DR. WENDY HARPHAM: Normal seven and eight-year-olds can be struggling with the issue of death and separation even if they don't have illness in the family. So it can be an exacerbation of normal processes that go on.

RANDI ROSENBERG: Excellent point. Thank you so much for your question.

MATT: We'll go to the site of Cambridge, Mass. Go ahead, please.

Question 3: *Hi, my son was one when I was diagnosed and we never really ... he didn't talk. So we didn't talk about it. And now he's two and I'm just wondering what to do in the years going forward. He's fairly oblivious to it all now. Thanks.*

RANDI ROSENBERG: Dr. Harpham, would you like to ...

DR. WENDY HARPAM: I'm happy to. I mentioned earlier that if you can make it just part of your normal history and keep your eyes open for windows of opportunity to bring it up in a very non-threatening, non-dramatic way. If you pass a big billboard about Komen's Race for the Cure, it would be very natural to say, "Oh, I had cancer once, and treatment got me better." Not a big deal. And always be alert to if he brings up something that would be an opportunity to talk about it.

RANDI ROSENBERG: Great. Sharilyn, how about from your vantage point? You also had a one-and-a-half-year-old (Overlap).

SHARILYN JONES: Yeah, I agree, too. But a one-and-a-half-year-old little girl turning two while through treatment is a big difference from a one-year-old boy at the time. It just is a big difference because she was a full talker before she was two, so she could communicate back to me and speak fully to me while I was going through this. But I agree. Like if you see something. That's why I do take my kids and just like with any instance when there's a tragedy that happens to another family in your community you talk about it with your children if it in some way is in their world. We recently had someone at my children's preschool last year lose a child. And we had been praying for that child for weeks and weeks and weeks. It was to cancer. We had blood drives. And so when that child died we naturally needed to speak about that. And I think it's the same thing. I think you look, like Wendy said, for your windows of opportunity when it's a non-threatening time, when it's a safe environment to talk about the things with your children. And I think exactly what you said, when it comes up, if you see a commercial for something, taking them to an event and wearing a pink shirt yourself and letting them see that you, along with these hundreds of other women there that day, are survivors. I don't know if I mentioned this but my children, whenever they see a woman in that sort of breast cancer pink-colored t-shirt, no matter what it is, they think she's a survivor. So there's a little marketing going on there. But I think finding non-threatening times to bring it up in a safe environment is the best way to ...

DR. WENDY HARPHAM: And remembering that your kids are not experiencing it the way you are, so that ...

SHARILYN JONES: Exactly.

DR. WENDY HARPHAM: Though you may be a little bit tremulous or emotional if you talk about it your kids probably won't be. And the other thing is embracing this power to shape their perception of the world. When a friend of mine was diagnosed with cancer a few years after my diagnosis I came home and told the kids because they knew this man. And my kids' reaction was, oh, they can be survivors, too. Which was in great contrast to the reaction of adults.

Question, continued: *What kind of language would you use with a two-year-old to talk about with this?*

DR. WENDY HARPHAM: The same language you use when you're talking about what you're making for dinner and where you're going for the weekend and when you're going to be out late and a babysitter is coming.

RANDI ROSENBERG: Thank you for your question. Matt, do we have any other questions in the queue?

MATT: Yes, we're standing by with an additional question from Masslin(?), Ohio, go ahead, your line is open.

Question 4: *Yes, my question had been somewhat similar to the previous one. I also have a small child. He is now three and a half. And I had been diagnosed almost two years ago with inflammatory breast cancer when he was only a year and a half old. He really has no conception, is completely oblivious for the most part to the fact that Mommy has cancer. And with the fact that I have inflammatory breast cancer, I have metastasis and so I'm continuing to undergo treatment. So it's not a situation where Mommy had ... you know, once we start discussing it, Mommy has cancer, it's over, Mommy's better now. It's an ongoing issue in our lives, and also in the last year his father, my husband, has left. So that further complicates the situation.*

DR. WENDY HARPHAM: Lots of changes, lots of losses.

Question, continued: *He realizes Daddy is not around, but he doesn't even fully comprehend that issue as well. But in the future we could have issues relating to my health as far as my possible potential mortality and with the fact that Daddy's not around now. And so I guess I have a complex situation. And I was just wondering in addition to the trying to introduce him slowly to the idea that Mommy has cancer once he's old enough to understand that, what else might I want to possibly consider as far as my own individual situation.*

DR. WENDY HARPHAM: This is Dr. Harpham. A long answer you can get from the book that's being released tomorrow. Because the book "When a Parent Has Cancer" has a new chapter in it that is for parents whose cancer recurs or becomes chronic. So it addresses all of these issues about when cancer is chronic how you help the children grow. How do you help them deal with the uncertainty, the possibility of death, the possibility of long-time illness. An important element is distinguishing hope from expectation. Children need hope. And they can be prepared for what is likely to happen or the uncertainty that you don't know what's going to happen with the hope that things can be good. Not only hope in terms of your health but hopes in terms of ... they can hope that they can do well in school and have friends and all of the other hopes that children have. I've found that in finding good answers for my children I found good answers for me as a patient. You're in a very challenging situation. A lot of uncertainty and a lot of losses. But there's also lots of things to be hopeful for and lots of reasons to have hope. So in your search for good answers for your child I think you'll find healthy and hopeful answers for yourself.

Question, continued: *But how do you relate to a child the difference between hope and having an expectation that things are going to happen a certain way?*

DR. WENDY HARPHAM: It's a hard concept for some adults, too.

Question, continued: *Because it's hard enough for me sometimes. And as a three-and-a-half-year-old, I mean, I don't know when the time is going to come where this is going to be something that he more understands. But I don't want to give him false impressions or false hopes. But I don't want him to have a negative view either.*

DR. WENDY HARPAM: Right, and it's an ongoing process. It's an ongoing process that you will tell the story in 20 different ways 100 different times. For example, on his birthday he can hope he's getting a pony. He can expect to get a board game. So you can use different words. It's not going to happen overnight, and it shouldn't. And that's not a bad thing. Because it gives you many opportunities to shape his understanding, his perceptions, his beliefs and his hopes. And again it gives you many times to inspire yourself and give yourself genuine hope of dealing with your illness and maximizing your chance of doing well.

RANDI ROSENBERG: Dr. Harpham, that was a great analogy. Thank you so much for your question and good luck to you. Matt, do we have any more questions in the queue?

MATT: We have no further questions at this time.

Conclusion

RANDI ROSENBERG: Very good, then. Well, thank you. For any of you who still have questions please feel free to submit them to info@youngsurvival.org. And just in closing before we end our call we have our final polling question for the evening. And again press the number on your touch-tone pad that corresponds with your answer. *We'd like to know how helpful you found tonight's teleconference in answering your questions. If you found the conference very helpful, please press one. If you found it somewhat helpful, please press two. If you didn't find it to be helpful to you, please press three. And your answers are very important to us because it helps us to gauge how our programs are helping and impacting young women affected by breast cancer.*

So again just to remind you that the YSC is here to provide you with the information that you need as a young woman affected by breast cancer, or a support person working with somebody or living with somebody with breast cancer. And we also want to serve as a point of contact for you and provide you with the resources you need. I assume many of you are already registered on the YSC web site. And if you are you'll continue to receive information

about upcoming programs and announcements of other interesting programs. If you're not we invite you to sign up at www.youngsurvival.org.

And just as an FYI we have a couple of related teleconferences coming up in the very near future. We're actually co-hosting two teleconferences on fertility after breast cancer with our partner Fertile Hope. The first one will be scheduled for October the 11th, and that program is specifically for patients and survivors. And a second program on fertility after breast cancer will be airing on October the 25th particularly for medical professionals helping their patients through treatment and fertility issues. And that does conclude our program for the evening.

Again I'd like to thank our wonderful panelists, Dr. Wendy Harpham, Sharilyn Jones and Emily Spivack for joining us and offering their viewpoints, their time and their experience. We'd also like to thank Aventis for underwriting tonight's teleconference and making it possible as well as Elly Kirschner and Anna Cluxton from the Young Survival Coalition for helping to coordinate the logistics and details for tonight's call. As I mentioned at the top of the call a transcript will be available in between two and three weeks. That will be posted on our web site. And we hope to have you join us again for future programs. And that concludes our program, and this is Randi Rosenberg. I wish you a good night and good health.

(END OF CALL)