#### FLORENCE AND JOSEPH APPLEMAN EDUCATIONAL BOOKLET SERIES

Our Voices: Inspiring Words from the Women of Sharsheret





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## Our Voices: Inspiring Words from the Women of Sharsheret

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#### GET TO KNOW SHARSHERET

Sharsheret supports young Jewish women and families facing breast cancer and ovarian cancer at every stage—before, during, and after diagnosis.

Our name, Sharsheret, means "chain" in Hebrew and represents the strong, nurturing connections we build to support Jewish women and their families at every stage of breast cancer and ovarian cancer. We help women and families connect to our community in the way that feels most comfortable, taking into consideration their stage of life, diagnosis, or treatment, as well as their connection to Judaism. We also provide educational resources and create programs for women and families to improve their quality of life. We understand that young Jewish women have unique concerns when it comes to breast cancer and ovarian cancer, and we are the only organization that specializes in serving them. Our programs are easy to access. From Boston to Burbank, Milwaukee to Miami, Sharsheret is wherever you are.

Sharsheret is a growing community of women and families. Together, we are creating a chain of strong links that reaches across the country so that no woman or family of Jewish descent needs to face the challenges of breast cancer or ovarian cancer alone.

Visit **www.sharsheret.org** or call us at **866.474.2774** to participate in our programs and to become a link in the Sharsheret chain. All inquiries are confidential and answered by qualified staff who can help.

## OUR PROGRAMS

#### The Link Program®

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer or ovarian cancer one-on-one with others who share similar diagnoses and experiences
- The Margot Rosenberg Pulitzer and Sheri Rosenberg Kanter Embrace<sup>™</sup> Program, supporting women living with advanced breast cancer or recurrent ovarian cancer
- Genetics for Life<sup>®</sup>, addressing hereditary breast cancer and ovarian cancer
- Busy Box®, for parents facing breast cancer or ovarian cancer while raising children or teens
- The Bella Chachky Diamond and Sylvia Diamond Geller Best Face Forward<sup>®</sup> Program, addressing the cosmetic side effects of treatment

- Best Face Forward 2.0, providing services and financial subsidies to enhance women's quality of life
- The Florence and Laurence Spungen Family Foundation Family Focus<sup>®</sup>
  Program, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports<sup>™</sup>, developing local support groups and programs
- Thriving Again®, providing individualized support, education, and survivorship navigation for young breast cancer survivors

#### Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women and Jewish women facing breast cancer and ovarian cancer
- Sharsheret on Campus<sup>™</sup>, outreach and education to students on campus
- Sharsheret Educational Booklet Series, culturally relevant publications for Jewish women, their families, and health care professionals

### INTRODUCTION

A few years after Sharsheret was founded, we realized we had a treasure of inspirational stories for breast cancer and ovarian cancer survivors. In 2008, we published "Our Voices," a collection of personal anecdotes that offered advice, humor, strength, and comfort from women and their families within the Sharsheret community.

We were thrilled with the response to "Our Voices." Readers told us it helped them feel spiritually uplifted, comforted, and most importantly, less alone on their journey through the world of breast cancer and ovarian cancer.

It's time for a new, updated edition. Included here are stories from women living with all stages of breast cancer, from diagnosis to treatment to genetics, as well as anecdotes about relationships, spirituality, and family. You may notice that all of these entries end on a positive note. While it certainly doesn't mean that breast cancer is a walk in the park, or that the authors never felt discouraged or hopeless, the point is to show you that there really can be a silver lining in every dark cloud — you just have to look for it.

At the end of the book we have included space for you to write your own personal reflection. Hopefully you will feel inspired by some of the anecdotes here to write about your own experience. Perhaps you, too, will be able to find your silver lining.

We have also included a Resource Directory to help you identify many Jewish organizations as well as cancer organizations available to you, your friends, and family. The Resource Directory is organized by subject area so you can easily access the organizations that will be most useful in addressing your particular needs.

> - Shera Dubitsky and Becky Wolf *Editors*



#### MY VOICE, OUR VOICES, AND THOSE OF THE NEXT GENERATION

When Sharsheret was first conceived, mine was one of only a few audible voices – the story of a 28-year-old woman, newly diagnosed while raising two children, in search of a community of similarly situated young and Jewish breast cancer survivors. Over the years since Sharsheret's founding, ours has become a chorus. As thousands have joined us to share their stories, Sharsheret has become fertile ground for conversations about breast cancer and ovarian cancer, and you have helped us lift the veil of secrecy.

The experiences we share offer strength, hope, and comfort to others facing cancer. But they also speak volumes to the next generation. A few years ago, my son Shlomo and I were picking up a package when the woman behind the counter appeared wearing a hat similar to the ones I had worn during chemotherapy. Shlomo, who was seven years old at the time, seemed a bit nervous, and I thought it might be a good opportunity to use the encounter as an example for him that cancer happens – not just to his mommy, but to lots of other women, too. So I gently probed, "I see you noticed that Cathy has no hair. What do you think that means?" I expected him to answer, "Well, she must be sick." Instead, he looked up at me and said, "You're helping her."

Sharsheret has turned cancer on its head. Having heard so many stories of those facing a diagnosis, living through treatment, and thriving beyond cancer, in Shlomo's eyes, cancer was no longer about illness but about healing and helping. Over the years, Sharsheret has enabled you, me, and thousands of women and men across the country to shape adversity into opportunity. And that will be our legacy - the voice of the next generation - the chorus of our growing community.

- Rochelle L. Shoretz a"h Sharsheret Founder

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# Wearing Your Jewish Genes

"I was chosen. If you are reading this then you probably were, too. One of the great strengths of the Jewish people over history has been our sense of humor. You couldn't find a better

time to make use of yours."

#### I WAS CHOSEN

In 2009, I had a routine mammogram. As usual, I played a head game of, "If they haven't called me by Thursday, I'm fine." And then, "If they haven't called me by Friday, I'm fine." My call came the next Tuesday.

"How are you, Sue?"

"I think you are calling to tell me."

"Well, Sue, I've been talking with the breast radiologist and we think because of your ethnicity that we do additional testing. You should have a breast MRI."

"My ethnicity?"

"Yes, Sue. Didn't you know that Ashkenazi Jewish women (Eastern European descent) have a higher risk of certain breast cancers?"

"No, I didn't know. I'll convert." (And yes, I did tell my Rabbi I said that. He laughed.)

"I don't think that will work, Sue. It's hereditary."

Further testing showed that I did indeed have breast cancer, and I had a double mastectomy. But it turned out I am negative for the BRCA gene. Who really knows if cancer is genetic, or something related to the environment, or simply the flying fickle finger of fate? All I know is that through the genetic testing and learning about the link with other Jewish women, I feel more connected with my Jewish heritage. I've never been observant but I feel a kinship with the beleaguered generations that came before me.

This experience made me think about Fiddler on the Roof, when the worndown Tevye looks up at the sky and says to God, "I know. We are your chosen people. But once in a while, can't you choose someone else?"

I was chosen. If you are reading this then you probably were, too. One of the great strengths of the Jewish people over history has been our sense of humor. You couldn't find a better time to make use of yours. Cancer is too serious not to laugh.

- Susan, Wisconsin

#### BEING BRCA+ DOES NOT DEFINE ME

Oh dating! People say it's fun, but is it really? The butterflies, bad dates, labels, unreturned phone calls. I would call it hard, to say the least. When you've tested positive for the BRCA gene mutation at 24, dating is even more challenging. I kept asking myself, who would want to date me with my increased risk for developing cancer? This is where I was about two years ago.

I met Liam on a blind date and entered the experience with a ton of preconceived notions. I assumed no guy would want to date a "BRCA positive girl". It took me almost three months to tell him about it. I built it up to be this undefeatable and overwhelming situation from which he had every right to walk away. Boy was I was wrong! He took everything in stride. He told me about how he lost his mom to breast cancer, and how he thought I was making good decisions. He tackled every aspect with me, together, and made me laugh along the way. He was there with me and pushed me to strive for better doctors and better outcomes. He helped me remember all the other things that make up who I am: sarcasm, Harry Potter, brightly colored sneakers, and Scrabble, not just BRCA - things that make me Emma.

Liam showed me that he loved all of me, even the parts that I assumed he wouldn't. I learned an important lesson: Accept BRCA as a part of your life, but don't let it define you. At the age of 27, the night before the second surgery of my prophylactic mastectomy, Liam proposed. I got my fairytale.

- Emma, 28, New York

C Accept BRCA as a part of your life, but don't let it define you. 33

#### A FATHER'S STORY

I lost my grandmother to ovarian cancer when she was 47 and I was 2, and my mother to breast cancer when she was 45 and I was 19. Over the years, I spoke to various doctors about what I perceived to be a risk of passing some sort of predisposition to these cancers on to my daughters. I was told, "Breast and ovarian cancers are passed from mother to daughter." One added condescendingly, "You don't have ovaries, do you? Don't worry about it."

Three years ago, my daughter, at age 36, was diagnosed with breast cancer. Even though she had told her surgeon of our family's heavy breast/ovarian cancer history and the fact that we are Ashkenazi Jews, the surgeon never recommended genetic counseling or testing, and her recommendation was a lumpectomy. The pathology report showed a triple-negative, invasive cancer. It was only then that it was mentioned to me that my daughter should be tested for the BRCA mutation. We both tested positive for BRCA1. My daughter decided to have a prophylactic mastectomy and a hysterectomy-oophorectomy, drastically reducing her risks for further breast or ovarian cancer. She went through four months of chemotherapy between her first surgery and her second surgery. I do not feel guilty about passing this mutation on to my daughter, but I do feel profoundly sad that she inherited it, developed breast cancer at such a young age, and will never be able to have a child naturally.

Her bright shining light after chemo has been, "Daddy, I do not want to find cancer 'early' and go through chemo again. I do not want to find it at all." I am not recommending a course of action for anyone, just sharing our family's experience.

It is my hope that doctors will pay attention to the patient's father's cancer family tree, and also speak to men to let them know that they can be at increased risk for prostate and other cancers if they are BRCA positive.

- Steve, California

#### KNOW YOUR FAMILY HISTORY

For those of us growing up in the 1950's, cancer was not an often-used word. It was referred to as "the big C" or by other euphemisms and was rarely discussed in public. That's not to say the disease was uncommon, but rather that the topic just wasn't discussed.

In 1960, my mother was diagnosed with cancer. She had surgery during the summer when I was away at camp and I was not told about it. Later, I found out that my mother had some type of "women's cancer." She had a full recovery and so the topic was never again discussed (and thankfully she lived another 41 years until she died of natural causes). A year after my mother's diagnosis, her sister was diagnosed with cancer. She died two years later. I was never told what type of cancer my aunt had and I never thought to ask. Cancer was a dreaded disease and not something one talked about.

In the mid 1990's, my aunt's son, who is a physician, called to tell me about a new test for ovarian cancer - the test for the BRCA gene mutation. I couldn't understand why this was so important until he told me that both my mother and aunt had battled ovarian cancer. At the time, the test was not being offered where my elderly mother lived, and because travel was too difficult for her, she never was tested. About three years ago, I decided to get myself tested for the BRCA gene mutation. The results came back negative. I felt a tremendous sense of relief until I spoke to an oncologist who told me that since my mother had never been tested, it was still possible that some other gene was linked to her cancer.

These words proved to be prophetic. A few months after the genetic testing, I had my annual pelvic sonogram and a growth was found on one of my ovaries. I had it surgically removed, and it turned out to be malignant. Luckily, I was diagnosed with Stage 1A ovarian cancer – only one ovary was affected and the cancer had not spread.

The early detection of my cancer was due to knowing my family history. Find out yours. It made all the difference for me.

- Sue, Maryland



# Thriving Through Diagnosis and Beyond

"My hair has grown back and all outward visual evidence that my life was changed will be gone. But I have my words and my voice."

#### THE BIG BAD "C", NOT ANOTHER CHAIN EMAIL

Some of you may have heard that I have the big bad "C." This is true, to some extent, although, based on research and logic, I prefer to call it the little, annoying, pain-in-the-you-know-where "C". Here are the answers as best as we know them to your questions – "we" being my husband Dave and myself, with Dave as the primary author.

#### Q. Does Dana have the big "C?"

A. Yes.

#### Q. Will Dana live?

A. She has every intention of being around for a really long time. Apparently, her type of "C" is the most common kind and the easiest to treat. Based on our current understanding, the long term survival rates are pretty good when it's caught early like this. They talk about "curing" this form of "C," (i.e. 95% survival rates). We're going to stick with that story.

## Q. What are some examples of things you don't want to hear?

A. Any of the following:

That everything will be okay. You're not a doctor and you don't know that. That's what we thought last week when they told us only 5-10% of these lumps are cancer.

That your Aunt Tillie had her "C" removed and she's fine. We know that most people get through this just fine. This isn't about what is sensible or logical. Right now, we're just frazzled emotionally and we don't give a darn about your Aunt Tillie. This week we're going to be self-indulgent. That this particular cancer caught early is the best cancer to get. See above. We understand things logically. For the time being we're not interested in logic. Right now we've got some tough steps to get through and progressing through them will ease the situation.

Any self-referential reasoning, homilies, down-home wisdom, aphorisms or solipsistic reasoning. Hugs are good. Empathizing is good. Your wisdom is not. We'll cheer up on a schedule as of yet to be determined.

## Q. Should I stare at where Dana had her surgery?

A. No.

**Q. What if I can't help myself?** A. Don't.

Q. What if I really can't help myself?

A. Buy her jewelry and consider that your punishment for your lack of discretion.

#### Q. Can I forward this email?

A. Yes. It's not a chain email and you won't get "C" if you don't forward it within 10 seconds to 10 of your friends. We're still not thinking clearly, so hopefully sending the email to a few folks will inform the right people.

- Dana and Dave

#### I CHOOSE LIFE

One November day a few years ago, my entire life changed. I experienced several shooting pains in my right breast. I tried to stay calm, but some of the pains were sharp and unbearable. Little did I realize the journey I was about to embark on, nor how it would change my entire life both physically and emotionally.

At the age of 5, I lost my mother to breast cancer. Because my mother passed away when I was so young, my memories of her are vague and fleeting. What I remember most about her is that she was sick and things at home were difficult. In a strange way, having the same type of cancer as my mom, and being the same age as she was when she was sick, has brought me closer to her. I feel more connected now to her than I ever did before. It was a *bracha* (blessing) that my cancer was detected at such an early stage, and it was another bracha that because of today's medicine. I was able to overcome cancer. Unfortunately, my mother was not so lucky and didn't have the same treatments back in 1972 that are available now.

Women who had breast cancer then didn't have the choices that women have today. She lost her battle at the young age of 39, while I, at that age, was in the middle of fighting my own. Today women with breast cancer can be proactive in decision-making concerning their treatment. Breast cancer in the 70's was referred to as "C" and it was rarely discussed in public. Today, people join thousands in walking through Central Park, wearing pink ribbons, and speaking honestly and publicly about the disease.

One can even increase their survival rate by making decisions based on genetics - very difficult and painful decisions. At age 39, upon finishing my chemo regimen, I had the most difficult decision of my life to make. Knowing my family history, I was advised by many doctors that it was in my best interest to undergo a radical surgery which would increase my survival rate. It was an extremely difficult and painful decision. I agonized, cried, soulsearched for hours, spoke endlessly to family, friends, doctors, and to women who were faced with similar decisions through the help of Sharsheret. While my mother's battle ended for her at age 39, I was able to make a choice to live. I endured a difficult surgery to make this happen. But at least I had the choice, and I chose life.

- Blair, 39, New York

#### PASS THE WORD

I was sitting at our computer, my knees curled up to my chest, watching "Nip/Tuck". In the episode, the character Liz thought she might have breast cancer. My butt started to feel numb, so I unfolded myself and thought, "You know, I haven't checked myself in a while." As I ran my fingers over my right breast, I thought, "Huh? What is that?"

My smile dropped. My fingers kept rubbing against the bottom of my breast against my rib. It felt like something. I took a deep breath. I was overreacting. It was nothing.

My mom and grandmother are cystic. "Yeah, it's probably nothing," I thought. I'll make an appointment.

I kept finding excuses. I had to be home with the kids, I had too much work. Jay was unemployed at the time, so I had to work. I'm too young for it to be anything. I ignored it. I assumed it was nothing. There was no history of breast cancer in my family – why should I think it was anything? It was a tiny ball of skin on the lower underside of my breast that didn't feel like the rest of my breast. It felt different. I knew I would get it checked out, but I was in no rush. It was nothing, right? God listened to me stalling. I thought I couldn't go for an appointment because my husband was out of work. Poof! He got a job. My job got in the way. Poof! The same day Jay got his job, I was let go from my job of 12 years. Problems solved. My excuses were all gone and I was given a health insurance deadline of less than 15 days.

I called my OB-GYN and explained that I had to be seen while I still had insurance. No appointments? I played my cancer card for the first time and didn't even realize it. "I kinda think I found a bump, but I want the doctor to check it out."

I saw my doctor. She did a breast exam and found nothing. Whew! Nothing. Hear that? Nothing. Nothing. I kept hearing "nothing" echoing in my mind. I could smell "nothing" – it was my doctor's perfume. I tried to taste nothing, and I had a bad taste in my mouth. "Something" I tasted in January, while my husband was cooking was still an aftertaste in my mouth. I told the doctor that when I was doing a self-exam I thought I found something. I just need her to tell me it's nothing. She said, "Okay, can you show me where?"

Her response after rubbing the spot and prodding it: "Huh." That's never what you want to hear. A sonogram and biopsy (or three) later, we got the news.

I should probably go back in a few months. Why would I even do a breast self-exam at age 35?

In August, I reconnected with an old friend. We schmoozed and caught up with each other's lives. Out of the blue, she mentioned that she was just recovering from a breast biopsy. She was not even 30.

"Why would you even think you should get yourself checked?," I asked. "That's crazy – you're a baby!"

"You didn't know? My sister is BRCA positive and had breast cancer at 35."

I checked myself because a friend shared her story with me.

I can do no less. I could continue and write about finding out that the tiny ball was actually stage III cancer, all the different appointments, doctors, the number of times I had conversations without a shirt on, the needles, the scalpels, the bottles of medications... My hair has grown back and all outward visual evidence that my life was changed will be gone. But I have my words and my voice.

Because a friend told me about her family and breast cancer, I did a self-exam.

I can do no less. As I stand here alive, I urge you to pass the word.

- Bonnie, 35, New York

#### LIGHT AT THE END OF THE TUNNEL

I was 27 and thought I had a bladder infection. It turned out to be a tumor on my right ovary. At first, my gynecologist was not concerned. "Could it be cancer?" I worried. "No," she replied, "You're too young to have cancer." I was married and trying to get pregnant at the time, so I scheduled surgery immediately to get it over with. The doctor assured me the worst that could happen is I'd lose one ovary and I would still be able to have children. She was confident the tumor was benign.

On the day of my surgery, I was wheeled into the pre-op room. That's when the medical assistant approached me with a legal form to sign, agreeing to the potential of having a hysterectomy. My doctor and I never discussed this. Five hours later, the surgery was over, and I was in the recovery room. I was in a lot of pain. That's when my doctor broke the news: "I'm sorry, but you have ovarian cancer. We had to do a complete hysterectomy."

Through the pain I heard, "You have cancer. You can't have children." The irony was that my doctor was six months pregnant. Her bulging belly at my eye level made me feel even more devastated. I had stage IIIc ovarian cancer spread throughout my abdomen. I faced infertility, followed by a bowel obstruction, and six months of chemotherapy. The other major difficulty I dealt with was not knowing anyone else my age with ovarian cancer. The average age of diagnosis at that time was 61 and I was 27. The worst side effect was infertility and I couldn't find anyone else who could relate to me. For this reason, I am so proud of Sharsheret for developing a peer support program for young, Jewish women living with ovarian cancer. I am excited to be a peer supporter and share the important message with other voung women facing ovarian cancer that there is light at the end of the tunnel, and there are fertility options.

Today, my husband and I are the parents of twin boys, age 5, who were born with the help of an anonymous egg donor and surrogate mom. Becoming a mom was the final piece to my healing.

- Marcia, 27, Colorado



#### WEAR PINK FOR TAMMI DAY

After being diagnosed with breast cancer, some people want to keep the news to themselves or share it only with a small group of loved ones. I was the opposite. When I was diagnosed with breast cancer I wanted to tell everyone so I could serve as a "cautionary tale" to prompt those in their 30's and 40's to perform regular self-exams and get annual mammograms. I also wanted to surround myself with as many wellwishers as possible.

I am fortunate to have a wide circle of loving and supportive family and friends. People from all over asked me, "What can I do? How can I help?" I came up with the idea of making my mastectomy date "Wear Pink for Tammi Day". I asked everyone to send me pictures of themselves, their family members, and even their pets wearing pink as a way to cheer me up after my surgery.

The response was incredible. On the day of my surgery, I received more than 50 photos from friends, acquaintances, and friends-of-friends I didn't even know, all of them wearing pink and wishing me well. When my parents and husband visited me in the hospital, they wore matching t-shirts airbrushed with my name and a pink ribbon. When I came home from the hospital, our nanny had decorated the entire house in pink. She and my young sons made a photo collage of them wearing pink, pasted it on pink paper, and hung it in my bedroom so I could admire the photos as I recuperated. My neighbor's daughter made a pink beaded bracelet for me and I wear it every day.

I understand that this approach might not be meaningful to everyone, but I felt completely enveloped in love and support, which helped to keep me in a bright disposition even on days when I was in pain or scared. I believe that this encouragement fueled my recovery and I feel truly blessed to have such wonderful people in my life.

- Tammi, 39, New York

6 Becoming a mom was the final piece to my healing.

#### FINDING THE NEW NORMAL

I often have difficulty conceiving of the idea that I have had breast cancer, and at the same time, I can't stop speaking about it. I am grateful to God that I am here, that my cancer was treatable, and occurred in a place that it could be removed without damage to other organs. But, at the same time, I want to scream to the world and say, "Look at me – I look normal. I am happy and smiling – BUT I am different!"

There are multitudes of conflicting feelings and emotions harboring within me while I run through my "normal" life, not stopping to sort them out or really speak about them. Doctors, people, tests, decisions, decisions, and more decisions, surgeries, family, friends, strangers, caring, praying, aches, pains, fear. Do I keep this new part of my life as the focus of my new life or do I try to get past it and resume what was normal before? Can there be a balance between the two? I think that the most important lesson that I have learned is that in life, good and bad happens to all. It is how we react to ALL of life's occurrences to us and to others that defines each and every one of us. Most people want to be the ones doing the *mitzvot* (acts of kindness) to help others. However, there are times that God uses us as the recipient, testing others to see how they will act, and giving others a chance to do many *mitzvot*.

- Anonymous

...I want to scream to the world and say,
Look at me - I look normal. I am happy and smiling BUT I am different!



#### ODE TO MY PERIOD

It's weird, the little things that we mourn when dealing with cancer. I'm 41 years old, about to start chemotherapy for breast cancer, and I will likely enter early menopause from the treatment. Oddly, in this midst of all of this other emotional turmoil, I feel I need to take a moment and say "goodbye" to my last period ever.

I wish I was more poetic – I'd write a better Ode to My Period. For all the times in my youth, I was happy to see you. For all the times trying to get pregnant, I was sad to see you. But, I never knew I'd be saying goodbye to you at such a young age. There's nothing anybody can say or do, just a sad moment for me.

Tomorrow I'll appreciate no more tampons and the extra space on my bathroom shelves.

#### - Lisa, 41, New York

#### WHY IS IT ALWAYS A BUS?

When people find out I'm dealing with breast cancer, they often try to comfort me by saying that no one knows when their time will come. After all, they could get hit by a bus tomorrow. What I want to know is, why is it always a bus? Are thousands of women dying each year because they're stepping out in front of a bus? If so, why aren't we hearing about it on the news? I demand to know more about these absent-minded women and these murderous bus drivers!

- Peggy, 36, New York

#### LEARNING TO RECEIVE

Having breast cancer, while difficult and traumatic, has had a positive side as well. I learned how important I am to my family and friends. Many people helped me and showed remarkable thoughtfulness. I had meals brought in, rides to chemotherapy, books given to me by my book group, many donations to charities, and phone calls and letters wishing me well. I am used to being the "caretaker" and being on the receiving end of help was a new experience for me. It was very heartwarming.

I am a physician used to caring for patients. This time, I was on the "other side of the table." While the doctors, nurses, and radiology technicians were wonderful, I learned it is hard to be a patient.

- Joyce, 64, Minnesota

#### OTHERWISE HEALTHY 32-YEAR-OLD WOMAN

I do not believe my story to be unique, my journey special or my life inspiring, even though for years people have been telling me just that. I will admit that being diagnosed with breast cancer in 1992 at the age of 32, the mother of two small children (then ages 5 and 3), married for nine years, and working full-time outside the home did put me in a club that I was not looking to join, where few others my age were to be found.

Have you heard of people having a sixth sense? That is the only explanation I can think of for the fact that I received a mammogram at such a young age. I had a gut feeling that something wasn't right and my doctor sent me for a mammogram based on my instincts. Sure enough, I was diagnosed with breast cancer. It was ironic hearing medical personnel continually call me an "otherwise healthy 32-year-old."

After a modified radical mastectomy, I was released from the hospital with drainage tubes. The next day my daughter came down with chicken pox and two days later, my son began to itch. I went from patient-mode to mother-mode and never looked back. I did not survive breast cancer - I lived it and lived my life every day. I made a commitment to my family that we would not let this define me or us. We would continue to do everything we always did. I would not miss a concert, recital, school conference or work. With the help of family and friends, we thrived and I would like to think I set an example of empowerment for all of them. Today, my children are ages 23 and 21 and my husband and I celebrated – and we always celebrate good things – 28 years of marriage.

It has been 18 years since that April day when I had my breast removed. I remember a day before my surgery someone had asked me, "How do you feel about having your breast removed?," and my answer was and would still be, "They can take my arm, leg or any other body part, because that is all they are, body parts. I just want to be here to see my kids graduate high school." Well, I made it and I'm looking forward to weddings and grandchildren!

- Bonnie

I made a commitment to my family that we would not let this define me or us.



#### WHAT ARE THE ODDS?

My daughter was living in New York and used to ride her bike to work every day. One day, when coming out of the grocery store, she noticed her bike was gone and went in search of a cop. When she found one and reported that her bike had been stolen, his reply was, "This is New York City, what are the odds of ever finding your bike?" My daughter was appalled and said, "My mom had cancer three times and is still alive, what are the odds?"

With that, the cop put her in his car and they drove around looking for her bike. They found both her bike and the thief about two miles from where she had left it.

What are the odds? Apparently they've never been better!

- Lyn, 46, Florida

#### CANCER INSPIRES A MAKEOVER

I was diagnosed with breast cancer after turning 40 and immediately had a lumpectomy.

Losing my hair and going through it alone was one of the most traumatic experiences for me. Experimenting with wigs was fun, but proved too troublesome. Finally, I decided to go bald. It was liberating, but scary at first. I had to build the courage. First, alone on the bus; then as I sat by myself in a park; then as I met with a friend; and finally at school – all in the same day. I experimented with scarves, makeup, and jewelry. I discovered this lifted my spirits on a daily basis, even if I had nowhere to go.

- Celia, 40, New York

#### SURROUNDING MYSELF WITH BLESSINGS

About three days before my second surgery, I invited all my girlfriends over for a party the night before my surgery. I wanted them to give me their blessings and share their love with me as I was about to have this major surgery, a mastectomy, and reconstruction. Instead of focusing on the loss from the mastectomy, I was able to focus on all the positive energy and love that my friends had showered on me the night before. I had surrounded myself with the support that I needed.

- Anonymous

#### CURIOUS OBJECTS

I was diagnosed with breast cancer in 2010 and had a single mastectomy. A few months later, my husband decided that a beach getaway would do me good. We planned a trip to Eilat (I live in Israel), and in addition to my swimming and breast prostheses, I also packed roller blades.

At the airport, the security officer pulled me aside regarding the "curious objects" in my luggage. Having read about the hassles that women go through when flying with prostheses I proceeded to tell the security officer my whole breast cancer story, ending with the need for these prostheses. At this point the security officer looked puzzled and said, "Yes, but why do they need wheels?" I think I've never laughed so hard in all my life. They, of course, were not interested in the prostheses at all, but in the roller blades. This experience taught me to be a bit less self-conscious (that the whole world is not as obsessed as I am with breast cancer) and that every adventure in life, even this, can contain light and laughter.

- Shari, Israel

#### FLOWERS OF LOVE

Before my first operation, I asked various friends to each bring me a flower after the surgery. When I looked at the bunch of flowers, I saw all the love from my friends.

- Anonymous



#### GRATEFUL

Having breast cancer was a lifechanging experience – it opened my eyes to the goodness in people. I was helped by so many friends, family members, my Sharsheret Link, and strangers, yes, strangers!

I came to realize through my year of surgery, chemotherapy, and more and more surgery, that I was indeed fortunate in so many ways. It was so uplifting to see people who I never met in my life organize rides and activities for my children. Dinner was delivered every night for a year. People I never met before brought me not just meals, but gourmet feasts that delighted all the senses. When later on I couldn't digest anything normal, my regular chicken soup gals brought me extrastrained chicken soup. I had delicious challahs dropped off at my door every Friday without fail. Many times it was dropped off at the door or brought by someone else, so I never really had an opportunity to say thank you face to face. When the rare opportunity came that I could thank the person, I would get a response like, "Oh, I was making this for my family anyway, and I just made a little bit more," or, "I was going there anyway." No one would ever let on that it was ever any effort or trouble for them in helping me.

My family and I were, and are still, so grateful. I knew I wanted to thank them all somehow, so about 6 months after my last surgery, I threw a "Grateful Party!" I sent out "You Kept My Light Going" invitations honoring all 75 people that participated in helping me and my family through the previous year. All but one of the invitees came to the special dessert party. Many I was meeting for the first time! I didn't know how else to thank them, but to let them know what a difference they made in my life and my children's lives and how grateful we were to each and every one of these special people.

- Nira, 43, Maryland

#### HOW COULD I ASK FOR MORE?

I am convinced that the ONLY reason I survived this ordeal thus far, and mostly intact, is because my family and friends willed me through it. My strength came from the living, so at each chemotherapy session I was surrounded by my family and friends. My husband became my rock. My parents put their lives on hold and would drive up from Virginia; my pals would drive up from surrounding states. Every session was a little party with food, gifts, manicures, any kind of thoughtful token. We joked, we laughed as we looked at old pictures and silly magazines, and told funny stories. We would laugh so hard and so loud that I remember saying one time, "Guys, we have to be a little quieter; there are sick people here." Honestly, it was only when they stopped laughing and looked at me that I realized I was one of those sick people.

The presence of my family and friends was the only inspiration that I needed to keep moving forward. Somehow everyone knew just what to do, just what to say and what NOT to say. People were flying in from as far as California and Amsterdam to sit with me through chemotherapy, to cheer me on. How could I ask for more? I would sit there with the drugs flowing into my arm and just marvel at how all of my worlds were colliding. My friends from all of my former lives were becoming friends with one another. It was a gift to me; it was the ultimate happiness and peace. In those moments I felt so loved, so lucky.

- Diana, 32, New Jersey

#### ON THE BRIGHT SIDE

I have to look on the bright side of this. I got two perky boobies and a flat stomach for a co-pay of \$5.00.

- Marla, 39, Pennsylvania



## ONE LESS THING TO WORRY ABOUT

When I was first diagnosed with breast cancer, I was very concerned about how it would affect my three children. I was especially concerned about my 12-yearold son, Adam, because he is a very sensitive kid.

I realized that we had all learned a lot from this experience when Adam turned to me one night and told me how proud he was of me. When I asked him why he was proud, he responded that even though I had been going through chemo and it was very difficult on me, I still took great care of him and his brothers. He said I was very brave and was a great role model for other moms in the neighborhood. They would know that they could get through this, since I had done such a great job getting through it myself.

I realized then that while there were many things for me to worry about in the days ahead, this wouldn't be one of them.

- Lisa, 45, New York

### ME, TOO

I was at a point in the dating process where it was appropriate to share my cancer history. I told my date that I was wearing a wig because I had gone through treatment for breast cancer. He responded, "Me, too. Well, at least the wig part." He was wearing a glued-on toupee.

I've found that my cancer history hasn't had the impact I thought it would when I entered back into the dating world. I've been sharing my history around the second or third date. I hope, at that point, the men I have dated have been able to get to know some of my great qualities to balance with the information. I also don't want to get too invested with someone who isn't going to be able to accept my history. I figure the more open and "cool as a cucumber" I can be, the easier it is for both of us. I invite questions, but they rarely ask at that moment. I haven't had a dating partner reject me following my disclosure, although I do feel a sigh of relief when it's out in the open.

- Emily, 35, Colorado

#### COMMUNITY'S PRAYER LIST

Shortly before my 30th birthday I was getting dressed when my thumb bumped into something hard on my breast. I ignored it and went on with my day. Later that afternoon, I checked again, and yes, the lump was still there.

I made an appointment with the first available doctor in my OB-GYN practice. That doctor said it was probably nothing, to try eliminating chocolate and caffeine from my diet and come back in a month. I was still 29 years old, which is probably why he thought it was reasonable to assume that it was nothing. I made my appointment for the following month and went home. However, somewhere deep in my gut I didn't feel right. I never had cysts and it didn't make sense to me that I would suddenly have one. I made an appointment with my regular doctor and she sent me for a mammogram, which came back suspicious, so she scheduled me for a lumpectomy.

Eventually I met with a surgeon who did a needle biopsy on three different places on my breast. All three came back positive for cancer.

A few days after my 30th birthday, I had a modified radical mastectomy. When I was first diagnosed. I didn't know what to do or think or even feel. I was a young wife and mother. I had three beautiful children ages 1, 3, and 5. They needed their mother. What could I do? Where could I turn? I put my name on our community's prayer list. I am the only Ronit in our city, so everyone in the community knew I was sick. That was the best thing I could have done for myself. Reaching out gave me the support and love that my family and I needed to get through this difficult time.

- Ronit, 30, Tennessee

### A SOUL UNTOUCHED BY CANCER

Even though I can't keep the cancer from invading my body, one thing I have come to realize is this: Cancer can't touch my *neshama* (soul).

- Rosalie, 47, Indiana



#### I WANT TO BE A HEALTHY MOTHER

I was diagnosed a few days before *Yom Kippur* (Day of Atonement). I was 29 years old, a mother of five children.

Yom Kippur night, I had one focus. I left my nine-year-old babysitting at night. I ran to shul, opened my heart, and let my tears go freely. I cried my heart out and said, "God you gave me five children, they're mine but they're also yours. God this is your problem. You gave me five children. They are your children. These children need a healthy mother. It was your kindness that I was diagnosed this time of year. On this day, I will cry and pray until you will answer me, but I promise to be happy and make it a happy holiday in my house on Sukkot (Feast of Tabernacles)."

Then came *Sukkot*. I kept my promise to bring the happiness of the holiday into my home. But my *Hallel* (prayer of praise) was full of tears. These are the words we say, "I thank you God for the pain, for me it was a help, salvation." I understand and feel that God is close to me, now more than ever. I pray that I should see salvation from this situation. For now, I surely know the spiritual salvation, since my life, my way of looking at life, has definitely changed to the good. Now, more than ever, I know to appreciate my life, my husband, my children, and these sweet ten years since I was married. I am so thankful for the family I have.

Now that I am wrapping up the past dark months, and my life is getting back to normal (of course, I'm not the same person), I thank God that I am a healthy mother to five children.

- Anonymous

#### THERE IS HOPE

All of the treatments put me into full-blown menopause even though I was in my early thirties. My husband and I decided that we would someday become parents regardless of how it came to us. Then we dropped the issue.

After I finished treatment, my husband and I returned to Israel to visit his family. We had not been there in three years because of the cancer treatment and the surgeries that followed. Although I did not grow up religious, I did want to go to the Holy Land and give thanks for surviving my cancer. I had a two-part mission: I wanted to go to the mikvah and spiritually cleanse myself from the disease, and I wanted to go to the Kotel and give thanks to God for having survived the disease. And I did just that, one day apart.

Sometime between the mikvah and the Kotel, I became pregnant. My oncologist, upon hearing the news, told us that I was not far enough away from the cancer, that I needed to wait at least three years (it had only been two) before even thinking about trying. He told us that if we wanted to do the right thing for my health, then we would terminate the pregnancy. It was a very sad conversation for him and for us. Very quickly, I decided that I would not strip myself of this unbelievable gift and that we would deal with whatever came our way when and if it did. We did not know what to expect from the initial baby ultrasound. Would we hear something, would we see something? Were we really pregnant, or would the ultrasound show us that this was just a dream? The technician looked at her screen and we looked at the monitor hanging from the ceiling. She was talking nonchalantly but we hung on to her every word. When she found the heartbeat she said. "There's one, and there's the other one. You have two babies!" My oncologist told me that I was his first patient to conceive post-treatment. The nursing staff told us that the entire cancer institute erupted in happiness when they heard about my pregnancy.

I write my story here to say that there IS hope. There IS life after cancer. I am beyond fortunate, and I realize that every breath is a gift. I am in love with my life.

- Diana, 32, New Jersey

#### BLESSINGS

My youngest daughter is running around excitedly practicing songs and dances and a one-sentence part for her upcoming *Chagigat HaSiddur* (prayer book celebration). This event is a major milestone for Jewish day school first-graders, a culmination of their being skillful enough in reading Hebrew to be able to pray from a prayer book and of reaching a maturity level appropriate for beginning their formal conversations with God.

I remember when I received my first siddur 38 years ago and the sing-song prayers that became part of my daily routine. Unfortunately, the recitation of the prayers eventually became rote and the meaning of the words didn't strike a chord anymore. Even after my father's death when I was eighteen, the tunes remained comforting, but the words didn't truly resonate until I faced breast cancer.

Last year, my prayers became different. I talked to God while I lay still in the diagnostic machines. Unable to move or breathe heavily, it was in my head that I pleaded with Him silently but urgently telling Him that I wanted to live, that I wanted to enjoy the milestones I had taken for granted, that I feared my young children would suffer the pains of losing a parent. Prior to my diagnosis, I had never deeply felt the words of the prayers. Now, as never before, I yearn dearly to be written in The Book of Life and tell God so outside of the machines.

How precious will it be sitting in the audience watching my seven-yearold daughter proudly receive her first siddur with her beautiful name embroidered on its cover? How incredible it will be that on that very same day, as she embarks on her own spiritual journey and begins her own conversations with God, I will be celebrating my first anniversary as a breast cancer survivor! And I will joyfully sing along with the kids when they close their show with the survivor's anthem, the *Shehechiyanu* – the blessing of something new.

- Helene, 41, New York

I am beyond fortunate, and I realize every breath is a gift.



# Living Life Fully with Advanced Cancer

"Before cancer, I focused on what my life would look like several years in the future. After diagnosis, I learned to appreciate my life as it is today."

#### DON'T COUNT ME OUT JUST YET

During some very scary moments in my journey through metastatic breast cancer, various doctors suggested that I put my affairs in order because they didn't think I had much time left. Well, its nine years later and I've outlived three of my doctors.

- Lyn, 46, Florida

#### GRATITUDE

Facing death puts new perspective on life. (It would, wouldn't it?) Everything looks different – nature, problems (mine and others), the future.

It's just not the same and never will be again.

When the results are good (at least stable)

We breathe a sigh of relief. When I feel miserable I just want to die.

When I feel better I have renewed hope because I really want to live.

And so, I feel deeply grateful for every new bud that reveals its little head, for every brilliant ray of sunlight, for every gentle drop of snow, for each word of compassion, for every look of understanding, for all those who help me, for being able to walk and talk and be in this world, for love freely given, and the capacity to give back, for yet another day alive.

- Rosalie, 47, Indiana


# **BEFORE CANCER, AFTER DIAGNOSIS**

I was 35 at the time of my advanced breast cancer diagnosis, not old enough to warrant even my first mammogram. I have no family history of cancer and no risk factors for it. *Rosh Hashana* comes now at the end of my treatment, bringing a fresh beginning, a new head of hair, and the opportunity to reflect.

The breast cancer community often separates the periods of time before breast cancer and after diagnosis, for it is impossible to go through such an experience without accepting that it changes our perspective.

Before Cancer, I felt independent.

After Diagnosis, I felt connected to my family, friends, and to my community.

Before Cancer, I often had self-doubt.

After Diagnosis, I accept that I am doing the best I can, and I am not perfect.

Before Cancer, I hoped my life would be only joyful.

After Diagnosis, I learned that only with the lows can we truly appreciate the highs.

Before Cancer, I took friendship and family for granted.

After Diagnosis, I learned to truly value the relationships I am blessed to have.

Before Cancer, I focused on what my life would look like several years in the future.

After Diagnosis, I learned to appreciate my life as it is today.

- Cheryl, 35, New Jersey



# WHILE WE LIVE, LET US LIVE

I was diagnosed with early stage breast cancer at age 39 and recurred with metastatic disease to my bones at age 42. I have been living with 20+ sites of bone metastases for more than 5 years.

On my cancer journey, I experienced significant losses. I took medical retirement from my profession. I applied for and received Social Security Disability with the accompanying loss of income. I had to accept that cancer had cheated my husband and me out of becoming parents.

But at the same time, I grew as a person by identifying and achieving life goals. I wrote a will, medical directives, and a living will, outlining my personal philosophy. I traveled with my husband to Paris and to Israel. I rescued a cocker spaniel, which then became my service animal. We bought our first house. I identified opportunities for volunteer work in breast cancer patient advocacy and in my synagogue community.

My philosophy? "*Dum vivimus, vivamus*: While we live, let us live!" Life is precious, and in a very real sense, we all have the same amount of time today.

- Jill, 42, Washington

# ONE DAY AT A TIME

Since I was diagnosed with metastatic breast cancer, I have definitely become more positive, more sincere, and more sensitive. Being grateful reduces my anxiety. Lowering expectations frees me from the pressure of "performance" that we must go on a trip, or must do exciting family outings because we don't know what the future holds. It's okay to have a low-key, relaxed evening with family. I feel much less competitive, much less "in the race" with others. I try to remember that I cannot control my situation, but I can control my responses. I take life, as often as I can, one day at a time.

- Techiya Tali, 36, New York

# THE GIFT OF LAUGHTER

My mom was diagnosed with Stage IV breast cancer at the age of 41. I will never forget how my mother looked cancer right in the eye and made a decision that her spirit would soar and gain strength with each new challenge. She had my 8-year-old cousin draw a placard that she wore as an old-fashioned sandwich board to her treatments which included a word of profanity. Attached to the board were colorful helium balloons, enough to seemingly lift her 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 29 years later. I thank my mom for the gift of being able to laugh, even during the scariest moments of life.

- Shera, 48, New Jersey

# CANCER IS LIKE A WHACK-A-MOLE

I have a chronic illness – metastatic cancer. I'm certainly not alone in this adventure. Sharsheret, with its website, social workers, and monthly phone calls reminds me that there are a lot of women just like me. We're all in this great big club that we'd rather not belong to, but we got "recruited" with the words, "You've got cancer."

I've decided cancer is like Whack-A-Mole, the arcade game where you whack a little critter over the head and another one pops up where you don't expect it. Having a hysterectomy nearly two years ago was like putting the coin in the slot to start the game. The calliope music started and I was full of hope and optimism. I was diagnosed with ovarian cancer that started in my fallopian tubes. I thought, "I'm gonna beat this thing!" I whacked that first "critter" with a whole lot of chemo. Then, just like in the game, another "mole" popped up - this time, on my liver. I tried to whack it with chemo - oops! - missed. Luckily I had many "whacking" options, and I got rid of that guy with surgery. Then, more chemo! Whew - this game is exhausting.

But, you know, just like in the arcade, there are good times along the way. Laughing at what cancer offers up actually is therapeutic. I've enjoyed picking out hats, taking long naps, appreciating the kindness of friends and medical staff, figuring out how to make it look like I really do have eyebrows, and stuffing down hamburgers while justifying it because I'm anemic.

I've had stretches of great times and some low times. What really matters is the present. How do I feel today? Great? Pretty good? Not lousy? Then I say to myself, enjoy the moment! I don't know how many moles I will have to clobber, how long it will take and how I'll do it - but I will. I'll be on and off chemo the rest of my life, but I can't be happy today if all I can think about is tomorrow - and I can't do anything about it anyway, so I pick my head up, put a smile on my face, and enjoy all the great things life has to offer!

- Beverly, 60, Connecticut

I've had stretches of great times and some low times. What really matters is the present. How do I feel today? Great? Pretty good? Not lousy? Then I say to myself, enjoy the moment! **99** 

# ONE WOMAN'S EPIPHANIES

I had an epiphany today. It seems that the expectation of the average woman living with metastatic cancer is that they don't feel good and they should feel grateful on a "good day." My expectation is that I'm going to feel good, and when I don't, it's unacceptable.

I'm not spending any more money on chemo. I'm spending all my money on shoes.

Soon after I was diagnosed with metastatic breast cancer, I went to buy a bird of paradise plant. I was told that the flower does not bloom for five years. I wasn't sure that I would still be alive in five years, so I didn't buy the plant. Well, it's ten years later, and I have an empty corner in my house to remind me that I need to live my life as if I'm going to die tomorrow, and die as if I'm going to live forever.

I can always gauge how I'm doing based on whether or not I can keep my manicure appointment that week.

Many people say to me that I should grow stronger every day. For now, I'm okay with growing stronger every other day.

- Lyn, 46, Florida



# HOW CAN SHARSHERET HELP ME?

If you are at risk or have been diagnosed with breast cancer or ovarian cancer, we can help.

**Connect with others** who share your experience in our national Peer Support Network.

**Discuss genetic concerns** related to your family history and cancer risk with our support staff.

Let us help you help your children through your cancer journey with parenting resources.

**Create** a survivorship plan tailored to your unique needs.

**Join our group** of women living with advanced breast cancer or recurrent ovarian cancer.

**Learn** how to address the cosmetic side effects of cancer treatment.

**Call us** for resources and with questions from family members, caregivers, and friends.

**Keep informed** by experts in the cancer community on our national teleconferences and webinars.

We offer the transcripts of Sharsheret's helpful symposia online at **www.sharsheret.org**, covering topics such as *The Whole Picture: A Holistic Approach to Breast Health and Breast Cancer* and *Breast Cancer and the Next Generation: Caring for Our Children.* Check our website for the continually updated list of relevant transcript topics. If you do not have access to the internet, you can call our office to request copies and learn about other relevant transcripts available to you.

For more information about Sharsheret's programs, please contact us toll-free at **866.474.2774** or at **info@sharsheret.org**. Sharsheret's programs are free and are open to all women and men. All inquiries are confidential.

Remember, wherever you are, Sharsheret is, and we will be there for as long as you need us.



# **RESOURCE DIRECTORY**

#### **Cancer Genetics**

American College of Medical Genetics and Genomics 301.718.9603 www.acmg.net

American Society of Human Genetics 866.HUM.GENE www.ashg.org

Basser Center for BRCA-Education and Outreach 215.662.2748 www.basser.org

BFOR BRCA Founder Outreach Study www.bforstudy.com

Bright Pink 312.787.4412 www.brightpink.org

Center for Disease Control and Prevention www.cdc.gov/genomics/disease/breast\_ ovarian cancer/index/htm

FORCE: Facing Our risk of Cancer Empowered 866.288. RISK www.facingourrisk.org

Genetic Alliance 202.966.5557 www.geneticalliance.org

**Genetics For Life (A Sharsheret Program)** 866.474.2774 www.sharsheret.org

National Society of Genetic Counselors 312.321.6834 www.nsgc.org

NCI Cancer Genetics Services Directory 800.4.CANCER www.cancer.gov/cancertopics/genetics/ directory

Norton and Elaine Sarnoff Center for Jewish Genetics 312.357.4718 www.jewishgenetics.org Right Action for Women www.rightactionforwomen.org/assistance

#### **Breast Cancer Organizations**

Are You Dense? www.areyoudense.org

beBRCAware www.bebrcaware.com/

Breast360.org www.breast360.org

Breastcancer.org 610.642.6550 www.breastcancer.org

Breasthealth.org www.breasthealth.org

Breast Cancer in Focus: Breast Cancer in Men www.lbbc.org/infocusmen

Breast Cancer Research Foundation 866.FIND.A.CURE www.bcrfcure.org

Dense Breast-Info: An Education Coalition www.densebreast-info.org

**Dr. Susan Love Research Foundation** 310.828.0060 www.dslrf.org

Living Beyond Breast Cancer 855.807.6386 888.753.5222 (Helpline) www.lbbc.org

Male Breast Cancer Coalition www.malebreastcancercoalition.org

National Breast Cancer Coalition 800.622.2838 www.Breastcancerdeadline2020.org **National Breast Cancer Foundation** 

www.nationalbreastcancer.org

SHARE: Self-Help for Women with Breast or Ovarian Cancer 866.ASK.SHARE www.sharecancersupport.org

Susan G. Komen Breast Cancer Foundation 877.456.6636 www.komen.org

**Tiger Lily Foundation** 888.580.6253 www.tigerlilyfoundation.org

Triple Negative Breast Cancer Foundation 877.880.TNBC www.tnbcfoundation.org

Triple Step Toward the Cure 877.880.8622 www.triplesteptowardthecure.org

United Breast Cancer Foundation 877.UBC.4CURE www.ubcf.org

Young Survival Coalition 877.972.1011 www.youngsurvival.org

## **Ovarian Cancer Organizations**

Camp Mak-A-Dream-Adult Retreats 406.549.5987 www.campdream.org

Foundation for Women's Cancer 312.578.1439 800.444.4441 (Hotline) www.foundationforwomenscancer.org

Gilda Radner Familial Ovarian Cancer Registry 800.OVARIAN www.ovariancancer.com

HERA Ovarian Cancer Foundation 970.948.7360 www.herafoundation.org National Ovarian Cancer Coalition 888.OVARIAN www.ovarian.org

Ovarian Cancer Research Alliance 202.331.1332 866.399.6262 www.ocrahope.org

Roswell Park Familial Ovarian Cancer Registry 800.682.7426 www.ovariancancer.com

Sandy Rollman Ovarian Cancer Foundation 610.446.2272 www.sandyovarian.org

SHARE: Self Help for Women with Breast or Ovarian Cancer 866.ASK.SHARE www.sharecancersupport.org

# Young Women Facing Breast Cancer

Stupid Cancer 877.735.4673 www.stupidcancer.org

Ulman Foundation 888.393.FUND Ulmanfoundation.org

Young Survival Coalition 877.YSC.1011 www.youngsurvival.org

## Survivorship

2Unstoppable www.2unstoppable.org

American Cancer Society Survivors Network www.csn.cancer.org

Breastcancer.org 610.642.6550 www.breastcancer.org

LIVESTRONG Foundation 855.220.7777 www.livestrong.org

Living Beyond Breast Cancer 888.753.5222 (Survivor's Helpline) www.lbbc.org



National Coalition for Cancer Survivorship 877.NCCS.YES www.canceradvocacy.org

Survivornet.com www.survivornet.com

**Thriving Again (A Sharsheret Program)** 866.474.2774 www.sharsheret.org

Young Survival Coalition 877.YSC.1011 www.youngsurvival.org

# Jewish Organizations Addressing Cancer and Health-Related Issues

**Bikur Cholim, Partners in Health** 845.425.7877 www.bikurcholim.org

Chai4ever 646.519.2190 www.chai4ever.org

Chai Lifeline 877.CHAI.LIFE www.chailifeline.org

Hadassah 888.303.3640 www.hadassah.org

Network of Jewish Human Service Agencies 201.977.2400 www.networkjhsa.org

Nishmat: Women's Health and Halacha 877.963.8938 www.yoatzot.org/home/

The Jewish Board 844.ONE.CALL www.jewishboard.org

## **Cancer Organizations**

American Cancer Society 800.ACS.2345 www.cancer.org American Psychosocial Oncology Society Helpline 866.276.7443 www.apos-society.org

**Cancer101** 646.638.2202 www.cancer101.org

CancerCare 800.813.HOPE www.cancercare.org

Cancer Hope Network 877.HOPE.NET 800.552.4366 (Helpline) www.cancerhopenetwork.org

Cancer.Net 888.651.3038 www.cancer.net/

Cancer Support Community 888.793.9355 www.cancersupportcommunity.org

Imerman Angels 866.IMERMAN www.imermanangels.org

National Cancer Institute 800.4.CANCER www.cancer.gov

Patient Resource 800.497.7530 www.patientresource.com

## LGBTQ Community

Center Link, The Community of LGBT Centers 954.765.6024 www.lgbtcenters.org

National LGBT Cancer Network 212.675.2633 www.cancer-network.org



# Family, Friends and Caregivers

American Cancer Society: Road to Recovery 800.227.2345 www.cancer.org/treatment/supportprograms-and-services/road-torecovery.html

Busy Box (A Sharsheret Program) 866.474.2774 www.sharsheret.org

Camp Kesem www.campkesem.org

Fighting Pretty www.fightingpretty.org

Gilda's Club 212.647.9700 www.gildasclubnyc.org

Kids Konnected 949.484.9092 www.kidskonnected.org

Lotsa Helping Hands www.lotsahelpinghands.org

Men Against Breast Cancer 866.547.MABC www.menagainstbreastcancer.org

Mommy has Breast Cancer 877.386.7322 www.mommyhasbreastcancer.org

Mothers Supporting Daughters with Breast Cancer 410.778.1982 www.mothersdaughters.org

SHARE Caregiver Circle for Family and Friends 844.ASK.SHARE www.sharecancersupport.org

Sister to Sister 718.338.2943 www.sistertosisternetwork.org

Take Them a Meal 800.951.7715 www.takethemameal.com Telling Kids About Cancer www.tellingkidsaboutcancer.com

The Breathing Butterfly www.elfenworks.org/butterfly/

The Florence and Laurence Spungen Family Foundation Family Focus Program (A Sharsheret Program) 866.474.2774 www.sharsheret.org

Wonders & Worries, We will, Together 512.329.5757 www.wondersandworries.org

## Fertility, Pregnancy, and Nursing

Alliance for Fertility Preservation www.allianceforfertilitypreservation.org

A T.I.M.E (Torah Infertility Medium of Exchange) 718.437.7110 www.atime.org

Bonei Olam 718.252.1212 www.boneiolam.org

Hasidah 415.323.3226 www.hasidah.org

Hope for Two- The Pregnant with Cancer Network 800.743.4471 www.hopefortwo.org

Livestrong Fertility 855.220.7779 www.livestrong.org/we-can-help/ livestrong-fertility

Oncofertility Consortium-Northwestern University 312.503.2504 www.savemyfertility.org

Path2Parenthood 888.917.3777 www.path2parenthood.org

Puah 708.336.0603 www.puahonline.org



**Reprotech** www.reprotech.com/financial-assistance. html

Resolve 703.556.7172 www.resolve.org

Will2Love www.will2love.com

Yesh Tikva www.yeshtikva.org

## Travel

Air BnB 877.793.0498 www.cancersupportcommunity.org/ airbnb

Angel Flight NE 877.AIR.LIFE www.angelflightne.org/

Corporate Angel Network 914.328.1313 www.corpangelnetwork.org

Joe's House 877.563.7468 www.joeshouse.org

Patient AirLift Services www.palservices.org

Transportation to Medical Care Referral Site 800.296.1217 www.patienttravel.org

# **Financial Assistance**

1 Cancer Source 508.630.2242 www.cancerlsource.org

A Silver Lining Foundation 312.345.1322 www.asilverliningfoundation.org

All4One Alliance 508.630.2242 www.all4onealliance.org Cancer Family Relief Fund www.cancerfamilyrelieffund.org

Cancer Financial Assistance Coalition www.cancerfac.org

Financial Wellness Tool Kit (A Sharsheret Resource) 866.474.2774 www.sharsheret.org

Genevieve's Helping Hands, Inc. 516.500.3702 www.genshelpinghands.org

HealthWell Foundation 800.675.8416 www.healthwellfoundation.org

Hill-Burton Free and Reduced-Cost Health Care 800.638.0742 www.hrsa.gov/gethealthcare/affordable/ hillburton

Impact One 623.738.6794 www.impactone.pink

My Hope Chest www.myhopechest.org

Myriad 800.469.7423 www.myriad.com/myriad-cares-2/ finanical-assistance-program/

National Association of Free Charitable Clinics 703.647.7427 www.nafcclinics.org

Patient Advocate Foundation 800.532.5274 www.patientadvocate.org/exploreour-resources/breast-cancer-resourcedirectory/

# Patient Resource LLC

913.725.1600 www.patientresource.com/financial\_ resources.aspx

Patient Services, Inc. 800.366.7741 www.patientservicesinc.org

Pan Foundation 866.316.7263 www.panfoundation.org

Rofeh Cholim Cancer Society 708.722.2002 www.rofehcholim.org

The Assistance Fund 855.845.3663 www.theassistancefund.org

The Breast Cancer Charities of America 936.231.8460 www.thebreastcancercharities.org/helpnow-fund

The Pink Fund 877.234.7465 www.thepinkfund.org

The SAMFund 617.938.3484 www.thesamfund.org

United Breast Cancer Foundation 877.UBC.4CURE www.ubcf.org

Zichron Shlome Refuah Fund 718.GET.WELL www.zsrf.org

# Holistic, Complementary, and Integrative Medicine

American Academy of Medical Acupuncture 301.379.8261 www.medicalacupuncture.org

American Association of Acupuncture and Oriental Medicine www.aaaomonline.org Foundation for Alternative and Integrative Medicine www.faim.org

Holistic Primary Care: News for Health and Healing www.holisticprimarycare.net

National Acupuncture Foundation www.nationalacupuncturefoundation.org

National Center for Complementary and Integrative Medicine www.nccih.nih.gov

National Center for Homeopathy www.homeopathycenter.org

Office of Cancer Complementary and Alternative Medicine www.cancer.gov/cam

Oncology Nutrition www.oncologynutrition.org

The Annie Appleseed Project www.annieappleseedproject.org

#### **Health Insurance**

**#Coverage4All** www.coverage4all.info/

Benefits.gov 800.333.4636 www.benefits.gov

Breast Cancer: Covered or Not 800.215.7494 www.pabreastcancer.org/fin-help/patientresources/commonwealth-programs/ insurance-guidebook.html

Cancer Insurance Checklist www.cancerinsurancechecklist.org

**Center for Patients Partnerships** 608.890.0321 www.patientpartnerships.org

Financial Wellness Tool Kit (A Sharsheret Resource) 866.474.2774 www.sharhseret.org HealthCare.gov www.healthcare.gov

Triage Cancer-How to Pick a Health Insurance Plan Video www.triagecancer.org/animatedvideos

Cancer and Careers www.cancerandcareers.org

#### **Physician Referral Service**

ECHO National Jewish Institute for Health 845.425.9750 718.859.9800

Ezra L'Marpeh 718.435.9788 www.ezra-lemarpe.org/en/

Medstar Health 718.787.1800 www.sbhonline.org

Relief 718.431.9501 www.reliefhelp.org

#### **Managing Cosmetic Side Effects**

Breastcancer.org-Managing Other Side Effects of Radiation 610.642.6550 www.breastcancer.org/treatment/ radiation/side effects

Chemocessories www.chemocessories.org

# Chemotherapy

800.813.HOPE www.cancercare.org/publications/24understanding\_and\_managing\_ chemotherapy\_side\_effects

Facing the Mirror with Cancer 312.420.5610 www.facingthemirror.org

Girl on the Go-Private in home wig consultations 800.355.6076 www.girlonthego.biz Hair to Stay www.hairtostay.org

Knitted Knockers www.knittedknockers.org

Lolly's Locks 240.428.1985 www.lollyslocks.org

Look Good Feel Better 800.395.LOOK www.lookgoodfeelbetter.org

Shop Well with You 800.799.6790 www.shopwellwithyou.org

The Bella Chachky Diamond and Sylvia Diamond Geller Best Face Forward Program (A Sharsheret Program) 866.474.2774 www.sharsheret.org

**"TLC" (American cancer Society Catalog)** 800.850.9445 www.tlccatalog.org

Understanding and Managing Chemotherapy Side Effects 800.813.HOPE www.cancercare.org/publications/24understanding\_and\_managing\_ chemotherapy\_side\_effects

#### **Technology Based Resources**

**Caring Bridge** 651.789.2300 www.caringbridge.org

Cancer Support Community 888.793.9355 www.mylifeline.org

Helpful Bikur Cholim Links www.jewishboard.org/resources/helpfulbikur-cholim-links/ Meal Train www.mealtrain.com

Navigating Cancer 800.925.4456 www.navigatingcancer.com

Think About Your Life 818.695.4334 www.thinkaboutyourlife.org

## **Clinical Trials**

About Clinical Trials www.learnaboutclinicaltrials.org

American Cancer Society www.cancer.org

Breast Cancer Trials www.breatscancertrials.org

Basser Center for BRCA www.basser.org

CancerCare www.cancercare.org

Central Watch www.centerwatch.com

Clinical Trials and Me www.clinicaltrialsandme.com

Dr. Susan Love Research Foundation www.drsusanloveresearch.org

eCancerTrials www.ecancertrials.com

Emerging Med 877.601.8601 www.emerginingmed.com

FORCE www.facingourrisk.org

Massive Bio 844.627.7246 www.massivebio.com/find-a-clinical-trial/ free-clinical-trial-matching

MBC Alliance www.mbcalliance.org/metastatic-trialsearch-expands

National Cancer Institute 800.4.CANCER www.cancer.gov/clinicaltrials

National Institute of Health www.clinicaltrials.gov

Search Clinical trials 877.MED.HERO www.searchclinicaltrials.org

Susan G. Komen Breast Cancer Foundation 800.IM.AWARE ww5.komen.org

#### **Advanced Breast Cancer**

ACOR (Association of Online Cancer Resources) listserv.acor.org

Expert Tips Shared with Women Living with Advanced Cancer www.sharsheret.org/resource/readexpert-tips-shared-with-women-livingwith-advanced-cancer/

Living Beyond Breast Cancer 610.645.4567 www.lbbc.org

MBC Connect www.mbcconnect.org

Metastatic Breast Cancer Information and Support www.bcmets.org

Metastatic Trial Search www.bcmets.org/

Online Resources for People Living with Advanced Breast Cancer www.advancedbreastcancercommunity. org



Sharsheret Embrace Community- A Private Facebook Group 866.474.2774 www.sharsheret.org

The Margot Rosenberg Pulitzer and Sheri Rosenberg Embrace Program (A Sharsheret Program) 866.474.2774 www.sharsheret.org

# **Recurrent Ovarian Cancer**

Sharsheret Embrace Community- A Private Facebook Group 866.474.2774 www.sharsheret.org

The Margot Rosenberg Pulitzer and Sheri Rosenberg Embrace Program (A Sharsheret Program) 866.474.2774 www.sharsheret.org

#### Jewish Organizations Addressing Spirituality

Aneinu: International Tehillim Organziation 516.239.6083 917.575.8719 www.aneinu.com

Institute for Jewish Spirituality 646.461.6499 www.jewishspirituality.org

Mayyim Hayyim Living Waters Community Mikkveh and Paula Brody & Family Education Center 617.244.1836 www.mayyimhayyim.org

Ritualwell 215.576.0800 www.ritualwell.org

Shira Ruskay Center 212.632.4608 www.jewishboard.org/about-us/ programs-services/jewish-communityservices/shira-ruskay-center/

## **Personal Health Journals**

CaringBridge www.caringbridge.org

MyLifeLine www.mylifeline.org

#### **Creating Living Legacies**

Caring Bridge www.caringbridge.org/

Memories Live 646.245.1698 www.memorieslive.org

Safe Beyond 800.844.0515 www.safebeyond.com

Thru My Eyes 914.725.1836 www.thrumyeyes.org

## **Breast Cancer Organizations in Israel**

Beit Natan 011.972.2.644.6052 www.beitnatan.com

Bracha 011.972.72.233.2974 www.bracha.org.il

Israel Cancer Association 011.972.3.572.1616 www.cancer.org.il

Lemonade Fund: Emergency Financial Relief for Israeli Women Recently Diagnosed with Breast Cancer www.lemonadefund.org

**One in Nine** 011.972.3.602.1717 www.onein9.org.il

Stop Cancer www.stop-cancer.co.il/

## Tishkofet-Ma'agan

011.972.2.631.0803 www.lifesdoor.org

#### Legal Assistance

Cancer Legal Resource Center 866.THE.CLRC 213.736.1455 www.disabilityrightslegalcenter.org/ cancer-legal-resource-center

# Disability Rights Legal Center: Cancer Legal Resource Center 866.THE.CLRC www.disabilityrightscenter.org

Law Help www.lawhelp.org

Lawyer Referral Service www.apps.americanbar.org/ legalservices/lris/directory

National Cancer Legal Services Network www.NCLSN.org

Patient Advocate Foundation 800.532.5274 www.patientadvocate.org

#### Lymphedema

American Physical Therapy Association, Oncology Section 800.999.APTA www.oncologypt.org

National Lymphedema Network 800.541.3259 www.lymphnet.org

# "What Every Woman With Breast Cancer Should Know" (An American Cancer Society Publication) 800.ACS.2345

www.citeseerx.ist.psu.edu/viewdoc/dow nload?doi=10.1.1.432.2496&rep=rep1&typ e=pdf

## Male Breast Cancer

## **American Cancer Society**

www.cancer.org/cancer/breast-cancerin-men/about/what-is-breast-cancer-inmen.html

Breastcancer.org www.breastcancer.org/symptoms/ types/male\_bc

Susan G. Komen ww5.komen.org/BreastCancer/ BreastCancerinMen.html

Living Beyond Breast Cancer www.lbbc.org/man-diagnosed-breastcancer

Male Breast Cancer Coalition www.malebreastcancercoalition.org

Men Against Breast Cancer www.menagainstbreastcancer.org/ information-for-male-breast-cancer/

National Cancer Institute www.cancer.gov/types/breast/patient/ male-breast-treatment-pdq

#### **Prescription Assistance**

Medicine Assistance Tool 888.477.2669 www.medicineassistancetool.org

NeedyMeds www.needymeds.org

Patient Advocate Foundation Co-Pay Relief Program 866.512.3861 www.copays.org

RxAssist www.rxassist.org

**Rx Outreach** 888.796.1234 www.rxoutreach.org

# Your Voice:







# BOOKLETS AVAILABLE IN THIS SERIES

Your Jewish Genes: Hereditary Breast Cancer and Ovarian Cancer

Facing Breast Cancer as a Jewish Woman

Facing Cancer as a Frum Woman

Facing Ovarian Cancer as a Jewish Woman

Breast Cancer and the Ritual Bath: A Guide for Mikvah Attendants

Thriving Again<sup>®</sup>: For Young Jewish Breast Cancer Survivors

Our Voices: Inspiring Words from the Women of Sharsheret

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For information about this booklet and other Sharsheret publications, E-mail: info@sharsheret.org Call Toll-Free: 866.474.2774

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