Welcome: Eight Years and Counting

by Sue Friedman

Every winter I wax nostalgic about FORCE. Ten years ago when I was diagnosed at 33 with breast cancer, my goal was to simply get through treatment. Learning I had a BRCA2 mutation made me want more: I hoped to move on and rejoin my life in progress as a mother, wife and veterinarian.

Then I discovered the Internet, a place to find support as I dealt with the issues of my cancer and genetic status. A world of people dealing with cancer opened before me. But something was missing. I found no single resource specifically for hereditary cancer. Naively confident, I set out to create a message board to fill the gap. I didn’t know if anyone would show up, but I felt I could make a difference. Astonishingly, our message boards were soon heavily visited. The FORCE community was born and I discovered a new role: advocate.

New Years Eve marks FORCE’s 8th Anniversary. We’ve grown and accomplished so much. Our website receives over 50,000 visits each month. Our message boards offer the largest database of personal experiences from the high-risk community.

Joining FORCES has a circulation of 7,000, and we’re busy planning our second Joining FORCES conference.

Now we have a community and a home, and we’re well on our way. 2007 holds exciting possibilities for FORCE. We hope it does for you too.

Vital Options: One Woman’s Cancer Experience Becomes a Resource for Many

by Selma Schimmel

My earliest memories are about cancer. My maternal grandmother, who lived with us, died when I was only two or three, but I have a deep memory of her presence in my life. I can still see the image of her colostomy and feel how scary that was.

In 1981, at the same age as her mother when she died, my mom was diagnosed with advanced ovarian cancer. Ten weeks later she was gone. Not long after that I found a lump in my breast. At age 27 I was told that I was just too young for breast cancer. The radiologist held my mammogram up to the light box and told me I was being neurotic and should “go home and forget about it.”

I think that was the day I became an advocate.

Four months later, I was diagnosed with breast cancer that had already spread to two lymph nodes. I was treated with a lumpectomy, radiation and chemotherapy.

It was a very isolating time. It seemed impossible to meet other young adults with cancer with whom I could identify. Support groups were composed of people many years older and our needs and life issues were so very different. Young adults with cancer were nowhere on the map. That’s why in 1983 I founded Vital Options, the first cancer support and advocacy organization for young adults between the ages of 17 and the early 40s. Vital Options has since grown into an international cancer communications organization for people of all ages, but remains actively involved in the current young adult advocacy movement.

In the 1990s I learned that I was BRCA1 positive. My older sister is also positive, as are two of five cousins, but miraculously, none of my sister’s four daughters have inherited the mutation. I opted for increased surveillance rather than mastectomy, and knew that ultimately I would need a prophylactic oophorectomy. Until then I would be diligent about using whatever screening was available, like the Doppler ultrasound and CA125.

In 2003 I celebrated my 20th anniversary of being free of breast cancer. Deciding it was time to invest in my next twenty years of health, I scheduled my elective oophorectomy.

Much like the shock my surgeon continued on page 3
Other Chemoprevention for Breast Cancer

Selective estrogen receptor modulators (SERMs)
SERMs block the effects of estrogen on breast tissue. Tamoxifen and Raloxifene are two SERMs that lower breast cancer risk in certain high-risk women. Most SERM research for cancer prevention has not focused on BRCA carriers.

Aromatase inhibitors
Aromatase inhibitors keep postmenopausal women from producing estrogen in their fat and adrenal cells. These medications are used to prevent recurrence of breast cancers that are estrogen receptor positive. Researchers are studying whether aromatase inhibitors can reduce breast cancer risk in postmenopausal, high-risk women. These research results will not be available for several years.

Nonsteroidal anti-inflammatory drugs (NSAIDs)
NSAIDs are pain relief medications, including many that are available without prescription. Researchers are trying to determine whether NSAIDs can decrease breast cancer incidence in women with BRCA mutations. These research results will not be available for several years.

Statins
Statins are commonly used to reduce cholesterol. In early studies, women using statins had a lower risk for breast cancer; however, a clinical trial is needed to show whether statins lower cancer risk in high-risk women.

All medications come with risks. Women should discuss the benefits and risks of chemoprevention with their healthcare team. For more information on chemoprevention and research, see the chemoprevention section on the FORCE website.

References

Fenretinide as Breast Cancer Chemoprevention?
by Drea Tbew

A risk-reducing option that is safe, effective and widely-accepted for women at high hereditary risk for breast cancer remains elusive. Recent results from a long-term study may be a step in the right direction.

Italian researchers report that fenretinide, a synthetic relative of Vitamin A, can prevent secondary breast cancers in premenopausal women. The researchers concluded that fenretinide should be “investigated further for prevention of breast cancer in young women at high risk.” The drug is currently unavailable in the United States.

The study included 1,739 women who were previously diagnosed with Stage I breast cancer or DCIS, and who were not treated with chemotherapy. Participants were randomly chosen to receive either no treatment or 200 mg of fenretinide daily (with a monthly three-day break) for five years. Over 15 years—the study period included 10 years beyond the end of participants’ fenretinide treatment—both groups of women were observed for any occurrence of breast cancer, including new primary cancers and recurrences of their original cancers.

Overall, the difference in second breast cancers between the two groups was small. Those who took fenretinide had a 17 percent lower incidence than the no-treatment group. However, when participant groups were compared based on menopausal status, fenretinide was more effective in premenopausal women. In fact, the younger the woman, the more fenretinide appeared to reduce her risk.

The women in this study were not BRCA tested, so we don’t know if fenretinide will work equally well in young BRCA carriers with breast cancer. In addition, the participants already had a cancer diagnosis in one breast. The study did not look at fenretinide as a chemopreventive agent to prevent breast cancer in high-risk women who never had breast cancer. Dr. Michael Sporn, Professor of Pharmacology and Medicine at Dartmouth Medical School, cancer chemoprevention expert, and one of the study authors, notes that...
Name-dropping to Empower Others

by Debbie Sokolov

“FORCE is the organization I turned to when I needed information and support.”

Thousands of women every year tell us how they have appreciated FORCE being there when they needed us. We love the feedback, but we want to do more. So many others can benefit from our support; we need to reach them as well.

You can help us to help others. Whenever you tell your story—sharing with friends, confiding with family, explaining to the media—seize the opportunity to mention FORCE. Each time you relate your experience to others, you raise awareness and personalize hereditary cancer. When you introduce FORCE to others, you expose them to the many voices, families and experiences that make up our very special community.

The best way to ensure your audience can access hereditary cancer experts is to send them to FORCE. We’re here to direct people to health care professionals who can give them credible information and help them make their own difficult personal decisions about dealing with hereditary breast cancer. FORCE’s Help-line, website and newsletter give them up-to-date information about clinical trials and the latest research of interest to the BRCA population. We provide all of these services at no charge; services many of our members consider priceless.

FORCE is fortunate to have so many wonderful advocates in our community. With continued advocacy and funding, FORCE will continue to save lives!

Debbie Sokolov is the Associate Director of Development for FORCE.

Vital Options: An Abundance of Services, Programs and Information

Vital Options (www.vitaloptions.org) provides a variety of cancer communications projects for patients of all ages and disease types, as well as for their families, friends and healthcare providers.

The Group Room® is broadcast live every Sunday on XM Satellite Radio, Internet simulcast, podcast and select radio stations throughout the country. Listeners may call into the show at 800-GRP-ROOM (800-477-7666). Toll-free numbers for other countries are posted on the website. Visit the Vital Options website for a list of radio stations that carry the program, to hear live broadcasts and to listen to past shows.

In addition to the regularly scheduled shows, you can listen to special broadcasts from the following conferences:

November 5, 2006: International Psycho-Oncology Society (IPOS)
December 3, 2006: American Society of Therapeutic Radiation Oncology (ASTRO)
December 17, 2006: San Antonio Breast Cancer Symposium (SABCS)
March 4, 2007: Society of Gynecologic Oncologists (SGO)
April 1, 2007: National Young Adult Cancer Awareness Week® (NYACAW)
June 7, 2007: American Society of Clinical Oncology (ASCO)

The Vital Options website also features:

• CancerTalk®—A multimedia Internet broadcast that includes printable visual aids to support patient-physician discussions.
• The Message Board
• Information about clinical trials
• Young adult resources (www.youngadultswithcancer.org)
• Links to US and international advocacy and support organizations
• Calendar of events
The Right Decision is the One That’s Best for You
by Kathy Steligo

Although many women prefer not to have reconstruction, we seem to hear more about the ones that do. Yet there are plenty of sound reasons for not pursuing reconstruction. It means having at least one other surgery (and probably more) and recovery that some women simply can’t endure. In some cases, treatment or other health conditions may preclude you from having immediate reconstruction. Perhaps, like Melissa, the loss of your breasts is not an insurmountable blow to your self-identity.

But if you’re undecided about your post-mastectomy options, how do you make that decision? First and foremost, know your options. Weigh the benefits and limitations of each one—both short-term and long-term—before making a decision. Consider the input of loved ones, physicians and other women who have had mastectomy, but ultimately listen to your own heart and mind. Make a decision you can live with. You’re the one, after all, who best knows how you feel about your body. Your decision may not be easy, but it should always be personal.

What to expect from mastectomy
Mastectomy is performed in the hospital under general anesthesia. The surgeon removes the skin, nipple, areola and breast tissue through an oval-shaped incision across the width of each breast. If you have invasive breast cancer, some of your lymph nodes may also be removed. Surgical drains are placed under the skin, where they remain for a week or two to keep fluids from accumulating, and the incision is closed. Typically, mastectomy without reconstruction lasts two to three hours, depending on the type of mastectomy performed.

Women are often surprised to feel little or no pain or soreness after mastectomy. You may be numb or have a feeling of heaviness in your chest and a pulling sensation under your arm. You’ll be up walking the day after your surgery but you’ll need extra rest for several days. Your surgeon will describe exercises to reduce stiffness and gradually return range of motion. It may take 3-6 weeks before you return to your normal routine.

After mastectomy without reconstruction, you may want to wear prostheses. You’ll find many different types of varying weight, feel and material. You may decide to wear prostheses all the time, only for certain occasions or not at all. Visit your local mastectomy shop to discover the array of camisoles, bras, prostheses and other post-mastectomy products.

Delayed reconstruction
Reconstruction can be done months or even years after mastectomy. If you change your mind or want to have new breasts when you complete treatment, you can have a delayed reconstruction. Your mastectomy scars will remain across the front of your new breasts, but will fade considerably in time.

Even in the future, when stem cells may be permitted to regrow a woman’s breasts after mastectomy, the choice to forego that option will remain. We are, after all, individuals with our own sense of self and the right to personal choice. And for that, we can all be grateful.

Kathy Steligo is the editor of Joining FORCES and author of The Breast Reconstruction Guidebook (www. breastrecon.com). Her article “The Language of Mastectomy” appeared in the Fall 2005 issue (Vol. 1, Iss. 2) of Joining FORCES.

Resource
Visit FORCE to view mastectomy photos.

Share Your Story
Do you have something to say that may inform our readers or ease their experience? We invite you to share your reflections or personal story about dealing with the issues of hereditary breast or ovarian cancer. Tell us how you feel, what you cope or what you’ve learned. Email stories of 500-550 words to info@facingsourrisk.org or mail to FORCE, 16057 Tampa Palms Blvd. W #375, Tampa, FL 33647. Please include your name and daytime telephone number so we can contact you if we decide to publish your story in a future issue.

Voices of FORCE

Each quarter, we’ll invite a FORCE member to share an insightful perspective, a valuable experience, or a touching story to help others who are dealing with issues of hereditary breast and ovarian cancer.

A Very Personal Decision: Mastectomy Without Reconstruction
by Melissa Taylor

While I was growing up, my mom seemed to get cancer every several years. She considered cancer to be “her disease,” but I felt a nagging sensation that it might be more. Watching a television program on Hereditary Breast and Ovarian Cancer (BBOC) syndrome and BRCA genetic testing, I recognized the risk factors in our family. I decided then if I ever found I had a genetic mutation, I would have prophylactic mastectomies without reconstruction. That decision came easily because my mom, after each of her cancer-related mastectomies, wore prostheses and went on with life as usual.

Years later in 2006, a doctor suggested my mom be tested to see if she had a BRCA1/2 mutation. Ultimately, my mom, sibling, and I learned we were all positive for BRCA1. I was just in my late 20s. After being concerned for years and working through all the “what ifs,” I already knew what to do, and felt relief that my decision had already been made.

In my experience, doctors seem to default toward reconstruction, especially with people my age. They automatically ask questions about reconstruction: “Would you like to consult a plastic surgeon?” and “Are you going to have reconstruction?” are common. Despite these questions, though, doctors did not try to pressure me in any way. They emphasized that reconstruction would always be an option for me. I especially appreciated the physician who told me about her friend who also decided not to have reconstruction, and was quite happy with her decision.

Many different reasons influenced my decision not to have reconstruction. I saw my mom do well without it. I didn’t want more surgery; after all, I’m only in my twenties. Once I explained my reasoning, everyone was very supportive. My mom remains my staunchest advocate—she feels not having reconstruction helped her find a cancerous lump after her mastectomy. Being sick throughout my childhood and teenage years also helped shaped my choice. While my peers strove to fit in, I spent my formative years learning that my physical looks don’t make me who I am—it is my faith, my soul, my interests. My body is something temporal and has nothing to do with the real me. Besides, I looked this flat before adolescence, and those were some of the happiest years of my life.

For me, not having reconstruction was the right decision. Once I made it, I never wavered. When my bandages came off, I felt my breast cancer surgery experience was over. Being flat is not nearly as obvious as people would imagine, though I went from a thin-bodied C-cup to smaller than AAA. Wearing comfy camisoles helps me to feel feminine and provides that “bra strap” look we’re all used to. Even when I go out without prostheses, I don’t get strange looks or pointed fingers. I realize we’re so much more invisible than we think, and others are not as concerned about our appearance as we tend to be.

The Bible says that true, feminine quality comes not from the outward, but from “your inner self, the unfading beauty of a gentle and quiet spirit.” My hope is that other women, no matter what choices they make regarding reconstruction, will realize their true essence shines from the inside, out.

Melissa Taylor is a career college student pursuing a degree in English. Her illustrations and articles have appeared in both health and pet publications. She maintains a website (www.geocities.com/muffypieboo) for women who choose mastectomy without reconstruction.

“…my physical looks don’t make me who I am…”
“Why her and not me?”
“Will this disease affect me too?”
“What can I do?”

These are common questions for women with sisters who face breast cancer. If your sister has been diagnosed, you can participate in the nation’s largest research effort to find contributing causes of breast cancer.

The National Institute of Environmental Health Sciences (NIEHS) is conducting the Sister Study, an ambitious long-term effort to determine how genetic and environmental influences affect who gets breast cancer. Launched in October 2004, the study hopes to follow 50,000 women whose sisters had breast cancer. More than 28,000 participants have already been recruited, but the study must add another 22,000 participants in less than one year.

“Many women have heard about the Sister Study, but they haven’t signed up yet, and we really need them now,” said Dale Sandler, Ph.D., Chief of the Epidemiology Branch at NIEHS and Principal Investigator of the Sister Study. “Doctors know very little about how the environment may affect breast cancer; that is why the Sister Study is especially important,” said Dr. Sandler. “We want to learn more about how to protect your daughters and your granddaughters from this devastating disease.”

You’re eligible to participate in the study if you meet the following criteria:

• You have a blood-related sister (living or deceased) who has/had breast cancer.
• You’re between the ages of 35–74.
• You reside in the U.S. or Puerto Rico.
• You have never been diagnosed with breast cancer.

Ada Pacheco, age 52, enrolled in the Sister Study in honor of her sister Carmen, a 14-year breast cancer survivor.

“The need to know why my sister had breast cancer and not me,” said Ada, who is 11 months younger than her sister. “We were born in the same place, raised together, and ate the same food. Why my sister Carmencita and not me?”

Calling All Sisters! Stand Up and Make a Difference Now!

by Kathy Steligo

The Sister Study Kit

If you participate in the study, you’ll receive a Sister Study Kit containing information and questionnaires. You’ll be asked to do the following:

**During the first few weeks immediately following enrollment:**

1. Provide a blood sample, which will be drawn by a specially-contracted female professional who will come to your home or workplace. During her visit, she will measure your height and weight, hip and waist circumference, and blood pressure.

2. Provide a sample of your first urine of the day, toenail clippings and house dust (collection materials are included in the Kit).

3. Complete four questionnaires (estimated to take about 90 minutes).

4. Complete a detailed phone interview (two one-hour sessions).

**Over the next 10 years:**

1. Notify the study of changes to your address, phone number or health status.

2. Fill out a questionnaire or do a telephone interview every other year you are in the study.

3. If diagnosed with breast cancer while you are in the study, provide permission to contact your doctor for information about your breast cancer, and to get additional biological samples. If you are diagnosed with some other type of cancer, or a disease such as osteoporosis, heart disease, diabetes, or autoimmune disease, we may also ask for permission to contact your doctor for additional information.

Visit the Sister Study website for more details.

Available in English and Spanish, the Sister Study requires very little time from its volunteers. The 10-year observational study begins with participants answering questions about diet, jobs, hobbies, and things they’ve been exposed to throughout their lives to determine what may influence breast cancer risk. Later, at a convenient time and location for the participant, a female health technician collects small samples of blood, urine, toenail clippings, and house dust, which will give researchers a better picture of the woman’s environment and genetic makeup.

Because breast cancer affects women from every walk of life, the Sister Study is seeking women of all backgrounds, occupations, ages, and ethnic groups. “If you’re a woman of color whose sister had breast cancer, your participation in the Sister Study is especially important,” said Dr. Sandler. “We want to learn more about how to protect your daughters and your granddaughters from this devastating disease.”

You’re eligible to participate in the study if you meet the following criteria:

- You have a blood-related sister (living or deceased) who has/had breast cancer.
- You’re between the ages of 35–74.
- You reside in the U.S. or Puerto Rico.
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“I need to know why my sister had breast cancer and not me,” said Ada, who is 11 months younger than her sister. “We were born in the same place, raised together, and ate the same food. Why my sister Carmencita and not me?”

If you’re eligible, stand up and make a difference. To volunteer or learn more about the Sister Study, visit www.sisterstudy.org or www.estudiodehermanas.org (Spanish), or call 877-4SISTER (877-474-7837). You can also watch the award-winning Sister Study video, *Sister by Sister: Discovering the Causes of Breast Cancer* on the website.
Pharmacogenetics: A Growing Area for Genetic Testing
by Sue Friedman and Lisa Kessler

Genetic testing is a rapidly-growing field that is providing researchers with new ways to apply testing to cancer treatment and prevention. Pharmacogenetics is one emerging area of genetics that looks at how individuals metabolize (activate or inactivate) medications.

What is intuitive to most of us, that people react differently to medications, is now being proven by genetic research. Just as genes like BRCA can help determine our chances for getting cancer, other genes, like CYP2D6, affect how our bodies change and clear medications. According to recent research on tamoxifen, 7-10 percent of women with breast cancer have a special variant of the CYP2D6 gene (also called 2D6), that may reduce the effectiveness of tamoxifen.

A genetic test requiring only a cheek swab can identify a woman’s 2D6 genetic status. The Tamoxifen 2D6 test is currently only appropriate for postmenopausal women who are taking or considering taking tamoxifen to prevent the recurrence of breast cancer. Knowing their genetic status, women can work with their physicians to identify whether alternative treatments, such as aromatase inhibitors, may be more effective for them.

Lisa Kessler is a board-certified genetic counselor with a background in cancer genetic counseling and research.

Stricter Medicare Guidelines for Coverage of BRCA Testing
by Sue Friedman

In June of 2006 Medicare revised its guidelines for coverage of BRCA genetic testing. The more stringent new rules provide coverage for fewer high-risk people. Prior guidelines approved genetic testing for any woman diagnosed with ovarian cancer and any man diagnosed with breast cancer. Under the new rules, these same individuals must meet additional criteria, such as having another breast or ovarian cancer survivor in the family, or be of Ashkenazi Jewish descent.

Earlier guidelines approved genetic testing for family members of individuals with a known BRCA mutation. Now only people diagnosed with cancer are covered. Those who have not been diagnosed with cancer are not covered under any circumstance. Further, the law requires physicians to demonstrate a medical benefit to the person being tested. For example, a woman with stage 4 ovarian cancer who is undergoing testing to inform her family about their risk may not be covered under the new guidelines, unless the results would change her own treatment or follow-up.

The Social Security Act of 1935, the law that created Medicare, states that benefits do not include testing in the absence of signs or symptoms of illness or injury. By this definition, testing for a BRCA mutation in someone without cancer is interpreted as “screening.” Medicare does provide coverage for some screening tests, including mammography, colonoscopy and PSA tests—Congressional statues were required to add these to the list of approved services. Similar legislation would be needed before Medicare provides coverage of BRCA testing for high-risk individuals who have never had cancer.

Visit the FORCE website for updates on Medicare coverage of genetic testing.

Who Qualifies For 2D6 Testing?

2D6 testing is available only for postmenopausal women who are taking or considering taking tamoxifen to prevent the recurrence of breast cancer.

This test is not appropriate for:

- Women who are pre- or perimenopausal. No alternative treatment options are as effective as tamoxifen. (This may change as researchers learn more about 2D6 and tamoxifen.)
- Women with hormone-negative cancers. Tamoxifen is only recommended as a treatment for hormone-positive cancers.
- High-risk women who have not had breast cancer. There is not enough data about this situation to make recommendations at this time. (This may change as researchers learn more about 2D6 and tamoxifen.)

References


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If you’d like to learn more about sponsoring FORCE, visit www.facingourrisk.org/sponsorship or call 866-288-RISK, extension 1.

We Want to Hear From You

What’s on your mind? What would most help you understand or cope with issues of prevention, diagnosis or treatment? Perhaps you’ve recently tested positive for a BRCA gene mutation and don’t know where to turn. Maybe you’re dealing with breast or ovarian cancer, or care about someone who is. Send your input, ideas and comments to info@facingourrisk.org or mail to FORCE, 16057 Tampa Palms Blvd. W. #373, Tampa, FL 33647.

What’s New @ FORCE

**Good News for FORCE**
Dean Distributors, Inc., a manufacturer of food products for the specialty food industry, has generously pledged a portion of its product proceeds to FORCE. The company’s goal is to donate $10,000 from January 2007 sales of its NutriCare product line to help FORCE continue providing free services to those affected by hereditary breast and ovarian cancer. Thank you, Dean Distributors!

**FORCE National Conference**
Join us in Tampa, Florida May 18-19, 2007, for our second Joining FORCEs national conference. The conference will feature internationally-acclaimed speakers with cutting-edge information, research, and workshops specifically for those affected by hereditary breast or ovarian cancer or hereditary cancer risk. Register at www.facingourrisk.org/conference.

**Magazines Recognize FORCE as a Breast Cancer Resource**
Shape magazine listed FORCE as one of the top four breast cancer websites in its September 2006 issue. FORCE is listed as a resource in SELF magazine’s new online Breast Cancer Handbook (www.selfbch.com) about breast health and breast cancer.

**Celebrating 8 Years: FORCE Annual Chat-a-thon**
We’ve planned our chat-a-thon to coincide with our 8th birthday! Join us Saturday and Sunday, January 6 and 7, for our around-the-clock online event. Help us raise awareness and needed funds for FORCE. Stop by for a few minutes or stay for a few hours. Everyone is welcome.

Help us make our chat-a-thon a success:
• Log in to www.chat-a-thon.com to join the discussions.
• Spread the word! “Chat” up the event to friends, family, and physicians.

Saturday, January 6 at 12:01 am (EST) - Sunday, January 7 at 11:59 pm (EST)

2 days + 2 nights
4 FORCE!