Welcome:
by Sue Friedman

Just like FORCE, this issue has something for everyone affected by hereditary breast or ovarian cancer. This month, we’re highlighting a topic that is all too close to many of us: mastectomy. So, with great pride, we’re announcing Life is a Carnival, our 2008 calendar presenting positive and powerful images of life after mastectomy—with or without reconstruction. A two-year effort, 14 FORCE members, including me, bravely modeled topless wearing only Mardi Gras masks and our smiles. Continuing the theme, Myself: Together Again is a very personal account of losing a breast to cancer and making the tough decision to remove the opposite breast to reduce future risk. And FORCE member Steve Kandel shares a poignant reminder that the legacy of hereditary cancer reaches across generations and genders.

FORCE’s 2008 Calendar: “Life is a Carnival”
by Kathy Steligo

There’s nothing unusual about a nonprofit organization publishing a calendar. But there’s something very unique about FORCE’s 2008 calendar. “Life is a Carnival” is a bold approach to mastectomy and reconstruction education. We put faces—although festively masked—to the mastectomy and reconstruction experience. More than just a calendar, “Life is a Carnival” is an intimate collection of real women who courageously volunteered to share their bodies and their experiences to help others understand what reconstruction really looks like. We chose Mardi Gras as a theme because it celebrates life; our calendar celebrates life after mastectomy. And as our photos attest, life after mastectomy—with or without reconstruction—does go on.

Featuring FORCE members as models, the 14-month color calendar represents a variety of post-mastectomy choices, including no reconstruction and breasts rebuilt with implants and/or flaps. Each model also shares her own story, what procedure she chose, and her likes and dislikes about her results. More than just a calendar, “Life is a Carnival” is a tool for exploring post-mastectomy options.

FORCE encourages decisions based on information. Mastectomy is a difficult decision, and a critical issue for anyone with a BRCA mutation or a hereditary cancer syndrome. Those who have been diagnosed may face mastectomy as treatment, especially since they have a 65 percent chance of developing the disease again. Others choose prophylactic bilateral mastectomy to reduce their lifetime risk of developing breast cancer, which can be as high as 85 percent. Whether you’re a cancer survivor or you’re exploring options to manage your risk, whether you’re considering mastectomy or have already had the surgery, we think you’ll find this calendar enlightening, inspiring and a reminder that you’re not alone.

The calendar may be purchased with or without a copy of The Breast Reconstruction Guidebook. Proceeds will be used to fund FORCE programs. Visit www.facingourrisk.org/calendar to order your

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If You’re Wondering Whether You Should be Tested...

...consult first with a genetics expert to review your family medical history, discuss all your options, and determine which test, if any, is appropriate for you. If you are tested, a genetics expert can properly interpret your test results, explain the implications of those results, and describe your overall risk for hereditary cancer.

The National Society of Genetic Counselors (www.nsgc.org) offers a lookup tool for finding a genetic expert by state and specialty. The National Cancer Institute (www.cancer.gov/search/genetics_services/) provides a lookup tool for health care providers offering genetic counseling and testing. This tool also provides information on the certification of the health care providers listed.

Resources

The Young Survival Coalition (YSC) is a national nonprofit organization devoted to action, advocacy and awareness concerning young women and breast cancer. The organization’s website (www.youngsurvival.org) includes comprehensive information about early-onset breast cancer and maintains a busy message board where visitors can share issues with other young women and find support.

Collaborating with Living Beyond Breast Cancer, YSC hosts the only national conference for young women with breast cancer. Their 2008 conference will be held in Jacksonville, FL, February 22-24. Visit the website at youngsurvivorsconference.org for more information.

Reference


Can BRCA Testing Benefit Young Breast Cancer Survivors Who Have Little or No Family History?

by Drea Thew

A strong family history of breast or ovarian cancer is a well-known hallmark for possible BRCA family mutations. When women from such families develop breast cancer before age 50, they may be appropriately identified by their health care team as candidates for genetic counseling and testing. The guidelines are less clear, however, for women who develop early-onset breast cancer but have no close relatives with breast or ovarian cancer.

Researcher and FORCE Health Care Advisory Board member Dr. Jeffrey Weitzel conducted a study which was recently published in the Journal of the American Medical Association. Dr. Weitzel found that having few women on each side of the family who reached an older age to express the trait can be an important predictor of whether a young breast cancer patient carries a BRCA mutation, even in the absence of any known family history of cancer. His research may help the medical community better determine which young women with breast cancer should consider genetic testing.

The 306 study participants were patients referred for hereditary cancer risk assessment at the City of Hope Cancer Screening and Prevention Program Network in California. All were diagnosed with breast cancer before age 50; only patients with no family history of breast or ovarian cancer in first-degree (parents or siblings) or second-degree (grandparents, aunts) relatives were included. Participants were divided into two equal groups based on their family history: A “limited” group included women with one or no first- or second-degree female relatives on either parent’s side who lived past age 45, and women with no information about their biological relatives. All other participants were considered to have “adequate” family structure.

When tested for BRCA mutations, 29 participants (9%) were found to have deleterious BRCA1 or BRCA2 mutations. Women in the limited family group were almost three times as likely to have a deleterious mutation than women with an adequate family structure. Specifically, a limited family structure on the father’s side was predictive of having a mutation. Three statistical models (Couch, Myriad and BRCAPRO) commonly used to predict the likelihood of BRCA mutations proved to be poor predictors of which women with limited female relatives had a mutation.

Having few female relatives past age 45 does not in and of itself increase risk of BRCA mutations, but it can allow a BRCA mutation to “hide” in the family tree until someone is diagnosed seemingly “out of nowhere.” Geneticists and genetic counselors specializing in hereditary cancer risk take this into account when counseling women with early-onset breast cancer about BRCA testing. Unfortunately, armed with just one or two generations of family history, oncologists, primary care physicians, and other providers without specific genetics training may fail to refer women with early breast cancer and a limited family structure for genetic counseling. This oversight may be falsely reassuring and leave many women with early-onset breast cancer in the dark about their own future cancer risks, as well as the risk of cancer in other family members. Hopefully, Dr. Weitzel’s study will allow health professionals to accurately assess which of their patients with early-onset breast cancer should be referred to a genetics expert.
Myself: Together Again
From One Young Woman’s Reconstruction a Lesson for Many

by Debbie Horowitz

I’ve never been a stranger to breast cancer. I lost my grandmother when I was a baby and lost my mother before I blew the candles out on my 10th birthday cake. Today, I am what they call a “survivor” of this disease, but I like to think of myself as an advocate.

Because I am Jewish and have a very strong family history of breast cancer, I began having mammograms in my late 20s. I did not feel the need to be gene tested at that time, but I knew self-exams would be critical for me. Early on, gene testing scared me. I feared that if I tested positive for a mutation at so young an age, I would be facing too many decisions that I would be unable to handle at that particular point in my life. I was sure, however, that if I ever was diagnosed with breast cancer, I would have a double mastectomy to reduce my worry about a second cancer in either breast.

In June 2004, I was newly engaged and busy planning my wedding. One evening in the shower I felt a lump in my breast. Two weeks later, I was diagnosed with unilateral Stage I breast cancer. At 32-years young, I found myself on the same path my mother and grandmother had walked before me.

Soon I was spending more time with doctors, specialists, and surgeons than my family or fiancé. I decided to have a double mastectomy (just as I had thought years earlier) followed by reconstructive surgery; this seemed like the right choice. It was a terrible time. I was reeling from the trauma and confusion of what was happening, and was not able to get a clear picture of what the reconstruction process would be like. This became my focus—some might even say my obsession. As a young woman and a bride-to-be I desperately wanted and needed photographs and literature about women my age going through reconstruction, but I could find no such resources.

The mastectomy, the damage to my body that cancer had wreaked, happened quickly. The reconstruction—putting the pieces back together—was a much longer process. What I found to guide me through the process were online before-and-after pictures, although they hardly captured the long journey that was reconstruction. For me, it was a harrowing and painful eight months. Among the many thoughts then going through my head were questions about other young women who were blindly fighting the same battle. I did not know it then, but not having pictures beforehand to help me cope with all that would lie ahead of me ended up motivating me in a way I had never imagined possible.

In the three years since my diagnosis, I’ve had my dream wedding and gave birth to a beautiful daughter. I also learned that I am BRCA1 positive, so my decision to remove both breasts was a reasonable one. I look to the future with a new sense of self, empowered by my victory over cancer.

Visit www.myselftogetheragain.org for more information about Debbie or the Myself: Together Again booklet.
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 Poem for Sari: A Father’s Tribute
by Steve Kandel

My mother Sari lost her breast to cancer in 1959. I’m sure it was caused by a BRCA1 mutation, because cancer ran in her family. Her own mother died from pancreatic cancer at age 49. Mom also lost two aunts (one to ovarian cancer) and two uncles to cancer. All were Ashkenazi Jews. Mom died at age 49—the same age as her mother. This brave, lovely, and vivacious lady was gone from my life. I was 19 years old.

In 2004, I was waiting for my daughter Sari, 36, (named for the grandmother she never met) and her husband Warren to join me in Athens when my cell phone rang. “Daddy,” she said, I hear the strain in her voice. “I have breast cancer.” I remember feeling chilled and faint. This cannot be, I thought. This is not possible. Sari was diagnosed with a nasty invasive cancer and DCIS. Three days later, I was in the hospital when she underwent a quadrantectomy. Later we learned that we both carry a BRCA1 gene mutation. For Sari, that meant more surgery after four months of aggressive chemotherapy: this time, bilateral prophylactic mastectomies. I wrote this poem for Sari early the next morning.

FORCE member Steve Kandel has a BRCA1 mutation, inherited from his mother and passed on to his daughter. He is actively involved in fundraising for Sidney Kimmel Cancer Center in San Diego and Mary-Claire King Breast Cancer Research Lab at the University of Washington.

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, how you cope, or what you’ve learned. E-mail stories of 500-550 words to info@facingourrisk.org or mail to FORCE, 16057 Tampa Palms Blvd. W. #373, 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.

I woke up at 3:00 with a start with an ache in my heart maybe this heaviness will go if I write organize my thoughts. nothing trite I still see you in my mind’s eye sitting beautifully erect as you try to keep your bearings before they start you know we will soon, be apart absent your eyebrows, lashes and hair your radiance and bravery so striking I stare you return my direct gaze perhaps not knowing my thoughts thru the haze? but then I see a twinkle in your eyes

My dear Sari, stay positive, please

Dr. Jacobsen is the director of the clinical program in Psychosocial and Palliative Care, and the research program in Health Outcomes and Behavior at the H. Lee Moffitt Cancer Center and Research Institute. Dr. Jacobsen’s work focuses on identifying and promoting behaviors that can lead to reductions in cancer risk, earlier detection of cancer, and improved quality of life following cancer diagnosis.

There is another aspect to the experience for some parents in families that share BRCA1/2 mutations. I am referring to a sense of guilt that they may have ‘passed on’ cancer to their children. Although not expressed in Steve’s poem, this guilt can have a corrosive effect on a parent’s feelings about themselves and on their ability to be helpful to their children. In many instances, parents who feel guilty can benefit from contact with a mental health professional who can provide them with a safe, empathetic environment to explore and resolve these feelings.

Steve’s poem vividly captures the intense feelings parents experience when, regardless of the child’s age, a son or daughter is seriously ill. The bonds between parent and child are powerful and reflect many beliefs about our responsibilities toward our children. Two of the most fundamental beliefs are that, as parents, we should be able to protect them from being hurt and, if hurt, we should be able to help heal them. The diagnosis of cancer in a child can seriously challenge both of those beliefs.

While working in the Pediatrics Department at Memorial Sloan-Kettering a number of years ago, I witnessed firsthand the anguish and helplessness parents feel when their child is ill with cancer. Although it was mostly mothers I saw accompanying their children during hospital stays and outpatient visits, I sensed that the fathers too were profoundly affected. Indeed, a number of fathers I talked with shared many of the same thoughts and feelings that Steve expresses in his poem about his adult daughter.

There is, however, an important element of Steve’s experience not shared by most other parents of sick children. I am referring specifically to his family’s multigenerational experience with cancer and his knowledge that he and his daughter share a BRCA1 gene mutation. In most families, the occurrence of a serious disease like cancer is an isolated event, and the likelihood that the same disease will affect other family members within or across a generation is remote. Unfortunately, this is not the case in Steve’s family or in other families with BRCA1/2 mutations. Parents in these families are likely to have already experienced the challenges of a cancer diagnosis, and quite possibly a death from cancer: in a close family member. Such experiences serve to heighten the fears

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Ovarian Cancer Detection and Prevention

The National Comprehensive Cancer Network (www.nccn.org) is a consortium of cancer centers with experts in management of hereditary cancer. Each year, the NCCN updates its risk management guidelines for people with hereditary risk for cancer, based on the latest research. Currently NCCN recommends prophylactic bilateral salpingo oophorectomy (removal of the ovaries and fallopian tubes) for BRCA carriers between the ages of 35 and 40 or after completion of child bearing.

For women with BRCA mutations who choose not to have oophorectomy, NCCN recommends concurrent transvaginal ultrasound and CA-125 every six months starting at age 35 or between five and 10 years earlier than the earliest age of first diagnosis in the family; preferably during the first 10 days of the menstrual cycle for premenopausal women. In addition to these guidelines, all women should have a pelvic exam at least yearly.

References


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New Consensus Statement Should Help Earlier Diagnosis of Ovarian Cancer

by Drea Thew

Women who carry a BRCA1 or BRCA2 mutation have a much higher lifetime risk of ovarian cancer than the general population. Ovarian cancer is the deadliest reproductive cancer, because it is typically diagnosed at an advanced stage when treatment is difficult. It has been called the “silent killer” because symptoms were thought to be non-existent, or so mild and vague that they progressed undetected until it was too late. However, research shows that ovarian cancer is not necessarily silent—women often do experience symptoms. But they don’t always act on them. The first national consensus statement on ovarian cancer symptoms should help to change that.

The Gynecologic Cancer Foundation led the effort to formulate the following consensus statement, supported by the Society of Gynecologic Oncologists, the American Cancer Society, FORCE, the National Ovarian Cancer Coalition, the Ovarian Cancer National Alliance, and many other cancer organizations:

Historically ovarian cancer was called the “silent killer” because symptoms were not thought to develop until the chance of cure was poor. However, recent studies have shown this term is untrue and that the following symptoms are much more likely to occur in women with ovarian cancer than women in the general population. These symptoms include:

- Bloating
- Pelvic or abdominal pain
- Difficulty eating or feeling full quickly
- Urinary symptoms (urgency or frequency)

Women with ovarian cancer report that symptoms are persistent and represent a change from normal for their bodies. The frequency and/or number of such symptoms are key factors in the diagnosis of ovarian cancer. Several studies show that even early stage ovarian cancer can produce these symptoms.

Women who have these symptoms almost daily for more than a few weeks should see their doctor, preferably a gynecologist. Prompt medical evaluation may lead to detection at the earliest possible stage of the disease. Early-stage diagnosis is associated with an improved prognosis.

Several other symptoms have been commonly reported by women with ovarian cancer. These symptoms include fatigue, indigestion, back pain, pain with intercourse, constipation and menstrual irregularities. However, these other symptoms are not as useful in identifying ovarian cancer because they are also found in equal frequency in women in the general population who do not have ovarian cancer.

“We know that when women are diagnosed in Stage I of the disease, it is 90% curable. Unfortunately, until now there has been no agreement on common symptoms,” said Dr. Barbara Goff, a gynecologic oncologist at the University of Washington who has conducted research on ovarian cancer detection. “This agreement on common symptoms of ovarian cancer hopefully will lead to earlier diagnosis when a cure is more likely.”

This simple, concise and consistent statement should lead to increased awareness, among women and the medical community, which in turn should save lives.
Conference Recap

by Drea Thew

We did it again! Our second annual Joining FORCEs Against Hereditary Cancer conference was held in Tampa on May 18 and 19, 2007. More than 350 people—members of high-risk families, health care providers, and patient advocates—traveled from 36 states, seven countries, and four continents to attend.

The conference had something for everyone, including continuing education credits offered to nurses and genetic counselors. Our 35 speakers included expert researchers, clinicians, psychologists, and patient activists who shared up-to-date and inspiring information for individuals concerned with issues of hereditary breast and ovarian cancer.

Our mornings began with presentations by experts in cancer and hereditary cancer syndromes. Dr. Rebecca Sutphen’s “Ovarian Cancer Detection” session introduced current efforts to develop a screening test for ovarian cancer. Dr. Christina Anunnziata of the National Cancer Institute presented encouraging information about PARP inhibitors, new agents to specifically treat cancer in BRCA mutation carriers, and pending clinical trials for treatment of hereditary breast and ovarian cancer. Dr. Judy Garber’s “Cancer Risk, Before and After” overview described how different management options affect cancer risk in BRCA carriers. Dr. Steven Narod presented his research on BRCA mutations and how hormones influence cancer risk.

Afternoons were filled with a variety of smaller, more focused sessions covering nearly every conceivable aspect of hereditary breast and ovarian cancer. Attendees learned about the most current research on risk and medical decision-making for high-risk individuals. “BRCA and Other Cancers” by pancreatic cancer expert Dr. Jason Klapman, for example, described a newly-opened clinical trial for pancreatic cancer detection. Researcher Dr. Cathy Phelan spoke about the risks BRCA carriers have beyond breast and ovarian cancer, and Dr. Karen Lu presented options for lowering ovarian cancer risk in BRCA carriers. Dr. Andrew Kaunitz gave a thorough overview of symptoms and management of menopause; he also included an overview of menopause research, identifying studies that are relevant to our community. Several plastic surgeons were also on hand to explain cutting-edge reconstructive techniques.

Networking with others can be a profound and rewarding conference experience, and our attendees had plenty of opportunity to do so. Whether mingling during breaks or meeting in sessions, participants discovered they shared concerns and benefited from the experiences of others. A popular roundtable session provided ample opportunity to speak one-on-one with physicians, researchers and other experts.

Several sessions explored the emotional aspects of living with hereditary cancer. Kathy Steligo’s workshop showed participants how to use writing techniques to find power and comfort while confronting their cancer-related fears. Psychologist Dr. Karen Hurley, whose work focuses on high-risk families, discussed ways to share cancer and risk information with children. She and Dr. Rebekah Hamilton joined forces to give specific insights to young pre-vivors who are coping with risk.

FORCE’s program, Looking Back, Living Forward, premiered at this conference. Andrew Filippone, Marnie Breecker, and Lauren Dubin presented film clips from the documentary Mina and the Family Treasure, and guided us through the process of thinking about, collecting, and documenting family stories and medical information. The conference closed with new footage from Joanna Rudnick’s powerful film in progress, In the Family.

We hope you’ll mark the date and plan to attend. If you’re concerned about hereditary breast and ovarian cancer, the Joining FORCEs conference is the most pertinent information you’ll find under one roof. And, once again, we’ll hold our fundraising gala at the Florida Aquarium. It’s a chance to enjoy music, great food and the company of presenters and attendees alike in a festive, family-oriented—and “fishy”—atmosphere. Proceeds help us continue to provide FORCE services and programs.

Joining FORCEs 2008:
Mark your calendars now!

Fresh on the heels of this year’s successful conference, we are already planning next year’s event.

Our third annual Joining FORCEs Against Hereditary Cancer conference is scheduled for May 16-17, 2008 at the Hyatt Regency in Tampa. While we’ve had overwhelmingly positive response to our previous conferences, we’ll use feedback from this year’s participants to make our 2008 conference more informative, more fun and well worth the time to attend.

In addition to our general session and workshop formats, next year’s gathering will include new features, including:

• Unique sessions specifically tailored to breast cancer survivors, ovarian cancer survivors, and pre-vivors.
• More networking opportunities.
• More popular workshops, including writing and using humor to cope with cancer
• Information about BRCA-related insurance issues.
• An opportunity to discuss and provide input to developing a research agenda for hereditary breast and ovarian cancer.

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What’s New @ FORCE

FORCE Announces “Young Women” Chats Hosted by Rebekah Hamilton, PhD, RN

We are excited to announce a series of online realtime chats with Rebekah Hamilton, PhD, RN, specifically for issues faced by young women (ages 18-39) who are BRCA-positive or at risk for hereditary breast or ovarian cancer. Dr. Hamilton, Assistant Professor in Health Promotion and Development in the School of Nursing at the University of Pittsburgh, has a special interest in the long-term psychosocial impact on individuals at risk for hereditary breast and ovarian cancer (HBOC) who are living with predictive genetic test results. Her interest also includes decision making in young women (ages 18-40) who have received BRCA mutation test results, and subsequently face many complex health care decisions. Dr. Hamilton also spoke on this topic at our 2nd Annual Joining FORCEs Conference.

The chats will be held on Fridays at 8:00 p.m. (EST):
- September 14th
- October 12th
- November 9th

To join the chat, visit www.facingourrisk.org/FORCE_community/chat_room.html

FORCE Developing New Ovarian Cancer Brochure

With input from our Health Care Advisory Board, FORCE is developing a new brochure for women with ovarian cancer. What Every Woman with Ovarian Cancer Should Know explains genetic counseling, genetic testing, and how to determine if your ovarian cancer is hereditary.

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