Welcome!

by Sue Friedman

Addressing ovarian cancer is half of FORCE's mission. So we know about the awareness disparity between breast and ovarian cancers. Breast cancer gets more attention. It strikes more women, with a greater lifetime potential for developing the disease in the high-risk community and the general population. But the imbalance goes much deeper. Many women know breast cancer can run in families. But few understand a family history of breast cancer can increase their risk of ovarian cancer. Ovarian cancer is more difficult to detect and cure, yet research funding is small compared to breast cancer funding. And, although MRI improves early detection of breast cancer in BRCA carriers, we have yet to see similar advances for ovarian cancer detection.

This issue of Joining FORCEs recognizes Ovarian Cancer Awareness Month throughout September with three informative pieces about ovarian cancer. You’ll find details of a new resource to help high-risk women sort out ovarian cancer risk management options, and the National Ovarian Cancer Coalition’s expanded effort to save lives by increasing awareness of the subtle signs and symptoms of ovarian cancer. Don’t miss the What’s New column for information about Passing of the Torch—our continuing effort to raise awareness of the breast-cancer-ovarian cancer connection.

Finally, we conclude our Joining FORCEs conference recap with summaries of the “Coping with Risk” and “Diet and Lifestyle” sessions. The conference webcast is still available at www.facingourrisk.org/webcast.

NOCC “Break the Silence”

by Jane Langridge

In May of this year we launched the new face of the National Ovarian Cancer Coalition (NOCC) to expand our reach and capture the attention of today’s women. We’ve designed a new logo, website, and educational materials with a contemporary look and feel to better educate and inform women and their families.

We also launched the Coalition’s first national media campaign called Break the Silence. Based on market research that revealed widespread misconceptions about prevention and diagnosis, our overall goals are to jumpstart public dialogue and increase general knowledge of early signs and symptoms in hopes of improving survival rates. To set the stage and motivate the media to champion our cause, it was essential to provide reporters with hard facts establishing what we all know is true—that knowledge and discussion of ovarian cancer symptoms among women is virtually nonexistent.

As a result of a Break the Silence media tour, campaign messages have reached more than 3.5 million television viewers and interviews from a teleconference have resulted in extensive media coverage. Throughout the summer and fall, popular women’s magazines such as Glamour, Family Circle and Healthy Living will run articles on ovarian cancer.

Ovarian Cancer Awareness month will see the next phase of the Break the Silence campaign with the launch of a national PSA starring NOCC’s first celebrity spokesperson, Eva La Rue, whose grandmother and great-grandmother died of ovarian cancer. Currently, Eva is lead actress on CBS’ hit show CSI: Miami and is a frequent correspondent on the entertainment show Extra. She is best known for her two-time Emmy winning role as Dr. Maria Santos on ABC’s All My Children.

We hope these activities, along with all our other programs, and the activities of our 80 divisions and friends at FORCE, really will help Break the Silence on this deadly disease. For more information on the Break the Silence campaign and to download a “Conversation Starter” visit www.ovarian.org.

After serving on the NOCC Board of Directors since 1999, Jane Langridge became Chief Executive Officer in 2005. She has over 20 years of oncology experience from working both in the health care sector and the pharmaceutical arena.
BRCA Test Results

Conclusive Test Results
Positive for a deleterious mutation means a BRCA1 or BRCA2 mutation that increases the risk of developing breast, ovarian, and certain other cancers was found.

No mutation detected means no known BRCA1/2 mutation was found. In families where someone has already tested positive for a BRCA mutation, a negative test result may be a “true negative.” In many circumstances the risk for cancer in the individual is no higher than the risk in the general population.

Inconclusive Test Results:
No mutation detected means no known BRCA1/2 mutation was found. In families with no identified BRCA mutation, family members with a negative test result may still be at high risk for cancer due to an unknown mutation or other risk factors that are undetectable by this test.

Genetic variant of uncertain significance means a gene change was found, but the cancer risk has not yet been determined with certainty.

Genetic variant, favor polymorphism means the test identified a common genetic change in BRCA1 or BRCA2 that is presumed, but not yet conclusively proven, to be unrelated to hereditary cancer risk. “Polymorphism” refers to benign genetic changes that are found in at least one percent of the general population and are not related to a significantly increased risk of disease.

If you think that cancer may run in your family, it is important to consult with a healthcare provider with training in cancer genetics. They have the expertise to help you sort through the complexities of cancer risk, identify which test is most appropriate for you, clarify the limitations of current genetic testing, and provide an accurate interpretation of your test results. Include the following questions in your discussion:

BRCA Testing: When Negative Results May Still Mean High Risk

by Kathy Steligo

For most people, receiving a negative test result for BRCA1/2 genetic mutations brings a huge sigh of relief. However, for people from families with a strong history of breast and ovarian cancer and no identified mutation, it may have an altogether different implication—they may be at increased risk despite a negative test result.

Genetic testing opened the door for predictive medicine, but it’s still a young science. We can only test for and identify mutations we know about. It’s like space exploration: we know how to navigate to Mars, but we haven’t a clue about finding as yet undiscovered planets in unknown solar systems—but we do suspect they’re out there somewhere. As researchers increase their understanding of breast and ovarian cancer, additional genetic risk factors will be identified and more comprehensive tests will find mutations that were previously missed.

In some cases where cancers “run in the family,” there are clear indications that hereditary factors are involved. Signs of hereditary cancers include:

• several relatives on the same side of the family with the same type of cancer
• family members who have cancer diagnosed at a young age (such as breast cancer before age 50)
• family members who have had more than one type of cancer
• uncommon cancers (such as male breast cancer).

The key to reliable genetic testing in these families is first testing a member who has had cancer, preferably the relative with the earliest age at diagnosis. If that relative is found to have a hereditary mutation, we can specifically identify the cause of the cancer occurring in that family. Other relatives who have not had cancer can then be tested to see if they have the mutation. Family members who test positive for the known mutation are at higher risk for cancer. Family members who test negative for the known mutation are true negatives with a cancer risk equal to people in the general population.

In some families it’s not possible to first test a cancer survivor. In this situation, testing a relative who has not had cancer is more likely to produce an inconclusive test, particularly if the result is negative. This may create a sense of false security—the person being tested may still carry a mutation we just don’t know how to find. The best way to assure correct interpretation of any genetic test is to consult with an expert in cancer genetics before and after testing.

Some families have a clear hereditary pattern for cancer, yet relatives consistently test negative for a known mutation. Because these families may have an undiscovered mutation, members are considered at high risk for cancer. As cancer genetic research continues, a future test may detect these unknown mutations. (See sidebar.)

Myriad Genetic Laboratories is the single source of BRCA1 and BRCA2 testing in the U.S. Myriad’s BRACAnalysis® test explores a portion of the BRCA genes where we would expect to find a mutation, although the current test cannot find all mutations along these genes. Additional hereditary syndromes found on genes other than BRCA1 or BRCA2 can also be linked to an increased risk for certain cancers. These mutations

“Individuals…who tested negative for a BRCA mutation prior to August 2006 may benefit from this expanded test.”
**BRCA Testing (continued)**

may require different testing procedures. Other genes, like CHEK2, for example, may increase the risk for breast cancer to a lesser degree than a BRCA mutation.

A large rearrangement is another type of BRCA1/2 gene mutation found in less than one percent of those tested. Since 2002, Myriad has been testing for the five most common large BRCA rearrangements. In August 2006, the lab added the BRACAnalysis Rearrangement Test® (BART) to find additional rearrangements. Myriad now automatically runs BART for individuals 1) from families with an inherited pattern of cancer but no identified mutation, and 2) whose family history meets certain criteria, and 3) whose initial testing produced a result of either “no mutation detected,” “genetic variant of uncertain significance,” or “genetic variant, favor polymorphism.” (See the sidebar for explanation of these terms.) Individuals who meet these criteria and who tested negative for a BRCA mutation prior to August 2006 may benefit from this expanded test.

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**Conference Recap: Coping with Risk and Family Dynamics**

by Drea Thew

*Presenter: Paul B. Jacobsen PhD, Program Leader, Psychosocial and Palliative Care Program, Moffitt Cancer Center*

Dr. Jacobsen, a clinical psychologist who specializes in psychosocial oncology, discussed the emotional, psychological and family concerns that arise from genetic testing.

Even before testing, the act of gathering family history or requesting that relatives be tested can generate conflict within a family. After testing, informing family members of the results can be very difficult in light of prior family estrangement—as in Dr. Jacobsen’s example, “I haven’t spoken to my cousins in 25 years. Now I’m going to call them out of the blue to say they may have a genetic mutation that increases risk for breast and ovarian cancer?”

Conflict can also arise when the information is perceived as upsetting or useless (particularly in male relatives). Dr. Jacobsen suggests providing information in a neutral way that allows relatives to make their own choices (“I was tested and I have my results, are you interested?”), rather than in a directive way (“I have this mutation—you and your daughters need to get tested too”). When there is preexisting family conflict, he recommends involving a neutral third party (such as a mental health professional) to help facilitate productive communication.

Dr. Jacobsen discussed why people might get “stuck” in choosing a risk management strategy. When an individual receives conflicting information from doctors, it can lead to mistrust of the information. Feeling there is always more information to acquire, that a new option is right around the corner, or that there is a “wrong” choice, may keep individuals from making a decision. Discord with a spouse or other loved ones about the right decision can cause confusion. Dr. Jacobsen discussed “problem-solving therapy” as a strategy to help individuals get “un-stuck” and move forward. This results-oriented therapy focuses on four steps: problem definition and formulation, generation of alternatives, decision making, and solution implementation and verification.

*Drea Thew is a FORCE Help-line volunteer.*

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**Finding a Genetics Expert**

For information on finding an expert in cancer genetics, see the FORCE website at: [http://www.facingourrisk.org/finding_health_care/finding_specialists.html](http://www.facingourrisk.org/finding_health_care/finding_specialists.html).

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**Coping: Additional Reading**


Promises
by Alisa Cowan

I've made many promises throughout my life. I never gave them much thought until my oldest daughter, Taylor, started asking me to make promises to her. I promised her I would make her a sandwich on her favorite potato bread, and that I would play our lullaby on the piano each night before she and her sister fell asleep. These were small promises, but they meant so much to her. She believed you should never make a promise that you can't keep. I had no problem upholding my end until the day she said, "Mommy, promise me you won't die." Wow! What do you say to that?

Knowing how random, how senseless, how quick and unexpected death can be, this promise suddenly meant more. Her weighty request for "passing on the gene," even if they knew that inheritance is completely random some parents may find it easier to blame themselves than to accept the more disturbing possibility that they cannot completely protect their children from all harm.

Having young children, and wanting to do everything possible to be around for them, is often a powerful motivation for undergoing risk-reducing surgery for breast and/or ovarian cancer. Other considerations, such as impact of surgery on body image, sexuality, and so forth, may fade into the background.

My mother was diagnosed with breast cancer. Like my grandmother and great aunt, my mother now faced the disease. My family fit the profile for a genetic mutation; my mother decided to have genetic testing. When she tested positive for a BRCA2 mutation, I knew I had to get tested myself. My test was positive too.

Even though I always assumed breast cancer was in my future, finding out that it was in my genes, in every cell in my body, was like a kick to my stomach.

"Mommy, promise me you won't die."

Now those words refused to leave my head. They were made even more painful mixed with the guilt I felt knowing my children have a 50% chance of having this horrid mutation as well.

Most importantly, I learned to view my knowledge of my genetic status as power. Knowing I was likely to get cancer eventually, I could make a pre-empive strike and do something about it now. A few months after getting the news, I scheduled a bilateral oophorectomy. Preparing my daughter for my surgery is exactly what helped me find the answer to her question.

"Mommy, promise me you won't die."

I will never say to her, "I promise honey, I won't die." I couldn't do that, and she wouldn't believe me. I'll tell her that I'm taking care of myself because I want to be around for a long time, and for me, this means having surgeries to remove parts of my body that will probably get sick. But I will never make a promise to her that I cannot guarantee I will keep. Maybe she'll grow up stronger because of it. Maybe not. But I know, in case of the unexpected, she will never have the added heartbreak of a broken promise.

Alisa Cowan lives in Maine with her husband, their two children, and their horse.

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.

Email stories of 500-550 words to info@facingourrisk.org or mail to FORCE, 16097 Tampa Palms Blvd W Suite 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.

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Having young children, and wanting to do everything possible to be around for them, is often a powerful motivation for undergoing risk-reducing surgery for breast and/or ovarian cancer. Other considerations, such as impact of surgery on body image, sexuality, and so forth, may fade into the background. However, it is important for a parent who is contemplating surgery to take care of herself psychologically with good presurgical counseling so that she is prepared for how the surgery may affect her.

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Conference Recap: Diet & Other Lifestyle Factors in Hereditary Cancers

by Drea Thew

Presenter: Nagi Kumar, PhD, RD, FADA, Director of Nutrition Research, Associate Professor, Department of Interdisciplinary Oncology, University of South Florida College of Medicine

Women with increased potential for hereditary breast and ovarian cancer often wonder if dietary and lifestyle choices can reduce their risk. Dr. Kumar discussed known causes of cancer in the general population, including tobacco, diet, obesity, and a sedentary lifestyle. She summarized studies that show diet influences risk. In particular, Western cultures, as in North America, where the typical diet is 45-75 percent meat, dairy and sugar, have a much higher incidence of cancer than Africa, Asia, and other cultures where fruits, vegetables and whole grains account for 50-90 percent of the average diet.

Cancers don’t develop overnight. Their multi-step evolution takes several years: from normal cells to irregular cells and eventually to cancer. Dr. Kumar described the current understanding of “carcinogenesis,” how cancer develops and disrupts the normal cycle of cell maturation, differentiation and apoptosis (programmed cell death). “Mutagenesis” occurs when genetics or external factors (smoking, sun exposure, etc.) cause cells to divide uncontrollably. Advances in molecular oncology and genetics suggest cancer may be preventable, even with a genetic predisposition. So we may have time to intervene during development and stop or reverse cellular damage. “We consume food every day. We know that nutrients can affect this process of carcinogenesis,” said Dr. Kumar.

Dr. Kumar shared good news about her research of how obesity and body fat distribution may affect breast cancer risk: fat concentrated in the upper body, usually described as “android” fat distribution or an “apple-shaped” body, was found to increase breast cancer five-fold. This was associated with a poorer prognosis among those who were diagnosed with breast cancer. Weight loss, however, had a significant positive impact. Dr. Kumar found with minimal weight reduction, even 10-15 pounds, most weight was lost in the upper body, meaning this android risk factor may be modifiable.

Dr. Kumar offered eight suggestions for women with hereditary risk for breast and ovarian cancer:

1. Maintain your “ideal” body weight. Limit intake of red meat, and increase protein with “good fats” such as seafood.
2. Eat reasonable portion sizes.
3. Eat a minimum of 8-10 fruits and vegetables a day. Research shows produce has more than 55 nutrients that can aid the DNA damage/repair process. (See sidebar)
4. Improve and maintain bone strength. A daily supplement of calcium citrate, phosphorus, magnesium and vitamins A and D is recommended. Increased physical activity and resistance training is also helpful.
5. Adopt a physically active lifestyle. Staying active prevents obesity, modulates hormone levels and lowers risks in unexplained ways. Try for 45 minutes of exercise, 5 days a week. This can be as simple as going for a walk.
6. Ideally, avoid liquor altogether. If you drink alcohol, limit consumption. Alcohol may have more damaging effects for BRCA carriers than the general population. If you choose to drink red wine for its health benefits, drink no more than one glass per day.
7. Stop smoking. Smoking is responsible for a very large percentage of many cancers.
8. Avoid sun exposure. UV rays promote mutagenesis. Wear sunscreen and protective clothing when you must be in the sun.
A Challenge Easily Answered
by Debbie Sokolov

Three years ago, when my mother was diagnosed with ovarian cancer, I never imagined the journey I was about to take. Subsequently, I tested positive for BRCA1 and was diagnosed with breast cancer. Suddenly, having a BRCA mutation took on a different meaning. Only because of FORCE was I able to understand my options—and not feel alone. Each of you has a similar story. You found FORCE because of your own genetic link to breast and ovarian cancer.

There is no question about the need for FORCE. The overwhelming response to the organization’s website (one million hits each month), first annual conference (sold out) and this newsletter (7,000 copies distributed each issue) are testament to the need filled by FORCE’s unique community and free services. But FORCE, operating on a shoestring budget, cannot exist without our support.

So, to all of you who are genetically predisposed to breast and ovarian cancer, I challenge you to join FORCEs with us. Please donate today. Your contributions of tax-deductible funds, in-kind services and/or volunteer time help FORCE continue to raise awareness of hereditary breast and ovarian cancer, and to support those who need FORCE’s helping hand. See our website for more information.

Debbie Sokolov is the Associate Director of Development for FORCE. She lives in St. Petersburg, Florida.

New Book for Women Considering Ovarian Cancer Risk-Reducing Surgery
by Carol Cbbery

If you’re at high risk for ovarian cancer, you may be struggling with a very tough decision: should you remove your ovaries to reduce your risk? If you’re facing that decision, there’s a new resource just for you. Ovarian Cancer Risk-Reducing Surgery: A Decision-Making Resource was written by Kristine M. Conner and health professionals from Fox Chase Cancer Center in Philadelphia.

The team at Fox Chase identified a clear need for this resource. While caring for women after oophorectomy (surgical removal of ovaries), they discovered patients felt differently, both physically and emotionally, but it wasn’t clear why. In some cases, women were unprepared for the intense post-surgical side effects of menopause. So Fox Chase organized focus groups to ask women and their partners about their experiences and what they wished they had known prior to surgery. Women suggested more information was needed about the pros and cons of surgery, different surgical options, and how “surgical menopause” compares to natural menopause. They also wanted to hear about other women’s experiences with the surgery.

The resource is divided into five sections:

- Understanding your risk of ovarian cancer
- Considering risk-reducing surgery
- What you need to know if you want to have risk-reducing surgery
- What you need to know if you do not want to have surgery now
- Sexuality and intimate relationships after risk-reducing surgery

Each section ends with a list of questions readers can discuss with their healthcare team. Resources for additional information and numerous real-life quotes are found throughout the text. There is also space for journaling, so women can write continued on page 8.
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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.

New Book (continued)

their personal preferences as part of the decision-making process.

FORCE Executive Director Sue Friedman was an early reviewer of the manuscript, and provided input to the final version. The book is free upon request. Just send an e-mail to surgerybook@fccc.edu. Include your name, mailing address and reason for wanting the book.

What’s New @ FORCE

Pass the Torch with FORCE!
Building on the success of last year's Passing of the Torch in Boston, FORCE will host this fall’s free event in three cities:

- Boston, Sept. 30, Jamaica Pond
  6:00 pm – 9:00 pm

- Tampa, Sept. 30, Cotanchobee Park
  (by Channelside) 5:00 pm – 8:30 pm

- Ft. Lauderdale, Oct. 7, Las Olas Riverfront Mall Gazebo
  6:00 pm – 9:00 pm

(The Ft. Lauderdale event is a collaboration with the National Ovarian Cancer Coalition.)

Passing of the Torch highlights the hereditary link between breast and ovarian cancer. The event honors cancer survivors and individuals at high risk, remembers those lost to cancer, and recognizes families affected by cancer.

Can’t attend? You can still show your support. Make a donation or purchase a luminary to be displayed at the event. Your donation helps raise awareness of hereditary breast and ovarian cancer and helps FORCE save lives! See our website (www.facingourrisk.org/torch) for more details.

Joining FORCEs Conference.
Save the Date: May 18-19, 2007!
The second annual Joining FORCEs Conference on Hereditary Breast and Ovarian Cancer will take place on May 18-19 at the Hyatt Regency, downtown Tampa. This year’s conference attracted internationally-acclaimed speakers and drew over 200 participants from around the world. We hope to attract 400 attendees for our 2007 event. Visit www.facingourrisk.org/webcast to view a webcast of the 2006 conference. See www.facingourrisk.org/conference for information about our 2007 conference.

FORCE: Facing Our Risk of Cancer Empowered
16057 Tampa Palms Blvd. W. #373
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