Welcome!
by Sue Friedman

This issue of Joining FORCES is all about community. We often hear how small the hereditary cancer community is; a minority of people diagnosed with cancers. Some consider our numbers too few to matter. Collectively we can challenge that perspective and have more power to raise awareness and guide the direction of research.

From the research community, we bring the latest developments specific to those with BRCA mutations. You’ll learn about the PROSE study group, a collaboration of multiple academic institutions providing research on hereditary cancer. Another significant study demonstrates that BRCA accounts for more cases of ovarian cancer than previously thought and suggests genetic counseling and testing should play a significant role in the medical management of ovarian cancer patients and their families.

For those who couldn’t attend our first Passing of the Torch, we share highlights of this moving, overwhelmingly successful event, where we raised awareness of the link between hereditary breast and ovarian cancer, and highlighted our Boston area network. We also present the concept of pre-vivors, a special segment of the hereditary cancer community. In our Voices of FORCE story, one woman candidly describes how she was genetically tested without adequate information. She relates how FORCE helped her face her challenges and fears, and understand her choices.

Finally, we are happy to introduce Looking Back, Living Forward (below), a program designed to increase documentation of family medical information while empowering families to find wisdom and strength in their own stories.

As you read these articles, remember you are a part of a growing alliance; a caring community affecting positive change for individuals and families concerned with hereditary breast and ovarian cancer.

Looking Forward to “Looking Back, Living Forward”
by Andrew Filippone Jr.

This February, at the first annual Joining FORCES conference in Tampa, FORCE will introduce “Looking Back, Living Forward: Stories, Wisdom & the Treasures of Family,” a new public education campaign for college students.

Through a series of live interactive workshops, a comprehensive website, and a library of educational literature, Looking Back, Living Forward will teach audiences to collect and share their family medical history while discovering the stories and lessons of their family’s past.

Looking Back, Living Forward was inspired by “Mina & the Family Treasure,” a new documentary from Executive Producer Rosie O’Donnell. A story of fearlessness in the face of a grave and lethal foe, the film begins with a question for its protagonist, Sue Breecker: What is the secret of her 99-year-old mother’s long life? Only 58-years old and battling an aggressive metastatic cancer, Sue needs to know, and her search for the answer is the focus of the film.

Over seven months Sue journeys from her home in New York to a remote seaside village in Ukraine, looking for help and hope, and rediscovering the legends of her mother’s past. Perhaps somewhere, she thinks, in the life of this indomitable woman, lies the answer—the treasure that will allow her a longer life too.

Looking Back, Living Forward features facilitated discussions around six core themes: Survival, Connection, Discovery, Inheritance, Storytelling, and Living Forward. Also included are selected scenes from the documentary and practical tips on how to collect and make sense of family histories.

Andrew Filippone Jr is a filmmaker living and working in New York City. “Mina & the Family Treasure,” his first feature-length documentary, will be broadcast on PBS in May 2006.
**PROSE Dinner**

At the annual meeting of the American Society of Human Genetics, Sue Friedman was invited to speak at a dinner for PROSE participating institutions. The group listened intently as the following issues were discussed:

- **A pre-vivor** population (individuals who are predisposed to cancer but haven’t yet been diagnosed) with more time to research options is leading to “empowered patients.” This group wants to know about all their medical options and issues that relate to their high-risk status, including:
  - Research into satisfaction and long-term outcomes that examines results by type of mastectomy and type of reconstruction
  - Long-term data on outcome, satisfaction and quality of life after prophylactic oophorectomy in premenopausal women based on type of surgery and use/type of hormone replacement
  - FORCE anecdotal perception that more people are being offered genetic testing without genetic counseling, or counseling by inadequately-trained providers
  - Misinformation regarding hereditary cancer, and certain organizations or media polarizing issues rather than presenting balanced information
  - Patient confusion from lack of consensus on risk management recommendations between different facilities

During the ensuing discussion, the group expressed interest in working together with FORCE to assure their research has input from our community and relevance to our members.

**References**


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**PROSE: Research Collaboration Provides Answers for Women with BRCA Mutations**

*by Kathy Steligo*

Women with BRCA mutations must decide how to best manage their risk of breast and ovarian cancer. They may choose to take chemoprevention medication, increase surveillance, or have prophylactic surgery. Unfortunately, there is still limited data about the appropriate use or efficacy of these risk reduction options. At best, these choices can be difficult, confusing and highly personal—what is right or appropriate for one individual may be unacceptable for another.

Funded primarily by the National Institutes of Health, the PRevention and Observation of Surgical Endpoints (PROSE) Study is an ongoing project examining outcomes in BRCA carriers from 23 participating North American and European medical centers. This collaborative approach is critical to obtain appropriate sample size, according to lead researcher Tim Rebbeck, Ph.D., Professor at University of PA School of Medicine. “Because women with BRCA mutations are often seen in high-risk referral clinics, studies done in the general population may not best represent individuals who are found to have BRCA1/2 mutations,” says Rebbeck. “Individual centers don’t have enough BRCA carriers for adequate study, but pooling our data provides the study and control groups we need for statistically significant results.” Participating centers operate independently, but follow a common set of standards for participant screening, data collection, and analytical methods.

While bilateral prophylactic mastectomy (BPM) is the most extreme breast cancer risk reduction strategy, PROSE research confirms it reduces breast cancer risk in BRCA carriers by 90%. (Because breast tissue blends with other tissue in the chest, it’s never possible to remove it all. That’s why a small risk of breast cancer remains after mastectomy.)

During the study, 105 BRCA women who had BPM were compared to a control group of 378 BRCA women who did not. Neither group had previous diagnoses of breast cancer. After an average followup of 6.4 years, only two (1.9%) women in the BPM group developed breast cancer compared to 184 (48.7%) in the control group. Average age of study participants was mid-30s (for those who had BPM, average age was 35-38 at the time of surgery; average age of control group participants was 34-36). BRCA carriers who had BPM but kept their ovaries reduced their breast cancer risk by 90%. Those who also had bilateral prophylactic oophorectomy (BPO) reduced their breast cancer risk by 95%. (Prior PROSE research found BPO alone, if performed prior to menopause reduces ovarian cancer risk by 90% in BRCA mutation carriers and lowers breast cancer risk by about 50%.)

Although a previous study suggested greatly reduced breast cancer risk after BPM, limited data hindered accurate risk estimates. The PROSE group results are especially meaningful to the BRCA-positive community, because the study data is specifically applicable to them. This knowledge may not make a woman’s risk management decisions easier, but it removes much of the confusion and mystery about the extent of risk reduction after prophylactic surgery.

Additional PROSE research of short-term hormone replacement therapy (HRT) may help premenopausal BRCA women decide whether to pursue BPO to reduce their risk of breast and ovarian cancer. There’s little doubt about the effectiveness of oophorectomy for women with BRCA mutations; it has been shown to reduce ovarian cancer risk by 90% and, if done premenopausally, to reduce breast cancer risk by at least 50%.

continued on page 3
Tampa Study Finds BRCA1/2 Mutations Cause Many Ovarian Cancer Cases

by Sue Friedman

Identifying women with a BRCA mutation who are diagnosed with ovarian cancer may lead to more options for detecting and preventing cancer in their relatives. To better understand hereditary ovarian cancer, the Tampa Bay Ovarian Cancer Study (TBOCS) set out to determine the percentage of ovarian cancer patients with BRCA mutations, and what types of the disease are more common in women with these mutations.

The TBOCS found BRCA mutations may account for more cases of invasive ovarian cancer than previously thought. When researchers at H. Lee Moffitt Cancer Center and gynecologic specialists from the Tampa Bay area genetically tested 209 women with invasive ovarian cancer, they found approximately 14% had a BRCA mutation. The majority of women with BRCA mutations had serous ovarian cancer. The study also found that some types of ovarian cancer—borderline or invasive mucinous tumors—were unlikely to be caused by a BRCA mutation.

Because genetic test results may impact screening and prevention for breast and ovarian cancer for patients and their relatives, and based on the relatively high percentage of ovarian cancer associated with BRCA mutations, it is prudent for women with invasive ovarian cancer to see a genetic counselor. (Medicare now covers the cost of genetic counseling and testing for eligible women with ovarian cancer.)

In premenopausal women, however, BPO produces surgically-induced menopause, and for many, the dreaded hot flashes, fatigue, vaginal dryness, reduced libido or other symptoms are a cruel tradeoff for lowered cancer risk. Although hormone therapy is one way to deal with these symptoms, previous research of post-menopausal women without BRCA mutations suggested HRT (estrogen plus progesterone) increases the risk of breast cancer, raising concern it may offset the risk reduction achieved by BPO. An increased risk for breast cancer was not seen in women who took ERT (estrogen alone). However, the application of this research to the BRCA community remains uncertain.

In a recent PROSE study, a group of 155 BRCA women who had BPO were compared to a control group of 307 BRCA women who did not have BPO. Ninety percent of the BPO group had surgery before age 50; the group’s average age at time of surgery was 42.7 years. After an average follow-up of 3.6 years, women who took hormones of any type after BPO still had significantly reduced breast cancer risk. In fact, they had only a third the risk of developing breast cancer as women who kept their ovaries.

More study is needed regarding the duration of HRT, the benefits and risks of taking estrogen alone compared to estrogen combined with progesterone, and timing of BPO relative to age or natural menopausal status. It is important for women to discuss BPO and the risk of hormone replacement with their healthcare team to make an informed decision.

PROSE (continued)

For more information and a list of participating centers, visit www.cceb.upenn.edu/prose.

Symptoms of Ovarian Cancer

Please consult your doctor if you notice the following persistent symptoms:

- Pain in the pelvis, abdomen, or lower back region
- Persistent bloating, nausea, gas, loss of appetite, or a feeling of fullness
- Unexplained weight gain, weight loss, or swelling of the abdomen
- Increased frequency or urgency of urination not caused by a urinary tract infection
- Changes in bowel movements
- Pain during intercourse
- Menstrual changes or postmenopausal bleeding

These symptoms can be caused by conditions unrelated to cancer. If a cause cannot be found for your symptoms ask your doctor about transvaginal ultrasound, CA125 blood test, pelvic/rectal exam, and referral to a gynecologic-oncologist. These doctors specialize in the diagnosis and treatment of cancers of the reproductive system.

Although ovarian cancer has been termed the “silent killer,” a recent study showed that many women found to have ovarian cancer had some symptoms several months prior to diagnosis (see reference below).

References


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.

Happy New Year, You’re at High Risk

by Diane Roth

My mother was always like a sister to me. Until she turned 59, she wasn’t sick a day in her life. Then one evening she noticed her legs were swollen. A trip to the emergency room found a blood clot in her legs, caused by an 18cm abdominal tumor. Two years later after surgeries, chemo, and alternative therapy, I lost my mom, my dearest friend, to ovarian cancer.

At my annual exam, my gynecologist mentioned a blood test to determine whether I carry a genetic predisposition to breast or ovarian cancer. “Since you have cancer on your father’s and mother’s side, you might consider this test for peace of mind,” he said. His nurse drew my blood. I left his office certain the test would be negative. On January 4, 2005, my gynecologist called with the results: “I have good news and bad news,” he said. “The good news is you’re negative for BRCA1. Not knowing what BRCA1 meant, I said, ‘I guess that’s great news, right?’ ‘No,’ he said. ‘The bad news is that you tested positive for BRCA2 and are at high risk for breast and ovarian cancer. Your daughter and sister should also be tested; there is a 50/50 chance they also are BRCA2 positive.’

I immediately went to his office to speak with him but he had already gone to lunch. The receptionist gave me my test results packet and a referral to a breast surgeon. I took a deep breath... I was relieved to realize I was not alone, but began to cry. I called FORCE and spoke with Executive Director Sue Friedman. She listened to my story. She told me she was sorry I found my test results the way I did. She suggested genetic counselors in my area. Her candor comforted me as she shared her own story: Taking her advice, I saw a certified genetic counselor who explained things I should have been told prior to testing, counseling me about issues I now faced, explaining my options, and putting them in perspective.

Subsequently, my daughter, sister and father tested negative for the mutation I inherited from my dear deceased mother. Sadly, genetic testing wasn’t available until after she died.

I feel lucky to have gained the knowledge I have; regardless of how I learned my results. The information empowered me to make an informed decision about my future. After extensive research, I decided to have bilateral mastectomies with DIEP flap reconstruction. Although I never again heard from my gynecologist, I am grateful he mentioned the BRACAnalysis® to me. I believe my doctor had only good intentions, but he handled my genetic testing poorly because of inexperience.

I know I made the right decision for myself. Every individual faced with an increased risk of cancer should have the knowledge that too many of us learn the hard way. I am determined to raise awareness of familial cancers in the medical community and the general public.

Diane Roth, 54, lives in Boca Raton, FL. She has three adult children and three grandsons.

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@l抗癌故事或向FORCE, 16055* Tampa Palms Blvd W #335, 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.

Scott M. Weissman is a certified genetic counselor who specializes in cancer genetics at The Center for Medical Genetics at Evanston Northwestern Healthcare. He is also the Co-Chair of the National Society of Genetic Counselors’ Familial Cancer Risk Counseling Special Interest Group.

A Professional’s Perspective (continued)

likely would have had a better understanding of the implications of her positive results, for her own health and the health of her family members. The test results would have been given to her in a more sensitive manner (instead of the dreaded ‘good news/bad news’); a genetic counselor would have spent as much time with her as she needed providing her with psychosocial support. Together with her counselor, Diane would have formulated a plan for managing her positive results and informing her family members of the results.

Because Diane had the courage to read materials included with her positive test results, she became aware of FORCE. Through FORCE and Executive Director Sue Friedman, Diane was able to turn her negative experience into a positive and become empowered in such a way that she now advocates for other women who have been affected by hereditary breast and ovarian cancer syndrome.

A Professional’s Perspective

Unfortunately, Diane’s story is one cancer genetics professionals hear all too often from their patients. Her experience highlights the importance of having genetic counseling before having genetic testing for BRCA1/2 mutations. Genetic counselors educate patients about the BRCA genes and lifetime cancer risks of individuals who harbor a mutation in either gene. A genetic counselor can perform a cancer risk assessment to determine if genetic testing is warranted. She can discuss the costs, benefits and limitations of genetic testing, and explain the implications of an individual’s test results for other family members. If a BRCA mutation is identified, the counselor can review medical management and cancer prevention options. Additionally, genetic counseling provides patients with the time to discuss their psychosocial concerns about their personal and/or family history of cancer or genetic testing. By having these discussions and providing this information to patients prior to testing, genetics professionals (like a genetic counselor) are able to empower patients to make informed decisions about BRCA genetic testing.

Although Diane’s physician had good intentions, Diane felt completely helpless after hearing her positive test results. If she had conferred with a genetic counselor prior to testing, she most likely would have had a better understanding of the implications of her positive results, for her own health and the health of her family members. The test results would have been given to her in a more sensitive manner (instead of the dreaded ‘good news/bad news’); a genetic counselor would have spent as much time with her as she needed providing her with psychosocial support. Together with her counselor, Diane would have formulated a plan for managing her positive results and informing her family members of the results.

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Promoting the Concept of Pre-vivorship

FORCE is undertaking the Cancer Pre-vivor Campaign to educate and inform others about breast and ovarian cancer pre-vivors—the decisions they face and the resources they need.

As we continue to build awareness and support for those with a BRCA mutation, there is much more to be done. We must also inform and educate the public, the medical community and our elected leaders about the issues and needs of those with genetic mutations, so BRCA-positive individuals needn’t be afraid to voice their confusion nor fear reprisal.

FORCE has worked hard to successfully build awareness throughout the medical community and among families of those who carry a BRCA mutation. You can help FORCE promote the concept of pre-vivorship by supporting our Cancer Pre-vivor Campaign:

• use “pre-vivor” when describing the high-risk population
• tell your cancer pre-vivor friends and relatives about FORCE
• tell your medical team about FORCE
• refer the media to FORCE to improve coverage of our campaign and raise awareness of the unique needs of the pre-vivor community.

“Until recently, no single term accurately depicted the predicament in which individuals in the high-risk cancer community find themselves. The medical community uses the term “unaffected carrier” to describe this population, but this term does not capture the full experience of those who face an increased risk for cancer or the need to make medical management decisions. In 2000, however, FORCE responded to a request by member Cathy Beaudoin, who posted on the message boards: “I need a label!” Deciding “unaffected carrier” was not only inadequate but inaccurate, FORCE and its members felt pre-vivor best described this special community.

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The term cancer pre-vivor describes individuals who are survivors of a predisposition to cancer but who have not had the disease. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. They may face multiple risks not wholly shared by the general cancer community, including a higher lifetime risk for cancer, a tendency for onset of cancer at an earlier age, a higher likelihood for multiple cancers, and a risk that can be inherited. Because they are at higher risk, this group faces difficult decisions regarding risk management and surveillance.

Pre-vivors: The Growth of a Voice

by Karen Dyer

The term cancer pre-vivor describes individuals who are survivors of a predisposition to cancer but who have not had the disease. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. They may face multiple risks not wholly shared by the general cancer community, including a higher lifetime risk for cancer, a tendency for onset of cancer at an earlier age, a higher likelihood for multiple cancers, and a risk that can be inherited. Because they are at higher risk, this group faces difficult decisions regarding risk management and surveillance.

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Cathy, the complexity of the term “matches the complexity of the situation. It’s a word that stops people, makes them wonder what it is, ask questions, and prompts for more dialogue.”

The growing popularity and usage of pre-vivor indicates the rising influence of an increasingly organized, unified and cohesive voice. For individuals who are newly identified as being at higher risk of cancer, having a label creates a sense of community, belonging and friendship. For them, pre-vivor speaks specifically to their situation and describes their needs. Cathy notes, “Having a group that is identified in a tangible way validates your situation and provides some sort of comfort in a new and scary situation.”

Until recently, existing legislation, medical interventions, and psychosocial support networks have not focused attention specifically on the needs and voices of the high-risk community. The use of the term pre-vivor facilitates the growth of a unified voice that is necessary for our community to be heard. FORCE hopes this will result in increased funding, research and legislation.

Cathy wants the term to become as well-known and well-used as cancer survivor has become. “I would like people to know the term, to understand it, to have it become common lingo among both the medical community and the lay population.”

Karen Dyer is the FORCE Director of Programs.
FORCE Event Highlights Link Between Breast and Ovarian Cancer

by Sheila Galland

Our Passing of the Torch event was held in Boston on the evening of October 1, marking the transition from Ovarian Cancer Awareness Month (September) to Breast Cancer Awareness Month (October). Our goal was to raise awareness of the two cancers and highlight the hereditary link between them by passing a symbolic lighted torch from an ovarian cancer survivor to a breast cancer survivor. We hoped for 50 people and would have been satisfied with that many attendees. We were astounded when 200 people came to watch the ceremony.

With soft classical guitar playing under a warm sky, people purchased pink and teal light-stick luminaries, decorated them, and placed them around the park to honor or remember loved ones who had faced cancer. At our information table, FORCE distributed hundreds of brochures on hereditary breast and ovarian cancer.

Sue Friedman opened the ceremony by speaking about hereditary cancer, mutations that cause breast and ovarian cancer in families, and the connection between the two cancers. She then discussed the work of FORCE.

As an ovarian cancer survivor who inherited BRCA1 from my father, I talked about the often vague symptoms of the disease and my own one-year struggle to pinpoint the cause of weight loss and abdominal distension. I urged the audience to be proactive and persistent if they had symptoms.

Breast cancer survivor Kim Clark spoke about her family’s hereditary link to the disease, and her own diagnosis, even in the absence of an identifiable mutation. She emphasized the need for better preventative and treatment options. Kim urged people to support FORCE to unite the hereditary cancer community and rally for more research. She then presented Event Chairperson Linda Pedraza with a crystal sculpture of a torch in honor of her dedication to FORCE, and her advocacy efforts towards hereditary breast and ovarian cancer awareness. Diagnosed with both breast and ovarian cancer, Linda was beginning treatment for a breast cancer recurrence to her brain.

Keynote speaker Dr. Judy Garber, Director of the Cancer Risk and Prevention Program at Dana-Farber Cancer Institute, spoke about research efforts to find better prevention, detection and treatment for hereditary breast and ovarian cancer. She offered hope of better medical options for future generations.

Linda’s 16-year-old daughter stole the show, dedicating her a cappella rendition of the Hilary Duff song “Someone’s Watching Over Me” to her mother. She sang of enduring strength, of not giving up, even when all around goes wrong. She sang of still believing someone was watching over her. Her beautiful voice touched everyone in the audience; there wasn’t a dry eye in the park.

Our finale was the passing of the ceremonial torch. Using my own teal torch, I sparked the flame of the pink torch held aloft by Linda, who then led a procession around the park. It was dark by then and the scene was beautiful and surreal.

continued on page 8
What's New @ FORCE

Same Web Address, Improved Information

In November 2005 we launched a completely redesigned website, www.facingourrisk.org, where visitors can view comprehensive information about hereditary breast and ovarian cancer. Now it’s easier to navigate through the many online information options, whether you’re looking for links to the latest research on hereditary cancers, looking for risk management options, or want to know how to find a genetic counselor in your area. You’ll find current and archived editions of our Joining FORCES newsletter, and easy-to-use online forms to subscribe to the print version, or send us feedback. Our popular message board is still available with the same format.

First Annual FORCE Conference

Our first FORCE national conference will be held February 10-11, 2006 in Tampa. Focused towards those with BRCA mutations or other risk factors for hereditary breast and ovarian cancer, “Joining FORCES Against Hereditary Cancer” will feature internationally-known physicians and researchers. Attendees will have plenty of opportunities for learning, networking and support. Dr. Susan Love, the featured speaker at an optional FORCE benefit dinner, will discuss her breast cancer prevention research. Our next newsletter will include highlights from the conference.

Passing the Torch (continued)

Sue Friedman offered the closing words: “May the passing of this torch symbolize our current and future efforts to spread awareness of ovarian cancer, breast cancer, and the hereditary link between the two. May the fire symbolize our burning commitment to work towards eradicating cancer. May the luminaries remind us to remember and honor those whose lives have been affected or cut short by cancer.”

Editor’s note: On January 6, Linda Pedraza lost her courageous battle with breast cancer. An active FORCE member, Linda was a profound inspiration within the FORCE community. She served on our Board of Directors, and tirelessly lent her energy, wit and spirit to those in need of information or comfort. We send our heartfelt thoughts to her family and everyone who knew and loved her. We will miss her and remember her every day.

Sheila Galland has worked on behalf of Jews in the former Soviet Union for the last 25 years. Diagnosed with stage 3 ovarian cancer in February 2004 at age 62, she has been cancer free since December 2004.

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.

FORCE: Facing Our Risk of Cancer Empowered

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Stanford Clinical Cancer Genetics Prog.

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

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