Welcome
by Sue Friedman

2009 was an exciting year for research and advocacy. The first clinical trial on PARP Inhibitors produced very positive results. FORCE advocated for and provided input to key policy issues, including the EARLY Act and implementation of GINA. We testified to the Secretary’s Advisory Committee on Genetics, Health and Society on direct-to-consumer marketing oversight, and published a response to the United States Preventive Services Task Force controversial recommendations for breast cancer screening in young women. You’ll read more about our 2009 policy work in this issue, and a session of our 2010 Joining FORCEs conference will show how to become involved, speak out on issues of importance to our community, and make a difference.

And speaking of our conference, last year we outgrew our Tampa facilities; we moved Joining FORCEs to Orlando, where 520 men and women attended. We’re returning to Orlando this June 24-26. You’ll find details in this issue and on our website.

In 2010, we’ll launch two new programs—our Be Empowered Webinar Series and the Expert Referral NEeeded Search Tool (ERNEST)—and we will introduce redesigned message boards. We’re also working to develop a specialty fitness week for survivors at Hilton Head Health Institute. And of course, our monthly email updates, website, helpline, outreach groups and other longstanding programs will be there when you need them. So stay connected with FORCE this year, and thanks in advance for your participation and support.

FORCE Conference: The Latest on Hereditary Cancer—All Under One Roof!
by Sue Friedman

Are you a survivor or previvor with cancer in your family?

Have you considered BRCA testing or have you already been tested?

Do you want to learn more about the latest treatments, prevention, surveillance, and quality-of-life research and results?

If you answered “yes” to any of these questions, Orlando is the place to be in June. That is the site for our 5th annual Joining FORCEs conference—the largest gathering of the BRCA-positive and hereditary cancer community. No matter what your circumstances, no single source of information compares to our Joining FORCEs conference for learning the latest information, getting support, sharing stories, learning your options, meeting others who know firsthand what you’re feeling, and getting the most out of life with hereditary cancer. Joining FORCEs offers something else you just can’t get anywhere else: unique opportunities to meet and talk one-on-one with world experts on hereditary cancer.

Based on feedback from last year’s conference, we’ve added new sessions and topics. This year, for example, we will offer sessions designed specifically for women who have completed prophylactic surgery. Our "Screening after Surgery" presentation pairs gynecologic-oncologist Robert Burger, MD from Fox Chase Cancer Center with Elsie Levin, a mammographer from Boston, to discuss the residual risks for cancer after surgery, screening recommendations, and related challenges. Dr. Sharon Bober will address the emotional and sexual issues of confronting your new normal after surgery, cancer or menopause. And Dr. Karen Hurley will moderate an interactive networking workshop where women can share their experiences and learn from the experiences of others who have “been there, done that.”

Conference attendees will have unprecedented access to new and emerging information. Dr. Noah Kauff will discuss the most current research that suggests many ovarian cancers in BRCA carriers actually begin in the fallopian tubes. He will discuss how this relates to primary peritoneal cancer and how it may change our approach to screening and prevention of gynecologic cancers in women in our continued on page 2
Joining FORCEs Conference (continued)

community. Based on your input, gynecologic-oncologist Dr. Diljoot Singh, who studies at the Arizona Center for Integrative Medicine under the renowned Dr. Andrew Weil, will discuss the benefits of integrative and complementary medicine. Dr. Mark Robson will address young women at high-risk, including his research on the risks and benefits of mammograms in high-risk women under age 30.

“How Do I Get Motivated?” is a new session presented by Bob Wright, Director of Education at Hilton Head Health Institute, a well-regarded fitness and weight loss facility. He will discuss simple ways to get on track and stay on track through fitness, healthy eating, and lifestyle changes. Kathy Steligo, author of The Breast Reconstruction Guidebook, returns with her "Breast Reconstruction Overview" and a new session, “Finding Dr. Right,” a lighthearted guide for finding, interviewing and keeping doctors who match your health care needs.

Survivor and producer Lori Benson will present her HBO documentary, Dear Talula, a film that chronicles her experience as a new mother who learns that her breast cancer is hereditary. Lori will be on hand to take your questions and autograph copies of her film.

The conference provides plenty of opportunities to network, learn, share, laugh and just kick back and relax. Once again, our pre-conference Fire(works) and Ice(cream) reception and art show will delight and dazzle against the background of Epcot’s spectacular fireworks show. After the conference sessions, attendees can visit our spouse support group meeting and the popular Show-and-Tell room.

Visit the FORCE website for information that will help you plan your conference and Orlando experience, including:
- A descriptive list of all conference sessions.
- Frequently Asked Questions (and answers) about the conference.
- A list of suggested sessions, depending on your circumstances.
- Travel and lodging information, including links to online hotel reservations, theme parks, recreation, and other things to do in Orlando.
- Information about our scholarship program.

“Be Empowered” Webinar Series

by Sue Friedman

Join us throughout the year for a series of free online seminars about hereditary cancer. Our Be Empowered webinar series is a wonderful opportunity to interact with others and learn about topics of interest and importance, all from the comfort and privacy of your own computer.

Our webinar series features presentations by experts on a variety of subjects that are important to our community. FORCE webinars are designed for anyone who is concerned about hereditary breast and ovarian cancer: survivors, previvors, relatives, caregivers, and health care providers.

The webinars are open to anyone; however, we do require registration in advance. For more information and to register visit www.facingourrisk.org/events/webinar.html. The series is funded by a generous grant from Genentech.

Our 2010 Be Empowered webinar calendar features the following topics (all times are EST).

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
</tr>
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<tbody>
<tr>
<td>March 3, 2010</td>
<td>7:00-8:00 p.m.</td>
<td>Exercise, Obesity and Cancer Prevention: An Update</td>
<td>Kathryn Schmitz, PhD</td>
</tr>
<tr>
<td>April 13, 2010</td>
<td>7:00-8:00 p.m.</td>
<td>GINA Update: The Newly Enacted Federal Ban on Genetic Discrimination and What It Means for You</td>
<td>Jennifer Leib, ScM, CGC</td>
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<tr>
<td>May 5, 2010</td>
<td>7:00-8:00 p.m.</td>
<td>Sharing Risk Information with Children</td>
<td>Karen Hurley, PhD</td>
</tr>
<tr>
<td>July 20, 2010</td>
<td>7:00-8:00 pm</td>
<td>Treatment Update: Triple-Negative Breast Cancer</td>
<td>Melinda Telli, MD</td>
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Lymphedema is fluid buildup and swelling that develops in a limb or other part of the body when the lymphatic system that ordinarily carries fluid back to the heart is disrupted. This disruption may be congenital or caused by surgery, trauma, or radiation. A common byproduct of breast cancer treatment, lymphedema may affect the arm on the same side of the breast that is treated with surgery or radiation. The swelling and impaired lymph function can cause pain, infection, and loss of arm mobility. Overuse or injury can cause lymphedema to flare up, and arm swelling may worsen over time.

Patients with lymphedema have traditionally been advised to avoid heavy exertion and weightlifting in the arm or on the side affected by lymphedema. However, experts know that weightlifting is an effective strategy to use muscle and build strength so the arm or affected limb will be less prone to injury. Previously, small studies suggested weightlifting as a safe strength-building regimen in these patients. Kathryn H. Schmitz, PhD, from Abramson Cancer Center at the University of Pennsylvania, conducted the Physical Activity and Lymphedema (PAL) Study to definitively answer the question of weightlifting safety in lymphedema patients.

The study recruited women who developed lymphedema after treatment for unilateral breast cancer. Each patient was carefully measured by specially-trained physical therapists before the study and throughout. The researchers also collected surveys of patient symptoms. The 141 patients were divided into two groups: an exercise group and a control group that did no exercise. The exercise group worked out at local YMCAs with fitness trainers who had undergone three days of training with Dr. Schmitz to learn how to work with breast cancer survivors with lymphedema. Both groups of patients were fitted with custom lymphedema sleeves; the exercise group was asked to use the sleeves whenever they performed the recommended arm-strengthening, trunk and leg exercises. The weight was gradually increased with a focus on building strength.

The PAL study found that patients who participated in the weightlifting program increased their strength when compared to the control patients. Women who lifted weights did not have any more swelling than the control patients who did not exercise. In fact, they had fewer swelling flare-ups, and on average, reported their symptoms as somewhat less bothersome after a year compared to the control patients.

Because none of the measures of lymphedema severity were worse in the exercise group than in the control group, the authors concluded that the study "reduced the concerns that weightlifting would worsen arm and hand swelling...and supports the potential benefits" of a weightlifting program for breast cancer survivors with lymphedema.

As a result of the study, Dr. Schmitz and her colleagues have developed the Physical Activity and Lymphedema (PAL) Weight Training Program. You can access the program at www.lymphnet.org/pdfDocs/PAL_guidelines.pdf. These guidelines should not be undertaken unless you have completed supervised sessions with a physical therapist to learn how to do the upper body exercises properly.

Dr. Margaret Snow is a previvor and a Physical Medicine and Rehabilitation physician who enjoys golfing and photographing birds. She serves as FORCE’s West Michigan Outreach Coordinator.
Voices of FORCE

In each issue, 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

Putting FORCE at the Forefront

by Lisa Schlager

As I look back on my decision to undergo genetic counseling and testing, I think my easy acquiescence was due partly to ignorance and partly to a false sense of invincibility. In 1999, my paternal aunt called to tell me that she’d tested positive for the BRCA1 mutation. I was in my early 30s, recently married, absorbed in my career, and trying to start a family. And yet, I quickly agreed to be tested. “Why not?” I thought. “It’s better to know.” My test was positive; I too had a BRCA mutation.

Unlike many affected by BRCA, I had not watched my mother or sister battle cancer. There were few women on my father’s side of the family who’d died of breast or ovarian cancer. Two children and a few surgeries later, I recognized that I have been given a gift: the gift of knowledge, and the ability to make personal choices to help ensure that I remain healthy. During my 10-year journey, I discovered FORCE. I was impressed with the comprehensive information and support the organization provided as I navigated my BRCA journey.

When my youngest child started kindergarten, I wanted to do something meaningful with my free time. FORCE welcomed me as an outreach coordinator and teamed me with a wonderful partner to reinvigorate the organization’s Washington, D.C. group. Our primary focus has been to provide support and networking opportunities to local members. We’ve also made a concerted effort to educate the community about hereditary cancer.

An important but often overlooked component of FORCE’s work is advocacy...

Last fall, I testified before the Secretary’s Advisory Committee on Genetics, Health and Science, an advisory panel to the Secretary of Health and Human Services on issues surrounding the development and use of genetic technologies. I spoke on behalf of FORCE about the marketing of BRCA tests to consumers and doctors who are not trained in genetics. In October, I represented FORCE at the White House as First Lady Michelle Obama and Jill Biden recognized Breast Cancer Awareness Month, with the goal of raising awareness about healthcare reform to help uninsured or underinsured women who can’t access health care because they have a cancer diagnosis in their medical history.

The past year-and-a-half has been more rewarding than I could have imagined and I have developed a passion for FORCE and its mission. We in the BRCA community carry an unfair cancer burden, yet we’re underrepresented in the cancer community. There are many cancer organizations, but none represents us like FORCE. It is our duty to educate people about hereditary cancer. FORCE needs more people to take leadership roles to realize this goal.

Please join me in advocating on behalf of our community. Together, we can save lives.

Lisa Schlager is FORCE Director of Community Affairs and D.C. Outreach Coordinator. She recently joined the FORCE Board of Directors.

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@facingsourrisk.org or mail to FORCE, 16057 Tampa Palms Blvd W #573, 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.

FORCE disagreed with these changes and published a response to the Secretary of Health, saying:

The USPSTF recommendations apply to women of average risk, but will detrimentally affect members of the high-risk community whose cancers tend to develop at a younger age, are more aggressive, and are often found at a later, less curable stage. Many learn about their high-risk status only after they are diagnosed with breast cancer detected by mammogram or breast self-exam. Research shows that the high-risk community benefits from BSE and mammography. By delaying screening mammography until age 50 we miss opportunities to identify breast cancers in young high-risk women. Changing mammography frequency after age 50 means aggressive, quicker-developing cancers will go undetected. We are concerned that these changes will cost lives.

Commentary to SACGHS

FORCE submitted testimony to the Secretary’s Advisory Committee on Genetics Health and Society about the need for more government oversight of the marketing of genetic tests to consumers and health care providers. Below are excerpts:

We are continuing to hear from people who have been tested without benefit of genetic counseling and received results from doctors or nurses who have no understanding of the significance of test results. We are also learning of incorrect or inappropriate tests ordered at significant expense to the consumer and/or their insurance company.

Despite published guidelines that outline genetic counseling prior to BRCA testing as standard-of-care, because much of the general population is unaware of the existence of genetics experts, and health care providers are being discouraged from referring patients, consumers have no way of knowing that they are receiving substandard care and have no venue for registering complaints.

We urge the SACGHS to recommend federal action to monitor, regulate, and track adverse events resulting from marketing by laboratories to both consumers and health care professionals, and to require doctors to know about, inform patients about, and refer patients or provide them access to standard-of-care genetic counseling prior to ordering genetic testing for a patient.

Since our testimony, the FDA is encouraging consumers, advocacy groups, and health care providers to submit these cases through the FDA’s MedWatch online portal at www.accessdata.fda.gov/scripts/medwatch/
New Tool

The table below reports estimated survival to age 70 for several groups of simulated BRCA carriers.

<table>
<thead>
<tr>
<th>Survival to Age 70</th>
<th>Survival %</th>
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<tbody>
<tr>
<td>General population</td>
<td>84</td>
</tr>
<tr>
<td>BRCA1</td>
<td></td>
</tr>
<tr>
<td>No intervention</td>
<td>53</td>
</tr>
<tr>
<td>Surveillance, no surgical intervention</td>
<td>59</td>
</tr>
<tr>
<td>Surveillance, oophorectomy at age 40</td>
<td>74</td>
</tr>
<tr>
<td>PBM at 40,* oophorectomy at age 40</td>
<td>77</td>
</tr>
<tr>
<td>PBM at 25, oophorectomy at age 40</td>
<td>79</td>
</tr>
<tr>
<td>BRCA2</td>
<td></td>
</tr>
<tr>
<td>No intervention</td>
<td>71</td>
</tr>
<tr>
<td>Surveillance, no surgical intervention</td>
<td>75</td>
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<tr>
<td>Surveillance, oophorectomy at age 50</td>
<td>79</td>
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<tr>
<td>Surveillance, oophorectomy at age 40</td>
<td>80</td>
</tr>
<tr>
<td>PBM at 25, oophorectomy at age 40</td>
<td>83</td>
</tr>
<tr>
<td>PBM at 40,* oophorectomy at age 50</td>
<td>83</td>
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</tbody>
</table>

* Includes screening with MRI/mammogram from age 25-40
PBM = prophylactic bilateral mastectomy

References


New Tool for BRCA Women Who Face Risk-Reduction Decisions

*by Margaret Snow, MD and Sue Friedman*

Researcher and oncologist Allison Kurian, MD and her colleagues at Stanford University created a sophisticated computer model to estimate the survival benefits of preventative surgery compared to surveillance in BRCA carriers. The results were published in the January 10 issue of the *Journal of Clinical Oncology*.

Not surprisingly, combining prophylactic bilateral mastectomy and bilateral salpingo-oophorectomy resulted in the highest predicted overall survival for mutation carriers. Age at surgery affected survival, and some differences were identified in survival benefits of BRCA1 carriers compared to BRCA2 carriers.

Based on prior research, survival to age 70 for women without a mutation is 84% (see sidebar). BRCA1 carriers who chose no intervention have an estimated survival of 53% to age 70. Those who choose surveillance and no prophylactic surgery improved their survival to 59%. The Stanford model predicted an increase to 74% survival when these women have prophylactic bilateral salpingo-oophorectomy (removal of the ovaries and tubes) by age 40. Adding a bilateral mastectomy at age 40 further increased survival estimates to 77%. When bilateral mastectomy is performed at age 25, the survival estimate for this group goes up to 79%.

Women with BRCA2 are estimated to have a 71% chance of survival to age 70 without any intervention. Survival improved to 75% if they choose surveillance without surgery. Survival increased to 80% when they have prophylactic bilateral salpingo-oophorectomy by age 40. Adding a bilateral mastectomy by the same age increased survival estimates to 83%. Surprisingly, the model projected a similar survival estimate for women with a BRCA2 mutation when they have mastectomy at age 40 and delay oophorectomy to age 50.

The key finding of this study was the impact of ovarian cancer on survival and the benefit of salpingo-oophorectomy for improving survival. Compared to women who did not choose oophorectomy, a BRCA1 mutation carrier improved her survival expectancy by 15% if she had an oophorectomy by age 40. The impact of oophorectomy was a 4-6% increase in survival for women with BRCA2 mutations. The benefit was not as profound in BRCA2 mutation carriers, but it is not surprising, given their lower rates of ovarian cancer.

Dr. Kurian expressed surprise at the small difference in mortality between the breast surveillance groups compared to the preventative mastectomy groups. This is due to the study’s finding that MRI screening in combination with oophorectomy at age 40 is very effective in improving survival for BRCA mutation carriers.

Rather than following actual patients, researchers used combined data from several prior research studies to establish their model and draw conclusions. This method has its advantages, since real-time research would require many participants in each study group and might last for many years and women might not wish to participate in a randomized trial between mastectomy and breast surveillance. In the meantime, improvements in surveillance techniques and cancer treatments would continue to affect study outcomes. The Stanford model allows researchers to consider more variables and produce more results than research studies with actual patients. Using this process, researchers can account for new developments in MRI surveillance, making this research more current than some published studies with actual patients.

One thing to keep in mind about this study: researchers focused on survival from breast or ovarian cancer, rather than considering a diagnosis as an end point. For many women, the risk for developing cancer is an equally important outcome that affects their risk-management decisions. Told they are predicted to survive a cancer diagnosis, many women with BRCA mutations would prefer to do what they can to avoid cancer altogether.

Models like this one help health care providers guide high-risk women in their risk-management decisions. But these models also have limitations. Risk assessment is still
Metformin: Does a Common Diabetes Medication Also Fight Cancer?

by Margaret Snow, MD

The most common medication used to treat type 2 diabetes is showing some potential that it may also inhibit breast cancer cell growth. Several studies found that diabetics who were treated with the oral drug metformin were less likely to develop cancer than those who did not take the medication. Increasingly, evidence is mounting that metformin not only reduces blood sugar and insulin levels, but also may improve breast cancer outcomes.

One interesting and promising aspect of the research is that the drug may target cancer stem cells, a small population of cells believed to cause tumor growth and recurrence, and that resist conventional chemotherapies. In laboratory tests at Harvard Medical School, researchers who examined the metformin response in four distinct types of breast cancer cells found that the drug acts directly on cancer stem cells, reducing tumors and prolonging remission after chemotherapy. Some tests were conducted on breast cancer cultures, while others were performed in mice. The combination of metformin and doxorubicin, a standard chemotherapy agent, was particularly powerful, preventing cancer cell growth and selectively destroying both estrogen-sensitive and triple-negative cancer stem cells. The authors reported the addition of metformin to the doxorubicin “has a dramatic effect on prolonging remission, and indeed may even represent a cure of these… tumors.”

The Harvard study differed from other tissue culture experiments: an important finding was that metformin did not appear to affect growth of healthy cells. This suggests metformin acts specifically on cancer cells.

Another recent study at M.D. Anderson Cancer Center involved diabetic patients with early-stage breast cancer who had neoadjuvant chemotherapy (chemotherapy given to shrink a tumor before it is surgically removed). In this study, diabetic patients who took metformin were more likely to have a complete response to chemotherapy (where the cancer shrank completely) than those who did not.

If metformin studies on larger groups and more non-diabetic patients prove that the drug acts as a cancer cell fighter, it could eventually become a component of breast cancer treatment, and may ultimately be used preventively to decrease risk of developing cancer. Equally exciting is the fact that metformin already has FDA approval for treating people with diabetes, and we know its safety profile from its use in that population. If future research with metformin is positive, the drug might more quickly become a standard treatment than a medication with an unknown safety profile.

New Tool for BRCA

not an exact science and we are still unable to express exactly what a woman’s risk for breast cancer and ovarian cancer will be in her lifetime. Individual benefits from surgical intervention may vary, limiting the predictive value of this model for any one woman.

Dr. Kurian and her colleagues are working on a followup article to provide more information about the percentage of patients experiencing cancer at different stages. Her team is also developing a program that will allow an individual BRCA mutation carrier to enter her own data to estimate differences in her projected survival based on different risk reduction choices.

References


Metformin Clinical Trials

Several clinical trials are now using metformin to treat early-stage breast cancer, while another trial is testing it as a metastatic cancer treatment. Information about these studies can be found on the National Institutes of Health clinical trials website at www.clinicaltrials.gov (search for “metformin breast cancer.”)
Our Sponsors

Your generous donations allow us to provide this newsletter at no charge to people at high-risk. Philanthropic support is critical to FORCE’s survival and ensures our continuing ability to provide publications like our newsletter to our community. Your charitable gift can help save lives—please consider making your gift today! To learn more about helping FORCE, visit www.facingourrisk.org/how_to_help.

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

Do These Genes Make Me Look Phat?

Join comedy hosts Judy Gold and her comedian friends for the 1st Annual Night of Laughter, Living and Love to benefit FORCE.

When: Monday, April 12, 2010
6 p.m. - Cocktails and hors d’oeuvres
7 p.m. - Performance and live auction
Media Check-in: 5:15 pm

Where: Hudson Terrace
621 West 46th Street
(between 11th and 12th Avenues)
New York, NY

For more information or to purchase tickets contact Craig Rosati (craigr@facingourrisk.org).

Spirit of Empowerment Awards

FORCE presents its annual Spirit of Empowerment awards to recognize the contributions of individuals and organizations that help us educate and support the hereditary breast and ovarian cancer community. The inaugural Spirit of Empowerment awards will be presented on June 26, 2010 at the 5th Annual Joining FORCES Conference in Orlando, FL.

Honorees for 2010 are:

Arts & Media: Joanna Rudnick
Research: Timothy Rebbeck, PhD
Advocacy: Representative Debbie Wasserman Schultz
Corporate Commitment: Enell
Individual Commitment: Michael Sosin

For more information, visit our conference web page www.facingourrisk.org/conference.