Welcome

The summer has flown by. Suddenly we are immersed in back-to-school details, fall festivities, and preparations for winter. It’s easy to neglect ourselves and our health during busy times like these; in this issue, we provide information to help you stay on track. You’ll read about the benefits of exercise, including the inspiring story of a survivor of both breast and ovarian cancer who transformed herself into a competitive bodybuilder. We have reviews of the latest research, including recaps from the American Society of Clinical Oncology annual conference and our own Joining FORCEs conference. We share the rousing acceptance speech of Dara Marias, who accepted a Spirit of Empowerment Award on behalf of her family, and her moving story behind the creation of The Butterfly Fund. We also provide the latest update on new laws regarding insurance coverage for genetic counseling services. Perhaps our most exciting news is formation of the first National Hereditary Cancer Research Fund. Read below for more details on why this fund is desperately needed and how you can help. As always, we hope that you will find this issue of Joining FORCEs informative and inspiring, and that you will pass it on to a friend, relative, or health care provider.

Be empowered and be well,

Sue

An Urgent Need for a National Hereditary Cancer Research Fund

by Sue Friedman

One of my favorite conference moments was announcing the FORCE Hereditary Cancer Research Fund to drive the research that will lead to better detection, prevention, and treatment of hereditary cancer. Why do we need an HBOC-specific research fund?

- Our community shoulders a disproportionate cancer burden that must be addressed. Although almost 1 in 500 people (about .2% of the population) are genetically predisposed to breast or ovarian cancer, they represent about 10% of all breast and ovarian cancer diagnoses—for every 998 people in the general population who together carry 90% of the cancer risk, just two of us bear the remaining 10% of the risk.

- Funding for hereditary cancer is limited. Most cancer research funding focuses on larger cancer populations, and obtaining research funding isn’t easy: government research funding is limited and the request process is lengthy.

- Our cancers are different. Hereditary cancers respond differently to certain treatments than sporadic cancers and require a different research approach. Because hereditary cancers often occur at a younger age before most people begin screening, and standard detection may be less effective, studying HBOC families is the quickest route to discovering better methods of detection and prevention.

- Options for prevention, detection, and treatment of hereditary cancer are inadequate. Too many people are still being diagnosed with and succumbing to hereditary cancers.

As the voice of hereditary cancer, FORCE has unmatched insight into the research needs and priorities of our community. We are uniquely positioned to identify and expedite the research that will most benefit our community. Our National Hereditary Cancer Research Fund will be the first of its kind. A panel of experts and consumers will review proposals to ensure that any research funded will significantly benefit the high-risk community. We need your help to build this fund from the ground up. Visit our website to learn more about this effort and how you can support it.

The Fix Our Genes campaign will endow our research fund
Conference Recap: Mental Makeovers and Savvy Insights

by Lisa Rezende, PhD

In her light-hearted yet moving session, Regina Savage reflected on how life before cancer helped her learn to emotionally cope with cancer and treatment after her diagnosis at age 36. She shared these insights from her inspirational book, *Mirror Makeovers and Savvy Insights for the Everyday Gal Surviving Cancer and Baldness with a Sense of Humor*.

One day after losing her hair from chemotherapy, Regina began drawing pictures of different hairstyles on her bathroom mirror. These “mirror makeovers” helped her through treatment. The hair she drew each day varied based on her mood: from a pretty blond wig complete with a bright pink bow to a Medusa-like head of snakes, to a cheerleader to root her on as she completed treatment. These reflections provided her with an outlet for her emotions.

After cancer, Regina embraced life and reached out to others facing cancer, demonstrating her mirror makeovers to cancer support groups. This work inspired her to write her book and produce a music video for women undergoing treatment (available at www.youtube.com/watch?v=9choRJAmoYA&feature=player_embedded). The video follows a woman from diagnosis through treatment, and highlights how the support of others brought light and color back into her world. When this video was screened at the FORCE conference, there was not a dry eye in the audience.

Conference Recap: Hereditary Cancer Research

by Lisa Rezende, PhD

The Hereditary Cancer Research Panel featured a presentation by Dr. Steven Narod, Director of the Familial Breast Cancer Centre in Toronto. Dr. Narod described some of the latest unpublished results from his multinational breast cancer study of over 11,000 women with mutations in BRCA1 or BRCA2. His research follows these women over many years, providing data about cancer risks, outcomes, and the efficacy of different risk management and treatment options. Dr. Narod discussed the following observations:

- A 12-year study of annual MRI screenings in women who carry BRCA1 or BRCA2 mutations found that 97% of their cancers were found in stage I; the 6-year survival rate for these women was 96%. Dr. Narod concluded that annual MRI scans reduced the risk of advanced breast cancer by 70%.
- BRCA1 or BRCA2 carriers who had prophylactic salpingo-oophorectomy but not prophylactic mastectomy had a 60% reduced risk of breast cancer. This risk reduction was found in both BRCA1 and BRCA2 mutation carriers and lasted for 15 years. Interestingly, risk reduction was also evident in women who had oophorectomy after natural menopause.
- BRCA1 or BRCA2 mutation carriers who used an oral contraceptive after age 20 did not have significantly increased risk of breast cancer.
- Among BRCA1 and BRCA2 mutation carriers who were initially diagnosed with early stage (stage I or stage II) breast cancer, the risk for a second breast cancer diagnosis was observed, most often 10 years or longer after the initial cancer, in:
  - 60% of women who had a lumpectomy
  - 47% of women who had a unilateral mastectomy
  - 2% of women who had a bilateral mastectomy
- Among 455 BRCA1 and BRCA2 mutation carriers who had small (0-2 cm) breast cancers that had not spread to the lymph nodes, survival rates were significantly higher in women who had chemotherapy. Dr. Narod concluded that, “All women with breast cancer and a BRCA1 or BRCA2 mutation are candidates for chemotherapy.”

Conference Recap: Communicating with Family Members

by Lisa Rezende, PhD

Dr. Lindsey Hoskins, post-doctoral fellow at the National Cancer Institute, and Dr. Allison Werner-Lin, Assistant Professor at the Silver School of Social Work at New York University, addressed the challenging issue of how to discuss cancer risk with family members.

The speakers provided strategies for individuals, families, and health providers to support communication within families so that everyone understands their family health history and can decide for themselves whether or not to pursue genetic testing, and make decisions based on their results. Disclosure can be a process of giving information in stages rather than all at once. Conversations with loved ones should focus on objective information about cancer risk in language everyone can understand, and personal opinions should only be given when asked for. Drs. Hoskins and Werner-Lin encouraged attendees to provide relatives with printed materials from health care professionals to give them a tangible and credible object on which to focus their attention. Communication should be carefully tailored, recognizing that both parties in a conversation have unique needs and considerations based on their age, health history, risk tolerance, family structure, etc. Regardless of the decisions they make, all family members want to be supported and heard.

Addressing the fear about how the information will be received, the speakers described a range of possible negative reactions, including guilt, blame, burden, anger, inaction, invalidation, and sadness. Family members may not react in the same way; they may choose different actions even when they hear the same genetic information. Drs. Hoskins and Werner-Lin reminded attendees to actively listen to family members’ reactions, provide support, and be prepared to refer them to qualified experts. They recommend five strategies for resolving conflicts when family members disagree:

- Communicate directly with family members rather than relying on a third party
- Identify points of contention
- Maintain privacy but don’t keep secrets from family members

continued on page 7
News from ASCO 2011
by Lisa Schlager

Each year nearly 30,000 oncologists and oncology-related healthcare professionals come together at the annual meeting of the American Society of Clinical Oncology (ASCO). ASCO 2011 featured nearly 4,500 abstracts (research summaries) and sessions covering every aspect of cancer, including highly anticipated research news and drug studies that could change current standards of care for patients. Attendees include a few hundred patient advocates who represent their constituents in the cancer community. I was fortunate to take part in the Focus on Research program of the Research Advocacy Network’s Advocate Institute.

Hereditary Cancer

A study specifically related to BRCA (Abstract 1512) suggested that women with DCIS and a family history of breast and/or ovarian cancer have an increased chance of having BRCA mutations regardless of age, and should consider genetic counseling and testing even though they do not have invasive cancer. Another study (Abstract 1517) showed that BRCA-positive men are more likely to have aggressive prostate cancer with lymph node involvement and metastases. These study results underscore the importance of knowing BRCA status when determining treatment.

Hormone replacement therapy (HRT) by women who have undergone a prophylactic oophorectomy is of great interest to the HBOC community. Promising news from the Prevention and Observation of Surgical Endpoints (PROSE) study indicated no increased risk of breast cancer risk when HRT is used after risk-reducing salpingo-oophorectomy (Abstract 1501). Another study (Abstract 1510) suggested that women with paternally-inherited BRCA gene mutations (mutation passed from the father) are diagnosed with cancers at earlier ages compared to women who inherit gene mutations from their mothers.

Ovarian Cancer

Researchers presented promising findings from the OCEANS (Abstract LBA5007) and ICON7 (Abstract LBA5006) trials, two studies that examined use of the drug bevacizumab (Avastin) to treat ovarian cancer. While overall survival benefits were not indicated, patients in these studies did experience improved “progression-free survival.” The concept of progression-free survival (PFS) compared to overall survival (OS) were common themes throughout the conference. PFS refers to the chance of stabilizing a disease without further progression after a particular treatment. OS measures the specific length of survival after treatment. Scientists use these terms to measure the success or efficacy of new cancer therapies. There is great debate about whether or not a drug should be approved if it doesn’t demonstrate OS benefits. For patients facing advanced disease, PFS may seem like an acceptable endpoint.

Quality-of-Life

A number of ASCO meeting sessions focused on quality-of-life issues. One abstract described the development of a standard method for including patient-reported outcomes in oncology drug clinical trials that compare drug effectiveness. Additional studies focused on developing tools to foster enhanced physician-patient interaction. Researchers reported that early palliative care (care or treatment that concentrates on reducing the severity of symp- toms) results in increased overall survival and reduced depression. A session on “Assessing Patients’ Psychosocial Needs” highlighted an area needing improvement by many medical professionals; at least a quarter of cancer patients are thought to experience significant depression or anxiety.

A Weighty Issue

Numerous studies have looked at the issue of lifestyle, weight or Body Mass Index (BMI) in relation to cancer—especially breast, prostate and colorectal cancer. The “Overview of the Current Evidence Supporting Body Weight Status, Adiposity, and Weight Loss on Cancer Outcomes” session explained that obese and overweight people are more likely to develop and die from cancer and have an increase in risk of recurrence. Presenters made a provocative point: Overweight patients often receive the same level of chemotherapy as leaner patients.

Update on PARP Inhibitors

by Lisa Schlager

Dr. Judy Garber of Dana-Farber Cancer Institute discussed recent PARP inhibitor (PARPi) research. Six different PARPis are being studied in three dozen clinical trials. Results on two PARPis, olaparib and iniparib, were presented at ASCO.

Despite early enthusiasm, the recent phase III trial for triple-negative breast cancer—cancer that does not express estrogen or progesterone receptors or the protein Her2neu—using iniparib did not demonstrate enough survival benefit to receive FDA approval. Promising early PARPi research focused on people with BRCA mutations, while the phase III trial was open to women with advanced breast cancer, regardless of BRCA status. Although women with BRCA1 mutations tend to get triple-negative breast cancer, not all triple-negative tumors behave alike. Yet BRCA testing was not conducted on study participants so we don’t know if mutation carriers responded best to the therapy. There is also speculation that iniparib may work differently than other PARPis, and that another mechanism may be responsible for its effects. More research is needed to determine target patients and gain FDA approval for iniparib.

AstraZeneca’s phase II olaparib trial improved progression-free survival by four months in women with a common type of ovarian cancer relapse. This is the first randomized trial using a PARPi in ovarian cancer. It is also the first ovarian cancer randomized trial to demonstrate benefit from maintenance therapy (therapy given over an extended period of time to prevent recurrence). Larger trials are needed to validate these results.

continued on page 7
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.

Spirit of Empowerment: A Family Gives Back

Our Spirit of Empowerment Awards shine the light on people who make a difference for our community. Tara and Molly Marias and Myron Caplan received the award for creating the Brenda L. Caplan Memorial Scholarship Fund and The Butterfly Project. Below are excerpts from Tara’s acceptance speech.

On behalf of our family, we are overwhelmed. We already received the most special gift from FORCE, a scholarship fund in my mom’s name. I would like to share how FORCE has impacted our lives and what this project has meant to our family.

Like so many in this room, our family’s lives have been irretrievably affected by hereditary cancer. I am BRCA1-positive. My mother, Brenda, had both breast and ovarian cancer. Her half-sister died in her 30s of breast cancer. My grandmother had bilateral breast cancer. Even my non-biological aunt is BRCA2-positive. Hereditary cancer—or the risk of it—is everywhere we look in our family.

With each generation the options become exponentially better. When my mother was diagnosed, no one suggested genetic testing despite her age and family history. Had she been tested and had her ovaries removed, maybe her outcome could have been different. We now have treatments specifically tailored to the genetic make-up of a tumor. We have researchers who seek to understand our unique population from a treatment and prevention perspective. With these advances, the most influential generational change relates to the creation of FORCE. Through FORCE, women and men find support, friendship, inspiration and knowledge. FORCE gives us opportunities to acquire information and find compassion and identity. FORCE is at the forefront of leadership on issues which affect the rights of our community.

All we have very individual and personal reasons for attending this conference. Yet, we share one fundamental unifying belief. None of us views ourselves as victims. Whether we have cancer or a genetic predisposition, whether we care for or treat someone with hereditary cancer, we are all empowered. We cannot control our genes, but we can control how we respond to the hand life has dealt us. Instead of victims, we are people committed to helping each other and the generations to come.

"Instead of victims, we are people committed to helping each other and the generations to come."

at-large, Kathy helped to develop much of the 500 pages of information on our website, edits this newsletter, and is co-author of Confronting Hereditary Breast and Ovarian Cancer, which will be re-released early next year.

Corporate Commitment: Tiny Little T-Shirt Company incorporated the FORCE message, logo, and mission of empowerment into a special t-shirt. Their “Life. Be Empowered.” clothing line provides an inspirational message for survivors and previvors. These shirts have become the unofficial uniform for our Passing of the Torch events.

Updates from Our 2010 Recipients

Corporate Commitment: ENELL, manufacturer of the HOPE Bra, is featured in an article on page 7.

Arts and Media: Joanna Rudnick is well-known and loved by our community as producer and director of the BRCA documentary, In the Family. This summer she took on a new role, giving birth to baby Eloise. Joanna shares her thoughts on motherhood and life since In the Family in her eloquent blog (http://inthefamily.kartemquin.com).

Individual Commitment: Glass artist Michael Sosin has donated pieces of his work for every Joining FORCEs conference reception. He and his wife Tedi Siminowsky are ardent FORCE supporters. This summer, they hosted a meeting in their Berkeley home to kick off our Major Gifts Campaign and raised almost $30,000. Thanks to Michael and Tedi for their continuing enthusiasm for FORCE.

Contact Tina Kral (link@facingsourrisk.org) for information about the Major Gifts Campaign.
Insurance Coverage for Cancer Genetic Counseling
by Lisa Rezende, PhD

Genetic counseling is recommended for anyone who is concerned that the cancer in their family may be hereditary. Meeting with a genetics expert is an important first step before being tested for a BRCA mutation. FORCE members often ask whether their insurance will cover genetic counseling. While many health insurance plans already cover genetic testing for high-risk women, under health care reform, the Patient Protection and Affordable Care Act requires health insurance plans to cover genetic counseling as a preventive service with no copay or deductible for women whose family history suggests an increased risk of mutations in BRCA1 or BRCA2.

Strong, Fit and Beautiful: From Cancer Survivor to Figure Competitor
by Domenick Salvatore, CSCS, CPT

Editor’s Note: You needn’t be a triathlete to realize the benefits of exercise. Studies suggest that just a few hours of moderate aerobic exercise per week may lower the risk of developing breast cancer, reduce the likelihood of recurrence and improve survival.

With a Ph.D. in Health Education, Dr. Leslie Spencer is focused and passionate about health and fitness. Before she began training with me, her exercise regimen consisted mostly of aerobics, so our work together began with learning proper resistance training techniques. Not long after we began working together, however, she received devastating diagnoses: both breast and ovarian cancer. Most women would have stopped training altogether to focus on surgeries, chemotherapy and radiation, but Leslie did not panic. She continued to train as much as possible, focusing more on range of motion than resistance. I believe that helped her to become better prepared physically and emotionally for the challenges of cancer treatment.

When Leslie completed treatment, she began working with increasingly heavy resistance, something that traditionally was thought to cause lymphedema. New research by Dr. Kathryn Schmitz at the University of Pennsylvania is now proving this to be incorrect: a controlled program of gradually-increasing strength training, in fact, improves lymphedema. In August 2010 Leslie competed in a professional figure competition; it was her way of flexing her muscles and saying, “Take that cancer!” She looked and felt amazing: an unbelievable testament to the power of the human spirit.

Exercise empowered Leslie to fight cancer head-on. Amazingly, she is healthier today than she was before her diagnosis. Never forget the power of lacing up your sneakers, putting on your sweatpants and breaking a sweat.

Domenick Salvatore is a fitness professional with over 10 years of experience. He is dedicated to promoting the benefits of exercise for cancer patients that can be applied to make significant changes in clinical practice. His goal is to help our healthcare system move towards prevention.

Study for Previvors Choosing Breast Surveillance: Can Exercise Lower Breast Cancer Risk?

The Women in the Steady Exercise Research (WISER) Sister study is aiding efforts to determine how exercise affects breast cancer risk. FORCE has partnered with this research since 2009 by helping to recruit three-quarters of the 185 high-risk women needed for the study. Participants are randomly assigned to one of three exercise groups, which determines their exercise program during the 8-month study. All participants are compensated for their time and provided with an in-home treadmill, which they may keep free of charge upon completion of the study. Women who have joined the study benefitted from an improvement in their physical health as well as their overall well-being.

Recruitment for the WISER Sister study is expected to continue through early spring 2012, so there is still plenty of time to get involved while you get in shape. Please refer any family members who will be age 18 or older in the coming year to this exciting and important research. Women of all backgrounds are encouraged to contact the research team for more information.

Visit the WISER Sister study website (bmic.upenn.edu/wiser) for more information or to sign up and participate.

Our participants are our heroes, and we’re grateful for each and every one of them.

Visit and “like” the WISER Sister study on Facebook.
**ENELL Sport Bras: Supporting Women, Supporting FORCE**

*By Karen Kramer*

Few people understand the value of a good support bra like a large-breasted athletic woman. For Renelle Braaten, finding that support became a business opportunity and a philanthropic mission. Unable to find a comfortable sports bra with the support that a well-endowed women needs, Braaten turned to her mom, a talented seamstress, and together they created the ENELL® SPORTS Bra, designed to provide superior support and comfort during high-impact activities, and the ENELL LITE bra, which is perfect for low-to-medium impact activities. These bras are endorsed by professional beach volleyball players and Olympic biathletes. Even Oprah has acknowledged ENELL bras, featuring them on the Oprah show, in O Magazine and in her famous “O” list.

In 2005, Braaten, President of ENELL, and Mara Bronson, Director of Marketing, decided to help people on a larger scale by reaching out philanthropically. “We wanted to contribute to an organization that benefited women with breast and ovarian cancers and stand alongside them as they supported the families of those battling these diseases,” said Braaten. Once they found FORCE, they knew it was a perfect fit.

Today, a network of 379 ENELL retailers provides support to thousands of women in 11 countries. ENELL donates 10% of its proceeds from sales of the HOPE Pink Bra collection to FORCE, thereby helping to educate women about hereditary cancers and saving lives. Each bra bears a hang tag with the signs of hereditary breast and ovarian cancer, extending FORCE’s message to thousands of women. FORCE deeply appreciates ENELL’s generosity and focus on hereditary cancer, and awarded the company with a 2010 a Spirit of Empowerment award.

Thank you, ENELL!

Karen Kramer, FORCE Vice President of Marketing, is a previvor who inherited a BRCA1 gene mutation from her father. She lives in Potomac, Maryland with her husband and three children. If your company is interested in partnering with FORCE, please contact Karen (karenk@facingourrisk.org).

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**Communicating with Family continued**

- Identify solutions to conflict
- Balance the need for individuals to make their own decisions with the need for them to be supported by loved ones

The session closed with recommendations for:

- finding genetic counselors (www.nsgc.org)
- receiving genetic counseling over the phone (www.informeddna.com)

**News from ASCO continued**

individuals, and may in fact be underdosed, which leads to poorer treatment response rates. The good news is that most people can improve their treatment outcomes by modifying their lifestyle (Abstract 167); research indicates that individuals who lose weight experience a decreased risk of cancer recurrence. Throughout the meeting, I was struck by the fact that genetics was a topic of numerous sessions and studies. Many researchers are focusing their efforts on identifying biomarkers and genetic changes in cancer tumors. This evolving area of science, in which genetics is linked to cancer biology, is very promising. Improvements in gene sequencing and targeted therapies will ultimately help guide cancer treatment and move us toward more personalized medicine—the goal is for doctors to know exactly what treatments to give which patients—resulting in better outcomes. That is certainly something to strive for. Access the abstracts at the ASCO website (www.asco.org).

Lisa Schlager is Vice President of Community Affairs & Public Policy for FORCE. A BRCA1 previvor, she lives in the DC area with her husband and 2 children.

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**Double Support**

When women buy ENELL’s HOPE Pink bra, they get much more than a pink article of supportive sportswear. Every bra includes a hang tag that lists the signs of hereditary breast and ovarian cancer. Sales of these bras not only translate into donations for FORCE, but also raise awareness, educate women about hereditary cancer, and potentially save lives.

You can support us by supporting ENELL. Please visit www.enell.com to purchase a HOPE Pink bra online or to find an ENELL retailer near you.
What's New @ FORCE

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, Tampa, FL 33647.

Help FORCE Go Green

Want to save some trees? Help FORCE save dollars? To receive an electronic version of this newsletter rather than a print copy e-mail us at: newsletter@facingourrisk.org. Include your name and city and state in the e-mail.

Patient Experience Contact Tool
Considering surgery? Use the FORCE website to search by surgeon, city, state, or type of surgery and contact patients who have used the same surgeon or had the same procedure. If you've already had surgery, submit your contact information to help others make surgical decisions. Visit www.facingourrisk.org/contact-tool for more information.

Survey on Insurance Coverage of Preventive Services
The Cancer Legal Resource Center and FORCE are conducting a survey about individuals' experiences with insurance coverage of preventive services. To share your experience with private insurance, employer-sponsored health plans, Medicare, and Medicaid coverage for preventive care, visit www.surveymonkey.com/s/AccessstoPreventativeCare. Your input will help us shape strategies to change the legal landscape.

Two New FORCE Publications in 2012
Co-authored by Sue Friedman, Kathy Steligo, and Rebecca Sulphen, MD, Confronting Hereditary Breast and Ovarian Cancer will be published by Johns Hopkins University Press early next year. Show and Tell: the Book will feature positive, powerful, and educational images of women after mastectomy, with and without reconstruction.

FORCE welcomes Tina Krall
We are pleased announce the appointment of Tina Krall as our Senior Vice President of Development. Tina will work closely with our Board of Directors, staff, and volunteers to expand financial support for existing programs and to identify and launch new funding partnerships. Additionally, Tina will be leading efforts to endow the FORCE Hereditary Cancer Research Fund. Contact Tina at: tinak@facingourrisk.org. Visit our staff bio page at: facingourrisk.org/about_us/staff.php to learn more about Tina’s background.