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Welcome: Together Again!

by Sue Friedman

It seems impossible that more than a year has passed since our first Joining FORCEs conference. Our upcoming conference, May 18-19 in Tampa, Florida, will be upon us soon.

One of the most gratifying aspects of directing FORCE has been the opportunity for me to speak with our constituents one-on-one, by phone or as I prefer, in person. For me, our conference is the ultimate face-to-face gathering. Meeting each of you, hearing your personal experiences, and learning about the devastating impact of hereditary cancer on families reinforces my urgency to fulfill FORCE's mission. At the same time, I share your hopefulness. Hearing your stories of courage and the very personal, very positive influence of FORCE reminds me of our diversity, and of our connectedness as well.

These meetings invigorate my resolve to unite us as a community, no matter what our differences. What better way to bring together our high-risk family than through a conference and the opportunities to listen, learn, share, grow, connect, and have fun on an intimate level with peers who "get it." Our goal is to make history by organizing the largest gathering ever of high-risk and BRCA individuals and families, and to grow the conference as an annual global force to affect change: more funding, more resources, more research for our community. Read on for more information about the conference. You can help shape our future and secure the legacy of FORCE by attending. ☺

Joining FORCEs Conference: The Sequel

by Kathy Steligo

Grab a pen and mark May 18 and 19 on your calendar. That's when FORCE's second annual symposium on hereditary breast and ovarian cancer will be held at the Hyatt Regency in Tampa, Florida.

By all accounts, last year's conference was meaningful, worthwhile and fun for all who attended. Sponsored by FORCE, the H. Lee Moffitt Cancer Center and Research Institute, and the University of South Florida, this year's conference will be bigger and better, with a larger venue and new sessions. Our speakers list is a veritable Who's Who of renowned medical professionals, experts and researchers.

This conference is for anyone concerned about hereditary breast and ovarian cancer: survivors, high-risk individuals with a BRCA mutation or family history of cancer, and health care providers who treat high-risk patients.

Come and hear the latest updates on hereditary cancer research, risk reduction, coping with being at high risk, clinical trials and advocacy, and options for breast reconstruction after mastectomy. Meet new friends and share experiences with other individuals who understand what living with hereditary cancer risk really means. It's also a great time to actually meet FORCE members who so diligently offer comfort, information and support from our online message board.

FRIDAY, MAY 18

- Current State and Future Challenges in Hereditary Cancer Research *Thomas Sellers, PhD*
- External and Environmental Modifiers of Risk *Steven Narod, MD, FRCP*
- Update on PARP Inhibitors for BRCA Cancers *Elise Kohn, MD*
- Concurrent Sessions:
 - BRCA and Other Cancers *Cathy Phelan, MD, PhD; Jason Klapman, MD*
 - Decision-making for Breast Cancer Risk Management *Kelly Metcalfe, RN, PhD*
 - Genetics 101: Back to Basics *Rebecca Sutphen, MD*
- Luncheon speaker: *Brenda Maddox* (Author, *Rosalind Franklin: Dark Lady of DNA*)
- Concurrent Sessions:
 - Men and BRCA *Alex Liede, PhD; Paul Jacobsen, PhD*
 - Mastectomy and Breast Reconstruction *Susan Hoover, MD; Andy Salzberg, MD; Paul Smith, MD; Joshua Levine, MD*
 - Managing Weight the Empowered Way *Kathryn Allen, RD*

continued on page 3



Atmosphere © Frances Falk, 2001

Testing the BRCA Phenocopy Hypothesis

The British study established the BRCA phenocopy hypothesis: that true negative women in BRCA families have a higher breast cancer risk than the general population. This hypothesis is already being tested by other prominent BRCA researchers.

Steven Narod of the University of Toronto and colleagues Jacek Gronwald, Cezary Cybulski and Jan Lubinski will publish their findings in the *Journal of Medical Genetics*. They note that the selection method could influence the findings of the British study: "The more cases of breast cancer [in a family], the more likely testing is to occur. That is, the presence of phenocopies in the family increases the likelihood that testing would be conducted. Hence, the greater than expected number of phenocopies observed in the families."

Dr. Narod, renowned BRCA researcher, intends to continue to counsel true negative women as if they are not at increased risk for breast or ovarian cancer. Researchers at Memorial Sloan Kettering and the University of Pennsylvania also plan to analyze their own databases of BRCA families to determine the rate of phenocopies among them. ♪

References

Smith A, Moran A, Boyd MC, Bulman M, et al. Phenocopies in BRCA1 and BRCA2 families: evidence for modifier genes and implications for screening. *Journal of Medical Genetics*, 2007; 44:10-15.

Antoniou AC, Pharoah PD, McMullan G, Day NE, et al. Evidence for further breast cancer susceptibility genes in addition to BRCA1 and BRCA2 in a population-based study. *Genetic Epidemiology*, 2001; 21:1-18.

Testing Negative Revisited: The Phenocopy Hypothesis

by Drea Thew

Women from BRCA families (families found to have a BRCA1 or BRCA2 mutation) who test negative for the mutation are usually considered "true negatives," and advised that their risk for breast and ovarian cancer is comparable to that of women in the general population. A British study published in the November 2006 issue of the *Journal of Medical Genetics* questions whether this is always true. Additional studies will be critical to deciding which assessment is correct.

The study involved 277 English families with a known BRCA mutation and high rates of breast and ovarian cancer. Information regarding 1,444 women in these families was collected and analyzed: 531 were living relatives of the first family member to test positively for a mutation. Of these, 258 tested negative for the family mutation, including 28 with breast cancer at ages ranging from 23 to 87 (median age 49), and four with ovarian cancer at ages ranging from 60 to 66. Researchers identified study participants who were diagnosed with breast or ovarian cancer but negative for their family mutation as "phenocopies"—they expressed a genetic condition (in this case cancer), even though they didn't actually have a known gene mutation. Compared to the expected number of cancers in the general population, the incidence of breast cancer in the study phenocopy group was about 5.3 times higher.

The authors concluded that among the families in this study, the female first-degree relatives of known BRCA1/2 carriers, who themselves test negative, have a breast cancer risk approximately 3.2 times that of the general population. They estimated the absolute risk for breast cancer in these women as approximately 6.4% by age 50 and recommended true negatives begin breast screening at age 35. This recommendation is significant, because it advises screenings begin 5 to 15 years earlier than current standards dictate. It is important to note, however, that this study did not suggest that a true negative's risk is nearly as high as women with a BRCA mutation. Similarly, the authors do not conclude that women

who tested negative are candidates for chemoprevention or risk-reducing surgery.

Limitations of the study involved the inclusion of "untested affected" women in the analysis (those who had breast or ovarian cancer, but whose mutation status was unknown because they had not received BRCA testing) as well as the inclusion of individuals who were diagnosed with cancer *prior* to genetic testing. Researchers estimated how many would *likely* test negative for the family mutation. This was done in part to include enough participants to assure that the differences in risk were not due to chance.

Due to these limitations and additional concerns, other researchers urge caution in reaching conclusions based on the results from a single study. "This is a fascinating and potentially disturbing study, but it is the first and requires confirmation before it changes our thinking and action," said Dr. Judy Garber director of the Cancer Genetics Program at Dana-Farber Cancer Institute. "Other groups need to look at their data to see whether the same finding is observed. If it is, then we need to change the way BRCA-negative women are counseled and cared for. If not, then we should not alarm all of those women unnecessarily."

Dr. Timothy Rebbeck of the University of Pennsylvania notes that early studies of BRCA families found higher lifetime risks for cancer than later studies. Risks have been revised downward as research has evolved with different populations and different study designs. "It's entirely possible that looking at the same question using larger or different samples, we will get different answers," said Rebbeck. "The message to BRCA-negative women reading this study should be 'don't panic over these numbers.'"

Geneticist Dr. Rebecca Sutphen at Moffitt Cancer Center points out another limitation of such studies: only a select group of families have been tested thus far. "Studying only tested families with large numbers of individuals with breast or ovarian cancer, *including due to other reasons*, would

continued on page 8

Conference *(continued)*

- Concurrent Sessions:
 - In Depth: Implants *Paul Smith, MD*
 - Breast Imaging: The Cutting Edge *Jonathan Wiener, MD; Susan Hoover, MD*
 - Young and High Risk: Pre-vivorship Issues *Rebekah Hamilton, PhD, RN*
- Concurrent Sessions:
 - Looking Back, Living Forward *Andrew Filippone, Marnie Breecker, Lauren Dubin*
 - Fertility and Adoption Options *David Keefe, MD; Ashley Staton, Joyce Reinecke*

SATURDAY, MAY 19

- Networking and Panel Discussion *Conference speakers*
- Cancer Risk Before and After *Judy Garber, MD*
- Ovarian Cancer Detection *Rebecca Sutphen, MD*

- Concurrent Sessions:
 - Ovarian Cancer Risk Management *Karen Lu, MD*
 - Journaling: Writing for Power, Peace or Publication *Kathy Steligo*
 - Concurrent Sessions:
 - Coping with Risk: Sharing Cancer Risk Information with Children *Karen Hurley, PhD*
 - Understanding Research and Advocacy *Cara Tenenbaum, JD, MBA; Debbie Sokolov*
 - Concurrent Sessions:
 - In Depth: Perforator Flaps *Scott Sullivan, MD*
 - Coping with Menopause *Andrew Kaunitz, MD*
 - *In the Family*: Presentation and Discussion *Joanna Rudnick*
- Visit www.facingourrisk.org/conference for full information and to register. ♡

Study: Oophorectomy and Bone Health

by Drea Thew

For women at high genetic risk of ovarian cancer, *oophorectomy*—surgical removal of the ovaries and fallopian tubes—before ovarian cancer is diagnosed can lower risk by at least 80 percent. In premenopausal women, however, oophorectomy greatly reduces estrogen production, which can lead to bone loss.

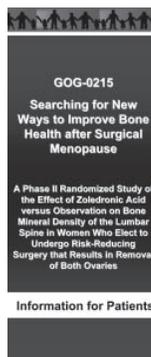
Some degree of bone thinning occurs naturally as we age. Health care providers categorize the results of bone density tests as “normal,” “osteopenia” or “osteoporosis” when compared to others of the same age and gender. Osteopenia refers to a loss of bone mass that falls below normal levels. It is not sufficiently severe to be considered osteoporosis, a condition characterized by porous, brittle bones that may easily fracture. Left untreated, osteopenia can lead to osteoporosis. Health care providers often recommend a baseline bone density test before prophylactic oophorectomy or soon after, with annual or biennial follow-up after menopause.

The Gynecologic Oncology Group (GOG) is sponsoring the multi-center GOG-0215 clinical trial to study whether a medication called zoledronic acid (Zometa®) can reduce bone loss in women who have risk-reducing oophorectomy. Participants will be randomized to two groups. Both groups will take calcium

and vitamin D supplements, give blood samples, and undergo bone density testing. In addition, one group will receive an intravenous injection of Zometa® every six months for a total of three treatments.

Eligible study participants must be at least 30 years old, have genetic risk of ovarian cancer, plan to have a prophylactic oophorectomy, and must not be taking certain medications, including hormones and bisphosphonates (such as Fosamax®). The study is open to women who have never had cancer and those who have previously been diagnosed.

Possible risks (such as side effects from Zometa®) and possible benefits (such as free bone density screening) of participating in this study should be assessed and discussed with a primary physician before enrolling. The information gained about bone loss in women undergoing early surgical menopause may well help high-risk women make informed choices in the future. For more information on GOG-0215, please visit <http://ovariancancer.gog199.cancer.gov/gog215/>. ♡



GOG 215 study brochure

Register Early and Save!

This year's conference is an amazing opportunity to get the latest research regarding hereditary breast cancer and ovarian cancer, and rub elbows with an elite group of speakers.

See the FORCE website (www.facingourrisk.org) for information about online, fax, or mail registration; travel, and accommodations. E-mail info@facingourrisk.org for more information or call conference planner Cindi Hughlett (813-745-1247).

General registration:
 • \$120 until April 1
 • \$150 after April 1

12.5 credit hours of continuing education credits for nurses and genetic counselors will be offered by the University of South Florida's College of Nursing (accredited by the American Nurses Credentialing Center's Commission on Accreditation).

Registration for genetic counselors continuing education credits:
 • \$150 until April 1
 • \$180 after April 1

Registration for nurses attending for continuing education credits:
 • \$160 until April 1
 • \$190 after April 1

FORCE Benefit Dinner at the Florida Aquarium

Join us Friday evening from 7 pm-11 pm at the award-winning Florida Aquarium (www.flaquarium.org) for our “It's in the Genes” gala: an evening of music, entertainment and dancing. Tickets are \$100 per person. All proceeds benefit FORCE.

Unwind and enjoy over 10,000 aquatic plants and animals native to Florida and from all over the globe. Dance the night away to the rockin'music of the Conch Critters band as they play favorites by Jimmy Buffett, the Grateful Dead, Bob Marley, Bob Seger and more. Bid on our auction of celebrity-autographed jeans. You may register and pay for this dinner as part of your conference registration. ♡

Commentary

by Rebekah Hamilton PhD, RN

Young women who know they may carry one of the BRCA mutations tend to face life differently, with a seriousness and appreciation uncommon in their peers. Heading off to college, for example, Arielle will take with her a crystal ball very few, if any, of her fellow students have.

When a young woman is trying to decide if she wants to have the BRCA mutation test she has many things to consider: What will she do if she has a mutation? Should she see a genetic counselor or have her blood drawn by her primary care physician? Will her health insurance—if she even has insurance—cover the cost of testing? Does she want her insurance company to know her test results? Does she have life insurance—“I’m 21! Who needs life insurance”? How does she discuss this issue with her boyfriend? How does she explain this to her girlfriends and will any of them really “get it”?

For Arielle and other young women who may have inherited a BRCA mutation, being tested is only the first of many difficult decisions. If they are found to have a BRCA mutation, their choices become complex and potentially life-altering. In my research with young women with BRCA mutations, for example, I have spoken with 24-year-olds about their struggle to decide whether to have a prophylactic mastectomy. How does one balance the dread of developing breast cancer with the incredibly personal choice of having body-altering surgery? If a woman considers prophylactic mastectomy to be the right choice, does she want to consider breast reconstruction, and, if so, which of the various procedures might be best for her?

While breast surgery decisions are difficult, reproductive choices present a complexity unique to young women. Current standards recommend young

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

Note: The essay below was written for a college application in response to the following question: “With each new experience comes a new discovery about one’s self and the world. Tell us about something you have experienced that may have changed your life or simply led you to a new understanding.”

A New Understanding

by Arielle (Last name withheld by request)



Imagine you were offered a crystal ball in which you could see your future. Imagine if it could predict whether you were going to have a serious disease. Would you look? In a few years I might take a look, but I’m not sure I want to know what the ball might reveal.

You see, I’ve had a life-altering experience, but it isn’t something that has directly happened to me—at least not yet. It’s an experience that my mom, grandmother, aunt, great aunt, and second and third cousins have gone through. They have all tested positive for the BRCA gene mutation, and they have all been diagnosed with and treated for breast cancer. When I turn 18, I can decide whether or not I want to have BRCA testing. Whether the result is positive or negative, I’ll always be a part of a family that has had to deal with hereditary cancer. One day, I may face my own diagnosis.

So, why write about this in my college application essay? Clearly, I am not the only daughter who has had to watch her mother go through breast cancer surgery and chemotherapy. I know that you know it’s devastating for a child to experience. I decided to write about my family’s genetic background, however, because it has led me to a new understanding that sets me apart from my peers.

My mom’s cancer was diagnosed two and a half years ago. She often says it was a relief to finally get the news she was waiting for and to then move forward. My memory of her cancer year is actually a positive one. Through her optimistic attitude, she taught me that breast cancer wasn’t the worst thing that could happen. Although it was frightening for me to watch her go through treatment, her courage comforted me. She never denied the seriousness of her disease, but she never got angry. During that year, I tried to block out my sad feelings. I preferred not to think about them. But now, a few years later, I’m beginning to see that ignoring my fears doesn’t take

away my risk. The lesson I continue to take from my mom’s cancer and our family’s predisposition to it is that none of us are invincible.

“...I’m beginning to see that ignoring my fears doesn’t take away my risk.”

My friends are so excited about going off to college to live on their own for the first time. They will not have to rely on their parents to make decisions about what to eat, when to study, and what they can and can’t do. My friends, however, don’t seem to pay attention to their future health. For most people my age, cancer is the furthest thing from their minds, but not for me. I can’t deny that I might face cancer one day.

My mom used to say that living with cancer risk was like having a dark cloud walk along with her at all times. My cloud might appear in that crystal ball. I’m pretty sure that someday though, I’ll have the strength to take a look.

Arielle lives in a suburb of DC with her mom and dad, brother Ethan and dog Jozu. Her mother, Lauren, wrote “Ending a Legacy of Silence” in the Summer 2005 issue of Joining FORCEs. In August, Arielle will join the Penn State University Class of 2011.

Share Your Story

Do you have something to say that may inform our readers or ease their experience? We invite you to share your reflections or personal story about dealing with the issues of hereditary breast or ovarian cancer. Tell us how you feel, how you cope, or what you’ve learned. E-mail stories of 500-550 words to info@facingourrisk.org or mail to FORCE, 16057 Tampa Palms Blvd. W. #373, Tampa, FL 33647. Please include your name and daytime telephone number so we can contact you if we decide to publish your story in a future issue.

Commentary

(continued)

women with BRCA mutations have a prophylactic oophorectomy at age 35 or when they are done having children. For women who want no more children, choosing a prophylactic oophorectomy may not be too difficult, but they still must deal with the early-onset of menopause brought on by the prophylactic surgery. How does an unmarried, 27-year-old who is dating deal with this sense of compressed time? How do 18-25-year-olds who haven’t even considered marriage and children react to such recommendations? One 24-year-old research participant burst into tears when her physician told her she needed to “hurry up and have babies.”

The sense of compressed time and of being “out of sync” with one’s peers is evident in this young population. Many young women find that a community of peers, such as FORCE, helps to ease their sense of isolation. Almost all of the young women I have interviewed consider themselves lucky to know if they are at increased risk for breast and/or ovarian cancer, while their grandmothers, mothers, and aunts generally could not. However, it does seem this luck requires much from our young women: many decisions, many physician visits, many medical interventions, but most of all, much courage. Remarkably, the young women I have spoken with have that in abundance.

Rebekah Hamilton is an Assistant Professor in Health Promotion and Development in the School of Nursing at the University of Pittsburgh. Her research focuses on the decision-making of 18-40-year-old women who are BRCA positive and face complex health care decisions as a result of their genetic status. Rebekah will be presenting “Young and High-risk: Preivor Issues” at the Joining FORCEs conference.

Other Tools in the Coping Kit

by Kathy Steligo

Let's face it: we live in hectic times. Fran's advice to simplify our lives is something from which we can all benefit, but may be particularly helpful for the FORCE community.

In addition to the stress of so-called "normal" life, we worry whether we have a BRCA mutation (Will I develop cancer? Will I pass the mutation on to my children?). If we're found to be BRCA positive, deciding what to do about it can be exceptionally draining (What option is best for me? How will I handle the side effects?). For too many of us, the anxiety of diagnosis and making treatment decisions can be debilitating. And as studies have shown, the younger you are, the tougher it is to handle these issues.

Stress wreaks havoc on our sleep patterns, our relationships, and our overall mental and physical well-being. So it pays to take the time to learn to slow down. Fran's suggestions for simplification are a great beginning. There's also exercise, meditation, support groups, volunteering, and many other methods of de-stressing to regain the control anxiety strips away.

FORCE's mission is to simplify your quest for answers by providing information, knowledge, support, friendship and peer counseling. Our goal is to provide services that bring comfort and respite to all who are concerned with hereditary breast and ovarian cancer. ♡

Simplify Your Life: 5 Tips to Focus and Energize in 2007

by Fran Miller

Most of us pack too much into the day, cluttering our lives and exhausting our resources. Simplify, balance and improve your life with the following five strategies.

1. Keep it simple

Remove unnecessary clutter from your life. Eliminate undesirable items from your environment and avoid people who drain your energy or affect you negatively. Embrace a less-is-more attitude.

2. Reassess your to-do list

Strive to replace an exhausting, unfulfilling pace with a simplified schedule. Carrying over a perpetual to-do list from month to month is an energy drain. If you are always yearning for and anticipating the next activity, you may miss out on the joy of being in the moment.

3. Redefine your boundaries

Gain more peace by saying "no" to requests for which you don't have the time, energy, or interest. Boundaries are healthy parameters that define personal needs and limitations; they facilitate clear communication and create reasonable expectations between you and other people.

4. Create a personal vision consistent with your priorities and values

Set personal priorities. Evaluate your activities and relationships with the following questions: Does it have a positive effect on my life? Is it consistent with my values? Does it help maintain my personal momentum?

5. Slow down and have fun

Create a simple plan with proactive steps for things you've always wanted to do. Prioritize activities to allow yourself to slow your pace. Schedule time to have fun each week and reflect on your experiences. Take the time you need to think clearly. ♡

Life coach Fran Miller helps people simplify their lives and create changes to thrive while fulfilling their personal goals. The founder of Full Circle Fulfillment (www.fullcirclefulfillment.com), Fran provides telephone seminars, one-to-one and group coaching, and life strategies and advocacy for people with chronic conditions.

Supporting a New Year of Services

by Debbie Sokolov

With 2007 well underway and passing quickly, FORCE is hard at work planning another year of activities and services for our members; that means another year of our website (and its message boards), Help-line, newsletter, Chat-A-Thon and Passing of the Torch. Before you know it, May will be here and we'll be meeting in Tampa at our second annual Joining FORCEs conference. We're working diligently to secure funding so we can continue to make all these programs available to you this year. Your contributions are the fuel that keeps our programs going and growing.

Donations to FORCE are greatly appreciated and are tax deductible. Here are five ways to help in 2007:

- Make a donation on your own behalf.
- Make a donation to honor a friend or

loved one, or to mark a special event.

- Ask your employer to make a matching donation.
- Attend our benefit gala at the Florida Aquarium during the Joining FORCEs conference. (See the conference preview on page 1.)
- Make a donation from your IRA. (Although IRA distributions are usually taxable at your current tax rate, new legislation allows tax-deductible charitable distributions up to \$100,000 through December 2007.)

So before 2007 passes by, please don't miss out on these tax-free opportunities to help FORCE. Visit our website to view a presentation of our programs. For additional information, please contact me at debbies@facingourrisk.org.

Peer Review: Personal Involvement is a Rewarding Experience

by Diane Rader O'Connor

When cancer survivors hear the words "consumer peer reviewer," they might think that only survivors with a strong scientific background qualify to review research grant proposals. In fact, consumers have an equal seat at the table with some of the nation's foremost scientists, researchers, and physicians.

While attending an ovarian cancer patient advocacy meeting in 2005, I was given an official-looking folder entitled "Consumer Peer Review for Department of Defense (DOD)." I wasn't sure how I might contribute, but I was surprised and encouraged to learn that, as an ovarian cancer survivor with a high school education, I met the minimum requirements for serving as a consumer peer reviewer. After securing sponsorship of the POCRC, completing the application, and undergoing a telephone interview, I was selected to serve as a consumer reviewer.

A large box containing scientific proposals arrived at my home. My assignment was to read all portions of the assigned proposals, focusing specifically on the "disease relevance" section, and comment online approximately two weeks before the review meeting. This was a rather daunting task for a liberal arts major, but with each proposal I gained more confidence in my ability to understand the gist of the research. Experienced consumer reviewers were assigned to be our mentors, so we novices could ask questions any time by e-mail or phone.

The actual peer review meeting was held in the Washington D.C. area. I was one of three consumer reviewers seated around a large boardroom table alongside highly-respected scientists, researchers, and physicians. In the shadow of this scientific brainpower, I momentarily doubted any contribution I could possibly make. However, I learned quickly that each member of the panel carried equal weight and was respected for their opinions.

We survivors were there for a reason and our presence was highly affirmed by the other

panel members. Many of them expressed their thanks to us for our participation. They were impressed that we had waded through countless pages of scientific proposals and were able to comment intelligently on them. They also praised the DOD for requiring the active involvement of survivors. Seeing our faces and hearing our stories added the human element to the peer review meeting.

This was a powerful experience for me, and one that I highly recommend to other survivors. I was able to read cutting-edge research, meet deeply-committed researchers, and experience the synergistic effect of survivor-scientist collaboration. It became even clearer to me that we survivors need to keep working diligently to secure more DOD funding for innovative ovarian cancer research.

I realized that we are fortunate enough to have the DOD's Ovarian Cancer Research Program only because of the relentless work of the Ovarian Cancer National Alliance (OCNA) and other dedicated organizations. In fact, from 1997 to 2005, almost 60 percent of the program's reviewers were nominated by OCNA or one of its Partner Members.

Having experienced the peer review process, my commitment is even stronger. We all need to join "forces" to augment our advocacy and support for the DOD program. ♡

Diane Rader O'Connor has been involved in advocacy since 2002, when she attended her first OCNA conference shortly after she was diagnosed with ovarian cancer. She is an OCNA board member and participates in the Ovarian Cancer Alliance of Oregon and SW Washington.



How to Participate in the Peer Review Process

by Kathy Steligo

Peer review is one component of cancer advocacy. It is the process by which research proposals submitted to funding agencies are scored to determine which projects are ultimately funded. Many funding agencies now include consumers in the peer review process. Some agencies only allow people who have been diagnosed with cancer to participate. The Department of Defense, one of the largest funding agencies for breast and ovarian cancer, requires cancer survivors to sit as peer reviewers on all research funding reviews.

The review process involves a panel of researchers who reviews and scores each proposal according to its scientific merits. Consumers, who may not need any formal training to participate, are asked to rate the relevance or importance of proposals, without necessarily evaluating a proposal's scientific merits.

You can find more information about peer review online at OCNA's website (www.ovariancancer.org.) Their primary goal is to establish a coordinated national effort to place ovarian cancer education, policy and research issues prominently on the agendas of national policy makers and women's health care leaders. The non-profit Research Advocacy Network (www.researchadvocacy.org) is devoted to consumer advocate participation in research. The Network maintains a list of consumer participation opportunities for national organizations involved in research. Local funding organizations and hospitals may need consumer input for research projects as well. Contact volunteer services at your local cancer center to inquire about advocacy opportunities.

Our May 18-19, 2007 our *Joining FORCES* conference in Tampa will include an "Understanding Research, Clinical Trials and Advocacy" workshop. Visit the FORCE website for more information and to register for the conference. ♡

Our Sponsors

FORCE proudly acknowledges contributions from our sponsors whose generosity make this newsletter possible.

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Stanford Clinical Cancer Genetics Prog.

DNA Level

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The Center for Medical Genetics
Reflections Boutique

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.

FORCE: Facing Our Risk of Cancer Empowered
16057 Tampa Palms Blvd. W. #373
Tampa, FL 33647

The Phenocopy Hypothesis *(continued)*

artificially elevate estimates of cancer risk. The published findings should be considered only in the research context and not be used to guide clinical decisions.”

Dr. Kenneth Offit at Memorial Sloan-Kettering says that the most definitive way to settle the question is to look at the occurrence of breast cancer prospectively in women after a negative BRCA test. His group and others are looking at that question (see pg. 2 sidebar). He points out that when the analysis of Smith et al. was restricted only to breast cancer cases diagnosed after a negative BRCA test, the observed risk was *not* increased, although there was a weak, statistically insignificant trend.

It is important to note that *all* women are at risk for breast cancer. None should be complacent about screening and following up on symptoms. If the phenocopy hypothesis proved to be true, what might be causing an increased breast cancer risk in women who are true negatives? One possibility is

the presence of unidentified “modifier genes” in families that may intensify the effect of BRCA mutations in carriers and somewhat elevate risk in non-carriers. Environmental exposures that are shared within families, diet and lifestyle choices, and reproductive factors may also play a role.

Although tremendous strides have been made since the early '90s, our understanding of hereditary breast and ovarian cancer is still relatively young. Many questions remain unanswered. Scientific inquiry by its very nature is slow. It takes time to design and complete quality studies, and requires a sufficient period for results to be challenged, reassessed and confirmed or refuted by the rest of the research community. For those of us whose lives and families are affected by hereditary cancer, it's not easy to remain patient as the process continues. FORCE will continue to advocate for research funding and attention for our community, so that we can have conclusive answers to these complex questions. ☺

What's New @ FORCE

Welcoming New Staff

FORCE welcomes Barbara Pfeiffer, our new Director of Volunteer Programs. Ms. Pfeiffer brings to FORCE her management skills developed while working at Microsoft for over 10 years.

New and improved volunteer programs

Under the direction of Barbara Pfeiffer, FORCE has updated and revised our volunteer programs. Our volunteers now have a formal training program and a veritable

toolbox of resources designed to help you help us. For more information about our volunteer programs, contact Barbara Pfeiffer at BarbaraP@facingourrisk.org.

Brochure with focus on Jewish women

Thanks in part to our generous sponsors, FORCE is developing a brochure on hereditary breast and ovarian cancer in Jewish women. We expect the brochure to be available in print and on our website by April.

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