

## What's Inside

Don't Miss Joining FORCEs 2008 . . . . .	1
Hereditary Cancer: How Do I Tell My Children? . . . . .	2
In the Genes: A Gala of Friends, Fish, Fun, and Fundraising. . . . .	3
International Variations in Prophylactic Surgery . . . . .	3
Voices of FORCE . . . . .	4
Young and High Risk: Pre-vivor Issues. . . . .	6
BRCA and the Risk of Pancreatic Cancer. . . . .	7
What's New . . . . .	8

## Staff

**Sue Friedman**  
Exec. Dir., FORCE

**Kathy Steligo**  
Editor

## Contributors

**Alisa Cowan**

**Lani Sinclair**

## Contact Us

FORCE  
16057 Tampa Palms  
Blvd. W. #373  
Tampa, FL 33647

Tel: 866-288-RISK  
Fax: 954-827-2200

info@facingourrisk.org  
www.facingourrisk.org

# Welcome

by Sue Friedman

## Good Things Come in Twos: Recapping Our 2007 Conference

New Year's is always a particularly meaningful time for me. It marks the time I embarked on my new career as an advocate, and it marks the birthday of FORCE. As I look forward to another year and more programs at FORCE I can't help but reminisce about our beginning. We have grown so much in the last year; perhaps nothing reflects that growth as much as the success and expansion of our Joining FORCEs national conference.

If you weren't able to attend the conference, or if you did join us and would like to review some of the excellent information provided, I have good news.

# Don't Miss Joining FORCEs 2008

by Sue Friedman

"Can't wait for next year!"  
"Greatly exceeded my expectations."  
"This is one-of-a-kind and *very* necessary."

That's how attendees described their experiences at our 2007 Joining FORCEs Conference. Our third annual conference, scheduled for May 16-17, is shaping up to be just as rewarding.

New sessions will address the interests of specific groups within our community: Dr. Ilana Cass will share developments in ovarian cancer treatment and survival, the PARP Inhibitor clinical trial, and management of breast cancer risk after ovarian cancer diagnosis. For breast cancer survivors, Dr. Susan Domchek will discuss response to chemotherapy and the latest information for women with triple-negative tumors. High-risk individuals who have not developed cancer will want to attend Dr. Judy Garber's session on new information for pre-vivors. Drs. Cathy Phelan and Alvaro Monteiro will demystify uninformative negative and variant BRCA test results. Dr. Joanne Armstrong from Aetna will help us understand how to navigate the insurance maze. And Christine Clifford Beckwith, founder and CEO of the Cancer Club, will show us how to use humor to relieve stress.

We'll also feature the latest research in hereditary cancer: Dr. Tim Rebbeck will update his PROSE study research on BRCA families, and Dr. Mark Greene will present results from GOG-199, a large national ovarian cancer surveillance study. Dr. Steven Narod, a favorite

Our 2007 conference exceeded expectations, and you can now access conference materials in two different ways: read the session recaps in this issue of *Joining Forces* or view our free webcast of select sessions at [www.facingourrisk.org/webcast](http://www.facingourrisk.org/webcast). The webcast is brought to you by FORCE, Moffitt Cancer Center, and is funded in part from the Charlotte R. Schmidlapp Fund, Fifth Third Bank, Trustee. I hope you'll make time to take a peek at our webcast—I think you'll be convinced how worthwhile it is to attend.

As we work on our 2008 conference, I grow more excited about the impressive agenda we have lined up. Until then, best wishes for a happy, healthy, and prosperous new year. See you in 2008, hopefully at the Joining FORCEs conference. ∞

from conferences past, will update research on BRCA response to cancer treatment, and will discuss promising new studies of DIM, a supplement he has been studying. Dr. Rebecca Sutphen will discuss advancements in personalized medicine.

Last year's most popular sessions will be updated and provided again, including our workshop for younger high-risk women, and our roundtable session where attendees can speak face-to-face with researchers and experts. Our own Kathy Steligo will conduct not one, but two writing workshops. Attendees may also participate in a forum panel discussion to build a national hereditary cancer research agenda.

Come join us to learn, share, and let your voice be heard. See you in Tampa! ∞



Two FORCE attendees welcome conference arrivals

## What to Consider Before Talking with Children about Cancer

- What are your child's emotional maturity and coping skills?
- How do you usually talk with your child about sex, death, religion, or other important issues? Use that template to guide you.
- How does your child ask for help? Does he come to you with problems, does he act out, or does he have stomachaches? Look for evidence that he might need more help coping with the information.
- What transitions may occur due to cancer risk? Prior to big disruptions such as surgery, start a dialogue and prepare for the change. Try to "uncouple" the actual event from the changes in the household.

### Communication Tools

- 1) Use simple, age-appropriate terms.
- 2) Avoid premature reassurances and validate your child's concerns. Pushing a child's fears aside makes the situation appear too big and scary to talk about.
- 3) Avoid unrealistic promises. Broken promises can diminish trust.
- 4) Allow your child to tell you how little or how much she wants to know. Some children are more curious, others are more private.
- 5) Allow your child age-appropriate participation in your process. Give him jobs to help him feel he is contributing.

Dr. Hurley also provided tips from the Parents at Challenging Time (PACT) Program at Massachusetts General, which focuses on parents who are dealing with cancer diagnosis:

- Euphemisms lead to confusion.
- The worst way to hear news is to overhear it.
- Welcome all questions.
- Figure out what the real question is.
- Questions do not require immediate answers.

## Hereditary Cancer: How Do I Tell My Children?

by Sue Friedman

*Presenter: Karen Hurley, PhD, Clinical Psychologist, Clinical Genetics Service, Memorial Sloan-Kettering Cancer Center*

Dr. Hurley, whose work focuses on high-risk families, spoke of sharing cancer and risk information with children, including the following.

Why should we tell our children about cancer and cancer risk? Although it's natural for parents to want to protect their children from difficult topics, children are already exposed to the disruption that cancer causes in families: the agonizing decision making, family members undergoing treatment and surgery, or loss of a family member to cancer. Absent an explanation they understand, children form their own beliefs, which may be based on incorrect information and can be difficult to resolve later.

There are two levels to the question, "How do I tell my children?" The first is: *What* words do I say? *When* should I tell them? The deeper, emotional layer is: *How* do I go through with this? How do I share this information when I'm still processing it myself?

Genetic status is a lifelong issue, although the details and focus change during our lifetimes. We do not have to be totally resolved about our genetic status, but we should be clear about how we feel before discussing the topic with our children. The goal is to communicate BRCA and hereditary cancer risk to children in a way that leads to their growth and resolution and averts problems later.

The discussion is complicated by our desire to protect our children, our guilt, and our beliefs about order and fairness. Inheritance of a mutation is random, with a 50/50 chance of passing our status to each child. Even acknowledging this, randomness goes

against our sense of order and fairness. Guilt is a normal response to uncontrollable events, especially with regard to passing on a gene mutation.

Preparing to discuss difficult topics with children:

1. Have at least one adult who is *your* support in dealing with your genetic status. Before talking with your child, call that support person for a pep-talk, and for a debriefing after the conversation.

2. Acknowledge your own feelings of sadness, fear, and guilt before talking with

your children. These emotions needn't be totally resolved, but it's important to identify them. Discuss your feelings with your support team; realize they are *your* feelings,

separate from your child's, which may be very different.

3. Think about your beliefs as a parent. Some of us feel it's our responsibility to ensure no harm ever comes to our children. Don't hold yourself to an impossible standard.

4. Reflect on your family's style of communication. If your family doesn't have a history of good, open dialogue, talk about other topics before discussing cancer.

5. Clarify your rationale for having the discussion. Is it to reassure your child about what is going on around her, or because you want her to have genetic testing to alleviate your own guilt? Be clear about your motives to help determine the appropriate content and timing of your discussion.

6. Verify information. Write what you want to tell your child. Double-check the facts with a genetics expert.

7. Consider your children's autonomy (present and future). They have their own life path to

*"Absent an explanation they understand, children form their own beliefs..."*

# In the Genes: A Gala of Friends, Fish, Fun, and Fundraising

by Sue Friedman

Everyone loves a party, and when Joining FORCEs 2007 conference attendees met for our In the Genes gala at the Florida Aquarium, the mood was fantastic, fun, and fishy! Against the backdrop of fascinating fish, miniscule seahorses, and luminous jellyfish, guests mingled with other attendees and conference presenters. In keeping with our “genes” theme for the evening, diners were encouraged to wear their denims, jeans and dungarees, and each received a denim gift bag filled with FORCE items and other goodies.

The Conch Critters, a popular local band, played favorite songs by Bob Marley, Bruce Springsteen, and Jimmy Buffett. Attendees strolled through the aquarium, sampling from stations offering roast beef, sushi, pasta, and salads. After-dinner sweets included fruit

kabobs with chocolate dipping sauce, tarts, and chocolate layer cake. Ricky Roberts Photography snapped commemorative photographs.

Our In the Genes silent auction was a huge hit. Celebrity denims, including jeans signed by Oprah Winfrey, a faux-fur-collared jacket signed by Bill Cosby, a denim shirt signed by the entire cast of *The Office*, and special jeans from designer Betsy Johnson’s private collection went to the highest bidders.

The gala raised our spirits, and more importantly, it raised about \$4,000 for FORCE. If you’re attending Joining FORCEs 2008, don’t miss the May 16 gala. Good friends, great dining, and our own private aquarium. A great time is guaranteed for all! 

# International Variations in Prophylactic Surgery

by Sue Friedman

*Presenter: Steven Narod, MD, FRCP, Canada Research Chair in Breast Cancer; Director, Familial Breast Cancer Research Unit, Women’s College Research Institute, Toronto*

Dr. Narod introduced data from an ongoing study of 8,058 women from 11 countries, all known BRCA1 or BRCA2 mutation carriers, who are followed with questionnaires every two years. He discussed the risks and benefits of oral contraceptives, fertility treatment, and hormone replacement therapy for BRCA carriers. An in-depth review of this discussion will appear in next quarter’s *Joining FORCEs*.

Dr. Narod also shared study data regarding international variations of the decision to undergo prophylactic surgeries:

Percentage of pre-vivors choosing prophylactic mastectomy:

- USA 35%
- France 25%
- Canada 22%
- Austria 21%
- Italy 13%
- Norway 5%
- Israel 4%
- Poland 4%

According to Dr. Narod, none of the 174 women in the study who chose bilateral mastectomy developed subsequent breast cancer. Of the 1,134 women who did not choose mastectomy, 76 developed breast cancer within a four-year followup period.

Percentage of breast cancer survivors choosing contralateral prophylactic mastectomy (removal of the opposite breast):

- Israel 52%
- USA 49%
- Canada 28%
- France 20%
- Austria 16%
- Italy 6%
- Poland 4%
- Norway 0%

Percentage of BRCA carriers choosing prophylactic oophorectomy:

- Norway 74%
- France 71%
- USA 68%
- Israel 66%
- Austria 54%
- Canada 54%
- Italy 36%
- Poland 34%

## In the Genes Sponsors

FORCE is most grateful for the generous donations of sponsors who made our In the Genes gala possible:

**Strength Level**  
GlaxoSmithKline Oncology  
The Center for Restorative Breast Surgery  
eWomen Network Foundation

**Courage Level**  
Fifth Third Bank  
Dan and Beau Maysey  
and Sue Friedman  
Gold Seal Roofing & Construction

**Hope Level**  
Celma Mastry Foundation  
Dean Distributors, Inc.  
Sembler Company  
Sokolov & Piper Family Dentistry  
West Coast Gynecologic Oncology

If your company or organization would like to support our 2008 FORCE gala dinner, please contact Debbie Sokolov at [DebbieS@facingourrisk.org](mailto:DebbieS@facingourrisk.org) or 727-871-0366. All donations are tax-deductible.



*In the Genes Gala invitation*

## Exercising the Mind-to-Pen Connection

by Kathy Steligo

For every action, there is a reaction. That was certainly the case in our *Writing for Power, Peace, and Publication* workshop during the 2007 Joining FORCES conference.

This session was about writing for ourselves. We weren't concerned with sophisticated techniques, clever turns of phrase, or what others might think of our words. Our goal was to simply have a written heart-to-heart chat with ourselves, by freeing and recording our innermost feelings about hereditary cancer.

We began with off-topic warmup exercises to help us get our minds in the mood. Using "clustering" techniques, participants freely associated words and ideas around a central theme of hereditary cancer. They then focused on writing about one or more of the themes in greater detail without immediately editing or censoring; that's something that can be done later. Putting aside our inherent constraints—concerns about grammar, style, punctuation, and sentence structure—while we write allows us to express our true emotions. This powerful methodology often produces surprising perspective, understanding, and awareness.

Although each participant held deeply personal experiences and thoughts about hereditary cancer, within the workshop's supportive environment, several common themes became apparent when people began sharing what they had written. What was revealing for one became a lesson or validation for others. Many attendees felt their writing brought clarity and understanding of fears, guilt, or anger about being BRCA positive. Others said the freeform exercise gave them a new awareness of previously unacknowledged emotions. One woman told us she gained

# 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

## Beyond the Beads

by Lani Sinclair



At the conference, most of us wore beads of different colors to signify whether we were breast or ovarian cancer survivors, pre-vivors, genetic counselors, health professionals, or supporters. I wore beads to indicate I am BRCA negative. Several people asked me, "Then why are you here?" The answer is complicated. My sister was a founding member of FORCE, and I'm now on the Board, but there's more to my commitment to this organization.

Last year, when I turned 57, it was an overwhelming yet triumphant birthday for me; a milestone no other woman in my family had achieved. My family history was devastating. My grandmother Lorene died of ovarian cancer when she was 39. My mother Betty died of breast cancer when she was 44. My cousin Donna died of ovarian cancer at 41, and four years ago my sister Sherry succumbed to ovarian cancer at age 56.

During Sherry's 10-year battle with ovarian cancer, she became involved with many organizations. But FORCE became pivotal for her: a burgeoning organization that was one of the first to address the impact of hereditary cancer on families like ours. As a founding member of the Board, her life soon revolved around FORCE activities and members.

My own genetic testing results came back negative. This was wrenching for me, given my sister's diagnosis. I suffered survivor's guilt, which Sherry and I discussed. She recruited me to volunteer for FORCE; since I'm a writing consultant, she suggested I help with grant applications. Thus began my involvement with FORCE, where I kept a low profile because Sherry was such an energetic, effective, and dominant influence wherever she went.

After Sherry passed away, I was reluctant to increase my participation. I knew I could never fill her shoes. Yet I felt committed to FORCE, knowing how incredibly important it was to Sherry. FORCE helped her immeasurably during her illness. FORCE members became her loving friends. FORCE as a community of people who understand

what my family has been through, and how family losses have impacted me, was important to me too.

When my mother died almost 40 years ago, nobody talked about hereditary cancer. My doctors noted her death in my files, but said

*"...I turned 57... a milestone no other woman in my family had achieved"*

little else about it. They didn't mention, and I had no idea, that breast and ovarian cancers were linked. My grandmother's abdominal cancer was probably ovarian but nobody talked about

ovaries in the 1930s. When my cousin was diagnosed with ovarian cancer in the 1980s, I assumed our family was doomed and that I would someday be diagnosed with cancer.

Sherry and I often discussed how an organization like FORCE could have helped us during those years. Now due to FORCE's efforts, families like ours are much more informed and have far better information and more options than we did when our family history was being written.

This is a longer story than colored conference beads can reveal. I may not have had cancer, prophylactic surgery, or breast reconstruction—but I share with the rest of our community a passion and dedication to FORCE. ∞

## 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](mailto: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.

## Exercising the Mind-to-Pen Connection

(continued)

a fresh perspective about being BRCA positive, one that she planned to use as a springboard for difficult conversations about genetic testing among other family members. Another attendee said that writing helped her to understand her long-held sentiments of denial and confusion regarding her mother's bout with cancer years ago; she felt further exploration of these feelings would help her open fresh dialogue about issues they were never able to discuss before.

In this workshop, we concentrated on a singular action: writing without constraint. For most, if not all participants, reaction was immediate: acknowledging and thinking about hereditary cancer issues in a new way. It was an inspiring and rewarding experience.

### Just Write! Five Tips for Getting Started

- Warm up by first writing something off topic.
- Write without editing or censoring yourself.
- Write what you feel, without analyzing your feelings beforehand.
- Write from your heart, not your head.
- Keep your hand moving!

### The 2008 Joining FORCES Writing Experience

An expanded version of this session and a separate advanced writing workshop will be offered at our May 2008 Joining Forces conference. Whether you're a novice or an experienced writer, come join us to see how compelling and revealing the writing experience can be. You never know what you'll find. ∞

## Achieving and Maintaining Emotional Health

Being at high risk is a lifelong situation. Here are Dr. Hurley's recommendations to maintain long-term emotional health:

- Take risk seriously enough to take action without becoming overwhelmed
- Balance chronic and periodic stress. Keep surveillance appointments, for example, without spending the prior week without sleep.
- Prepare emotionally to make difficult choices, even if you're not ready to make those decisions right now.
- Prepare to address future crises. Unfortunately, pre-vivors may face crises throughout life: false positive screening, relatives who are BRCA positive, or health issues (either their own or of loved ones).

Dr. Hurley's Emotional Health Tool Kit for young pre-vivors:

- **Develop a support system.** Have people who are attentive and who listen nonjudgmentally.
- **Learn to monitor your thoughts.** Correct or substitute negative thoughts with positive thoughts.
- **Distinguish between what you can and cannot control.** You can change your own thoughts, but you cannot change other people's reactions.
- **Prioritize enjoyable activities.** Balance doctor appointments, work, childcare, and caretaking of others. Plan for fun and recreation to prevent burnout and stress.
- **Be aware of your physical and emotional needs.** Recognizing your own needs will help you take better care of yourself and articulate your needs to friends and family.
- **Set an "information thermostat."** Many people deal with threat by gathering as much information as possible. It's important to know when to stop.
- **Allow time to make good decisions.** Even under the most critical circumstances, most women can afford to take a day or more to decide what is best for them. ∞

## Young and High-Risk: Previsor Issues

by Alisa Cowan

*Presenters: Rebekah Hamilton, PhD, RN, Assistant Professor, Health Promotion and Development, University of Pittsburgh School of Nursing, and Karen Hurley, PhD, Clinical Psychologist, Clinical Genetics Service, Memorial Sloan-Kettering Cancer Center*

Using examples and quotes from her research interviews, Dr. Hamilton presented common issues of high-risk women under age of 40.

### Relating to Others

Young previvors face unique relationship challenges. While there is a sense of obligation to be honest because the genetic issue affects the entire family, including future children, there is often a fear of damaging a growing relationship. Should previvors reveal their BRCA status? At what time during a relationship should they do so? Will partners abandon them once they know about their BRCA status? Dr. Hamilton noted that only one of 76 interviewees was abandoned by her partner once she made her BRCA status known.

### Out of Sync

Most 20- and 30-year-olds don't think of their own mortality, yet many young women consider their BRCA status to be a death sentence, and they become preoccupied with a sense that life is fragile. Once the initial shock passes, mortality remains on the previvor's mind. Feelings of isolation can develop when they are unable to share these issues with friends who are not at high risk.

### Abruptly Changing the Life Plan

Young women at high risk feel a sense of compressed time. Dr. Hamilton found that young women often make choices based on being high-risk, changing or accelerating their life plans. Their BRCA status exerts pressure to decide whether/when to have prophylactic surgeries, and to choose between a career and having children at a young age. One 24-year-old woman

said, "My doctor recommended having an oophorectomy before age 35. I feel like I should start [having children soon]... but I don't know if I am ready for that."

Despite the fear of passing the genetic mutation to their children, none of the women interviewed indicated they would forego giving birth because of that fear. There is general optimism that science will provide more solutions by the time their children might have to worry about being high risk.

### What It Means to Live with High Risk

Dr. Hamilton summarized the high-risk previvor experience with quotes from participants:

*"While there is a sense of obligation to be honest ... there is often a fear of damaging a growing relationship"*

"It isn't cancer; it isn't not cancer. It is something in between."

"Having the mutation can be seen in a positive light. It doesn't have to be the end of the world. Everyone faces circumstances in

their lives; this is just another thing that will make us stronger and teach us to grow, if we let it."

Dr. Hurley discussed how young high-risk women who are faced with the challenges of being previvors can remain emotionally healthy while learning about the world and responsibility. She finds that although most people cope well with their genetic test results, young women are particularly at risk for becoming distressed. Common warning signs—intrusive thoughts, nightmares, and physical symptoms such as stomachaches—may indicate that a previvor might need more help or support. She emphasized that women who show signs of distress or who have unresolved grief and bereavement issues should consider one-on-one therapy. ∞

*Alisa Cowan lives in Maine with her husband, their two children, and their horse. She is the northern New England Outreach Coordinator for FORCE.*

# BRCA and the Risk of Pancreatic Cancer

by Sue Friedman

(Adapted/Excerpted from the session *BRCA and Other Cancers*)

Presented by Jason Klapman, MD and Cathy Phelan, MD, PhD, H. Lee Moffitt Cancer Center

Dr. Klapman is an expert in gastrointestinal cancer, with a special interest in pancreatic cancer. He explained that pancreatic cancer is a difficult disease to screen for because there is currently no reliable method of early detection. Approximately 37,000 new cases of pancreatic cancer are diagnosed each year; most people diagnosed die from the disease within one year. Some risk factors for pancreatic cancer include smoking, diabetes, and *pancreatitis* (chronic inflammation of the pancreas). Hereditary factors account for about 10 percent of pancreatic cancer cases.

Dr. Klapman discussed different cancer syndromes that increase the risk for pancreatic cancer. Of hereditary pancreatic cancers, BRCA2 is the most common mutation found, accounting for about one-fifth of pancreatic cases where there is a family history of the disease. BRCA2 is found in up to 10 percent of pancreatic cancers, even when there is no family history of pancreatic cancer, underscoring the importance for people with pancreatic cancer to consult with a genetic expert. Dr. Phelan estimated lifetime risk in the general population to be about one percent, compared with a BRCA2 mutation carrier, whose risk is estimated at three to five percent. BRCA1 carriers also have an elevated risk for pancreatic cancer; about two percent or double the average risk.

Family history is an important factor in determining pancreatic risk. A person with two first-degree relatives with pancreatic cancer has an 18-fold increase in risk. A person with three or more relatives with pancreatic cancer has a 57-fold increase in risk. According to Dr. Klapman, the elevated

risk in BRCA1 carriers is not considered very high, and not high enough to warrant inclusion in the early detection study, unless there is a history of pancreatic cancer in the family. He identified two rare hereditary syndromes which increase the risk for pancreatic cancer: Peutz-Jegher and a rare type of familial melanoma syndrome.

Dr. Klapman presented the symptoms of pancreatic cancer, but stressed that most pancreatic tumors are symptomless until they advance enough to block the bile ducts, which leads to jaundice. Individuals with symptoms often report nonspecific conditions such as:

- Painless jaundice
- Pancreatitis
- Weight loss
- Abdominal pain
- Loss of appetite

Absent effective screening techniques, 75 percent of pancreatic cancers are identified in the latest stage. Dr. Klapman stressed that pancreatic cancer is deadly, but it is uncommon, making it impractical to screen the general population. His research involves screening those at highest risk for the disease.

Studies to develop early detection for pancreatic cancer involve passing a small ultrasound device on the tip of an endoscope through the mouth and into the stomach. This allows physicians to visualize the pancreas, which lies behind the stomach, in great detail and potentially find masses as small as 3 mm. The procedure is considered relatively safe, but does involve anesthesia and subjects patients to related side effects and risks.

According to Dr. Klapman, the sensitivity and specificity of this procedure has so far been promising. The study is also looking at ways to develop a blood test for pancreatic cancer.

## How to Participate in Dr. Klapman's Study

Participation in the pancreatic cancer early detection study is open to high-risk individuals who meet any of the following criteria:

- Have two or more relatives with pancreatic cancer and have a first-degree relationship with at least one of the relatives with pancreatic cancer.
  - If only two family members are affected, both must have had pancreatic cancer and a first-degree relationship with the individual screened.
  - If more than two affected individuals are on the same side of the family, at least one must have a first-degree relationship with the member being screened.
  - Be at least age 40 or older, or 10 years younger than the youngest affected individual.
- Peutz-Jeghers Syndrome patient under age 30.
- Hereditary pancreatitis patient.
- Familial Atypical Multiple Mole Melanoma Syndrome patient.
- Patients with a BRCA2 mutation and at least one first- or second-degree relative with documented pancreatic cancer.

Participants must also be willing to undergo:

- Endoscopic ultrasound (EUS) with possible fine needle aspiration (FNA).
- Surgical evaluation for abnormal EUS/FNA finding.
- Radiographic evaluation if screening findings are abnormal.

Contact Jennifer Gonzalez BS, clinical trial coordinator, H. Lee Moffitt Cancer Center, at 813-745-1805 for more information. 

## Our Sponsors

This newsletter was made possible through a generous donation by Steve and the supporters who contributed to our Friends of FORCE campaign.

If you'd like to learn more about sponsoring FORCE, visit [www.facingourrisk.org/sponsorship](http://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](mailto:info@facingourrisk.org) or mail to FORCE, 16057 Tampa Palms Blvd. W. #373, 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](mailto:newsletter@facingourrisk.org). Include your name and city and state in the e-mail.

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

# How Do I Tell My Children? *(continued)*

follow. If you test children or pressure them to test, you take their choice away.

We cannot control genetics. The legacy we can control is the life lessons we teach our children. We can use this discussion to teach

our children how to tackle challenges: cope with uncertainty, adversity, and uncontrollable events, and handle the agonizing predicament of making decisions when there are no good choices but a choice must be made. ♡

## What's New @ FORCE

### It's Time for Chat-a-thon

2 days + 2 nights  
4 FORCE!

Our 2008 chat-a-thon commemorates our ninth birthday and helps assure we'll be around for another nine years! Join us in the chatroom on Saturday and Sunday, January 18-20, for this around-the-clock online event.

FORCE coined the term "chat-a-thon" seven years ago to describe an internet-based awareness event. Our virtual chat enables members throughout the world to connect and share experiences from the comfort of their homes. Join us and help make our chat-a-thon a success. This year you can create your own team page. Visit [www.chat-a-thon.com](http://www.chat-a-thon.com) for details or e-mail Barbara Pfeiffer at [barbarap@facingourrisk.org](mailto:barbarap@facingourrisk.org).

### New Ovarian Cancer Brochure

*What Every Woman with Ovarian Cancer Should Know*, a new brochure produced by FORCE and sponsored by the Ovarian

Cancer Research Fund, includes information on BRCA and HNPCC hereditary syndromes, genetic counseling, and genetic testing. Order from our web page (click on "Our Publications," then "Brochures"). Allow 4-6 weeks for delivery.

### You! In Our Genetics Experts and Programs Resource

Are you a health care provider who offers genetic services to individuals and families affected by hereditary cancer? Complete the online form at [www.facingourrisk.org/genetics\\_services](http://www.facingourrisk.org/genetics_services) to include your listing in our upcoming resource guide.

### Coming Soon: FORCE's New Look

We're beginning our 10th year with a fresh look. Our signature pink-and-teal heart will appear in an updated design emphasizing "empowerment" — a theme of great importance for FORCE. Watch for our new look on the website and in our new publications.



Non-Profit Org.  
US Postage  
PAID  
Permit No. 638  
Tampa, FL