Lucky 13

Like many people I have superstitiously avoided the number 13, but as FORCE celebrates its 13th birthday, it’s time to challenge that particular fear. When I started FORCE, I had no idea of the impact we would have and the leadership role our organization would play in uniting, educating, advocating for, and helping families to fight hereditary breast and ovarian cancer. Over the course of this year, we will focus on celebrating this milestone with our “Thirteen Things about FORCE” theme.

Even as we celebrate 13 years of success, we are constantly moving forward to do whatever it takes to face hereditary breast and ovarian cancer head on and to support our community. From our blogs, e-mails, and this newsletter, you can see that we have been busy. As the year progresses we will continue to introduce new programs, report on the latest research, and advocate for all of us in our fight against hereditary cancer. Visit our blog at facingourrisk.wordpress.com and read about the issues that challenge our community and how FORCE is addressing them.

Be informed. Be empowered. Be well.

Sue

Confronting Hereditary Breast and Ovarian Cancer: Identify Your Risk, Understand Your Options, Change Your Destiny

by Sue Friedman

Decisions about hereditary cancer may be the most difficult you’ll ever make. But with FORCE’s new book, you’ll have the roadmap you need to make the best decisions for you and your family.

Confronting Hereditary Breast and Ovarian Cancer began with FORCE’s unparalleled understanding of what it means to live in a high-risk body. Then we added meaningful extras: knowledge from the world’s leading experts; personal stories; clarification about risk, preventive options, insurance coverage, and discrimination; and unique insights we’ve learned from serving our community for more than 13 years. The result is a comprehensive composite of research, acumen, and inspiration, all bundled together in a single resource for previvors, survivors, and their families.

In the words of Mark Greene, MD, of the National Cancer Institute, who wrote the book’s foreword, “The substance of each chapter is impeccably accurate, and the authors honestly acknowledge the limits of our current understanding of this incredibly complex disorder. Where all the facts are not yet known, they present the carefully considered best medical judgment of investigators and providers who have devoted their careers to the study of HBOC...the tone of the book is an extraordinary combination of indubitably authoritative and insightful information, presented in a voice that is calm, clear, direct, balanced, realistic, and yet optimistic.”

Here’s a sampling of reader reviews posted on Amazon.com:

“I have carefully read every book on hereditary breast and ovarian cancers since learning that I carry the BRCA1 gene mutation and this book is without doubt the best.”—Anna

“All the questions you might have—and also the ones you haven’t thought of yet—are answered.”—Ami H

“…a step-by-step guide to learning about the world of HBOC.”—Tara

“As a BRCA1 breast cancer survivor, this is the best, most informative, well-written book on the topic of hereditary breast and ovarian cancer out there.”—Lisa M

After you’ve had a chance to read your copy, we hope you’ll take a moment to post your own review.
Free webcasts of select sessions from previous conferences are available on the FORCE website. Visit facingourrisk.org/events/annual_conference/past_conferences.php.

The following sessions are available for viewing on-demand from our 2011 conference:

- **Diet and Other Lifestyle Factors**
  Nagi Kumar, PhD

- **Focus on BRCA and Triple-Negative Breast Cancer**
  William Audeh, MD and Melinda Telli, MD

- **Hereditary Breast and Ovarian Cancer: Recent Findings**
  Steven Narod, MD and Elise Kohn, MD

- **Mastectomy Options: The Changing Face of Mastectomy**
  Christine Laronga, MD

- **Reconstruction Panel Q & A**
  Paul Smith, MD, Scott Sullivan, MD, R. Michael Koch, MD and Roger Khouri, MD

- **Why Does the Hereditary Cancer Community Need a Say in Research?**
  Sue Friedman, DVM

- **Young Previvors: Medical and Emotional Issues**
  Ken Tercyak, PhD and Tiffani DeMarco, MS

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**Joining FORC3es 2012: Education, Inspiration, Celebration**

*by Sue Friedman*

Our conferences just keep growing! If you have attended one of our Joining Forces conferences, you know what an amazing experience it is. And if you have never been, it’s time to join us October 18-20, 2012 in Orlando and be part of the largest gathering by and for the hereditary cancer community. Learn the latest information from the world’s experts, gain support, and network with others who face similar situations. Our sessions and workshops offer insight on all areas of hereditary cancer, including new treatments, risk-reducing lifestyle behaviors and medications, early detection and surveillance, mastectomy and reconstruction, oophorectomy, topics related to improving quality-of-life, and workshops devoted to family communication.

New agenda highlights include:

- understanding research, risk, and statistics
- healthy heart and bones after surgery and menopause
- post-mastectomy recovery and rehabilitation
- the role of the fallopian tubes in ovarian cancers
- hereditary cancer and your legal rights

Visit our conference web pages (facingourrisk.org/conference) to view the agenda, list of speakers, conference FAQs, or to book your room. Registration will open later this spring.

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**Decoding Annie Parker: Entertaining and Educational**

*by Karen Kramer*

It is rare when a Hollywood film both entertains and starts a serious conversation that can save lives. For producers Stuart Ross and Johnathan Brownlee, making *Decoding Annie Parker* was more than just a film. It was a mission.

*Decoding Annie Parker* is the story of a sharp-witted, irrepressible young woman who watches her mother and her sister diagnosed with breast cancer. When Annie is also diagnosed, she resolves to fight back against immeasurable odds. The film is also the story of Dr. Mary-Claire King, the geneticist whose discovery of the BRCA1 gene and its link to breast cancer was one of the most important scientific discoveries of the 20th century.

Like many of us, Stuart Ross has a personal connection to breast cancer. He took a year off from his job to care for his mother after her diagnosis with stage IV disease. During this time, the script for *Decoding Annie Parker* arrived. Ross’ mother ultimately lost her cancer battle, but not before she shared her support for the film. “This movie shows how cancer affects an entire family, both physically and mentally,” said Ross. “Originally, I was saddened by its theme. But in meeting Annie Parker and becoming her friend, I now fully understand the optimism in her story. The movie is truly a testament to hope and opportunity.”

While the quality of the script and skill of the cast ensure its entertainment value, the producers want the movie to energize viewers with curiosity about their own family histories and cancer risk. “We believe the film evokes a myriad of emotions. We hope the audience will laugh and cry with us,” said co-producer Brownlee. “We want a movie-goer to call their mom or sister and ask the important health questions. Then we’ve done our job.”

FORCE is proud to be a partner in promoting *Decoding Annie Parker*. The film, which stars Samantha Morton as Anne Parker and Helen Hunt as Dr. Mary-Claire King, will be released later this year.
Update on FORCE’s Hereditary Cancer Research Fund

by Sue Friedman

We have a responsibility to future generations to develop better options so our children will not have to face the fear of inherited cancer or make the agonizing decisions that confront us today. We will not prevail over hereditary cancer without HBOC-specific research that will provide better options for future cancer prevention, detection, risk management, and treatment. FORCE’s Hereditary Cancer Research Fund will be the first and only research fund by and for our community. To rapidly initiate and fund the research we so desperately need, we must raise $100,000 by the end of 2012. We still have far to go to achieve this milestone and need your help.

For more information, visit the FORCE Research Fund page at facingourrisk.org/research-fund.

How Many Times Have You Been Asked for Your Input about Research?

If you are like most of the population, your answer is “never.” Our Hereditary Cancer Research Fund is your opportunity to be heard. As part of the HBOC community, it is your right to help guide the direction of this research.

You can help by completing our short survey, which will guide our prioritization of the most relevant and urgent aspects of hereditary cancer research. (Look for the survey results in a Joining FORCES issue later this year.) We will match our collective priorities to studies with the highest need and the best likelihood of improving hereditary cancer care. Visit facingourrisk.org/research-fund for more information or to take our survey.

How Children Respond to a Parent’s BRCA Test Results

by Tracy M. Diaz

After testing positive for a BRCA mutation, experts recommend that people communicate their results to adult family members. Facing hereditary cancer, undergoing genetic testing, and pursuing risk management options can be a stressful process for entire families, especially when young children are involved. Although experts recommend against genetic testing of minors, children are frequently aware of the serious and inherited nature of cancer in their families.

Dr. Angela Bradbury at Fox Chase Cancer Center studied how children respond when told of a parent’s mutation status. In her study, a total of 253 parents participated in a telephone interview. All participants received genetic counseling before and after their BRCA testing, which occurred while they had at least one child under the age of 25. Their test results were categorized as either true negative (6% of participants), true positive (29% of participants), uninformative negative (57% of participants), or a variant of undetermined significance (VUS) (9% of participants). True negative refers to individuals who tested negative for a known mutation identified in the family, while uninformative negative refers to participants who tested negative and belong to families without a known mutation. VUS refers to an identified gene change with an unknown effect on cancer risk.

Most parents (84%) informed their children within one month of learning their test result. The majority of children over 14 years old were informed, while about half of children between ages 10 and 13 were informed. When children heard the test results, most of their reactions were neutral (41%) or relieved (28%). Those who expressed relief and happiness (28%) had been told of a parent’s negative result. A smaller percentage of children felt concern (13%) or distress (11%)—distress was more common when results were positive or VUS. Some parents reported that children did not understand the information (7%), asked questions or seemed curious (5%), and/or appreciated the information and found it useful (4%).

This is the largest study to explore communication of BRCA test results between parents and their children. The study found that most parents share results with their children, and that the majority of children do not find this information distressing. Other findings include:

- Parents were more likely to communicate results when their tests were negative, when they had daughters, and when they had older children.
- Parents were more likely to share negative test results and less likely to share positive results with their daughters.
- Parents more often shared negative test results with daughters than with sons. This difference was not seen in parents who had a positive result.
- Children were most often concerned about a parent’s positive test result.
- Children who were distressed or didn’t understand results were most often younger than age 10. Concern was more common in children between ages 14 and 24.
- Neutral responses were mostly reported in sons, while distress and finding the information useful was mostly reported in daughters.

Tracy M. Diaz is a doctoral graduate student in the Cancer Biology program at UT Southwestern Medical Center in Dallas, TX. She researches cancer vaccines and enjoys doing volunteer work in her free time. She is also a BRCA2 mutation carrier.

How Children Respond Reference

Looking for a Better Way to Detect Pancreatic Cancer
by Sue Friedman

Symptoms of pancreatic cancer can be vague, and because the pancreas (a small but important abdominal organ) is positioned behind the stomach, diagnosis can be difficult. The disease is frequently not found until it has advanced. Several researchers are looking for better ways to detect pancreatic cancer. Susan’s cyst was discovered because she was fortunate to learn about, qualify for, and participate in a pancreatic screening study for high-risk people.

Many factors, including genetic influences, age, gender, and ethnicity contribute to pancreatic cancer risk. The risk is also higher for people who smoke and for those who have long-standing diabetes or chronic pancreatitis. Although people with BRCA mutations have a greater risk for pancreatic cancer than people in the general population, most studies restrict participation to individuals who also have a family history of pancreatic cancer.

Pancreatic screening study
If you are at high risk for pancreatic cancer and have a family history of the disease, you can help researchers find a better way to detect early-stage tumors. Moffitt Cancer Center in Tampa, Florida is recruiting individuals to study pancreatic cancer screening using endoscopic ultrasound. The procedure requires mild sedation (like a colonoscopy) while a flexible tube with a small ultrasound imaging device is passed through the esophagus and into the stomach. The ultrasound allows doctors to look more closely at the pancreas for any abnormal changes and take tissue samples to determine if cancer is present. The goal of the study is to determine whether screening high-risk people can detect early asymptomatic precancerous or cancerous changes in the pancreas, leading to better outcomes.

Who qualifies for this study?
Moffitt’s study is open to people with any of the following criteria:
• two first-degree relatives with pancreatic cancer
• three family members with pancreatic cancer, including at least one first-degree relative
• diagnosed with Peutz-Jeghers Syndrome and are age 30 or older
• diagnosed with hereditary pancreatitis
• diagnosed with Familial Atypical Multiple Mole Melanoma Syndrome
• a BRCA2 mutation and a family history of pancreatic cancer

Participants will be asked to:
• consult with a clinician to determine if they are eligible for the protocol.
• consent to undergo an Endoscopic Ultrasound screening exam with possible Fine Needle Aspiration (EUS/FNA), and surgical and radiographic evaluation if the EUS/FNA test result is abnormal.

More information
To find more information about the study, contact Tiffany Campos, Research Coordinator (813-745-8358 or Tiffany.Campos@moffitt.org) or Jason Klapman, MD, Principal Investigator (813-745-8361 or Jason.Klapman@moffitt.org).

Visit the FORCE clinical trials page to find other studies for people at high risk for cancer.

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.

Pancreatic Cancer Screening
by Susan Beausang

As a carrier of a BRCA2 mutation, I knew about my elevated lifetime risk for pancreatic cancer. Having the mutation and losing my father to pancreatic cancer qualified me to participate in a pancreatic screening study using endoscopic ultrasound (EUS) for early detection. I felt fortunate to participate in the study, which identified a precancerous pancreatic cyst. I then underwent a Whipple procedure (surgery that removes a portion of the pancreas, stomach, gallbladder, bile duct, and small intestine). Since then, two of my sisters have had similar screenings. My younger sister, a two-time breast cancer survivor, was diagnosed with a pancreatic cyst—devastating news, but the tumor is small and her prognosis is excellent. My older sister has two pancreatic cysts. None of us are grateful for our predisposition to cancers, but we are thankful that I started this search-and-destroy ball rolling.

After witnessing the breast cancer diagnoses and treatment of my grandmother, maternal aunt, mother, and two sisters, I was desperate to avoid what felt like my inevitable disease. My siblings were divided; some didn’t want testing, but I persisted. Genetic testing revealed that four of my six siblings also have BRCA2 mutations. Upon learning of my mutation, I underwent a prophylactic double mastectomy and salpingo-oophorectomy, knowing this was the right decision for me.

Soon after my surgeries, my hair started falling out. In three months, I was bald with no hair anywhere: no eyelashes, eyebrows, or hair on my arms or legs. I had alopecia universalis, a disease in which my immune system attacks my hair follicles. Having surrendered my breast and ovaries, complete hair loss was almost more than I could handle. Little by little, I faced the reality of life with baldness and I started looking for headwear that would allow me to feel remotely normal. Wigs were conspicuous and uncomfortable; maybe fine for a night out, but not an option for every day. With no fashionable solution, I decided to design my own—the beaubeau®, a high-fashion head scarf for women and girls with medical hair loss. Unfortunately, my baldness wasn’t my last bump in the road.

The decision I faced with my pancreatic cyst was much harder than my decision for preventive mastectomy and oophorectomy. The pancreas fulfills multiple functions, and because pancreatic cancer symptoms are vague, most people are diagnosed at an advanced stage. My father died within nine months of his diagnosis. But a cyst is not cancer, and a Whipple is no small intervention. I changed my mind back-and-forth right up until the surgery. I consulted with three different specialists, none of whom agreed with the others. I chose to be proactive and proceed with the Whipple, and my recovery has gone remarkably well. Prophylactic surgeries are never free of second-guessing. Soon after my procedure, when I was figuring out what I could and couldn’t eat, I wondered whether I had made the right decision. The passage of time and my sister’s diagnosis convinced me that my decision was the right one.

Life is full of mottos. One that has special meaning for me is “knowledge is power.” My grandmother went in for a biopsy and came out with a radical mastectomy (she was never even asked for her permission), but my generation has options. I didn’t get to choose my genes, but I can choose how I manage my risks.

Susan Beausang is a third-generation breast cancer survivor and a BRCA mutation carrier. She is also president of 4Women.com, a company that provides fashionable headwear for women and girls with medical hair loss.

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., 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.
Attention GOG-0199
Study Participants

GOG and the National Cancer Institute have launched a new five-year follow-up study for women who participated in GOG-0199. The new study—GOG-8199—aims to improve cancer risk estimates and increase the usefulness of GOG-0199-related biospecimens. Participation requires only a new consent form and completion of a brief annual questionnaire by mail, telephone, or email. In-person visits to GOG study centers are not required.

Unfortunately, recruitment has been slow, and GOG may lose funding if a substantial number of additional participants do not sign up by May. If you were a GOG-0199 participant, we urge you to act at your earliest convenience to contact the GOG site where you were originally enrolled. We need your participation to avoid closure of this important addition to GOG-0199.

For more information about GOG-8199, please visit facingourrisk.org/featured.

GOG-0199 References


GOG-0199: The National Ovarian Cancer Prevention and Early Detection Study

by Sue Friedman

GOG-0199 is a unique collaboration between the National Cancer Institute, the Gynecologic Oncology Group (GOG), and the NCI-sponsored Cancer Genetics Network to study women who are at increased genetic risk for ovarian cancer. The research design is a two-arm, prospective, nonrandomized study. “Two-arm” means researchers are comparing high-risk women in two groups: those who elected risk-reducing salpingo-oophorectomy (RRSO) and those who chose high-risk screening for ovarian cancer. “Prospective” means that these women are being followed from the time of enrollment forward—in the case of GOG-0199, for a period of five years from the time they joined the study. “Nonrandomized” means that the participants chose which group they would be assigned to (surgery or surveillance) based on their risk-management plan. Women who chose surveillance were followed with a new ovarian cancer screening strategy, the “Risk of Ovarian Cancer Algorithm,” aka ROCA, and had CA-125 levels drawn every three months. Instead of using one annual CA-125 level compared against a “normal range” of test results, ROCA looked at changes in the levels of CA-125 over time as the basis for deciding whether or not additional tests were needed to look for ovarian cancer.

The study was designed to answer the following important questions:

• Does ROCA have potential for improving ovarian cancer screening?
• How is ROCA affected by other characteristics of the women being screened, such as age, prior pregnancy, and various medications?
• Are there new protein or chemical markers detectable in the collected blood samples which might be more effective than CA-125 in detecting early ovarian cancer?

GOG-0199 completed enrollment in November 2007, with 1,000 women in the RRSO arm and 1,600 women in the screening arm. Follow-up ended in November 2011. Final analysis is underway to examine the Primary Study Endpoints, which include comparing women in each arm of the study for:

• cancer incidence
• medical decision making
• quality-of-life
• performance characteristics of the ROCA algorithm in detecting ovarian cancer

The BRCA mutation status of all participants is now known, and central review of the surgical specimens from risk-reducing salpingo-oophorectomies has been completed. Researchers have collected a valuable repository of DNA, serum, plasma, and tissue samples from high-risk women to answer important questions about the development of ovarian cancer. The tissue specimens collected during preventive surgery include normal tissue from women who were cancer-free and malignant tissue from women whose cancer was found at the time of their preventive surgery.

Another focus for GOG-0199 relates to its membership in CIMBA (Consortium of Investigators of Modifiers of BRCA1/2), an international collaboration of 30 research groups that has assembled a collection of 30,000 BRCA mutation carriers to look for new genes that modify risk in BRCA mutation carriers. GOG-0199 has contributed samples to five CIMBA projects looking for candidate genes that influence cancer risk. Two of the most important observations to date are: (1) 12 genetic variants that are known to modify sporadic breast cancer risk are now confirmed to play a similar role in BRCA-related breast cancer risk; (2) several new locations of gene variants which may affect risk for ovarian cancer in BRCA mutation carriers have been identified. Over time, researchers expect these studies will help to improve and individualize BRCA-related cancer risk assessment and help women make risk-management decisions.

“...several new locations of gene variants which may affect risk for ovarian cancer in BRCA mutation carriers have been identified.”
Study to Follow Women After Fallopian Tube Removal

Have you had your fallopian tubes removed to reduce your ovarian cancer risk, and kept one or both of your ovaries? Researchers at the University of Washington are collaborating with FORCE to study the long-term outcomes of prophylactic salpingectomy (removal of the fallopian tubes).

To learn more about this study, call 206-685-7927 or email vhy@uw.edu or kagnew@uw.edu. (They cannot ensure the confidentiality of any information sent by email.)

FORCE Research Surveys

FORCE conducts and partners with researchers who conduct surveys to better understand and address the needs of our community. By participating in surveys for which you are eligible, you help us promote and advance hereditary cancer research.

Visit facingourrisk.org/survey to learn more and participate.

Institute of Medicine Report on Environmental Causes of Breast Cancer

by Amanda Grannis

Inherited gene changes can affect the risk for breast cancer. But scientists know that there is more to cancer risk than just genes. Non-genetic factors such as hormone exposure, alcohol, chemicals, and radiation are also known to influence risk. Susan G. Komen for the Cure asked the Institute of Medicine (an independent health arm of the National Academy of Sciences) to review the current evidence on breast cancer and the environment, consider gene-environment interactions, and provide recommendations for future research. The results of this study were presented at the San Antonio Breast Cancer Symposium in December 2011.

IOM researchers are aware that breast cancer is complicated, and tying environmental factors to cancer risk is difficult because breast cancer can be triggered by multiple causes which may vary between individuals. Nonetheless, after reviewing a wide scope of scientific research and data, the study examined the interplay between environmental conditions and life stages of breast development. Certain periods of life were deemed to be “critical windows” for personal breast cancer risk—specific episodes of hormonal change, whether in times of puberty, childbearing years, or menopause, may trigger a particular vulnerability to environmental cancer-causing exposures. The study authors emphasized that these and other age-related periods of heightened susceptibility to environmental risks might be an appropriate focus for future investigations.

Researchers formulated strategies for breast cancer risk reduction and other suggestions for future studies. While casual links between environment and breast cancer occurrence continue to be elusive, the study identified controllable lifestyle factors that can reduce a woman’s odds for a breast cancer diagnosis. Researchers concluded that women can reduce their risk by limiting alcohol, abstaining from smoking, avoiding combined progesterone-estrogen hormone therapy, and exercising to control weight, especially after menopause.

Strategies for risk reduction cannot be boiled down to one-size-fits-all advice. Rather, as researchers concluded, future studies must take into account that environmental agents present varying risks according to age, development, and genetics. Scientists will need to adopt innovative approaches to study the complex and individualized impact of environmental factors on breast cancer occurrences.

Amanda Grannis is a college senior who is impacted by generations of hereditary breast cancer. Passionately committed to women’s health and the courageous community of BRCA previvors and survivors, she plans to attend law school next year, pursuing a career in health law.


Visit the website listed above for the IOM’s table of risk-reducing actions. (Scroll down to “Report at a Glance” and click on “Table: Opportunities for Action.”)

Environmental Causes of Breast Cancer

Reference

What's New @ FORCE

**Meaningful Mitzvahs**
Raise Awareness of Hereditary Breast and Ovarian Cancer and Support the FORCE Hereditary Cancer Research Fund. Jewish boys and girls around the country are teaming up to make a difference. We hope you will join them by selecting FORCE as your Bar/Bat Mitzvah project. The goal is to educate the Jewish community about hereditary breast and ovarian cancer, fund important research, and help save lives. There is no better way to celebrate your Mitzvah!

**Helpline Now in Spanish**
Spanish-speaking callers can now connect with a volunteer or a genetic counselor by calling our toll-free Helpline at 866-288-7475, ext. 720. If you are a health care provider or you know someone who needs peer support or resources in Spanish, we encourage you to refer them to our Helpline.

**Enhanced Reconstruction Pages**
Our website’s newly-upgraded reconstruction pages will allow members to upload and share their before-and-after photos with other women who are considering post-mastectomy options. Visit the FORCE website to upload or view photos.

**FORCE Launches Research Advocacy Training**
FORCE’s Research Advocate Training Program is an introductory course that will lay the foundation for members of our community to become engaged in research review and safety panels. The program will consist of webinars on topics including cancer basics, genetics, intro to clinical trials and research, patient protection, ethics, and more. Visit facingourrisk.org/advocacy for more information.

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.