

Prevention *matters*

| A FOX CHASE CANCER CENTER RISK ASSESSMENT PROGRAM PUBLICATION | SPRING/SUMMER 2016 |

Risk Assessment Program – 25 years at Fox Chase Cancer Center

The Risk Assessment Program (RAP, formerly the Margaret Dyson Family Risk Assessment Program) is celebrating its 25th anniversary in 2016. Founded in 1991, it was the first program of its kind in the region and one of the first in the U.S. RAP began with funding from the Dyson Foundation, as a memorial to Margaret Dyson, who died of ovarian cancer in 1990. The program, initially for ovarian and breast cancer risk, now also includes risk assessment for several types of cancer, including prostate, gastrointestinal, lung, melanoma, and kidney. The goal of our program is to help those at high risk of developing cancer learn about risk factors and preventive measures. RAP provides education, individualized counseling, genetic testing, and screening to high risk patients.

Many milestones in genetics have occurred during this period – the discovery of the *BRCA1* and *BRCA2* genes, Lynch genes and other genes for which genetic testing is now available; new screening methods such as breast MRI; chemoprevention options (Tamoxifen and Raloxifene); and gene panel testing.

Our participants have graciously agreed to take part in our many research studies. They have offered their personal experiences at support groups, education programs and training courses, and they allowed us to use this information to develop guides, education videos and websites. Many of our staff members have worked in our program for over 20 years, getting to know our participants and their families, providing familiar faces and voices over the years.

The program now includes 14,867 participants representing 11,078 families, with 6,628 getting genetic testing. Having a large population base of high risk individuals and family members has enabled us to broaden research in areas such as behavioral medicine and communication. Collaborations have been formed with other institutions, providing many opportunities to



**Fox Chase Cancer Center
Risk Assessment Program
Celebrating 25 Years
1991-2016**

conduct research that might help prevent or diagnose cancer at an earlier and more treatable stage.

RAP has provided a training ground for genetic counseling and public health students, nurses, and medical oncology fellows from across the United States. Education materials have been developed to provide genetic information to our participants, including breast/ovarian cancer risk books, and an online education website where participants can complete their personal and family histories.

We look forward to continuing to provide our participants with service and support offered through the Risk Assessment Program at Fox Chase.



Mary B. Daly, MD, PhD, Chair of the Department of Clinical Genetics



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Next Generation Sequencing-Based Tumor Genomic Profiling Aids in Detecting Hereditary Variants in Cancer Risk Genes

Michael Hall, MD, MS, Associate Professor, Director, Gastrointestinal Risk Assessment

More cancer patients are having their tumors tested using comprehensive genomic tumor profiling (GTP). The testing helps to find genetic changes in tumors that can be treated by precision therapies. This means that cancer is treated based on a person's genes, rather than by specific location in the body, such as the breast or colon.

In a new study, Dr. Michael Hall, along with Foundation Medicine, examined 15,060 tumor samples using Next-Generation Sequencing (NGS) technology, which is more accessible, quicker and cheaper than previous methods. Investigators looked at 20 hereditary cancer risk genes. The American College of Medical Genetics and Genomics determined these genes to be very important to share with patients if a variant (inherited alteration) is found by genomic testing.

The study found that 30.8 percent of tumors had at least one germline variant (inherited alteration in a gene or cell that can be passed to children) in a cancer risk gene. A likely pathogenic variant (alteration in a gene which is likely to contribute to the development of cancer) was found in about 3.1 percent of tumors, and suspicious alteration in 3.9 percent of tumors.

Based on these results, it is predicted that 3-7 percent of patients receiving genomic tumor profiling using Next-Generation Sequencing (NGS) could have a genetic mutation inherited from a parent. Dr. Hall presented the study results at the 2015 American Society of Clinical Oncology Annual Meeting in Chicago, IL.



www.foxchase.org/news/2015-05-20-genomic-profiling-detects-variants-in-cancer-genes

Genomic Tumor Profiling in Community-Based Metastatic Colorectal Cancer Patients

Michael Hall, MD, MS, Associate Professor, Director, Gastrointestinal Risk Assessment

A research study at Fox Chase Cancer Center is offering access to free genomic tumor profiling (GTP) to cancer doctors from 4 community cancer centers in Pennsylvania and New Jersey. Community doctors can enroll their patients with advanced colorectal cancer to receive free tumor testing. The goal of this study is to increase awareness of GTP among community doctors and patients, and to help them understand complex tests

results through a phone consultation with a genomic expert. Early results show that 100 percent of 25 patients enrolled in this study are glad GTP was performed on their tumor, and 80 percent feel GTP results are valuable to their future health. Doctors' satisfaction using GTP for their patients will be reported once the study is complete. The initial study results were presented at the 2016 Gastrointestinal Cancers Symposium in San Francisco.

Biospecimen Research Participation in Chinese American Community

Carolyn Fang, PhD, Associate Professor, Co-Leader, Cancer Prevention and Control

Medical research often relies on the availability of human samples (biospecimens), such as blood or tissue, to explore the basic biology contributing to disease risk or treatment outcomes. However, people from racial and ethnic minority groups have historically been less likely to donate samples for research purposes. Low rates of racial/ethnic minority participation may have a negative impact on advances in medical research and may limit the ability to address scientific questions about patterns of disease risk and outcomes across all populations. There is a growing need to identify barriers to participation in biospecimen research in many communities.

Dr. Carolyn Fang, in her research at Fox Chase Cancer Center, found that Asian Americans report limited knowledge and awareness about biospecimen research. Asian Americans may also hold cultural beliefs about the

physical toll or harmful health effects of blood donation. To address these concerns, the researchers developed a culturally-specific course on biospecimen research and made it easier to donate a sample. This educational course, which was delivered to the Chinese American community along with several Chinese community-based groups in Philadelphia, was successful in addressing questions about biospecimen research. Following this program, 83 percent of participants donated blood samples for future medical research. Providing culturally-specific educational programs about biospecimen research, and addressing concerns, may be helpful in increasing awareness and interest in participation in biospecimen research, among communities that have been underrepresented.



www.ncbi.nlm.nih.gov/pubmed/24609847



Risk Assessment Program 25th Anniversary Celebration

The Fox Chase Cancer Center Risk Assessment Program (RAP) is hosting a special event in April to celebrate 25 years of cancer risk assessment. The evening's emcee will be Pat Ciarrocchi, Emmy Award Winning Philadelphia TV News Anchor. We will bring together RAP participants, alumni, and staff for an evening of celebration, information and shared experiences at Knowlton Mansion in Philadelphia.



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New Risk Assessment Program Website

Fox Chase Cancer Center, and the Risk Assessment Program (RAP), have a new website. The new Fox Chase website focuses on clinical and research excellence, patient support, and community involvement. The website is viewable on your phone, tablet, laptop and desktop computer. On our RAP website, you will find our latest brochures and newsletters, get information on making an appointment, read the latest cancer genetics news, view our cancer information blog, learn about cancer risk and prevention, genetic counseling, and testing, and meet the risk assessment team. Our Risk Assessment Program website is found at www.foxchase.org/rap.

Have Mammogram Guidelines Changed?

Agnes Masny, RN, MPH, MSN, CRNP and Susan Montgomery, RN, BSN, OCN, GCN

You may have heard that in January 2016, the United States Preventive Services Task Force (USPSTF), a panel of medical experts, released guidelines recommending that women need fewer mammograms than had been recommended in the past. This can often be confusing, especially for women at increased risk for breast cancer.

These new guidelines are based on age and apply to women at AVERAGE RISK. Among the key recommendations are mammography every two years from ages 50-74, and individualized decision making about mammography based on a woman's values, preferences and health history between ages 40-49. No recommendations were given for women age 75 and older as the task force felt more research is needed.

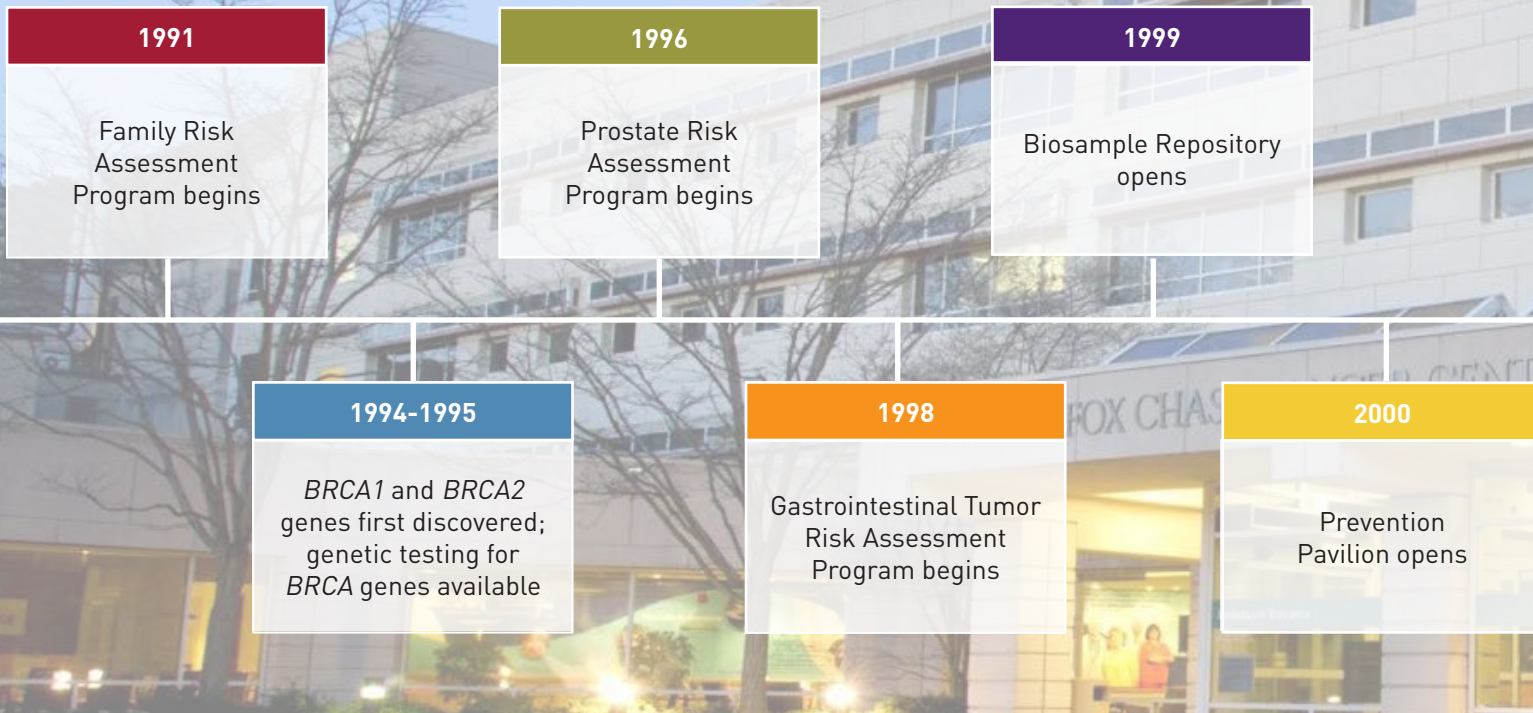
Other medical groups offer different advice about screening. The National Comprehensive Cancer Network (NCCN), an alliance of prominent cancer centers, recommends mammograms every year starting at age 40. They also recommend earlier screening with mammogram and possibly breast MRI based on having a gene mutation or a family history.

In addition, Congress passed a bill in December, 2015 requiring insurers to pay for screening mammograms for women 40 and over every one to two years without copays, coinsurance or deductibles, through 2017.

The Fox Chase Cancer Center Risk Assessment Program follows the NCCN guidelines. We would not change recommendations for high risk women to start screening later or have fewer mammograms.



RISK ASSESSMENT



Updating Your Family History – an Important Thing to Do

If you have been a participant in the Risk Assessment Program (RAP) for any length of time, you would have filled out a Health History Questionnaire (HHQ) when you first joined the program. It is important to keep us updated on changes to your medical and family cancer history. Information is stored in our secure RAP database. If you also joined our RAP Registry (the research part of our program), the data is analyzed and used when applying for research grants and writing papers for medical and scientific journals. When new grants are funded, we may use this information to find out who may be eligible to participate in these new research studies.

Updating your medical and family history is also an important part of your health care plan. Letting your doctors and nurses know about any deaths, cancer or other diseases gives your health care team the information they need to keep you well. When you have your annual visit here at Fox Chase or with other doctors, it is important to communicate any changes to you or your family members' health.



For these reasons, you can see why it is very important to update your information on a regular basis. We thank all of you who have taken the time to fill out the health history questionnaires. RAP participants can contact Joann Sicilia, Clinical Genetics Assistant at 1-800-325-4145 if you have any updates to your family cancer history.

THROUGH THE YEARS

2009

Women's Cancer Center opens

2010

RAP offers online health history questionnaire and education website

2013

Gene panel testing begins offering genetic testing beyond *BRCA1* and *BRCA2*

2009

Department of Clinical Genetics
(All Risk Assessment Programs combined)

2011

RAP celebrates its 20th anniversary

2016

RAP celebrates its 25th anniversary



ASK THE GENETIC COUNSELOR

Michelle Savage, MS, LCGC

There is colorectal cancer in my family and several years ago I had genetic testing that included some hereditary colorectal cancer genes. This testing came back negative. Is there any new genetic testing available now for other hereditary colorectal cancer genes?

Genetic testing for hereditary colon cancer has expanded over the past few years. Three new hereditary colorectal cancer and polyposis genes have recently been discovered. Testing is now available for these genes for individuals who have personal and/or family histories suggestive of these syndromes.

The *POLE* and *POLD1* genes are newly discovered genes which are associated with early onset colon cancer and polyps called adenomatous colon polyps. Some people with these mutations make very few colon polyps, while others can make dozens or even hundreds of colon polyps. People with *POLE* or *POLD1* mutations may also have an increased risk of developing uterine and brain cancer, although research is not certain regarding these risks at this time.

The *GREM1* gene has also been recently described as a gene responsible for some cases of hereditary mixed polyposis. Individuals with *GREM1* mutations have a high risk of developing early onset colon cancer. *GREM1* mutation carriers can make many different types of colon polyps and these polyps can start developing in adolescence or young adulthood. So far, alterations in the *GREM1* gene have only been seen in families with Ashkenazi (Eastern European) Jewish ancestry.

There are currently multi-gene panel tests available that include the *POLE*, *POLD1* and *GREM1* genes. Most health insurances will cover genetic testing if you or close family members have had colon cancer diagnosed under age 50, more than 10 colon polyps, or colon polyps found at very young ages of onset. You may be eligible for additional genetic testing of the *POLE*, *POLD1* and *GREM1* genes, if you have had negative or indeterminate genetic test results for Lynch syndrome or Familial Adenomatous Polyposis (FAP) in the past. If you have questions regarding additional testing for yourself or a family member, please contact a genetic counselor at the Risk Assessment Program (877-627-9684).



MAN 2 MAN



American Society for Clinical Oncology (ASCO) recent research highlights

Elias Obeid, MD, MPH

Metastatic castration-resistant prostate cancer (mCRPC) is when the cancer has spread to parts of the body other than the prostate, and is able to grow and spread despite treatments being used to manage the cancer. For men with this type of disease, additional treatment is needed to help control the growth of the cancer.

A recent presentation at the American Society of Clinical Oncology (ASCO) meeting on Genitourinary Cancers (DeBono et. al.) discussed the role of DNA repair as a target in treatment of mCRPC. 20-30 percent of patients with this type of prostate cancer are not able to repair DNA damage in the cell, sometimes due to inherited mutations in genes such as *BRCA2*. There is recent evidence that DNA repair defects lead to much worse outcomes.


PARP inhibitors (a type of cancer treatment targeting DNA repair) seems to have a promising activity in treating those mCRPC with DNA repair defects. PARP inhibitors are currently approved for use in ovarian cancer arising in the setting of an inherited *BRCA1/BRCA2* mutation. This study paves the way for more research in this field with potential use of this therapy for certain mCRPC.

At ASCO, researchers discussed a clinical trial which used PARP inhibitor Olaparib for patients with mCRPC. The goal of the study was to evaluate the effectiveness of Olaparib as well as to find clinical biomarkers to see which patients will respond to this drug. The research has shown that PARP inhibitors may be a promising treatment for some patients with this type of prostate cancer, particularly if the mCRPC has a DNA repair defect or arising in the setting of an inherited *BRCA* mutation.

At Fox Chase, we currently have a clinical study, in collaboration with researchers from Jefferson, that is looking at the relationship between genetic mutations (some of them are involved in DNA repair) and the risk of prostate cancer. The results from this study are anticipated to inform men and their families about their risk of getting prostate cancer from an inherited predisposition. Given the findings by Debono et. al., our findings may help identify those at risk and potentially those who may benefit from targeted therapy for their cancer.

 <http://meetinglibrary.asco.org/content/117109?media=vm>

For additional information about prostate cancer risk assessment and research, visit:

 <https://www.foxchase.org/rap/high-risk-cancer-clinics/high-risk-prostate-clinic>

PHILADELPHIA BREAST CANCER FAMILY REGISTRY (BCFR) new follow-up questionnaire

The six Breast Cancer Family Registry (BCFR) sites (Philadelphia, New York, California, Utah, Canada and Australia) have sent out a new, standardized questionnaire to participants. Using the same questionnaire at all the BCFR sites enables us to easily combine data to fully use the very valuable research resource provided by the Registry. We thank everyone who already took the time to complete the new follow-up questionnaire, mailed out over the

past few months. We appreciate all the support our participants give to this ongoing research. Our BCFR data continues to be used by cancer researchers around the world in order to find new ways to prevent, diagnose, and treat cancer. Many individual investigators at all stages of their careers have used the BCFR data since its start in 1996, generating over 300 scientific publications. We are grateful for 20 years of funding from the National Cancer Institute.

HEALTHY GROCERY LIST

Make fruits, vegetables, beans and whole grains the biggest part of every meal. Use this list next time you shop.

Produce

- Sweet potatoes
- Cauliflower
- Brussel sprouts
- Bok Choy
- Spinach
- Kale or collard greens
- Peas
- Romaine lettuce
- Edamame
- Tomatoes
- Garlic
- Pears
- Oranges
- Grapes (red or purple)

Protein

- Lean chicken or turkey
- Lean fish (salmon, halibut, red snapper)
- Tofu
- Black, red or pinto beans
- Garbanzo beans/chickpeas

Dairy

- Skim milk
- Low-fat cheese
- Eggs or egg substitutes

Grains

- Wild or brown rice
- Whole grain pasta
- Lentils
- Whole grain bread

Cereal

- Bran flakes
- Oatmeal

Snacks

- Popcorn
- Whole grain tortilla chips
- Hummus
- Almonds (plain, unsalted)

Condiments

- Olive oil
- Canola oil
- Low-fat or fat-free salad dressing

Beverages

- Juice (100 percent juice, no added sugar)
- Green or white tea

HEALTHY RECIPES

Fusilli with Broccoli Rabe Pesto and Burst Cherry Tomatoes

- 1 bunch broccoli rabe
- 4 Tbsp. extra virgin olive oil, divided
- 8 oz. whole-wheat or whole-grain fusilli
- 1/4 cup slivered blanched almonds
- 1-2 large garlic cloves, coarsely chopped
- red pepper flakes, optional
- 1/4 cup (1 oz.) freshly grated pecorino cheese
- Salt and freshly ground black pepper
- 1 1/2 cup (10.5 oz.) small cherry tomatoes

Bring large pot filled with water to boil. Cut off bottom 2 inches of stems from broccoli rabe. Break off and discard remaining woody part from thick stems. Pinch off and set aside florets.

Add 1 tablespoon oil to boiling water. Add broccoli rabe. Cook with water bubbling until greens are tender but firm, 8 minutes. Drain greens.

Cook pasta according to package directions. Pulse almonds, garlic and red pepper flakes (if using), in food processor until coarsely chopped, 10-12 pulses.

Add broccoli rabe and pulse until it is coarsely chopped. Add cheese and pulse 10 times, then drizzle in 2 tablespoons oil. Pesto should be finely textured with white flecks of nut, not a smooth puree. Season to taste with salt and pepper.

Drain cooked pasta. Add pesto and combine with pasta. In medium skillet heat remaining tablespoon oil over medium-high heat. Add tomatoes and keep tomatoes rolling in pan until skin cracks. Put tomatoes on top of pasta and serve.

Per serving: 424 calories, 21 g total fat (3 g saturated fat), 48 g carbohydrate, 12 g protein, 3 g dietary fiber, 110 mg sodium.

Makes 4 servings.

(Yield 1 1/4 cup pesto, about 1/3 cup per serving).

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The Department of Clinical Genetics offers one of the most comprehensive risk assessment programs in the Philadelphia region. It encompasses all of Fox Chase Cancer Center's clinical services for people at risk for cancer, as well as innovative research in the areas of cancer prevention and genetics.

CONTACT THE RISK ASSESSMENT PROGRAM:

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MARK YOUR CALENDAR

March is Colorectal Cancer Awareness Month, and Kidney Cancer Awareness Month

Colon Cancer Coalition Get Your Rear in Gear 4M Run/Walk
April 3, 2016
Memorial Hall, Philadelphia
www.coloncancercoalition.org

Sandy Rollman Ovarian Cancer Foundation
12th Annual Sandy Sprint
April 23, 2016
Philadelphia Museum of Art
www.sandyovarian.com

May is Skin Cancer Prevention and Detection Month

Komen Philadelphia Race for the Cure
May 8, 2016
Philadelphia Museum of Art
komenphiladelphia.org/race/

FORCE (Facing Our Risk of Cancer Empowered)
10th annual "Joining FORCES Against Hereditary Cancer"
conference
October 6-8 2016, Orlando, Florida
www.facingourrisk.org

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