Prevention Matters

| A FOX CHASE CANCER CENTER RISK ASSESSMENT PROGRAM PUBLICATION | SPRING/SUMMER 2020

Living with Lung Cancer - A Patient Perspective

Interview with **Sue Galeone, a member of the Patient and Family Advisory Council at FCCC**

How were you diagnosed with lung cancer?

In 2013, I had a persistent cough that would not go away. I was being treated by my primary care physician for allergies and from there went through two rounds of antibiotics and steroids. When the cough still did not clear up, I was sent for an X-ray, which showed something suspicious. My PCP immediately set me up with Dr. King at Fox Chase, and from there I had a CT scan, PET scan, MRI and eventually a bronchoscopy. I was then diagnosed with metastatic adenocarcinoma lung cancer. Dr. King felt I was a good candidate for molecular testing which showed that I have an ALK-Positive mutation. Only five percent of patients test positive for a specific mutation. This allowed me to be treated with a targeted drug therapy instead of traditional chemo therapy.

What kinds of reactions did your family and friends have when you told them you have lung cancer?

I think the overall reaction from family, friends, and myself was total shock. I had always been a healthy person who exercised every day, ate a healthy diet, didn't smoke, was just a social drinker, and never took drugs. I prided myself on this and to this day I'm still working and exercising daily and eating healthy. I joke with everyone that except for the cancer, I'm a healthy person. Other than my cancer medicine I am on no other drugs, no blood pressure or cholesterol medication, nothing.

What resources have you used to find out more about your disease?

Like everyone else I went on the internet but quickly learned that the statistics were terrifying and outdated. Cancer treatment is changing and improving so quickly and the statistics online are not keeping up as quickly. I have found some wonderful inspirational online sites with other cancer patients where you can discuss and ask each other questions and share your journey. I have learned that there are many people out there who have been living with cancer for many, many years. I also discuss everything with Dr. Borghaei, who is a total rock star in my eyes. He is always keeping me aware of the new drugs that are being approved. One of his favorite lines he uses when I get nervous is, "Don't worry, we have three more drugs right behind this one." And my personal favorite is, "It's not the end of the world." And I always laugh and say, "Yeah not for you, but could be for me!" He always makes me feel better after we talk. He gets my weird sense of humor.

How has your disease changed your lifestyle?

Not a whole lot; I still do the same things that I did before cancer. Not that I would wish cancer on anyone, but in some ways, cancer has changed my life for the better. I certainly don't sweat the small stuff anymore. I'm grateful for every single day, no matter how mundane. In the beginning, it was hard for me to plan ahead, but as time went on I realized that I wasn't going to let fear take me down before my time. I get up every day and thank God for another beautiful day of life and I try to live it to the fullest. I'm grateful for my family and friends and have enjoyed many wonderful holidays, vacations, and days just hanging out together, and as a result there are many times that I actually forget that I have cancer. That's pretty great!

Continued on Page 2

FOX CHASE CANCER CENTER
TEMPLE HEALTH

IN THIS ISSUE

RESEARCH NEWS • page 3
MALNUTRITION AND CANCER • page 5
MAN 2 MAN • page 6

Living with Lung Cancer - A Patient Perspective *Continued from Cover*

Do people usually assume your cancer was caused by smoking?

If they did assume that they certainly did not say that to me. Honestly, when I tell someone who doesn't know me, I always feel that I have to tell them that I wasn't a smoker, so I guess that's just me projecting, because I feel that it's important to get it out there that more and more younger nonsmoking women are being diagnosed with lung cancer. As long as you have a pair of lungs, you can get lung cancer.

Do you have a family history of cancer? Any environmental exposure?

No environmental exposure that I'm aware of. As for the family history, my father had melanoma. My mother had breast cancer which was caused by hormonal treatment for menopause. She never had a recurrence and lived another thirty years. I did have an aunt, my father's sister, who died of bone cancer in her sixties.

Right now we have very little evidence that lung cancer is related to inherited genetic changes. If a hereditary gene was known to cause lung cancer, would you seek testing?

Of course I would; again, knowledge is power. If I knew I should be looking for something, I would make absolutely sure I was being proactive about screenings and my health. The sooner you can detect cancer, the more likely you can cure it. I would also make sure my children and siblings were tested too, even if I had to take them kicking and screaming. Burying your head in the sand accomplishes nothing.

How do you maintain a positive outlook while living with this disease?

I really believe that is just who you are as a person. I was always the glass half full kind of gal, the eternal optimist. When I was first diagnosed, I was just overwhelmed by fear: fear of the unknown, fear of dying, fear like I had never known before. However, as time went on and I started feeling better, I realized that yes, I would probably die of cancer, but not today. It kind of became a mantra for me. I decided I wasn't going to waste what time I had left living in fear, so I started living normally again, one day at a time. And little by little I started planning for the future: vacations, graduations, weddings and grandchildren. It does help that I have a wonderfully supportive husband, family, and friends who really just make my life worth living.

What's a piece of advice you've learned on your journey that you might offer someone newly diagnosed with lung cancer not related to smoking?

Don't drive yourself crazy wondering how or why. Take one day at a time and know that this isn't the death sentence it once was, that you can actually live with cancer just like any other chronic disease, like heart disease and diabetes. The single most important piece of advice that I always give to someone newly diagnosed is that I don't care which hospital you go, to but make sure that you get yourself to a cancer hospital. This is what they do and they have all the latest treatments and it's your best chance at beating cancer.

Thank you for sharing your story with us.

WELCOME ABOARD

Hannah Campbell, ScM, a new genetic counselor in the Department of Clinical Genetics

I am thrilled to join the team at Fox Chase and return to my hometown. Originally from Cheltenham, I left the Philadelphia area to earn a degree in Cell and Molecular Biology from Connecticut College. After graduation, I joined the Lymphoma Clinical Trials group at Weill Cornell Medicine where I helped to coordinate treatment for patients on clinical drug trials, and collaborated on projects aimed at identifying risk factors for lymphoma.

I went on to receive my Masters in Genetic Counseling from the Johns Hopkins/ National Institutes of Health Genetic Counseling Program, where I recently completed my training. I am excited to learn and grow with the RAP team and look forward to helping patients navigate the cancer risk assessment process.

Germline genetic testing for hereditary cancer risk in patients with lung cancer not associated with smoking and biliary tract cancer

Lung cancer is the leading cause of cancer death, regardless of gender or ethnicity. Tobacco use remains the primary cause of most lung cancer cases, yet cancer in never smokers accounts for nearly 20 percent [1 in 5] of cases. While Americans are smoking less and rates of tobacco related lung cancers have decreased in the U.S. and many other developed countries, the cases of lung cancer in never smokers are increasing. More women than men are diagnosed with this disease.

Researchers have theories on what may cause lung cancer in never smokers. Risk factors such as second-hand smoke, environmental toxins, infectious factors, hormone exposure, and genetics have all been suggested as possible causes.

While second hand tobacco smoke exposure is known to be a primary risk factor, the contribution of other risk factors is not clear. One factor is heredity. Research studies suggest an increased risk for lung cancer in patients with a family history of lung cancer, especially those with first-degree relatives. Some evidence points toward a genetic link in a few cases. However, it is unknown whether shared environmental or behavioral factors, play a greater role in a family's history of lung cancer than genetics.

Similarly, the biliary tract cancers, which include aggressive invasive cancer arising in the liver, gallbladder, and bile duct, also have limited data related to hereditary risk.

Pancreatic cancer has shown to be a hereditary risk in approximately 10-15% of cases. The current NCCN (National Comprehensive Cancer Network) guidelines recommend that germline testing should be considered for any patient with personal or family history of pancreatic cancer.

Since the pancreatic head/neck and the distal bile duct share many similar surgical and chemotherapy treatment options, it is reasonable to think that biliary tract cancers may also have a significant familial factor.

At the present time, genetic testing for never-smoking lung cancer and biliary tract cancers is not standard of care. There is not enough data to support a hereditary link and warrant genetic testing in these tumors. Therefore, insurance companies are unlikely to cover the cost of genetic testing for such patients, even when criteria for a hereditary syndrome are met, leaving patients and their families unaware of cancer risks.

We are conducting a study at Fox Chase that will offer genetic testing for hereditary syndromes to patients with never-smoking lung cancer and patients with biliary tract cancer. Participants will be tested using a multi-gene panel that will examine genes associated with hereditary breast, ovarian, uterine, colorectal, gastric, prostate, melanoma, pancreatic and other cancers.

We will recruit patients at Fox Chase to undergo genetic testing at no cost. Participants will be asked to provide either saliva or blood sample for testing.

The study will allow us to estimate the prevalence of germline mutations in the common hereditary cancer risk genes in both of these under-tested populations.

The long-term goal of this study is to inform doctors and counselors of the possible hereditary risks underlying these cancers, and possible patient and family-history related factors that predict those individuals at highest risk.

Prevention Clinical Trial for Lynch Syndrome

We continue enrolling patients and family members with Lynch syndrome in the prevention clinical trial.

This study is looking at new ways to lower the risk of developing colorectal cancer by taking aspirin, an oral medication commonly used for treatment and prevention, and atorvastatin (known commercially as Lipitor), a medication that treats high cholesterol. It is our hope that the results of this research will be helpful in developing better ways to prevent colorectal cancer in patients with Lynch syndrome.

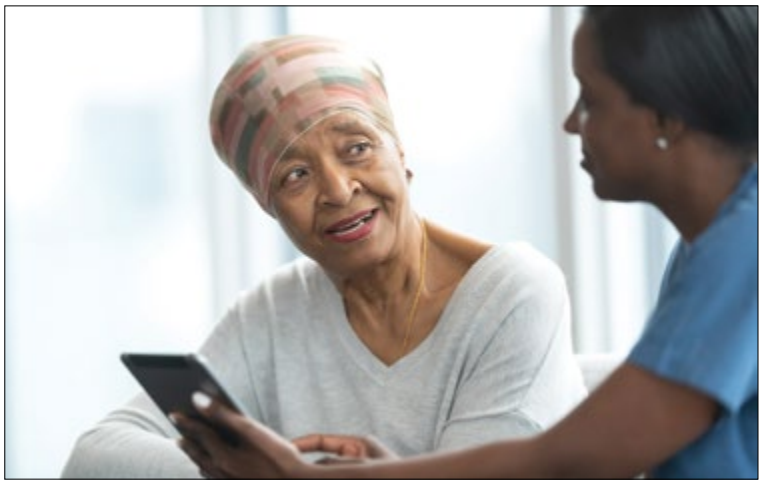
For this study, we are looking for individuals with Lynch syndrome who currently have their screening colonoscopies performed at Fox Chase or who would be willing to do their usual screening colonoscopy at Fox Chase one time and take a preventive medication(s) for 6 weeks.

For more information about research studies, please call 1-800-325-4145

National Minority Cancer Awareness Month, observed in April, is sponsored by the National Cancer Institute (NCI) and other organizations across the country. This month is dedicated to calling attention to minority cancer health disparities and the need for awareness

A new, multi-phased study, titled **"E-IMPART: Enhancing Informed-decision Making in Physicians and African American patients on Tumor Genomic Profiling Testing",** is being offered at Fox Chase and Temple Hospital for African American cancer patients. The study is sponsored by the American Cancer Society (ACS) and led by Dr. Michael Hall, a GI oncologist at Fox Chase Cancer Center, and Dr. Sarah Bass, an Associate Professor at Temple University's College of Public Health.

Tumor Genomic Profiling (TGP) testing is increasingly being used in oncology to identify genetic markers in tumors to inform treatment decisions. Sometimes, tumor testing can also identify patients' hereditary cancer risks, which can be passed from parents to their children. In the case where hereditary cancer risk is found in testing, patients must be involved in complex decision making around knowing, understanding and sharing genetic information with their family. However, many patients, especially minority patients who may have less trust of healthcare and have lower knowledge of genetic risks, are vulnerable to misunderstanding how to make decisions about genetic risk information. Relatedly, many oncologists may not know how to effectively communicate about these genetic risks with their patients. The study investigates African American patients' experiences with making treatment decisions, especially their thoughts about genetic testing like tumor profiling and as well potential communication barriers for oncologists. The ultimate goal is to develop web-based programs that will help African American patients understand what tumor genetic testing is, and what information they would want shared with them in order to make a decision, as well as tools for oncologists to better communicate with their patients.



Five focus groups with African American cancer patients were conducted at Fox Chase Cancer Center and Temple University Hospital from November 2018 to February 2019.

From these discussions we learned that:

- Participants had concerns about having to share genetic information with family due to stigma, lack of support or to protect loved ones.
- Participants were skeptical of undergoing genetic testing or having genetic information as part of their medical record. Some expressed concerns about health insurance denial.
- Feelings were mixed related to receipt of hereditary information from tumor testing, but most agreed that this is important for their treatment and their families.
- Some participants expressed mistrust of medical information, doctors and health systems in general.
- Many discussed poor communication with doctors and being not well informed.
- Most agreed they would like to share responsibility with doctors in treatment decision making.

Data from these discussions has informed development of an in-depth survey which has been completed by 150 African American cancer patients. Similar work is being done with oncologists. Web-based educational programs for patients and physicians will be developed based on the participants' responses to the survey. The preliminary study results were presented at the APHA (American Public Health Association) annual meeting in November 2019.

A big thank you to all patients who participated in the focus groups and completed the survey. We greatly appreciate your time and honest opinions.

MALNUTRITION AND CANCER

Rishi Jain, MD, MS, DABOM, a medical oncologist whose research interest focuses on the intersections between diet, nutrition, physical activity and cancer therapy.

Studies have shown that up to 80% of patients with cancer experience involuntary weight loss at some point during the course of their disease. Malnutrition due to poor food intake is often complicated by a cancer-specific syndrome of body wasting (cachexia) and loss of muscle mass (sarcopenia) with or without loss of fat mass, which can be present in both early-stage and advanced cancers.

What is the cause of malnutrition?

Many factors can lead to malnutrition. Inflammatory substances released by a cancerous tumor can directly impact food intake in the brain and affect liver function. Side effects from cancer treatment can decrease appetite and eventually lead to mass and muscle loss. Other factors can influence nutrition intake among cancer patients, such as depression, tiredness and reliance on others.

Certain cancers like pancreatic, gastro-esophageal, and stomach cancer have higher rates of malnutrition, and a majority of these patients are dealing with this issue even before diagnosis.

How do we measure nutritional status in patients?

The most common tool we use in clinic is looking at changes in body weight. Some labs can be helpful, as well. There are multiple validated questionnaires that can be used to evaluate for malnutrition, but these are not always used in busy oncology clinic. Some imaging, such as MRI and CT-scan can measure body composition and muscle mass which may be related to nutritional status. These tests are routinely done by radiologists for diagnostic purposes, but measures of muscle mass are not typically reported. To evaluate physical performance, our physical therapy colleagues use walk assessments, chair rises, and hand-grip strength methods. There is no consensus on the best method; however, using a combination of tools can be effective in assessing the nutritional status of patients.

How can we help patients with malnutrition?

The ideal scenario involves nutrition counseling with a dietitian. This can be challenging, because it requires a separate visit, which is often not covered by insurance. The next step is nutritional supplements. A physician may recommend nutrition drinks such as BOOST and ENSURE after identifying malnutrition.

The next level is an enteral feeding for specific types of cancer, such as head and neck cancer, or esophageal cancer. We often really need this type of support for these specific cancers. The most aggressive support is a parental feeding, when nutrition is given intravenously. This method is not good for long- term outcomes, because of the risk of infection or stress on other organs.

Why is it important to identify patients with malnutrition?

Malnutrition and muscle loss are associated with poor cancer outcomes in a variety of different cancer types. Studies have shown that patients with malnutrition may experience more side effects from cancer treatment, and have reduced response rates to treatments. Malnutrition has also been shown to reduce quality-of-life and even survival rates. In the era of immunotherapy, there is emerging data where muscle loss may also impact how much patients benefit from immunotherapy.

Phase I clinical trials are the foundation of oncology. Unfortunately, only approximately 5% of the oncology drugs tested in the Phase I clinical trial setting lead to FDA approved treatment. We suspected that many patients enrolled in these studies are malnourished and have higher risk of side effects. There is very little data regarding the rates and clinical significance of malnutrition in clinical trial participants. Thus, our study team at Fox Chase conducted a research study to understand how malnutrition affected outcomes in 100 patients enrolled in Phase I and II clinical trials.

What did the results of your study show?

The study results showed that 39% of patients enrolling in a Phase I or II clinical trial were severely malnourished at the time of study initiation. Those who were malnourished had poorer outcomes including significantly increased rates of treatment-related side effects, hospitalizations, treatment response rates and even lower overall survival. Also, patients who were malnourished were only able to stay on the clinical trial study for half as long. While we suspected that patients with malnutrition may have worse outcomes, the magnitude of this effect was alarming. We also found that 52% of patients were sedentary, with minimal physical activity. Low physical activity was also related to reduced ability to stay on the clinical trial.

These findings contribute to the growing literature showing that compromised nutritional status and physical performance negatively affect cancer care and outcomes. Given how important Phase I and II clinical trials are to the identification of future cancer therapies, there is an urgent need to understand the specific reasons why malnutrition may interfere with the effectiveness of these novel treatments, including immunotherapies.

MAN 2 MAN

GENETIC COUNSELING FOR MEN: AN OPPORTUNITY TO PROMOTE PHYSICAL ACTIVITY

In the last few years, genetic counseling and testing for men with prostate cancer and men at risk for prostate cancer (PCA) has expanded rapidly. Genetic counseling sessions can be a time to review healthy lifestyle choices with men.

Participants from Fox Chase Cancer Center and Thomas Jefferson University enrolled in the Genetic Evaluation of Men study completed a physical activity questionnaire. The questionnaire assessed physical activity for the past year, including aerobic and strength training. Data was evaluated based on demographics, prostate cancer status, Gleason score, metastatic disease, family history and body mass index (BMI).

Results show in men with PCA (n=158) or at risk for PCA (n=96), 84% were overweight or obese. Men with PCA did not exercise regularly according to current guidelines. Age, BMI and education were predictors of physical activity. This information can help guide future genetic counseling interventions to promote healthy lifestyle choices for men.

Read more about the study: **https://ascopubs.org/doi/abs/10.1200/JCO.2020.38.6_suppl.360**

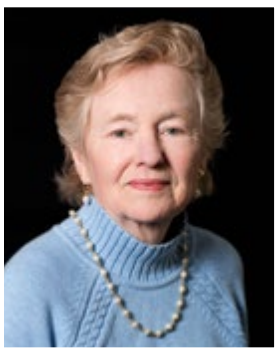
A NEW STUDY OPPORTUNITY

Dr. Elias Obeid, Interim Chief, Division of Breast Medical Oncology and the Director of Breast, Ovary and Prostate Cancer Risk in collaboration with Dr. Sarah Bass at Temple University is launching a new study for men with a diagnosis of prostate cancer: **Exploring the Prostate Cancer Genome in Men of African Descent**.This study will recruit both African American men as well as Caucasian men with prostate cancer from Fox Chase and Temple University Hospital. Participants will watch an educational video to learn about genomic tumor testing, agree to allow a sample of their cancer tumor to be sent to Caris Life Sciences for genomic testing, provide a blood sample for research, and complete several questionnaires.

The study will compare various somatic alterations (DNA changes in tumor tissue) in prostate cancer tumors of African American men with low risk localized, high risk localized, and metastatic prostate cancer and compare to those of men of Caucasian descent. Over the past few years, many patients with a cancer diagnosis are getting tumor genomic tests done, but little is known regarding patients' insights and understanding of the results. This study will assess the understanding of all men participating in the study regarding genomic tumor information. The study team hopes to learn about any barriers, by assessing the perception and interpretation of patients of their test results.

NCCN UPDATES GENETIC SCREENING GUIDELINES FOR PANCREATIC CANCER

Mary Daly, MD, PhD, FACP, an oncologist and genetic risk specialist at Fox Chase who chairs the panel that writes the NCCN (National Comprehensive Cancer Network) guidelines for hereditary breast, ovarian and pancreatic cancers comments on the new guidelines.



The National Comprehensive Cancer Network (NCCN) has been issuing guidelines for genetic testing for hereditary breast and ovary cancer for over 20 years. During that time it has become evident that pancreatic cancer is part of the spectrum of cancers seen in families with BRCA1/2 and other gene mutations, such as CDH1, PALB2, PTEN, and TP53.

It appears that approximately 10% of all cases of pancreatic cancer have a genetic basis. This number may be higher if there is also a family history of pancreatic cancer or a personal history of pancreatitis.

As a result, the NCCN recently expanded its recommendation for genetic testing to any patient with a diagnosis of pancreatic cancer. Finding a mutation may provide new treatment options for patients.

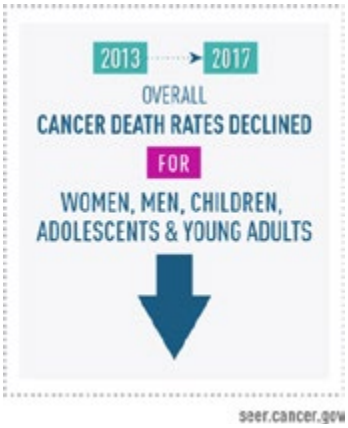
Now, PARP inhibitors are being made available to patients with pancreatic cancer who have BRCA mutations and also to men with prostate cancer. It may also provide options for screening for unaffected relatives who carry the same mutation.

Annual Report to the Nation: Cancer death rates continue to decline

According to this year's report released by the National Cancer Institute (NCI), cancer death rates have continued to decline on an average 1.4% per year among women and an average 1.8% per year among men from 2001 to 2017. This report also found that the rate of existing cancer case deaths decreased among all racial and ethnic groups between 2013 to 2017.

While lung cancer continues to be the leading cause of cancer death (about ¼ of all deaths), significant decreases in death rates of 4.8% per year and 3.7% per year were seen in men and women respectively. Among men, death rates for 11 of the 19 most common cancers decreased and death rates for women for 14 of the 20 most common cancers also decreased from 2013 to 2017.

This year's Special Section focuses on progress toward the federal governments' 10-year national objectives for improving American's health, an effort known as Healthy People 2020. Specifically, researchers focused on progress in four common cancers: lung, colorectal, female breast, and prostate. Many of the Healthy People 2020 targets for death rates, cancer screening, and major risk factors related to these cancers were met- although not in all individual sociodemographic groups. Despite some progress over the past decade, the report shows the need to address disparities in cancer screening and in certain risk behaviors.



Healthy People 2020 targets were not met for adults to decrease cigarette smoking; to increase smoking cessation success; to reduce excessive alcohol use; or to reduce obesity prevalence—all behaviors linked to cancer risk.

Read the full report here:
cancer.gov/news-events/press-releases/2020/annual-report-nation-2020

Peach Basil Salad

Our delicious salad marries summer's juicy, sweet peaches and aromatic basil with slightly briny, velvety fresh mozzarella. This quick to fix, simple salad has an enticing bouquet – peaches are related to roses after all – and lots of vitamin C, beta-carotene, calcium and fiber. It would be peachy-keen to serve as a light main dish or side salad at your next summer soirée.

Ingredients:

- 1 lb. peaches, sliced into wedges, then cut crosswise (frozen may be used)
- 8 oz. part skimmed, fresh mozzarella cheese, cut into 3/4-inch cubes
- 1 cup loosely packed fresh basil, torn into medium pieces
- 2 tsp. extra virgin olive oil
- 2 tsp. rice vinegar
- Pinch salt
- Freshly ground black pepper, optional

Directions:

1. In large mixing bowl combine peaches, mozzarella and basil
2. Drizzle on oil and vinegar, add salt and pepper, if using, and toss gently until evenly coated. Serve immediately or refrigerate up to 4 hours.

Makes 4 Servings (5 cups)
Per serving: 240 calories, 14 g total fat (7 g saturated fat, 0 g trans fat), 35 mg cholesterol, 15 g carbohydrates, 15 g protein, 2 g dietary fiber, 410 mg sodium, 11 g sugar, 0 g added sugar..

Reprinted with permission from the AICR

Prevention *matters*

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:

1-877-627-9684 | foxchase.org/rap | rapinfo@fccc.edu

Mary Daly, MD, PhD
Director
Risk Assessment Program

Michael Hall, MD, MS
Chair
Department of
Clinical Genetics

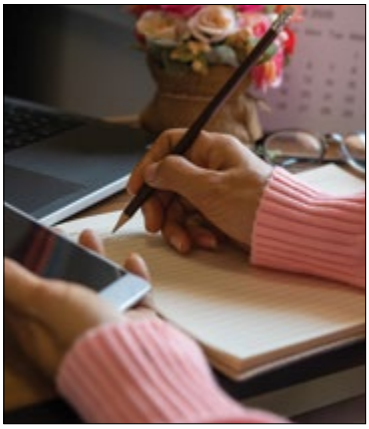
Kristen Whitaker, MD
Assistant Professor
Breast Cancer Risk

Elias Obeid, MD, MPH
Assistant Professor
Director
Breast, Ovary, and Prostate
Cancer Risk

Think *Ahead*

Schedule Your Screening Appointment Now

Our high risk clinic continues to see new and follow-up patients who are interested in receiving screening and examinations. We currently schedule appointments for anyone who has a family history of breast cancer, a genetic positive alteration, or a breast biopsy with atypia or lobular carcinoma. We are currently scheduling into the fall months, so if you are interested, please call now to get on the schedule. Our schedulers **Deb (215-728-2683)** and **Maggie (215-728-4765)** would be glad to assist you.



29

Fox Chase Cancer Center
Risk Assessment Program
Celebrating 29 Years
1991-2020

Editors: Yana Chertock, Lisa Bealin, Meredith Patrick, Joann Sicilia and Nicole Ventriglia
Designed by 4545 Creative

Risk Assessment Program
333 Cottman Avenue
Philadelphia, PA 19111-2497

FOX CHASE CANCER CENTER
TEMPLE HEALTH