Sidney Kimmel Cancer Center
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Cancer Risk Assessment and Clinical Cancer Genetics Newsletter

| March 2020 | For appointments: 215-955-1011

Message from the Director: 2019 Year in Review

Veda N. Giri, MD
Director

Greetings for 2020!

Our Clinical Cancer Genetics Program had an amazing year in 2019. The mission of the Cancer Risk Assessment and Clinical Cancer Genetics Program, which launched in late 2014, is to offer comprehensive expert genetic counseling, advanced genetic testing, and novel research opportunities to all patients. We evaluate patients with all types of cancer concerns, with thorough assessment of risk factors, family cancer history, and personal medical history for patients to make an informed decision about genetic testing. Since late 2014, we have assessed over 3,000 patients for genetic testing, cancer screening, and cancer management. Our recommendations span tailored cancer screening and cancer risk reduction, precision medicine, lifestyle modification, implications for family members, and psychosocial support for patients and their families. The "Innovation Arm" of our program centers around going "Beyond Standard of Care" by developing novel research studies to address needs in genetic counseling, genetic testing, and accelerate the knowledge of cancer predisposition and patient fulfillment with genetic testing. Of absolute importance toward achieving this goal is to embrace and promote translational research involving participants of our program to gain critical insights into genes involved with cancer predisposition, cancer risk factors, and behavioral factors that motivate decision-making for testing. Indeed, our impact spans Philadelphia, Greater Philadelphia region, southern NJ, and NE PA through our Sidney Kimmel Cancer Center- Jefferson Health sites and telegenetic services.

Some highlights from 2019 include:

Technology-enhanced AcceleRation of Germline Evaluation for Therapy – The TARGET study. SKCC-Jefferson team has received a $1M Challenge Grant from the Prostate Cancer Foundation to study the use of technology to increase access of men to genetic testing for prostate cancer. Dr. Giri is leading the study and Jefferson is the lead study site. The study is being conducted in collaboration with New York University, Manhattan VA Hospital, and University of Washington.

Peer-Based Intervention for Genetic Evaluation for Prostate Cancer among African American Men: The Peer Genetic Study. The SKCC-Jefferson team has also received a 3-year Idea Award from the Department of Defense to reduce genetic testing disparities among African American men. Dr. Giri and Dr. Leader are lead co-investigators on this novel project.

Philadelphia Prostate Cancer Consensus Conference 2019: Implementation of Germline Testing for Prostate Cancer. The Conference addressed the following key areas: (1) Which men should be considered for prostate cancer genetic testing? (2) What are optimal ways to deliver genetic counseling? (3) Which genes should be prioritized for testing? (4) What prostate cancer-specific recommendations should be considered based on genetic results? (5) What is the impact of genetic testing in families?
The conference brought together approximately 90 experts, national organization leaders, and patient advocates from around the globe to address and develop a genetic implementation framework.

2019 Philadelphia Prostate Cancer Consensus Panel;
Hosted by Sidney Kimmel Cancer Center;
Chairs: Drs. Giri, Knudsen, and Gomella

We are very excited for more progress in 2020! If you would like to learn more about our patient care, research, and programs, please contact the Jefferson Clinical Cancer Genetics Program at 215-503-5285 or email Laura.Gross@jefferson.edu. We look forward to hearing from you!

Is Your Cancer Genetic Testing Up to Date?

Jessica Russo, MS, LCGC
Genetic Counselor

Cancer genetic testing is rapidly evolving. Recent advancements in genetics research and testing technology have provided us with better ways to identify the best candidates for genetic testing, the best genes to test, and to more efficiently analyze and understand our DNA. This has led to more comprehensive and affordable genetic testing for patients. To keep up with these changes, national testing guidelines are routinely updated.

Recently, the National Comprehensive Cancer Network (NCCN) revised their testing guidelines to expand eligibility criteria for patients. The NCCN is a nonprofit organization supported by 28 cancer centers to provide guidelines for cancer treatment. If you did not meet NCCN criteria for genetic testing in the past, now you might***. A brief summary of changes in NCCN testing criteria are listed below:***

- Patients diagnosed with breast cancer that did not meet criteria in the past may now meet criteria based on personal and family risk factors.
- Patients of Ashkenazi Jewish descent may be eligible for genetic testing regardless of personal or family history of cancer.
- Certain patients with metastatic breast cancer regardless of age of diagnosis may meet testing criteria if testing is pursued for treatment purposes.
- Patients with a personal or family history of pancreatic, ovarian, and metastatic prostate cancer

Additionally, as more cancer predisposition genes are discovered, genetic testing is shifting away from single gene/syndrome testing to multi gene testing panels and testing guidelines have evolved to reflect this. For example, if you have had *BRCA1* and *BRCA2* testing in the past, you may now be eligible for more extensive genetic testing.

It is important to note that while testing criteria is expanding, insurance coverage differs between plans. However, out of pocket cost of testing has become more affordable. Even if you don't meet current genetic testing guidelines, you may still opt to pursue genetic testing and pay out of pocket. Having a genetics consultation or formal cancer risk assessment with a qualified provider is the first step to help determine your next steps. If you are interested in pursuing genetic testing and were not eligible or had limited testing in the past, we encourage you to reach out to your genetics provider for more information.

Call us at 215-955-1011 to learn more about updated genetic testing and if this is relevant for you and your family

Decreasing Barriers to Care Using Telegenetics

Colette Hyatt, MS, LCGC
Genetic Counselor

Telemedicine or telehealth is when healthcare services are provided remotely using telecommunication technology such as a telephone and/or computer. Telegenetics is the use of technology to provide genetic services. In-person appointments are challenging for some due to travel distance, time off from work or family. In addition, there is a shortage of genetic counselors and genetic providers which makes it difficult for patients especially those in rural areas where they might not have local genetic providers.

Through our program, we are able to offer cancer genetic counseling by telegenetics. We use a HIPPA-compliant, secure program to allow for video chatting between a patient and genetic provider. This provides the same service as meeting in-person. It allows patients to speak and see the genetic provider in the comfort of their own home.

We also use telegenetics for one of our Sidney Kimmel Cancer Center Network members- Delta Medix in Scranton, PA. Patients are scheduled by the clinical team there and go to the DeltaMedix office to use the computer for their telegenetic appointment. Onsite staff assist with the appointment and gene testing retrieval if indicated.

We continue to receive good feedback from patients after their telegenetic –cancer genetic counseling appointment with their likelihood to recommend this service to others.

BENEFITS OF TELEHEALTH

- **Increase access to care**
- **Improved health through timely care interventions**
- **Convenience**
  - **Connect from local Healthcare Provider's office, from home or on the go**
  - **Decrease cost - in travel, time off from work**

EMPOWER …*yourself*

Laura Gross, BA
Program Manager and Coordinator

A research study for men with prostate cancer and men at higher risk for prostate cancer is currently available at Sidney Kimmel Cancer Center at Jefferson Health in Center City and Asplundh Cancer Pavilion (Abington).

The **"Evaluation and Management for Prostate Oncology, Wellness, and Risk (EMPOWeR)"** study provides men with an opportunity to gain genetic information and decide on clinical genetic testing to learn more about inherited prostate cancer. The results may be helpful in providing information about prostate cancer treatment, cancer screening, and cancer risks for men and their families.
The study involves completion of surveys to gain meaningful insights regarding sharing of genetic test results in families and health and wellness.
Who is eligible? Any man with a personal history of prostate cancer, as well as men without prostate cancer who are at higher risk for prostate cancer (such as men with a family history of prostate cancer), are eligible for the study.

- taking part in the study involves viewing a genetic education video or having a genetic counseling session with a trained genetics provider
- followed by the collection of a blood or saliva sample for genetic testing

The purpose of this genetic test is to find out if patients carry any mutation(s) causing increased risk for prostate or other cancers. Once results return, participants will discuss their genetic test results with a genetics provider in order to help them understand how these results may affect them and/or their family members to be proactive about health. Participants also have the option to participate in a research registry which will store some of their DNA for future research. We hope that information gained from this study will help to improve men's experiences with genetic testing, promote wellness of men and their families, and lead to overall fulfillment with the genetic evaluation experience for men regarding inherited prostate cancer. To date, 107 men have been enrolled in the study.

For more information, please call research coordinator Laura Gross at 215-503-5285 or email laura.gross@jefferson.edu

Why an Intake or Triage is Helpful When Making an Appointment with a Cancer Genetic Provider

Why are all those questions asked of you prior to making an appointment for cancer genetic consultation and counseling so important –for you and for the genetic provider.

My role in the Cancer Risk Assessment and Clinical Cancer Genetics program revolves heavily around making sure we have a good understanding as to why you are seeking an appointment and important elements of your personal and family health history. This information assists providers in calculating your individual risk, determine if gene testing and what specific gene testing may be offered and helpful for you by ultimately assuring that you receive an informative consultation.

Key questions I ask during an intake/triage include-

- **Family history of cancer (three generations and both maternal and paternal side)**
- **Ancestry for both your maternal and paternal side, for example; Ashkenazi Jewish ancestry**
- **Personal health history including cancer prevention/screening – mammograms, breast biopsy, colonoscopy and related findings including polyps, high risk lesions**
- **Personal health questions related to identified risk factors**
- **Personal and family history of gene testing and what those results were**

Karen Robison, CMA,
Program Intake Coordinator

This information also assists me in making sure we have any test results or other health record information that will be informative for your appointment.

Another important aspect of the intake/triage process is that I take time to make sure you have a good understanding of what to expect during the cancer genetics consultation and to provide my contact information if you have any further questions regarding your appointment.

It may take a few minutes longer upfront but it is so worth it. We find by doing a good intake prior to your clinical cancer genetics consultation appointment helps you be more prepared for what to expect and ultimately have a good experience that is helpful to you and your health.

Direct to Consumer (DTC) Genetic Testing: How to make sense of the *"Wild Wild West"* in Genetic Testing

Sue Miller-Samuel, MSN, RN, AGN-BC
Advanced Practice Nurse in Genetics

By now you have probably seen ads for direct to consumer (DTC) genetic testing. Ads are everywhere- television, websites, magazines, and newspapers. Flyers in grocery stores, spas, doctors' offices. Your friends are doing it; your family is doing it, the person that cuts your hair is doing it. What about YOU? It depends on what you hope to get out of it. It depends on how well you understand what the testing includes along with its limitations and possible benefits.

Here are some key questions for you, your friends, and your community to think about when considering at-home genetic tests:

- Why are you thinking of genetic testing? Clarifying your purpose for genetic testing is important. If might be to learn your ancestry, disease risk, cancer risk, or drug metabolism. Ask your healthcare provider or a genetics specialist before you undergo any at-home test as many of these tests are not comprehensive and may miss genes relevant to your health.

- What policy does the genetic company have in place to protect your personal and confidential information? Will your information be sold to other industries? Is it automatically shared with potential lost family members? It is important that you find out the privacy and selling policies of the genetic testing company to determine your level of comfort regarding your data.

- Are you aware of the Genetic Information Non Discrimination Act (GINA)? The GINA law provides protections for genetic mutation carriers from genetic discrimination regarding health insurance and employment (if the company has more than 15 employees). GINA does not protect people from discrimination in life insurance, long-term care, or disability plans. Therefore, you would need to have your plans in place before undergoing genetic testing to reduce jeopardizing your financial future.

Overall, compose a pro/con list. Read the consent/release forms. Find out if the testing company offers genetic counseling after your results come back. Do your homework before you give a specimen for genetic testing.
Then make a decision that's right for you.

PEER *NAVIGATION*

New research study dedicated to evaluating peer navigation and its impact on prostate cancer genetic testing among African American

Nicole Crumpler, MS, MBA
Laboratory Manager

While African American males have some of the highest rates of development and death from prostate cancer in the US, they represent less than 10% of those who seek genetic testing. The results from a genetic test can be used in making decisions for active surveillance among men with early-stage disease, can provide vital information regarding the aggressive nature of prostate cancer, can be used to inform options for targeted therapy in men with metastatic prostate cancer, as well as can influence screening decisions among men without prostate cancer.

Peer navigation has been successfully used in various healthcare settings, such as HIV care and substance abuse, resulting in improved compliance, patient understanding, and outcomes. Genetic evaluation is an area that is ideal for studying peer navigation particularly in the area of prostate cancer risk and treatment. Peer-based intervention can be used to address the barriers, beliefs, and needs of African American men and to promote informed engagement in the genetic evaluation process.

The Peer Genetic Study also known as the ***"Peer-Based Intervention for Genetic Evaluation for Prostate Cancer among African American Men: The Peer Genetic Study"*** will evaluate the impact of to peer-led health education verses traditional mailed information among African American Men. The study will explore possible limitations and barriers to genetic testing with African American males initially through focus groups. The information gathered will be used to conduct a randomized trial in a community clinic setting. The trial will consist of 176 men who will receive prostate cancer genetic testing information either by a trained peer-led health educator or mailed information material. Finally, the study will assess the effectiveness of the peer-led health education to deliver prostate cancer genetic testing information. It will also assess the rate in which African American men meet national genetic testing guidelines and evaluate their satisfaction and experience with the genetic counseling session for those who opted for testing.

The primary focus of the study is to identify the potential challenges that have led to the low rate of African American men participating in genetic testing for prostate cancer and the impact peer navigation will be on addressing these barriers. With these results, a long term goal will be the development of a healthcare systems-based approach of utilizing peer navigation to improve awareness, access, and participation of genetic testing for African American men to inform strategies for prostate cancer screening and treatment otherwise missed for African American men.

For more information, please call Amy Leader, PhD at 215-955-7739 or email amy.leader@jefferson.edu or Nicole Crumpler at *Nicole.crumpler@jefferson.edu*

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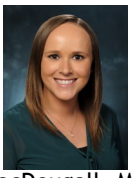

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Physician Contributors
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Meet Our New Member

Carey McDougall joined our Clinical Cancer Genetics program in 2019 and comes with over four years' experience in clinical genetics. Prior to coming to the Sidney Kimmel Cancer Center- Jefferson Health, Carey was a Genetic Counselor at The Children's Hospital of Philadelphia, specializing in children's genetic disorders including, Turner syndrome, Klinefelter syndrome, and cleft and craniofacial disorders. Carey is board certified by the American Board of Genetic Counseling, she received her B.A. in Psychology and Sociology from Rutgers, New Brunswick, and her M.S. in Genetic Counseling from Arcadia University.

Sidney Kimmel Cancer Center –Jefferson Health provides clinical cancer genetic services at our following Jefferson Health locations:

Center City, Philadelphia

Washington Township, New Jersey

Northeast (Torresdale), Philadelphia

Willow Grove, Pennsylvania

We also provide clinical cancer genetic services to the following Sidney Kimmel Cancer Center Network members:

Mercy Health

Delta Medix