Clinical Cancer Genetics

Translating Hereditary Cancer Research into Personalized Prevention and Treatment

ANNUAL REPORT 2015

THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®
2015 PROGRAM HIGHLIGHTS

Launched genetic counseling services at Regional Care Centers in the greater Houston metropolitan area

Increased clinical service volume by 6% from 2014

Added genetics Advanced Practice Nurse and Genetic Counselor to the breast center staff, thus providing genetic counseling every day of the week

Launched Stand up to Cancer project to test different genetic testing and counseling care delivery models

Conducted a patient education conference on Hereditary Breast and Ovarian Cancer (HBOC)
Message from the Medical Directors

We are pleased to announce several outstanding achievements of the Clinical Cancer Genetics (CCG) Program in 2015. As one of the largest genetic counseling programs in the nation, we focus on providing clinical genetic counseling services, conducting research in the multidisciplinary areas of hereditary cancer and providing education to clinicians, patients, at-risk family members and the general population.

As a clinical service, we are committed to providing evidence-based risk assessment, genetic testing, risk reduction by chemoprevention and prophylactic surgery, and screening for high-risk patients and their families. Several research projects that we have been working on for the past few years have reached their initial milestones. In this report, we describe several CCG investigators who have published their findings in high-impact peer-reviewed journals and presented at international meetings. We are pleased to share with you highlights of the past year in this annual report.

One of our key mission areas is to increase awareness among providers, patients and family members to undergo risk assessment for hereditary cancers, should they meet the criteria. Universal BRCA testing for all Triple Negative Breast Cancer and High Grade Serous Ovarian Cancer patients has now become a standard of care practice at our clinics, as a direct result of the Women’s Moon Shot Project. We are developing novel genetics delivery care models to assist all types of practice settings. In addition, we continue to develop prevention strategies to reduce mortality from hereditary cancer syndromes.

CCG faculty are conducting several studies to understand barriers to genetic testing and counseling to improve communication among family members who are susceptible to hereditary cancers. For example, our family outreach initiative, which is part of the Women’s Moon Shot Project, focuses on identification of family members who are at increased risk of developing hereditary cancer. Once identified, we use an active intervention approach to communicate with patients’ family members. We continue to develop and deploy the most up to date information technology tools for education and data collection to support our research-driven patient care.

Using a multidisciplinary approach, CCG clinical faculty in collaboration with basic scientists, epidemiologists and behavioral scientists, are also making significant advances to harness the power of next generation tumor sequencing and germline panel testing, while educating patients and provider’s on nuances of this new technology.

We look forward to continuing our growth and our commitment to our patients.

Banu Arun, MD
Co-Medical Director
Breast Medical Oncology

Karen Lu, MD
Co-Medical Director
Gynecologic Oncology
FACULTY/STEERING COMMITTEE

Banu Arun, MD
Co-Medical Director
Breast Medical Oncology

Karen Lu, MD
Co-Medical Director
Gynecologic Oncology

Elizabeth Grubbs, MD
Surgical Oncology

Jennifer Litton, MD
Breast Medical Oncology

Patrick Lynch, MD, JD
Gastroenterology, Hepatology and Nutrition

Nancy Perrier, MD
Surgical Oncology

Susan Peterson, PhD, MPH
Behavioral Science

Miguel Rodriguez-Bigas, MD
Surgical Oncology

Louise Strong, MD
Cancer Genetics

Y. Nancy You, MD, MHSc
Surgical Oncology

GENETIC COUNSELORS

Molly Daniels, MS, CGC
Senior Genetic Counselor

Sarah Bannon, MS, CGC

Erica Bednar, MS, CGC

Samuel Hyde, MMSc, CGC

Maureen Mork, MS, CGC

Kimberly Muse, MS

Emily Parham, MS, CGC

Jessica Profato, MS, CGC

Nadine Rayes, MS, CGC

Kayla Rosau, MS, CGC

Grace Tran, MS, CGC

Rachel Webster, MMSc, CGC

Ashley Woodson, MS, CGC

DATA COORDINATORS

Holly Oakley
Woman’s Moon Shot (Ovarian)

Trisha Emborgo
Woman’s Moon Shot (Breast)

Angelica Gutierrez-Barrera
Laboratory Coordinator (Breast)

Angela Perro
Breast Medical Oncology & CCG

Julia Guzman
Surgical Oncology & CCG

CLINICAL CANCER GENETICS ADMINISTRATION

Bhanu Pappu, PhD, MHA
Program Director

Linda Hill
Senior Administrative Assistant

Ann Molinaro, BSBM
Program Manager

Madhumita Ghosh, PhD
Clinical Research Program Coordinator

Angela Walker, BA
Applications Systems Analyst

Nathaniel Hernandez, BS
Programmer Analyst II

Nisreen Elsayegh, MA
Clinical Studies Coordinator
Nine Years of Dynamic Growth

In 2015, we have expanded our services to Sugar Land and Katy Regional Care Centers. We currently serve the Breast, Gynecologic, Gastrointestinal, Endocrine, Cancer Prevention, Melanoma, Pediatrics, Brain & Spine, Sarcoma, Genitourinary and Leukemia Centers at the Main Campus and three regional care centers (Woodlands, Sugar Land and Katy).

Other important areas of growth in 2015 increased access to genetic counseling at the Lyndon B. Johnson Hospital. Our services at Lyndon B. Johnson Hospital are of tremendous significance because it is an avenue through which we provide care to Houston’s underserved and uninsured breast cancer patients.

After nearly 15% growth in 2014, we continued to expand our services by 6% in 2015. CCG continues to receive funding from several internal, state and private sources to pursue basic and translational genetics research and patient outreach.

2015 HIGHLIGHTS

Patient Visits Per Year

<table>
<thead>
<tr>
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<th>Visits</th>
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<tbody>
<tr>
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Cumulative Number of Patients Tested for a Hereditary Cancer Mutation

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Cumulative Number of Patients Identified with a Hereditary Cancer Mutation

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<td>801</td>
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Care Centers Served

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<td>2015</td>
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Genetic Counselors

<table>
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</tr>
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<td>2015</td>
<td>14</td>
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</tbody>
</table>

Progeny Clinical and Family History Tool
Enhancements to database synchronization were implemented

CCG Research
Standup to Cancer grant to implement low-cost cascade testing was funded

Conferences Hosted
HBOC patient conference was hosted
In 2015, the breast team welcomed a fifth genetic counselor to the team, Ms. Monica Helm as well as an Advanced Practice Nurse, Ms. Wendy Brouwer, expanding the availability of genetic counseling in the Breast Center. With the addition of these two new providers, the breast genetics team is able to provide genetic counseling services every day of the week. Dr. Banu Arun, the Co-Medical Director of CCG, and Dr. Jennifer Litton lead a team comprised of experts in hereditary breast cancer diagnosis, treatment and research. Building on the launch of the Moon Shots program last year, a lot of progress has been made in several areas of hereditary breast cancer research as highlighted below.

Despite advances in hereditary genetic testing, risk assessment, and counseling for hereditary cancers, such services remain an unmet need in medically underserved and uninsured populations. Ashley Woodson and Jessica Profato, genetic counselors in the breast center, analyzed the experiences of providing hereditary cancer risk assessment and counseling services in a safety net county hospital, Lyndon B Johnson General Hospital in Houston. They have adopted a new care delivery model that combines a group pre-counseling education video, specifically developed for the target population, followed by one-on-one genetic counseling and recommended testing for those who meet the criteria. They found that 87% of patients eligible for genetic testing opted to get tested, which is higher than previous reports and shows that these services are highly utilized. The flexible and modified delivery model allowed the authors to see more patients in an efficient manner in a community safety net hospital setting where resources are limited compared to an academic medical center. This delivery model, which includes pretest counseling, also helps to reduce anxiety associated with genetic testing and result disclosure, which are often not available in under resourced hospitals. In this study, the average number of days between testing and result disclosure were reduced from 40 to 15 days, thus providing a positive impact on medical and psychosocial aspects of patient care. This analysis also identified that without active intervention by healthcare officials, transportation, language and financial barriers may prevent patients with similar socioeconomic and demographic backgrounds from seeking appropriate genetic testing and counseling.
Elsayegh et. al., conducted a multifactorial analysis to predict likelihood of women with ductal carcinoma in situ to undergo contralateral prophylactic mastectomy (CPM). Although it has been established that the presence of a BRCA1/2 mutation increases the chances of women electing CPM, their analysis found a relatively high CPM rate among women without a BRCA1/2 mutation. The authors found that factors influencing a woman’s decision to have a CPM included being 45 years old or younger and having a family member with ovarian cancer. Interestingly, married women are found to elect CPM at a higher rate than unmarried. Thus, this study has identified several factors that influence prophylactic surgical decision making among women who are negative for a BRCA1/2 mutation. This finding will serve as a guide for healthcare providers in targeting groups of women who could benefit from CPM but who are currently not electing the optional risk mitigating surgery.

In another study by Dr. Arun’s group, Sanford et al. have evaluated the rate of BRCA1/2 mutations in patients with low expression of estrogen receptor (ER), progesterone receptor (PR), and human epidermal growth factor receptor 2 (HER2). Current guidelines do not consider these tumors to be “triple negative breast cancer” (TNBC) thus genetic testing and counseling are not recommended as standard of care without other factors indicative of hereditary cancer predisposition. However, the authors have found that incidence of BRCA1/2 mutations is similar in patients with HER2-low-positive and HER2-negative breast cancer. Hence, this study has resulted in an important recommendation that genetic counseling and BRCA1/2 testing should be offered to all patients under the age of 60 who have HER2-low-positive breast cancer regardless of family history.

A study by Bayraktar et. al., examined genotype-phenotype correlations of specific BRCA1 and BRCA2 mutations in multi-ethnic populations in the USA. Prevalence of BRCA1 exon 2 mutations were significantly higher in Ashkenazi Jewish (AJ) women compared to Caucasians (41% versus 15%; p = 0.001). Similarly, AJ women with breast cancer were more likely to have BRCA1 exon 2 mutation compared to other ethnicities (47% positivity in AJ women versus 0–12.5% positivity in other ethnicities; p = 0.004). Women carrying the exon 20 BRCA1 mutation had the highest
probability of having combined breast and ovarian cancers compared to women carrying mutations in other exons \( (p = 0.05) \). The median age at initial cancer diagnosis, phenotypic features of breast cancer tumors, and overall survival did not vary significantly by ethnicity or mutation. The data suggest that ethnicity does not affect age of onset, overall survival or confer different risks of breast and ovarian cancer development in BRCA1/2 carriers. These results are particularly important because they indicate that genetic counseling and testing may be modified based on a patient’s ethnicity and mutation. These results also suggest that women carrying the exon 20 BRCA1 mutation may warrant mutation-specific counseling and be more aggressively managed for risk reduction.

Dr. Litton led a study to explore how BRCA1/2 mutations influence the incidence of cancers other than breast and ovarian. The researchers examined 1072 mutation carriers with 30 different cancer types. Although patients with BRCA1 mutations did not show a higher rate of cancers other than breast and ovarian cancers compared to the general population. Individuals with BRCA2 mutations were found to have a higher incidence of pancreatic cancer compared to the expected general population rate. Men with BRCA2 mutations also show higher incidences of prostate cancer than expected based on general population incidences. This study provides an important framework for modifying screening guidelines to include screening for additional cancers that individuals with BRCA1/2 mutations are at risk of developing.

Recent Publications


2015 PROGRAM HIGHLIGHTS

They found that 87% of patients eligible for genetic testing opted to get tested, which is higher than previous reports and shows that these services are highly utilized.

The average number of days between testing and result disclosure were reduced from 40 to 15 days, thus providing a positive impact on medical and psychosocial aspects of patient care.
The gynecologic oncology team welcomed two new members in 2015, genetic counselor Nadine Rayes and research data coordinator Santiago Ramirez Vargas. Nadine’s clinical responsibilities include providing genetic counseling for patients in the Gynecologic Oncology Center as well as other centers. Nadine and Santiago are both actively involved in the Stand Up To Cancer research projects described below.

The research focus in Gynecologic Oncology and Reproductive Medicine continues to be on optimizing identification, treatment and management of women at risk for hereditary gynecologic cancer syndromes. Supported by the Women’s Cancer Moonshot project, and in particular by Moonshot team members Erica Bednar (genetic counselor) and Holly Oakley (research data coordinator), universal BRCA1/2 genetic testing for all women with high grade serous ovarian cancer (HGSOC) continues. The overall aim of this ambitious project is to identify all HGSOC patients that have HBOC syndrome and offer them and their at-risk family members advanced, specialized clinical care to save lives and, for unaffected family members, prevent cancer from occurring in the first place.

Ovarian Cancer Dream Team

Dr. Lu is a principal member of the ovarian cancer dream team recently established by Stand Up To Cancer (SU2C) and partner organizations. The team is co-led by Dr. Alan D’Andrea (Dana-Farber) and Dr. Elizabeth Swisher (University of Washington) and includes collaborators from several institutions. The dream team was awarded a $6 million grant to be used over three years towards ovarian cancer research. Highlights of this multifaceted project where MD Anderson is taking the lead include: WiSP (Women Choosing Surgical Prevention), a multi-center study of interval salpingectomy with delayed oophorectomy as a novel strategy to reduce ovarian cancer risk in genetically high risk women while delaying menopause as long as possible; and MAGENTA (Making Genetic Testing More Accessible). The MAGENTA study will recruit women from across the country who are at increased risk to develop ovarian cancer based on their personal or family history to enroll in a non-inferiority study comparing telephone genetic counseling to online genetic education.

King Award

A genetic counseling graduate student, Katherine Dempsey, worked with PI Dr. Karen Lu, senior genetic counselor Molly Daniels, and colleagues to complete her master’s thesis project that culminated in the publication, “Is it all Lynch syndrome?: An assessment of family history in individuals with mismatch repair-deficient tumors.” [Genet Med. 2015 Jun;17(6):476-84]. Recently, Kate was awarded the 2016 Richard King Trainee Award for the year’s best trainee publication in Genetics in Medicine, and was the first genetic counseling student to ever win this award. Congratulations Kate and team!
Additional Research Highlights

Despite the benefits of risk reducing salpingo-oophorectomy (RRSO) for BRCA 1/2 mutation carriers, the adverse effects of surgical menopause on young women are problematic. Mounting evidence suggests the fallopian tube is the site of origin of BRCA-associated ovarian malignancies. However, no data exist to demonstrate whether salpingectomy lowers the risk of developing ovarian cancer (OC) in women with BRCA mutations. Dr. Denise Nebgen recently completed enrollment to a proof-of-concept clinical trial to compare ovarian cancer screening, risk-reducing salpingo-oophorectomy (RRSO), and prophylactic salpingectomy with delayed oophorectomy (PSDO) in BRCA mutation carriers. The goal of the study was to determine the compliance with delayed oophorectomy in women who initially elect to undergo PSDO. Dr. Nebgen presented initial results of the study during an oral abstract session at the ASCO annual meeting in June 2016. At present, 40 BRCA pts were enrolled in the PSDO feasibility study with no adverse events. Compared with the RRSO arm, the PSDO arm showed a trend toward preservation of sexual functioning and absence of menopausal symptoms. Researchers suggest PSDO is an acceptable alternative for select BRCA patients. Long term outcome data on larger populations is needed.

Building on this study, Dr. Lu and MD Anderson is leading a Stand Up to Cancer Ovarian Cancer Dream Team-funded multi-site clinical trial called WISP (Women Choosing Surgical Prevention), investigating fallopian tube removal and RRSO in 300 women with BRCA and additional mutations that elevate their risk of ovarian cancer. Premenopausal women with deleterious mutation in one of the eleven ovarian cancer associated genes are enrolled in the WISP study. The goal of this clinical research study is to compare how these surgeries affect quality of life by measuring female sexual function between two surgical invention strategies: interval salpingectomy with delayed oophorectomy (ISDO) and risk-reducing salpingo-oophorectomy (RRSO).

The WISP study is funded by Stand Up to Cancer, and examines a novel prevention strategy for women with deleterious mutations in ovarian cancer associated genes.

Genetic counseling from a trained healthcare provider can help women at increased risk to make informed decisions about the advisability of oophorectomy. Genetic counseling graduate student Victoria Breen, working with PI Molly Daniels and thesis committee members including Dr. Lu and Dr. Nebgen, successfully defended her thesis titled “Factors influencing uptake of risk-reducing salpingo-oophorectomy by BRCA1 and BRCA2 mutation carriers.” Victoria administered a survey to BRCA positive women being followed in the MD Anderson high risk ovarian cancer screening clinic, in order to better understand how they make decisions regarding whether and when to undergo risk reducing surgery. She plans to publish her results in the near future.

Recent Publications


The Gastrointestinal (GI) team, comprised of multidisciplinary experts actively engaged in patient care as well as research investigations, aims to understand the cause, optimize the management, and advance the prevention of hereditary GI cancers. The Gastrointestinal (GI) core faculty includes Drs. Patrick Lynch, Miguel Rodriguez-Bigas, Y. Nancy You, and Eduardo Vilar-Sanchez, who are actively engaged in research studies to investigate the causes, management and prevention of hereditary GI cancers including familial adenomatous polyposis (FAP) and Lynch Syndrome (HNPCC).

The MD Anderson Familial High-risk Gastrointestinal Cancer Clinic, established since 2011, is under the leadership of Dr. Y. Nancy You. It is a comprehensive clinical program dedicated to patients and their families with hereditary colorectal and GI cancer syndromes that is unique among major cancer centers in the U.S. Through coordination of genetic counseling, diagnostic testing, cancer surveillance, and prophylactic surgery services, we develop a comprehensive and personalized cancer treatment and prevention program for each patient with a hereditary GI cancer syndrome. The clinic also serves all at-risk blood relatives of the patient, thereby extending the mission of MDA to provide care across the entire cancer spectrum to more individuals. Through generous philanthropic support, a dedicated coordinator is working to help expand genetic services to family members.

Patients and families benefit from a multi-disciplinary group of uniquely experienced clinical experts, including Dr. Lynch’s expertise in gastroenterology and advanced endoscopy, Dr. Rodriguez-Bigas’ expertise in surgical treatment of colorectal cancer, Dr. You’s expertise in minimally-invasive surgery for cancer treatment and prevention, as well as Dr. Vilar’s expertise in gastrointestinal medical oncology. Together with our dedicated genetic counselors Ms. Bannon and Ms. Mork, a coordinated and personalized care plan is developed for each patient and family.

Active areas of research investigation includes developing an electronic medical record registry system to facilitate the care of families with hereditary syndromes, deciphering ethnic variations among patients with hereditary syndromes, designing preventive-health interventions to improve the health behaviors of families, and understanding the implications
of germline panel testing. Additional research investigates the clinical, epidemiologic and molecular aspects of colorectal cancer that develop at a young age but is currently not linked to a known hereditary syndrome, as well as mapping the genomic landscape and the biology of premalignant lesions that arises in the colon and rectum.

“In an effort to increase identification of families with Lynch syndrome, our group has been conducting universal testing of colorectal tumors for microsatellite instability. ...”

The GI Team is building a web-based outreach registry to facilitate family outreach to relatives of patients with Lynch syndrome. Typically, patients with inherited gene mutations communicate with a limited number of relatives to apprise them of their potential cancer risk and the need for genetic testing and screening. The family outreach project is expected to significantly expand the number of at-risk family members that are reached and can undergo genetic testing and screening. The web-based tool is designed to promote online communication between patients and their family members, including more distant relatives either directly via email communication that the patient can generate themselves or facilitated by registry staff where direct communication is not desired by the patient. The online approach is expected to minimize resources and personnel as the participants do much of the work themselves. This project has substantial cancer prevention potential. A universal protocol submitted to the IRB to operationalize this novel approach for any hereditary syndrome was approved. Importantly, the web-based family outreach project was one of the sub-projects approved and funded for the Colorectal Cancer Moon Shot. Our team is actively working with software development teams to design and operationalize the web-based outreach tool, called FamilyCONNECT. Testing the feasibility and usability of FamilyCONNECT is ready to commence and additional funding will be sought to fully operationalize the project. A Colorectal Cancer Moonshots Pilot Project grant entitled “Penetration of genetic risk communication in Lynch syndrome families” to study family outreach achieved with existing standard of care was awarded to Dr. Mala Pande.

In an effort to increase identification of families with Lynch syndrome, our group has been conducting universal testing of colorectal tumors for microsatellite instability. This program has successfully identified patients with Lynch syndrome, allowing for personalized treatment recommendations aimed at improving clinical outcomes and the identification of at-risk family members who will benefit from genetic testing, genetic counseling, and increased cancer surveillance to significantly reduce the risk of cancer in these high-risk families.

In the area of cancer prevention, our group is conducting active research (1) To study the molecular biology of premalignant polyps in patients diagnosed with Lynch Syndrome and Familial Adenomatous Polyposis using high-throughput technologies (next-generation sequencing) as a source for target identification,
and then to proceed with the validation of those targets in cell line models and genetically engineered animal models; (2) To design chemoprevention trials for patients diagnosed with Lynch Syndrome and Familial Adenomatous Polyposis. Dr. Vilar-Sanchez currently serves as the national principal investigator of a Phase Ib clinical trial testing the safety and tolerability of Naproxen in patients diagnosed with Lynch Syndrome sponsored by the National Cancer Institute. At MD Anderson Cancer Center, Drs Vilar-Sanchez and You serve as the institutional principal investigators, and have accrued more than 20 patients. In the laboratory, Dr. Vilar-Sanchez’s group has made progress profiling with next-generation sequencing technologies adenomatous polyps in patients diagnosed with Familial Adenomatous Polyposis and Lynch Syndrome in a project funded by the NCI through a R03 grant and also by philanthropic funds provided by the Feinberg Family. These projects have the overarching goal to identify novel biomarkers and targets for chemoprevention.

A major international randomized, double-blind, Phase III clinical trial with 21 study locations distributed over United States and Europe has been initiated with the goal to defer or obviate the need for additional surgical interventions in patients with familial adenomatous polyposis. Dr. Lynch and his team of experts seek to determine if the combination of eflornithine plus sulindac is superior to sulindac or eflornithine as single agents in delaying time to the first occurrence of any FAP-related event. In patients treated with total abdominal colectomy with ileo-rectal anastomoses, the addition of sulindac combined with eflornithine has the potential to defer or eliminate the need for a complete proctectomy by polyp control which may result in less frequent and less extensive endoscopic or surgical interventions. This study will also look to see if this new treatment for FAP can reduce the number and/or size of colon polyps and will look at how the medication might change quality of life.

Additional research projects have focused on genetic and environmental modifiers of cancer risk in hereditary GI syndromes, such as identification of novel genetic polymorphisms that suggest a link between breast and colon cancer (research related to NIH K07 grant by Dr. Mala Pande). Furthermore, her interest includes characterizing cancer risk associated with variants of unknown significance (VUS) in families that meet the clinical definition of Lynch syndrome. She is the principal investigator for the protocol “The use of mismatch repair gene variants in risk assessment for Lynch Syndrome within families.”

Recent Publications


2015 PRESENTATION HIGHLIGHTS

American Society of Clinical Oncology Gastrointestinal Cancer Symposium, 2015
Dr. You and Dr Vilar-Sanchez presented a poster on “Somatic mutations in young-onset colorectal cancer unrelated to hereditary syndromes: A comparative study using high-depth targeted exome sequencing.”

American Association for Cancer Research Annual Meeting, 2015
At the AACR Annual Meeting, Dr. M Pande and Dr. P Lynch presented a poster entitled “Risk loci for a breast-colon cancer phenotype: results from a genome-wide association study”. Dr. Pande also co-authored/presented another poster entitled “Risk loci in telomere structure and maintenance genes across five cancer types: GAME-ON Consortium.”

International Society for Gastrointestinal Hereditary Tumors-Insight Biennial Meeting, 2015
Dr. M Pande and Dr. Vilar-Sanchez presented a poster on “Variants of unknown significance in DNA mismatch repair genes: results from a hospital based hereditary cancer registry.”

Collaborative Group of the Americas on Inherited Colorectal Cancer, Oct 2015
Dr. P Lynch and Dr. M Pande presented a poster on “Web-based platform for communicating genetic mutation risk in extended families with Lynch syndrome.”

Publication in Journal of Clinical Oncology
The publication, High Prevalence of Hereditary Cancer Syndromes in Adolescents and Young Adults with Colorectal Cancer by Maureen Mork et. al., in J Clin Oncol in July 2015 was accompanied by an editorial, and was highlighted in The ASCO Post email. This work was also featured in Houston Chronicle

Grand Rounds Tulane Univ: Hereditary Colon Cancer, Dec 2015

Italian Society of Inherited GI Cancer: Inherited Colon Cancer, Nov 2015

World Gastro Society (Brisbane, Australia): Guidelines for Inherited Colon Cancer Screening, and Mutated DNA in the stool for HNPCC screening, Sept 2015

World Gastro Society (Brisbane, Australia): European Workgroup on Inherited Cancer (Mallorca) Chemoprevention trials in FAP, May 2016

Creighton Univ Henry T Lynch Honorary Symposium, Omaha: FAP Chemoprevention: Any Progress Made, Sept 2015

A group of experts from Endocrine Neoplasia and Hormonal Disorders, Head and Neck Surgery, and Surgical Endocrinology provide multidisciplinary care for patients with hereditary endocrine cancer syndromes. The two most prominent hereditary cancer syndromes in the Endocrine Center are Multiple Endocrine Neoplasia (MEN) types 1 and 2. Nearly 100% of MEN1 patients will develop parathyroid tumors, 30-75% will develop pancreatic tumors, and between 10-60% will develop a pituitary tumor. Individuals with MEN2 have a greater than 95% chance of developing medullary thyroid cancer in their lifetime. The Endocrine team was thrilled to welcome a new addition to the team in Sam Hyde-certified genetics counselor with dedication to endocrine disease.

The Surgical Endocrinology group has been productive and has grown clinically, educationally and from a research perspective. Our faculty have assumed growing roles nationally. Dr. Perrier has served as the editor of ENDOCRINE TUMORS for the 8th edition of the AJCC Cancer Staging Manuel. Important changes will be the addition of parathyroid carcinoma and neuroendocrine adrenal tumor staging; increasing the age cutoff from 45 years to 55 years for all low stage disease; renaming of positive lymph node disease to include size of metastases for well differentiated thyroid carcinoma and down staging microscopic thyroid capsular invasion. Also, level 7 lymph nodes will now be included as N1a disease- in continuity with level VI central neck disease. Local lymph node involvement of adrenal cortical carcinoma has been downgraded in the staging system as survival curves have better delineated local-regional disease outcomes. Dr. Perrier is the chief editor of the American College of Surgeons group on intraoperative decision making- a premier priority for ACS members nationwide. She and Dr. Grubbs both serve on the American Society of Clinical Oncology Patient Education boards. Dr. Grubbs represents the group on ITOG and ThyCa. Dr. Perrier serves on the PDQ Endocrine Tumor board of the NCI- which has had increased growth in familial tumor updates. Her role on the von Hippel Lindau alliance continues with representation for surgical management of the adrenal gland.

Educational – Journal Club, Medullary and Parathyroid conferences are held monthly. We have welcomed new research fellowship positions and have international fellows from large institutions in China, Chile and Greece. The section has continued to provide a bi-annual case video teleconference.
for sister institutions and for providers and trainees from more than 25 other institutions with relevance to case teachings, scenarios and multidisciplinary panels discussions of care. The plan to extend that service (free of charge) to all surgical endocrine and surgical oncology trainees on career building opportunity and job quests is being planned. We continue to provide opportunities for international fellow exchange- having hosted trainee colleagues from Mexico, the Netherlands and Ecuador this past year. Our two postdoctoral students have successfully taken projects from conception to publication- with Dr. Danica Vodopivec presenting stellar work on bone disease outcomes – referencing the significant improvement previously unrecognized in males. For this work she received the prestigious minority trainee award at the 2016 Endocrine Society meeting.

“We continue to provide opportunities for international fellow exchange- having hosted trainee colleagues from Mexico, the Netherlands and Ecuador this past year.”

We have worked to enhance our understanding of outcomes of surgical interventions on PNETs, with particular attention to the value of Chromogranin as a predictor and estrogen as chemo-protection. The group is working towards evaluating the relationship of serum global metabolic profiles with others in Epidemiology. In addition, thymic carcinoma, bone mineral density and other aspects of disease have been reported and advanced. Dr. Kika Silva made a national presentation at the AAES and Dr. Long presented a well- received poster on disease aggressiveness with relation to family presentation of MTC. This is another excellent demonstration of the advancing work on MEN2 disease continues to grow with a patient centered registry that has included and plans to reach multi-institutional participation. Dr. Grubbs continues work assessing factors affecting the clinical course of medullary thyroid cancer- with support from the American Cancer Society, the MD Anderson/Ohio State Spore and the American Thyroid Association. The long term outcomes of a large kindred diagnosed with MTC continues to be studied. In addition, more information on RET fusion mechanisms have been described. Our group continues to participate in ongoing trials, consensus statements, evaluation the role of aggressive lymph node dissection and neoadjuvant therapy for patients with ACC. The Multidisciplinary Parathyroid Consortium organized in conjunction with our colleagues in Endocrine Neoplasia, Translational Medicine, Pathology has collectively moved the mark for classification and stratification of parathyroid tumors- with added information on gene profiling and aggressiveness for sporadic and hereditary disease.

Research – Advances in better understanding the MENIN tumor suppressor gene and its effect on families with a goal towards chemoprevention and adjuvant treatment. Drs. Christakis, Kika Silva and
2015-16 PRESENTATION HIGHLIGHTS

American Association of Endocrinologist
Surgical Endocrine Clinical fellow presentations

American Association of Endocrine Surgeons 2016
MEN1 Parathyroid Disease and Bone Mineral Density Changes – Dr. Angelica Kika Silva; Predicting Aggressiveness of Medullary Thyroid Carcinoma – Dr. Kristin Long; The Historical Lecture of the Oliver Cope Award – Dr. Nancy Perrier; Registry Panel – Dr. Libby Grubbs

Society of Surgical Oncology 2016
Differentiating Atypical Parathyroid Disease from Carcinoma – Dr. Ioannis Christakis; Posterior Retroperitoneal Resection of non Adrenal Tumors – Dr. Jamii St. Julien.

Neuroendocrine Society of North America 2016
Pancreatic Neuroendocrine Tumors in MEN1 disease-Outcomes of Resection – Dr. Qui Wei

Endocrine Society 2016
Bone Mineral Density Changes Comparing by Gender in a Large Cohort of PHPT patients – Dr. Danika Vodopivec; Parathyroid Carcinoma-Changes thru the Decades – Dr. Angelica Kika Silv
International Association of Endocrine Surgeons; Teaching and Performing Safe Endocrine Surgery in Impoverished World – Dr. Kristin Long.

Adrenocortical Cancer Consortium
ACC Resection – Dr. Jeff Lee

The American College of Surgeons
Panel Moderator: Changes of Thyroid Cancer Treatment Guidelines – Dr. Nancy Perrier

The Southern Surgical – Discussant
Calculating Outcomes of Adrenocortical Carcinoma – Dr. Nancy Perrier

Recent Publications
The Hereditary Genitourinary (GU) Malignancies clinic was launched in 2014, and has received a significant number of referrals for patients suspected of having a hereditary genitourinary malignancy. Dr. Eric Jonasch, an expert medical Oncologist and Ashley Woodson, a dedicated genetic counselor with in-depth knowledge in GU cancer, staff this clinic that takes place every Wednesday and provides multidisciplinary, subspeciality care in the diagnosis and treatment of GU cancer. Dr. Eric Jonasch is Professor of Medicine in the Department of Genitourinary Medical Oncology and the Director of the Von Hippel Lindau (VHL) Clinical Center at MD Anderson Cancer Center. Dr. Jonasch has a strong interest in all forms of hereditary GU malignancies and is active in basic, translational and clinical research for patients with hereditary kidney cancer syndromes. Dr. Jonasch published the first prospective clinical trial testing the antiangiogenic agent sunitinib in patients with VHL disease, and is principal investigator of an ongoing trial testing pazopanib in the same patient population. He has multiple NIH funded grants related to kidney cancers, and is a Board Member of the VHL Alliance.

Ashley Woodson is a Cancer Genetic Counselor in Clinical Cancer Genetics within the Department of Breast Medical Oncology at the University of Texas MD Anderson Cancer Center. She has a B.S. degree in Human Biology from the University of Texas at Austin and a M.S. in Genetic Counseling from the University of Texas-Houston Health Science Center Graduate School of Biomedical Sciences.

Current recommendations from the NIH propose that patients with renal cell carcinoma diagnosed before the age of 46 be referred for genetic counseling and potential genetic testing for hereditary disorders.

The Hereditary Genitourinary Malignancies clinic welcomes referrals from physicians who have patients with GU malignancies and a suspicious family history, or early onset disease. In the past year the clinic saw and performed genetic testing in 49 patients of whom 3 were found positive. Current recommendations from the NIH propose that patients with renal cell carcinoma diagnosed before the age of 46 be referred for genetic counseling and potential genetic testing for hereditary disorders. Similarly, patients with bladder or prostate cancer with either a very strong family history or early onset of disease should be considered for referral. You can contact Ashley Woodson or Eric Jonasch for questions or to facilitate a consultation.
Long considered sporadic cancers, hematologic malignancies such as acute and chronic leukemia, myelodysplastic syndrome, and bone marrow failure have rarely been targeted for genetic counseling and research in adult patients, even in clearly familial cases. Over the past 5 years, over 30 genes related to hereditary forms of blood cancer have been discovered and are quickly being integrated into clinical practice. Driven by her interest in the clinical and research needs for these patients and families, Dr. Courtney DiNardo (Assistant Professor, Department of Leukemia) sought to bring genetic counseling services to hematologic malignancies, with initial funding provided through recipient of the inaugural MD Anderson R. Lee Clark Fellowship Award for evaluation of heritable leukemia predispositions and ongoing funding through the MDS/AML MD Anderson MoonShot as a pilot project. Through 2015, this clinic has now evaluated over 100 patients and families at risk for inherited predisposition to hematologic malignancies.

Dr. DiNardo and Sarah Bannon provide genetic counseling, risk assessment, and genetic testing to individuals suspected to have inherited predispositions to blood cancers, based on personal and family histories as well as distinguishing characteristics such as the presence of various somatic gene mutations.

The Hereditary Hematologic Malignancy Clinic (HHMC) is engaged in clinical and research studies to investigate the identification, causes, and management of hereditary leukemia and bone marrow failure syndromes, including dyskeratosis congenita (DC), Fanconi anemia, Li-Fraumeni syndrome, familial platelet disorder with predisposition to acute myeloid leukemias (FPD-AML), GATA2 deficiency, familial AML with mutated CEBPA, among others. In addition, patients and families with hereditary leukemia are offered participation in a research protocol through collaboration with Dr. Andrew Futreal and the Department of Genomic Medicine, in which there is potential for the identification of rare or under-described hereditary conditions and new gene discovery through whole exome sequencing. In 2015, the ground-breaking efforts of the HHMC were highlighted as a platform presentation at the National Society of Genetic Counselors annual education conference in Pittsburgh. Sarah’s submitted abstract on the outcomes from the HHMC over its first year was presented at the conference to over 100 genetic counselors. Several peer-reviewed manuscripts including original research and invited reviews directly stemming from this clinic are now published.

Due to increasing referrals and high demand, the HHMC has expanded to a weekly clinic; confirming that this clinic will flourish over the next years in its capacity for patient care, research opportunities, and cancer discoveries.
Behavioral Science

Dr. Susan Peterson’s research focuses on psychosocial and behavioral outcomes of genetic testing for hereditary cancer syndromes in cancer survivors and their families; specifically, how genetic risk notification influences the adoption of risk management recommendations (i.e., screening, risk-reducing surgery, chemoprevention). Dr. Peterson’s ongoing and completed research has focused on cancer survivors’ and families’ decision-making about genetic testing and receiving genetic test results, and the subsequent psychological and behavioral impact of those decisions, including the impact on quality of life and related factors. Dr. Peterson’s studies range across a variety of conditions including Hereditary Breast and Ovarian Cancers, Li-Fraumeni Syndrome, FAP, and Lynch syndrome.

A cross-cutting theme of Dr. Peterson’s research involves the development and evaluation of novel technology-based behavioral interventions to reach a variety of populations at risk for hereditary cancers. Examples include: an Internet-delivered intervention to facilitate coping and adjustment to FAP in teens and adolescents who carry an APC gene mutation; a novel digital health strategy to improve collection and communication of family health history and genetic risk information in Lynch syndrome families; and, an intervention to improve energy balance behaviors in families with BRCA1/BRCA2 or Lynch syndrome mutations using mobile technology. Dr. Peterson’s research has been funded by the National Cancer Institute, the National Human Genome Research Institute, and the Women’s Cancer and Colorectal Moon Shots, among others.

Recent Publications


Understanding the complexity of genetic testing can be daunting for patients. Our multidisciplinary team is comprised of specially trained genetic counselors and physicians who work together to provide hereditary cancer risk assessment, genetic counseling and genetic testing for patients and their relatives who are concerned about their personal and family history of cancer. Our expert team works with patients to determine if genetic testing is right for them and what genes should be analyzed. In addition, we provide individualized cancer screening and prevention programs.

**CCG services include:**
- Medical and Family History Review
- Hereditary Cancer Risk Assessment
- Discussion Regarding Genetic Testing
- Individualized Cancer Screening and Prevention Recommendations
- Referrals to Clinical Research Trials and Research Registries

**Patients who have the following risk factors may benefit from a hereditary risk assessment:**
- Cancer before the age of 50
- Same type of cancer in several generations of the family
- Two or more different cancers in the same person
- Two or more family members who have had the same type of cancer
- Ashkenazi Jewish ancestry (Eastern or Central European) with breast or ovarian cancer
- Polyposis (multiple polyps in the sarcoma, male breast cancer, medullary thyroid cancer, or pheochromocytoma)
- Concerns about developing cancer because of family history

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**BENEFITS OF GENETIC COUNSELING**

Often lost on the discussion of genetic counseling are the tangible benefits to a cancer patient of a genetic test result and the implications it may have on future care. For instance, if a breast cancer patient has a BRCA mutation, management decisions regarding specific types of surgery and knowing the risk of a second breast cancer or future ovarian cancer could be life-saving.
Breast and Ovarian Cancer Moon Shot Flagship Project

The Breast and Ovarian Cancers Moon Shot Flagship 1A project is committed to providing access to genetic testing for all patients with triple-negative breast cancer (TNBC), high grade serous ovarian cancer (HGSOC), and their at-risk family members. The goals of the Flagship 1A project have been to maximize BRCA genetic testing in patients with these cancers and to actively recruit interested individuals to research studies. Our current research studies include: 1) Universal Clinical BRCA1 and BRCA2 Genetic Testing for Women with Triple Negative Breast Cancer and 2) Outreach to Families with a known BRCA mutation through the REACH (Research, Education, and Awareness of Cancer family History) Registry.

Clinical Cancer Genetics has seen over 600 patients with TNBC in 2015. Through the Universal Clinical BRCA1 and BRCA2 Genetic Testing protocol, patients who did not meet clinical testing criteria were able to undergo BRCA genetic testing. The team presented their work on December 10, 2015 during a poster session at the 2015 San Antonio Breast Cancer Symposium.


Clinical Cancer Genetics and the Breast and Ovarian Cancers Moon Shot Flagship 1A team have been working to identify patients with ovarian cancer who have not had genetic testing. These individuals are being offered the opportunity to meet with a genetic counselor and have BRCA1 and BRCA2 genetic testing. With the increased use of PARP inhibitor therapy for patients with recurrent ovarian cancer and a BRCA mutation, Clinical Cancer Genetics is excited to ensure that all individuals with ovarian cancer have the opportunity to pursue standard of care genetic testing. Data from this initiative is expected to be presented at conferences in 2016.
The family outreach protocol has enrolled many TNBC and HGSOC patients and their family members since activating the study in 2014. Nearly 300 patients and family members have enrolled in the study. By engaging family members, we actively promote genetic testing, high-risk screening, and cancer prevention. This year, the team developed an educational video entitled, Introduction to the REACH Registry, to help families learn about the study, and to add to the educational videos and resources patients and their family members access.

In 2014, Clinical Cancer Genetics and the Breast and Ovarian Cancers Moon Shot Flagship 1A activated genetic counseling services at Lyndon B. Johnson (LBJ) Hospital of the Harris Health System. In 2015, this outreach clinic has expanded to service the Gynecologic Oncology department. Universal genetic testing initiatives have been successful in ensuring that patients with TNBC and HGSOC have the opportunity to receive genetic counseling and genetic testing in a historically underserved community.

**BREAST AND OVARIAN CANCERS MOON SHOT IN THE COMMUNITY**

The Moon Shot Flagship 1A team participated in the Clinical Cancer Genetics Hereditary Breast and Ovarian Cancer patient conference on June 27, 2015. The conference provided education and support to BRCA positive patients and their family members, as well as the opportunity to learn more about our current research studies.

The Moon Shot Flagship 1A team participated in the 27th annual Anderson Network Survivorship Conference on September 25-26, 2015. The team engaged patients, caregivers, family members, and survivors with resources and research options.

Genetic Counselor, Grace Tran, led a breakout session where she delivered a presentation entitled, El cáncer hereditario: lo que necesita saber, to a predominantly Spanish speaking audience. The team met television broadcast journalist and triple-negative breast cancer survivor, Robin Roberts.

The Moon Shot Flagship 1A team partnered with the Mauli Ola foundation to participate in the 2nd annual Battle for the Breasts competition. The team won 3rd place and was awarded $10,000 in free genetic testing through Ambry Genetics Laboratory.

The Breast and Ovarian Cancers Moon Shot project currently funds two genetic counselors and two research data coordinators housed within CCG, one of each in the Breast and Gynecologic Oncology clinics and the Woodlands Regional Care Center and Lyndon B. Johnson Hospital – Harris Health System.
Patients with Li-Fraumeni syndrome, and often many of their family members, are very prone to cancer, including recurrences and additional, new cancers. Over the past several years, the longstanding Li Fraumeni syndrome (LFS) research team and Clinical Cancer Genetics (CCG) Genetic Counselors have teamed up with a multidisciplinary clinical team from many departments to establish a screening program for individuals with LFS, a hereditary cancer syndrome caused by mutations in the TP53 gene.

Individuals should be tested for Li-Fraumeni syndrome if they meet the criteria defined by the National Comprehensive Cancer Network (NCCN). In general, patients who develop any of the cancers associated with the syndrome at a relatively young age—for example, women who develop breast cancer before age 35 years and do not carry BRCA mutations, children or young adults who develop sarcomas, brain tumors, adrenal cortical tumors, leukemias, are at increased risk of carrying the mutant TP53 gene and should be tested. In addition, all first-degree relatives of LFS patients should be tested. Characteristics including multiple cancers in the LFS tumor syndrome spectrum at any age also warrant genetic testing.

Surveillance
Patients diagnosed with LFS should undergo frequent surveillance for new cancers that can occur at any site. In accordance with the NCCN guidelines, adult participants in the LEAD program typically undergo a physical examination every 6–12 months that includes whole-body and brain magnetic resonance imaging (MRI), dermatological and neurological evaluations, and blood tests for thyroid and adrenal function and various cancer biomarkers. Colonoscopy and breast cancer screening are begun at an earlier age than in the general population. Other types of cancer screenings at specific sites may be undertaken depending on the individual. The program’s surveillance strategy for children with Li-Fraumeni syndrome varies by age but includes whole-body and brain MRI.

Individuals should be tested for Li Fraumeni syndrome if they meet the criteria defined by the National Comprehensive Cancer Network (NCCN).

Progress
In little over 2 years since its inception, LEAD program had screened 24 asymptomatic individuals of ages between 18 to 61 years, and 21 of these individuals had finds of interest. Most were benign cysts, and only four required follow-up. The program identified three patients with invasive cancers, including a breast cancer, gastric cancer and metastatic thyroid cancer in an 18-year-old. These tumors were likely to have been life threatening if their detection had been delayed; early diagnosis allowed successful treatment with surgery alone.
Counseling and Educating Patients

In addition to testing people for LFS and screening carrier individuals for cancer, a major focus of the LEAD program is educating patients and their family members about diagnostic testing, surveillance, and other strategies for managing their condition. The LEAD program group created a video-based decision aid to help families navigate the disorder, and the program offers a wide range of counseling services, including discussion of possible outcomes of genetic testing, risks and benefits of prophylactic surgeries such as mastectomy and reproductive counseling.

CCG genetic counselors Michelle Jackson, Jessica Profato and Emily Parham have teamed up with the LEAD team and provided genetic counseling and testing under the LEAD program. Because of programs like LEAD, there is a general increase in understanding of Li-Fraumeni syndrome and networking had developed among LFS families and the health care providers who care for them. However much more public awareness is needed for optimal early diagnosis and cancer surveillance.

Education

Hereditary Breast and Ovarian Cancer (HBOC) Patient Education Conference, June 27, 2015

Clinical Cancer Genetics (CCG) is committed to a patient centered approach; as evidenced by the multitude of outreach and cancer prevention patient education conferences organized by its staff. To continue with its strive towards patient education, CCG organized the Hereditary and Breast Ovarian Cancer Conference at The University of Texas MD Anderson Cancer Center, with over 36 attendees. The main objectives were to discuss the importance of addressing fertility issues in reproductive age women with HBOC, examine various reproductive options that can help women achieve their family-building goals, and help review how collaboration between gynecologic oncologists and reproductive specialists can optimize treatment planning and outcomes.

The take home message for women with HBOC was that there were options available for them to help them build families they desire. This conference was well appreciated by the audience as evidenced from the positive comments that CCG received.
**Education Outreach**

In addition to CCG’s commitment to provide cancer patients and their families with the most up-to-date information on hereditary cancer syndromes, CCG strives to educate oncologists and health care providers on recognizing cancer patients that should be referred for genetic counseling. Over the last year CCG has hosted multiple health care provider and patient education events at MD Anderson, the MD Anderson Regional Care Centers and across Houston. Furthermore, through funding received from the Cancer Prevention Research Institute of Texas, CCG faculty experts have expanded the web-based Professional Oncology Education program at MD Anderson to include, free of charge, provider training and Continuing Medical Education credit on the topic of Hereditary Breast and Ovarian Cancer syndrome ([http://bit.ly/1bTQ1y](http://bit.ly/1bTQ1y)).

**JULY 2015**

Genetic counselor Kimberly Muse was the invited speaker at the annual MD Anderson Physicians Network Nursing Conference at Fort Washington, Maryland from July 25-26, 2015. She reviewed genetic risk assessment and evaluation, and also discussed its impact on the patient and their family members.

**SEPTEMBER 2015**

On September 25-26, CCG participated in MD Anderson’s 27th annual Cancer Survivorship Conference held at the Omni Houston Hotel Westside. Topics ranged from the latest treatments and advances in lung cancer to nutrition and exercise for cancer survivors. The keynote speaker for the conference was Paul Mansfield, M.D., gastrointestinologist at MD Anderson Cancer Center who specializes in the treatment of mucinous tumors of the appendix. Over the course of the conference, CCG provided education on hereditary cancer syndromes to over 600 participants. Also Grace Tran, CCG genetic counselor took a step further and gave her presentation in Spanish for the benefit of the non-English speaking society. She emphasized the importance of regular surveillance and explained various risk mitigation options.

As a part of our education and outreach effort, genetic counselor, Monica Helm, Co-Chair of the Student/New Member Special Interest Group (SIG) within the National Society of Genetic Counselors (NSGC) is responsible for promoting communication, mentorship, and collaboration between students of genetic counseling programs, new members to NSGC, and prospective students. Monica also serves as a member of the NSGC Public Policy Committee which is tasked with monitoring and recommending responses to policy issues of interest to NSGC and the genetic counselor profession.
Community Outreach and Services

In addition to diagnosis and treatment of cancer, one of the challenges remains in the area of early diagnosis and adoption of risk reduction strategies to mitigate risk of hereditary cancers. We found that there are challenges in communicating the risk of hereditary cancer among the family members, lack of understanding about genetic testing and counseling process, and lack of awareness about prophylactic surgical and chemoprevention options that drastically reduce the risk of hereditary breast and ovarian cancers. Hence, Dr. Banu Arun and CCG have initiated genetic counseling, testing and patient navigation services to high-risk breast cancer patients within the MD Anderson General Oncology clinic at Lyndon B. Johnson (LBJ) General Hospital through funding from the Avon Foundation for Women and the Susan G. Komen for the Cure – Houston chapter. LBJ Hospital provides medical care to low income and medically underserved residents of Harris County. One of CCG’s missions is to increase awareness and educate health care providers and the community about hereditary cancer syndromes – hereditary breast and ovarian cancer syndrome (HBOC), in particular. HBOC is caused by a germline mutation in the BRCA1 or BRCA2 genes and puts the patient at an increased lifetime risk of 40-80% for breast cancer, and at lower lifetime risks for ovarian, prostate, and pancreatic cancer. According to the Texas Department of State Health Services (TDSHS) statistics for 2007-2012, the top cancer diagnoses for women in Harris County included lung, breast and colorectal cancer. Based on 2012 projections, the population of Harris County is almost 4.4 million, making it the largest county in Texas and the third largest in the US. Clearly there is a critical need for the services we provide.

High-Risk Breast Cancer Clinic

Once a BRCA1 or BRCA2 mutation has been identified in a family, genetic testing of family members can be offered along with other risk management strategies, such as surgery and chemoprevention, potentially saving lives due to early intervention. We have initiated genetic counseling, testing and patient navigation services to high-risk breast cancer patients within the MD Anderson General Oncology clinic at Lyndon B. Johnson (LBJ) General Hospital in order to provide medical care to low income and medically underserved residents of Harris County. This clinic is held every Thursday at LBJ. Past year a total of 209 patients representing various demographics (African American, Hispanic, and Caucasian) in Harris County were seen for genetic counseling, of which 120 (64%) patients were recommended for genetic testing.
New Gynecologic Genetic Counseling Clinic in Lyndon B. Johnson (LBJ)

The Gynecologic Oncology department at Lyndon B. Johnson (LBJ) hospital, of the Harris Health System saw its first patients in the newly developed genetic counseling clinic on June 30, 2015. The clinic occurs twice each month with Dr. Ralph Freedman, and focuses on providing genetic counseling and genetic testing services to patients diagnosed with ovarian cancer, a known hereditary cancer-susceptibility mutation in their family, and women with endometrial cancer suspicious for Lynch syndrome.

In 2015, the new clinic saw 27 patients for genetic counseling, with Spanish being the primary language for one-third of these patients. Twenty-three (85%) patients were candidates for, and pursued, genetic testing. More than 50% of patients who consented to genetic testing were able to have the cost of their testing covered through the Myriad Financial Assistance Program. The Myriad Financial Assistance Program is designed to help improve access to genetic testing by eliminating the out-of-pocket expense for patients facing financial hardship. Of the 23 patients tested, 30% were identified to have a mutation in BRCA1 or BRCA2. This mutation rate is higher than what has been observed in the MD Anderson Gynecologic Oncology department. Genetic testing is available to the at-risk relatives of these patients, and we anticipate increased referrals from within these families.

In addition to our genetic counseling services at LBJ Hospital, we also provide bi-lingual, genetics-specific patient navigation services. The genetics navigator assists breast cancer patients who are at a high risk for a second cancer, or those who are positive for a BRCA mutation in scheduling and attending their screenings and surgeries. The navigator also assists in answering the patient’s questions regarding hereditary cancer, translation services, transportation and other difficulties that the patient might encounter.

Past year of the 100 plus patients who were seen at the oncology clinic in LBJ, 10% of these patients tested positive for BRCA1/2 mutation. Our patient navigator reached out to all of these 11/12 patients and their families, and helped them navigate through the complex medical and financial maze. New genetic counseling templates were created and there was increased interaction with different specialties and personnel at LBJ. We are currently in the process of making available research opportunities and clinical trials to patients at LBJ. CCG is honored to be able to provide MD Anderson’s high standard of care to our own uninsured and underserved community members.
Affiliate Faculty

Constance Albarracin, MD, PhD  
Pathology  
Research Interest: Breast Cancer progression, high throughput analysis, and characterization of BRCA1/2 tumors

Deepak Bedi, MD  
Radiology  
Research Interest: Ultrasound, ovarian cancer screening

Russell Broaddus, MD, PhD  
Pathology  
Research Interest: Molecular diagnostic tissue testing for HNPCC in endometrial and colorectal cancer

Thomas Buchholz, MD  
Radiation Oncology  
Research Interest: Genetic and molecular determinants in radiation treatment for breast cancer

Naifa L Busaidy, MD, FACP, FACE  
Endocrine Neoplasia and HD  
Research Interest: Thyroid cancer, multiple endocrine neoplasia

Gilbert Cote, PhD  
Endocrine Neoplasia  
Research Interest: Genetics of hereditary endocrine neoplasia and development of targeted therapeutics

Robert Gagel, MD  
Endocrine Neoplasia  
Research Interest: Multiple Endocrine Neoplasia (1 and 2), metabolic bone disease, and endocrine tumor

Ann Marie Gillenwater, MD  
Head and Neck Surgery  
Research Interest: Detection and treatment of early oral cancer, prognostic factors for thyroid cancer

Dan Gombos, MD, FACS  
Ophthalmology  
Research Interest: Retinoblastoma, VHL, and other genetic eye diseases

Ellen R. Gritz, PhD  
Behavioral Science  
Research Interest: Psychosocial aspects of genetic testing and counseling

Stanley Hamilton, MD  
Pathology  
Research Interest: Molecular genetics and markers for management of colorectal cancers
Cynthia Herzog, MD  
Pediatric Oncology  
Research Interest: Retinoblastoma, FAP, and Li-Fraumeni in pediatric patients

Karen Hoffman, MD, MHSc, MPH  
Radiation Oncology  
Research Interest: Prostate cancer screening

Mimi I. Hu, MD  
Endocrine Neoplasia and HD  
Research Interest: Hereditary endocrine neoplasia syndromes, thyroid cancer, hyperparathyroidism

Winston Huh, MD  
Pediatric Oncology  
Research Interest: Soft tissue sarcomas; childhood cancer survivorship

Vicki Huff, PhD, MS  
Cancer Genetics  
Research Interest: Molecular genetics and predisposition of Wilms tumor

Camilo Jimenez, MD  
Endocrine Neoplasia  
Research Interest: Genetics of hereditary pituitary disorders

Elizabeth Keeler, MD  
Gynecologic Oncology  
Research Interest: Ovarian cancer screening/risk factors

Ralf Krahe, PhD  
Department of Genetics  
Research Interest: Molecular genetics and predisposition of Li-Fraumeni Syndrome

Jeffrey E. Lee, MD  
Surgical Oncology (Endocrine, Pancreas and Melanoma)  
Research Interest: MEN1 and MEN2, pancreas and adrenal disease, melanoma

Jeffrey H. Lee, MD  
Gastroenterology, Hepat, & Nutr  
Research Interest: Hereditary pancreatic cancer, detection of early pancreatic cancer and staging, staging and endoscopic treatment of gastrointestinal carcinoids

Huong Le-Petross, MD  
MRI/Radiology  
Research Interest: Breast cancer and ovarian cancer screening and imaging for BRCA patients

Ian E McCutcheon, MD  
Neurosurgery  
Research Interest: Novel agents and surgical treatment for von Hippel-Lindau disease, MEN1, neurofibromatosis type 1 and 2, and schwannomatosis

Funda Meric-Bernstam, MD  
Surgical Oncology (Breast)  
Research Interest: Surgical management and molecular mechanisms of hereditary breast cancer

John Slopis, MD  
Neuro-oncology  
Research Interest: Neurofibromatosis (NF1)

Steven Waguespack, MD  
Endocrine Neoplasia  
Research Interest: Multiple Endocrine Neoplasias (MEN) and Von Hippel Lindau Syndrome, thyroid cancer, pituitary tumors

Michelle D. Williams, MD  
Pathology  
Research Interest: Biomarkers for head and neck neoplasia and thyroid cancer

Wei Tse Yang, MD  
Diagnostic Radiology, Breast Imaging  
Research Interest: Novel breast cancer imaging (optical and nuclear medicine) and markers for high risk women

Anita Kuo Ying, MD  
Endocrine Neoplasia and HD  
Research Interest: Multiple Endocrine Neoplasia (MEN) and Pediatric Tumors