



**Partial content excerpted from Cancer SIG Starter Packet**

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**Disclaimer**

This “Cancer Genetic Counseling Starter Packet” is a compilation of material provided by the membership of the National Society of Genetic Counselors’ Cancer Special Interest Group. Materials and resources were gathered over a period of many years from various centers with different focuses and orientations. This packet is meant to serve as a general resource (“place to start”) in developing a clinical cancer genetics service.

**THIS MATERIAL IS NOT INTENDED TO PROVIDE EVERYTHING NEEDED TO CREATE A CLINICAL SERVICE.** Nor is it meant to serve as an example of “how things should be done”. Rather it is meant to be a resource of how various cancer genetics clinics were established, useful reference materials and issues to be considered in providing cancer genetic services. Additional reading, investigation and work within one’s own institution will be necessary to develop a cancer genetic program.

**PLEASE NOTE:** As cancer genetics is a rapidly changing field, some of the enclosed materials will quickly become out of date. It is the intention of the Cancer Special Interest Group to periodically update and add to this packet, as time and priorities permit. However, it is up to all who offer cancer genetics services to stay abreast of current information, practices, and resources.

## Justification for New Cancer Genetics Program

You are interested in starting a cancer genetic counseling program, but need to convince your department chair, hospital administrator, or other specialty providers of the value of such a service. Here are some suggestions of how to justify a new cancer genetics program:

1. **Volume:** 5-10% ([www.cancer.gov](http://www.cancer.gov)) of cancer patients are estimated to have an underlying gene mutation. This translates into many patients, and family members, in need of cancer risk counseling. Additionally, patients with polyposis or a variety of apparently benign endocrine conditions (e.g. primary hyperparathyroidism, pheochromocytoma, etc) should be evaluated for an underlying gene mutation.

2. **Standard of Care:** For health care providers working with cancer patients, it is becoming standard practice to ask about the family history of cancer or refer for cancer risk counseling. ASCO has issued a statement (J Clin Oncol 2006; 24(31):5091-5097) indicating that it is the responsibility of the clinical oncologist to ascertain the families at risk for inherited forms of cancer. Other professional societies with published guidelines recommending cancer risk assessment include: the American College of Obstetrics and Gynecology (Obstet Gynecol, 113:957-66), the United States Preventive Services Task Force (Ann Intern Med 2005;143(5):362-79), the Society of Gynecologic Oncology (Gynecol Oncol 2007;107(2):159-62), the National Comprehensive Cancer Network ([www.nccn.org](http://www.nccn.org)), and the American Gastroenterological Association (Gastroenterology 2001;121(1):195-7)

Furthermore, patient interest and awareness of genetic testing has increased, particularly with the advent of direct to consumer advertising campaigns (Genet Med 2005;7(3):191-197). Rather than referring patients who might inquire about genetic testing to outside facilities, patients could be referred to a clinical cancer genetics program within their current facility.

3. **Complete Package of Services:** Many medical centers like offering "specialty clinics", which offer a variety of services geared towards patients with specific medical problems or issues. Examples of "specialty clinics" relevant to a clinical cancer genetics program include a high risk breast/gynecologic/colon screening clinic, which could be utilized by patients who have survived one cancer but are at an increased risk for a second cancer, or by at-risk relatives. These types of clinics also provide the opportunity for enrolling patients in genetic research studies. This aspect is particularly important if one is applying for accreditation through the Commission on Cancer, which requires that an institution enroll a certain number of patients in research (<http://www.facs.org/cancer/>).

4. **Financial Incentive:** Although a clinical cancer genetics program does not bring in a lot of money through the provision of genetic counseling, there is potential for downstream revenue, as patients tend to stay at the center in which they had cancer treatment and genetic testing for further surgery and screening related to hereditary cancer syndromes (Ho, 2004). If you have access to data regarding the number of patients identified with hereditary cancer syndromes and their risk management options (i.e. number who pursue increased screening vs. number who pursue prophylactic surgery), you may be able to determine your institutions potential downstream revenue (Ho, 2004 and Daly, 2005)

Alternatively, you may be able to estimate potential downstream revenue based on the rate of uptake of various risk management options in published literature (as described in Int J Cancer 2008;122(9):2017-22 and Cancer 2005;104(2):273-81).

Daly MB, Stearman B, Masny A, Sein E, Mazzone S (2005) How to establish a high-risk cancer genetics clinic: limitations and successes. *Curr Oncol Rep.* 7 (6):469-74.

Ho C (2004) How to develop and implement a cancer genetics risk assessment program: clinical and economic considerations. *Oncol Issues*, 19:22–26.

**5. Liability:** There is at least one successful lawsuit against a medical institution that did not identify a patient who likely had a *BRCA* mutation. In the Estate of Ann Chadwick v. Virginia Mason Medical Center, Ann Chadwick's family was awarded \$1.6 million for the wrongful death of Ann Chadwick who had a history of bilateral breast cancer diagnosed at ages 27 and 38 and subsequently died at age 43 from ovarian cancer. The family argued that Ms. Chadwick's death could have been avoided had she been identified as having a *BRCA* mutation and undergone oophorectomy. There have also been at least two successful lawsuits (Florida, Pate v. Threlkel; New Jersey, Safer v. Pack) against physicians who did not warn their patients that the patients' offspring were also at risk for having a cancer genetic disorder (see Petrila, 2001; Severin, 1999). These cases suggest that genetic counseling needs to be offered to cancer patients with a positive family history as well as to their family members to ensure that they are informed of their genetic risk.

Petrila J (2001) Genetic risk: the new frontier for the duty to warn. *Behav Sci Law.*;19(3):405-21.

Severin MJ (1999) Genetic susceptibility for specific cancers. Medical liability of the clinician. *Cancer.* 86(11 Suppl):2564-9.

**6. Health Benefits:** A clinical cancer genetics program will provide prevention and screening options, which may save lives and/or decrease cancer rates. In addition to benefiting the physical health of patients, a clinical cancer genetics program may also provide significant benefits to behavioral and psychological health. The references below illustrate these two themes within the hereditary cancer cohort:

#### **6a. Physical Health** Hereditary Breast and Ovarian Cancer

Kauff ND, Satagopan JM, Robson ME, et al. (2002) Risk-reducing salpingo-oophorectomy in women with a *BRCA1* or *BRCA2* mutation. *N Engl J Med*, 346(21):1609-1615.

King MC, Wieand S, Hale K, et al. (2001) Tamoxifen and breast cancer incidence among women with inherited mutations in *BRCA1* and *BRCA2*: National Surgical Adjuvant Breast and Bowel Project (NSABP-P1) Breast Cancer Prevention Trial. *JAMA*, 286(18):2251-2256.

Kurian AW, Sigal BM, Plevritis SK (2010) Survival analysis of cancer risk reduction strategies for *BRCA1/2* mutation carriers. *J Clin Oncol*, 28(2):222-231.

Kwon JS, Daniels MS, Sun CC, Lu KH (2009) Preventing Future Cancers by Testing Women With Ovarian Cancer for *BRCA* Mutations. *J Clin Oncol*, 28(4):675-82.

Meijers-Heijboer H, van Geel B, van Putten WL, et al. (2001) Breast cancer after prophylactic bilateral mastectomy in women with a *BRCA1* or *BRCA2* mutation. *N Engl J Med*, 345(3):159-164.

Narod SA, Brunet JS, Ghadirian P (2000) Tamoxifen and risk of contralateral breast cancer in BRCA1 and BRCA2 mutation carriers: a case-control study. Hereditary Breast Cancer Clinical Study Group. *Lancet*, 356(9245):1876-1881.

Olopade OI, Artioli G (2004) Efficacy of risk-reducing salpingo-oophorectomy in women with BRCA-1 and BRCA-2 mutations. *Breast J*, 10 Suppl 1:S5-9.

Rebbeck TR, Levin AM, Eisen A, et al. (1999) Breast cancer risk after bilateral prophylactic oophorectomy in BRCA1 mutation carriers. *J Natl Cancer Inst*, 91(17):1475-1479.

Rebbeck TR, Friebel T, Lynch HT, et al. (2004) Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: the PROSE Study Group. *J Clin Oncol*, 22(6):1055-1062.

Rebbeck TR, Lynch HT, Neuhausen SL, et al. (2002) Prophylactic oophorectomy in carriers of BRCA1 or BRCA2 mutations. *N Engl J Med*, 346(21):1616-22.

Hartmann LC, Sellers TA, Schaid DJ, et al. (2001) Efficacy of bilateral prophylactic mastectomy in BRCA1 and BRCA2 gene mutation carriers. *J Natl Cancer Inst*, 93(21):1633-1637.

Schrag D, Kuntz K, Garber J, and Weeks J (2000) Life expectancy gains from cancer prevention strategies for women with breast cancer and BRCA1 or BRCA2 mutations. *JAMA*, 283:617-624.

### Lynch Syndrome

de Vos tot Nederveen Cappel WH, Nagengast FM, Griffioen G, et al. (2002) Surveillance for hereditary nonpolyposis colorectal cancer: a long-term study on 114 families. *Dis Colon Rectum*, 45(12):1588-94.

Jarvinen HJ, Aarnio M, Mustonen H, et al. (2000) Controlled 15-year trial on screening for colorectal cancer in families with hereditary nonpolyposis colorectal cancer. *Gastroenterology*, 118(5):829-34.

Lindor NM, Petersen GM, Hadley DW, et al. (2006) Recommendations for the care of individuals with an inherited predisposition to Lynch syndrome: a systematic review. *JAMA*, 296(12):1507-17.

Schmeler KM, Lynch HT, Chen LM, et al. (2006) Prophylactic surgery to reduce the risk of gynecologic cancers in the Lynch syndrome. *N Engl J Med*, 354(3):261-9.

South CD, Hampel H, Comeras I, Westman JA, Frankel WL, de la Chapelle A (2008) The frequency of Muir-Torre syndrome among Lynch syndrome families. *J Natl Cancer Inst*, 100(4):277-81.

### Compendium

The National Comprehensive Cancer Network (<http://www.nccn.org/>) regularly updates its "Practice Guidelines in Oncology" for inherited cancer predisposition syndromes. Check the NCCN website's Practice Guideline area regularly for the most up-to-date practice recommendations. Currently available guidelines include Hereditary Breast and Ovarian

Cancer, Cowden Syndrome, Li Fraumeni Syndrome, Lynch Syndrome, FAP/ AFAP, and MYH associated polyposis.

**6b. Behavioral and Psychological Health Benefit:**

Bowen DJ, Burke W, McTiernan A, Yasui Y, Andersen MR (2004) Breast cancer risk counseling improves women's functioning. *Patient Educ Couns*, 53(1):79-86.

Bowen DJ, Burke W, Culver JO, Press N, Crystal S (2006) Effects of counseling Ashkenazi Jewish women about breast cancer risk. *Cultur Divers Ethnic Minor Psychol*. 12(1):45-56.

Burke W, Culver JO, Bowen D, Lowry D, Durfy S, McTiernan A, et al. (2000) Genetic counseling for women with an intermediate family history of breast cancer. *Am J Med Genet*, 90(5):361-8

Bowen DJ, Powers D, Greenlee H. (2006) Effects of breast cancer risk counseling for sexual minority women. *Health Care Women Int*, 27(1):59-74.

Collins VR, Meiser B, Ukoumunne OC, Gaff C, St John DJ, Halliday JL (2007) The impact of predictive genetic testing for hereditary nonpolyposis colorectal cancer: three years after testing. *Genet Med*, 9(5):290-7.

Meiser B. (2005) Psychological impact of genetic testing for cancer susceptibility: an update of the literature. *Psychooncology*, 14(12):1060-74.

Meiser B, Collins V, Warren R, Gaff C, St John DJ, Young MA, et al. (2004) Psychological impact of genetic testing for hereditary non-polyposis colorectal cancer. *Clin Genet*, 66(6):502-11.

Meiser B, Halliday JL (2002) What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Soc Sci Med*, 54(10):1463-70.

## **Points to Consider When Developing a Cancer Genetics Program**

The following are questions to consider when establishing a new cancer genetics program at an institution or at an outreach clinic at your own institution. This list of questions is not comprehensive, but is meant to serve as a resource. If you are establishing a clinic, you are encouraged to speak with the administrators, legal advisors, and compliance/risk management department as well as other regulatory/governing bodies at your institute.

### **Commitment and Expectations**

- What are your goals for the clinical services?
- What are the institution's goals for the clinical service?
- How often will clinics with your services be held?
- Are you expected to be there a given amount of time in a week or month, as needed, or only for scheduled clinics?
- Will you be seeing patients in an in-patient setting?
- Are you expected to be on call?

### **Communication**

- Who is your main contact person and what is his/her preferred method of communication?
- Who should you contact in the event of an emergency or sick day?
- Who should you contact in the event of conflict with other employees?
- Are you expected to review cases with your attending physician(s) in advance, and, if so, what is the appropriate venue for that?
- After evaluating a patient are you expected to review the case with the physician?

### **Referrals**

- How will referrals be generated and received?
- Who can refer patients to this clinic?
- What paperwork needs to be done before you see a patient (i.e. does an order form need to be filled out by a physician)?
- Can patients self refer?

### **Scheduling**

- How are your appointments scheduled?
- Who will schedule appointments?
- What type of appointment will be scheduled?
- How many time slots will be dedicated to new patients versus follow up patients?
- How much time needs to be set aside for the appointment?
- Who can request patients be added to your schedule?
- Will a risk assessment packet (with family history questionnaire, etc) be sent to the patient before an appointment?
- Who will create, send, and follow up on the packet?
- Will the appointment be scheduled after mailing the packet or after received the completed packet?
- How will the referring physician be notified that a genetic counseling appointment has been scheduled?

## **Space**

- Will you have an office?
- What type of space is available for you to see patients in?
- Is there space for you to work in between patients?
- Will you have access to a computer? Phone? Fax machine? Photocopier?
- Will the location you see patients have signage for your services?
- How will patients be notified of/directed to your clinical space?
- Will there be a waiting area for your patients?
- Will the operator/front desk know where to direct your patients?
- Where will the test kits be stored?

## **Clinic Flow**

- How are patients checked in for appointments?
- Are you responsible for getting them registered for the appointment and/or collecting a co-payment?
- Will the patient be taken to the room by a nurse or other healthcare provider?
- Are you responsible for getting your own patients out of the waiting area?
- Are you seeing patients independently or with a physician?
- Do patients see the physician or the genetic counselor first?
- Are patients undergoing procedures that same day that may require sedation?
- How much time are you allotted with the patient?

## **Documentation**

- Will you be documenting in an electronic medical record, institution paper chart, and/or shadow chart?
- What type of documentation is expected for an outpatient clinic visit?
- What type of documentation is expected for an inpatient consultation?
- Will you have dictation/transcription services for your documentation?
- What is the timeline for completing this documentation?
- How will your pedigrees be stored in the patient's file?
- Is there someone available to help you build documentation templates for the electronic medical record?
- Will your documentation be easily accessible to the referring physician and other health care providers?
- Will you send a summary letter to the patient? After each visit or at the conclusion of a series of visits?

## **Administrative Time and Assistance**

- How much administrative time will you be given in your work week?
- If paper charts are used, how will these be created and filed?
- How do you order office supplies (charts, envelopes, etc.)?
- Will you be given access to an administrative assistant?
- If so, how much of his or her FTE will be dedicating to helping you?

## **Patient Tracking**

- How will your patient data (demographics, reason for referral, etc.) be tracked?
- Is there an existing data manager that can be adapted for your services?
- Who will be responsible for entering this data?
- Who will have access to this information?

## **Billing**

- Will you bill for your services?
- Will you be billing with 96040 incident to the physician, a flat fee, or a facility fee?
- How are charges submitted?
- Who is your contact person for billing issues?
- How quickly are you expected to have the charges submitted for your services?

## **Blood Draws/Genetic Testing**

- Do you need to use an outpatient laboratory for draws or is there a phlebotomist on the floor to do draws?
- Can blood samples be drawn from IV lines for patients that are undergoing procedures with sedation or ports when necessary?
- How are orders for blood draws and/or genetic testing placed?
- Who will package the sample and get shipping arranged?
- Is a physician signature or sign off necessary to place an order?

## **Results Disclosure/Creating Referrals**

- Will results be given to patients in person, over the phone, or a combination?
- How do you refer a patient to other healthcare providers?

## **Advertisement of Services and Education**

- What venues are available to you to meet the other healthcare providers in the practice?
- What educational opportunities are available for you?
- Are there opportunities to participate in training healthcare providers (such as residents, fellows, genetic counseling graduate students, etc)?
- Will you need to develop a patient handout about cancer risk assessment? A health care provider handout?
- At tumor boards or cancer conference, how does your institution plan to integrate your services into the existing format? Will the genetic counselor be able to present cases?

## **Compliance/Risk Management**

- Will you be covered under the institution's liability and malpractice insurance?
- Who is your contact person for compliance issues?
- Consider setting up a process at your institution for the following situation:
  - Patient died before genetic testing result was received
  - Who is defined as next of kin when requesting medical documents (sibling, child, current spouse, etc.)?

## **Research**

- What training (such as CITI training) is required at your institution to conduct research and/or consent patients into research studies?
- What opportunities are available to you at your institution to conduct research?
- Can you enroll patients in outside research studies?

## **Other**

- Will you have access to risk assessment tools like CaGene, Progeny, etc.?
- Would it be possible to add standard language to pathology reports for patients that are an indication for a genetic risk evaluation (i.e. colorectal cancer less than age 50 per NCCN guidelines)?

- Would your healthcare providers like a risk assessment tool to help identify those that would benefit from a genetic risk evaluation?
- Is there a budget for books, articles and other reference material?
- Does the institution have a library than can help with gaining access to journal articles?

### **Additional Resources**

Daly MB et al (2005) How to establish a high-risk cancer genetics clinic: limitations and successes. *Curr Oncol Rep*, 7(6):41–47

Egan C (1997) Models for Cancer Genetic Risk Assessment Programs. *Oncol Issues*. March/April: 14-17.

Fowler ES et al (2008) Cancer genetic counseling: trends in patient referrals and genetic testing in a community-based program. *Community Oncolog*, 2(3):253–260

Ho C (2004) How to develop and implement a cancer genetics risk assessment program. *Oncology Issues*. November/December: 22–26.

Kausmeyer DT et al (2006) A survey of patients' experiences with the cancer genetic counseling process: recommendations for cancer genetics programs. *J Genet Couns*, 15(6):409–431.

McPerson et al (2008) Clinical genetics provider real-time workflow study. *Genetics in Medicine*, 10(9):699 – 706.

Peters JA et al (1999) *Components of a Genetic Cancer Risk Clinic*, Cancer Genetics for the Clinician, Gail L Shaw, ed., Kluwer Academic/Plenum Publishing, New York

Ponder BAJ (1994) Setting Up and Running a Familial Cancer Clinic. *Br Med Bulletin*. 50(3): 732-745.

Wham et al (2010) Assessment of clinical practices among cancer genetic counselors. *Fam Cancer*, Feb 6. [Epub ahead of print]

### **Alternative Service Delivery Models- Descriptions**

Phone Counseling - GC provides pre-test and/or post-test counseling over the telephone using educational materials sent to patient prior to consultation. Pros: 1) Geography is no longer a limitation. 2) Patient may receive consultation in comfort of own home. Cons: 2) Counselor is unable to read important non-verbal cues that assess understanding and psychosocial status. 2) Counseling over the phone may have billing limitations.

Telemedicine Counseling - GC provides pre-test and/or post-test counseling using videoconferencing equipment and educational materials sent to patient prior to consultation. Pros: 1) Similar benefits to phone counseling, but with the addition of allowing the counselor to get a visual assessment through video. 2) May eliminate need for outpatient clinics. Cons: 1) Feasibility. Equipment is required and must be available at both locations. 2) Technical difficulties (e.g. poor video/audio feed) affect counseling interaction.

Referral after Testing - Physician provides informed consent and testing for all appropriate patients and refers some or all patients (high-risk negatives and variants of uncertain significance) to a genetic counselor after receiving test results. Pro: Allows busy GC to focus schedule. Con: Complex cases may be missed.

Referral of Complex Cases - Physician provides informed consent and tests straightforward cases, and refers complex cases (complex family history, strong family history with negative test result) to a genetic counselor for pre-test risk assessment, counseling and testing. Pro: Allows busy GC to focus schedule. Con: Complex cases may still be missed.

Group Genetic Counseling - GC provides counseling to groups of patients with or without follow up individual sessions. Pros: 1) Patients receive mutual support from peers. 2) May be cost effective. Cons: 1) Individuals in group may have diverse needs. 2) Group counseling may have billing limitations.

Mid-Level Provider - Mid-level provider identifies patients and does informed consent and testing. Difficult cases are triaged to the genetic counselor. Alternatively, the mid-level provider could segregate patients into categories such as: refer to a genetic counselor, need more information, physician provide test, low risk for hereditary cancer. Pro: Allows busy GC to focus schedule. Con: Complex cases may be missed.

Consultant Model - Genetic counselor is a consultant to physician providing informed consent and testing. Provides "second opinion" on family history and test result interpretation, without actually seeing the patient. Pro: Feasible approach for GC working with multiple health care centers. Con: Vulnerable job security.

Public health model - GC educates a community of providers (within hospital, city, region) through group education with expectation that the providers will manage routine cases and refer complex ones. Pro: GC is casting a wide net for appropriate patients for testing. Con: Provider participation/interest may be limited.

Allain D, et al. (2010) Evolving Models of Cancer Risk Genetic Counseling. *Perspectives in Genetic Counseling*. 32 (1).

## **1. Example - Only Cancer GC in Town**

I currently work at an oncology and hematology center that employs six oncologists. When I was hired, I was the only genetic counselor in town of 225,000. There are two major hospital systems in the city; however, they mostly employ hospitalists. The majority of physicians here practice in private group clinics. I started our hereditary cancer risk assessment program and use two service delivery models for patients that I see at our center: 1) Traditional face-to-face pre-test and post-test counseling; and 2) Traditional face-to-face pre-test and telephonic post-test counseling. I have contracts with other group practices to see their patients using the collaborative service delivery model. I help the physicians at those practices with risk assessment and they manage low risk cases while I see their high/moderate risk cases for genetic counseling.

## **2. Example - Outreach Cancer Genetic Counseling from Duke Hereditary Cancer Clinic**

Access to cancer genetic counseling in North Carolina is limited to those who live near a few large cities or are able to travel to these cities. Thus, many individuals in underserved areas are unable to reap the well documented benefits of counseling. In 2005, we sought to address this problem by offering monthly, no-cost counseling at several rural oncology clinics affiliated with Duke University Medical Center. The process of setting up the service took several months and involved such tasks as reviewing referral criteria with physicians and staff, publicizing the service in the local communities and applying for clinical privileges at each clinic (an often time-consuming process in hospitals with no experience credentialing genetic counselors).

During the first year of offering the service, we found that it was well accepted among patients and reached individuals who otherwise would not have had genetic counseling (Buchanan, 2009). However, it was inefficient to drive to the clinics (up to 5 hours round-trip). Further, the monthly format may have prevented newly diagnosed individuals from using genetic test results to guide their cancer management. Thus, we applied for and received funds to test telemedicine as a means of improving access to genetic counseling in a more timely, efficient manner. We are now in the process of conducting a randomized trial comparing patient satisfaction and cost-effectiveness of counseling offered in-person vs. telemedicine. If we find that telemedicine counseling is as satisfactory as in-person counseling, and is more cost-effective, we will plan to reach other underserved areas in the state via this technology.

Buchanan AH, Skinner CS, Calingaert B, Schildkraut JS, King RH, Marcom, PK. (2009) Cancer genetic counseling in rural North Carolina oncology clinics: program establishment and patient characteristics. *Commun Oncol*, 6:70–77.

## Billing For Genetic Counseling Services

Billing for genetic counseling services can be complex and vary based on individual clinic models. It is highly suggested that you speak with your administrators and hospital compliance team to ensure optimal billing practices in accordance with the policies of your institution. The recent introduction of CPT code 96040 has allowed for genetic counselors to have a billing code specific to the practice of genetic counselors. Alternate CPT codes may be used by genetic counselors who practice with a physician.

NSGC Billing Reimbursement Toolkit [link:  
[http://www.nsgc.org/members\\_only/tools/br\\_index.cfm](http://www.nsgc.org/members_only/tools/br_index.cfm)]

NSGC's Policy and Government Relations department can provide consulting services for a genetic counselor's institution to optimize reimbursement rates. As of September 2010, the fee is \$350/hour and the executive office estimated that most institutions would require no more than one hour of consultation.

NSGC online course "Learn the 3 C's to Maximize your Service Delivery Model: Coding, Credentialing and Compliance"- <http://www.nsgc.org/conferences/CodingCourse2009.cfm>

- Define the role of a genetic counselor as a member of the health care management team Describe the basics of healthcare billing
- Identify the complexities of billing for genetic services
- Identify the benefits and limitations of various strategies of billing for genetic services

NSGC biannual Professional Status Survey and PSS Cancer Genetics Analysis – [www.nsgc.org](http://www.nsgc.org) - available through NSGC members only access

CPT Code 96040 Medical Genetics and Genetic Counseling Services – Frequently Asked Questions- [www.nsgc.org](http://www.nsgc.org) - available through NSGC members only access

Harrison, TA et al (2010) Billing for medical genetics and genetic counseling services: a national survey. *J Genet Couns*, 19(1):38-43.

## Insurance Discrimination Based on Genetic Testing

Patients who seek cancer genetic counseling services often express the concern that their insurance company would discriminate against them based on genetics evaluation or genetic test results. Fortunately, with state and federal legislation, this is considered to most likely be an unfounded concern.

Various states in the US have laws protecting patients from being discriminated against based on genetic information. The federal law called Genetic Information Non discrimination Act (GINA) provides protection against health insurance and employer discrimination based on this information. GINA, together with already existing nondiscrimination provisions of the Health Insurance Portability and Accountability Act, generally prohibits health insurers or health plan administrators from requesting or requiring genetic information of an individual or the individual's family members, or using it for decisions regarding coverage, rates, or preexisting conditions. The law also prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment. There are limitations to GINA's protections. GINA's health coverage non-discrimination protections do not extend to life insurance, disability insurance and long-term care insurance. GINA's employment provisions generally do not apply to employers with fewer than 15 employees. Also not subject to GINA are the United States military (or the Tricare military health system), veterans' health care administered by the Veterans' Administration, the Federal Employees Health Benefits Plan, or the Indian Health Service. The websites that provide more information about GINA and other state laws are as follows:

<http://www.dnapolicy.org/gina/faqs.html>

<http://www.ginahelp.org/GINAhelp.pdf>

[www.genome.gov](http://www.genome.gov) <http://www.ncsl.org/programs/health/genetics/prt.htm>.

[http://www.nsgc.org/client\\_files/providers/cancer/GINA\\_%20insert\\_2.pdf](http://www.nsgc.org/client_files/providers/cancer/GINA_%20insert_2.pdf)

[http://www.nsgc.org/consumer/genetic\\_discrimination\\_resource.cfm](http://www.nsgc.org/consumer/genetic_discrimination_resource.cfm)

Baruch, S., & Hudson, K. (2008) Civilian and military genetics: nondiscrimination policy in a post-GINA world. *Am J Hum Genet*, 83(4):435-444.

Erwin, C. (2008) Legal update: living with the Genetic Information Nondiscrimination Act. *Genet Med*, 10(12):869-873.

Hudson KL, Holohan MK, Collins FS (2008) Keeping pace with the times--the Genetic Information Nondiscrimination Act of 2008. *N Engl J Med*, 358(25):2661-3.

Rothstein, M. A. (2008) Currents in contemporary ethics. GINA, the ADA, and genetic discrimination in employment. *J Law Med Ethics*, 36(4):837-840.

## **Maintaining Patient Confidentiality**

As stated by the NSGC Code of Ethics, “the primary concern of genetic counselors is the interest of their clients”. Therefore, genetic counselors strive to maintain confidentiality of any information received from clients, unless released by the client.

Every cancer genetic counseling program has a different mechanism for maintaining the confidentiality of their medical records. It is important to note that some hospitals require all information, including genetic information, to be stored in the hospital medical record. Check with your institution’s Medical Records Department and/or attorney.

Just as in other genetics clinics, cancer clinics often have identifying information on family members (family history questionnaires, medical records, genetic test results). It is important to consider how you will ensure confidentiality of your patient’s family members’ records.

For more information about the Health Insurance Portability and Accountability Act (HIPPA), including FAQ, visit: <http://www.hhs.gov/ocr/privacy/>.

## Sample Family History Questionnaire and Consent Forms

An accurate family history is an integral part of any hereditary cancer risk assessment. There are several approaches to obtaining the family history. Some will obtain the family history at the visit, some will obtain a family history over the phone prior the visit, and others may utilize a pre-visit family history questionnaire.

A major benefit of the pre-visit family history questionnaire is that it allows the genetic counselor to review the family history prior to the patient's visit. In addition, a pre-visit family history questionnaire can save time; the genetic counselor may spend less time obtaining the family history. Lastly, the pre-visit family history questionnaire allows the patient to speak with family members prior to his/her visit clarifying diagnoses and ages of diagnosis. Consequently this may lead to a more accurate family history. One drawback of the pre-visit questionnaire strategy is that the patient may find the process time-consuming and therefore opt not to follow up with a genetic counseling visit.

When utilizing a pre-visit family history questionnaire it may be helpful to consider how and when the patient should return the questionnaire. Some require patients complete the questionnaire prior to receiving an appointment. This increases the likelihood that the counselor will have the family history prior to the appointment, however this may prevent some patients from scheduling an appointment. Some require patients to send back the completed questionnaire prior to their appointment. This allows patients to schedule an appointment but a drawback of this approach is that not every patient will complete and return the questionnaire before his/her appointment. Lastly, some ask patients to bring the completed questionnaire to his/her appointment. While the genetic counselor may have more accurate information, this strategy does not give the genetic counselor time to review the family history prior to the patient's visit.

### Family History Questionnaires :

NSGC members' family history questionnaires examples:

[http://www.nsgc.org/members\\_only/tools/family\\_history\\_forms.cfm?](http://www.nsgc.org/members_only/tools/family_history_forms.cfm?)

Surgeon General's "My Family Health Portrait" tool: <https://familyhistory.hhs.gov/>

Genetic Alliance "Does it run in the Family" <http://www.doesitrunithefamily.org/>

### Consent Forms

Certain situations may require the use of consent forms. Check with your institution regarding which situations may require informed consent. Some clinics require documentation of informed consent with genetic testing and/or certain procedures.

### Sample Consent Forms:

NSGC members' consent form examples:

[http://www.nsgc.org/members\\_only/tools/consent\\_forms.cfm](http://www.nsgc.org/members_only/tools/consent_forms.cfm)

## References & Resources

The following is a list of internet resources which may be of assistance to genetic counselors, health care providers, and patients.

### Genetic Counseling Resources for Professionals

Genetic Alliance Resource Repository <http://www.geneticalliance.org/rr>

National Cancer Institute <http://www.cancer.gov> Cancer Genetics Overview (PDQ®)  
<http://www.cancer.gov/cancertopics/pdq/genetics/overview/healthprofessional>

Cancer Genetics Risk Assessment and Counseling (PDQ®)  
<http://www.cancer.gov/cancertopics/pdq/genetics/risk-assessment-and-counseling/HealthProfessional>

Genetics resources  
<http://www.cancer.gov/cancertopics/pdq/genetics/overview/HealthProfessional/pa-ge5>

NSGC Resources- [www.nsgc.org](http://www.nsgc.org) - available through NSGC members only access  
NSGC Cancer Special Interest Group  
NSGC Listserv  
NSGC biannual Professional Status Survey and PSS Cancer Genetics Analysis

Wham et al (2010) Assessment of clinical practices among cancer genetic counselors.  
*Fam Cancer*, Feb 6. [Epub ahead of print]

### Practice Guidelines/Position Statements:

Many of the professional organizations listed publish regularly updates of their practice guidelines for inherited cancer predisposition syndromes. For example, NCCN published an updated Colorectal Cancer Screening guideline in 2010. This guideline covers Lynch/HNPCC, FAP, MYH-associated polyposis, etc. Be sure to check these professional organizations' websites' practice guideline areas regularly for the most up-to-date practice recommendations.

American Gastroenterological Association (AGA)  
<http://www.gastro.org/wmspage.cfm?parm1=2>

Winawer S et al (2003) Colorectal Cancer Screening and Surveillance: Clinical Guidelines and Rationale-Update Based on New Evidence *Gastro*, 124: 544-560.

American Society of Breast Surgeons <http://www.breastsurgeons.org>

BRCA Genetic Testing for Patients With and Without Breast Cancer:  
<http://www.breastsurgeons.org/brca.shtml>

American Society of Clinical Oncology (ASCO) <http://www.asco.org>

American Society of Clinical Oncology Policy Statement Update: Genetic and Genomic Testing for Cancer Susceptibility (2010) *J Clin Oncol*, 28(5):893-901.

Khatcheressian J et al (2006) American Society of Clinical Oncology 2006 Update of the Breast Cancer Follow-up and Management Guidelines in the Adjuvant Setting. *J Clin Oncol*, 24(31): 5091-5097.

American Society of Clinical Oncology Policy Statement Update Genetic Testing for Cancer Susceptibility. (2003) *J Clin Oncol*, 21(12):2397-406.

Statement of the American Society of Clinical Oncology: Genetic Testing for Cancer Susceptibility (1996) *J Clin Oncol*, 14(5):1730-1736.

Evaluation of Genomic Applications in Practice and Prevention (EGAPP)  
<http://www.egappreviews.org/default.htm>

EGAPP Working Group (2009) Hereditary Nonpolyposis Colorectal Cancer: Diagnostic Strategies and Their Implications. *Genet Med* 11(1): 35-41.

National Society of Genetic Counselors  
[http://www.nsgc.org/journal/Practice\\_Guidelines.cfm](http://www.nsgc.org/journal/Practice_Guidelines.cfm)

Berliner J and Musial Fay A (2004) Risk Assessment and Genetic Counseling for Hereditary Breast and Ovarian Cancer: Recommendations of the National Society of Genetic Counselors *J Genet Couns*,16(3): 241-260.

Hampel H, Sweet K, Westman JA, Offit K, Eng C (2004) Referral for cancer genetics consultation: a review and compilation of risk assessment criteria. *J Med Genet*, 41(2):81-91.

*A merge of the practice statements of many professional societies into one comprehensive cancer referral guideline.*

Trepanier A et al (2004) Genetic Cancer Risk Assessment and Counseling: Recommendations of the National Society of Genetic Counselors *J Genet Couns*,13(2) 83-114.

National Comprehensive Cancer Network (NCCN): <http://www.nccn.org>

NCCN Practice Guidelines in Oncology: Colorectal Cancer Screening

NCCN Practice Guidelines in Oncology: Genetic/Familial High Risk Assessment: Breast and Ovarian

Society of Gynecologic Oncologists (SGO) <http://www.sgo.org>

SGO Committee (2007) Statement on Risk Assessment for Inherited Gynecologic Cancer Predispositions. *Gynecologic Oncology*, 107:159–162.

### **Professional Organizations:**

Professional Organizations can be a valuable resource to understand the various aspects of patient care. These organizations have guidelines that help genetic counselors keep up to date with guidelines and recommendations for the care of their patient. The following links will help guide you with topics such as appropriateness of genetic testing, cancer risks, screening and management.

American Cancer Society (ACS) ([www.cancer.org](http://www.cancer.org))  
American Gastroenterological Association (AGA)  
(<http://www.gastro.org/wmspage.cfm?parm1=2>)  
American Society of Breast surgeons (<http://www.breastsurgeons.org/>)  
American Society of Clinical Oncology (ASCO) (<http://www.asco.org/portal/site/asco>)  
Breast Cancer Surveillance Consortium (<http://breastscreening.cancer.gov/>)  
Gynecologic Cancer Foundation (<http://www.thegcf.org/>)  
National Comprehensive Cancer Network (NCCN) (<http://www.nccn.org/>)  
National Cancer Institute (<http://www.cancer.gov/>)  
NSGC Cancer Special Interest Group  
([http://www.nsgc.org/members\\_only/sig/sig\\_familial\\_crc.cfm](http://www.nsgc.org/members_only/sig/sig_familial_crc.cfm))  
NSGC listserv ([http://www.nsgc.org/members\\_only/nsqlist.cfm](http://www.nsgc.org/members_only/nsqlist.cfm))  
Society of Breast Imaging: (<http://www.sbi-online.org/>)  
Society of Gynecological Oncologists (SGO) (<http://www.sgo.org/>)  
Surveillance Epidemiology and End Results (<http://seer.cancer.gov/>)

### **Hereditary Breast and Ovarian Cancer:**

NCI Genetics of Breast and Ovarian Cancer (PDQ®)  
<http://www.cancer.gov/cancertopics/pdq/genetics/breast-and-ovarian/healthprofessional>

ACOG Practice Bulletin No. 103: Hereditary breast and ovarian cancer syndrome.  
(2009) *Obstet Gynecol*. 113(4):957-66.

*Practice statement from the **American College of Obstetricians and Gynecologists (ACOG)**.*

Berliner JL, Fay AM (2007) Risk assessment and genetic counseling for hereditary breast and ovarian cancer: recommendations of the National Society of Genetic Counselors. *J Genet Couns*,16(3):241-60.

*Practice recommendations from **NSGC**.*

Lancaster JM, Powell CB, Kauff ND, Cass I, Chen LM, Lu KH, et al. (2007) Society of Gynecologic Oncologists Education Committee statement on risk assessment for inherited gynecologic cancer predispositions. *Gynecol Oncol*, 107(2):159-62.

*Practice statement from the **Society of Gynecologic Oncologists (SGO)**.*

Khatcheressian JL, Wolff AC, Smith TJ, Grunfeld E, Muss HB, Vogel VG, et al. (2006) American Society of Clinical Oncology 2006 update of the breast cancer follow-up and management guidelines in the adjuvant setting. *J Clin Oncol*, 24(31):5091-7.

*Practice statement from the **American Society of Clinical Oncology (ASCO)**.*

NHS. Familial breast cancer: the classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care (partial update of CG14). (2006) National Collaborating Centre for Primary Care.

*Practice statement from the **National Health Service (NHS)** of the United Kingdom.*

Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. (2005) *Ann Intern Med*,;143(5):355-61.

*Practice statement from the **U.S. Preventive Services Task Force (USPSTF)** recommendations on genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility*

American Society of Breast Surgeons, "BRCA Genetic Testing for Patients With and Without Breast Cancer" (<http://www.breastsurgeons.org/>)

#### **Hereditary Colon Cancer:**

NCI Genetics of Colorectal Cancer (PDQ®)

<http://www.cancer.gov/cancertopics/pdq/genetics/colorectal/healthprofessional> Palomaki GE, McClain MR, Melillo S, Hampel HL, Thibodeau SN. (2009) EGAPP supplementary evidence review: DNA testing strategies aimed at reducing morbidity and mortality from Lynch syndrome. *Genet Med.*;11(1):42-65.

*Evidence report from the **Evaluation of Genomic Applications in Practice and Prevention (EGAPP)** Working Group*

Winawer S, Fletcher R, Rex D, Bond J, Burt R, Ferrucci J, et al. (2003) Colorectal cancer screening and surveillance: clinical guidelines and rationale-Update based on new evidence. *Gastroenterology*, 124(2):544-60.

*Practice guideline from the **American Gastroenterological Association (AGA)** Gastrointestinal Consortium Panel.*

#### **Other:**

Brandi ML, Gagel RF, Angeli A, Bilezikian JP, Beck-Peccoz P, Bordi C, et al. (2001) Guidelines for diagnosis and therapy of MEN type 1 and type 2. *J Clin Endocrinol Metab*, 86(12):5658-71.

*Practice guidelines from the **Seventh International Workshop on Multiple Endocrine Neoplasia***

NCI Genetics of Medullary Thyroid Cancer (PDQ®)

<http://www.cancer.gov/cancertopics/pdq/genetics/medullarythyroid/healthprofessional>

NCI Genetics of Prostate Cancer (PDQ®)

<http://www.cancer.gov/cancertopics/pdq/genetics/prostate/healthprofessional>

NCI Genetics of Skin Cancer (PDQ®)

<http://www.cancer.gov/cancertopics/pdq/genetics/skin/healthprofessional>

#### **Research opportunities:**

ClinicalTrials.gov- [www.clinicaltrials.gov](http://www.clinicaltrials.gov) - registry of National and International federal and privately supported clinical trials

NSGC Cancer SIG research directory- available through NSGC Cancer SIG webpage

## **Patient Resources**

### **Genetic Counseling Resources for Patients**

Making Sense of Your Genes: A Guide to Genetic Counseling (Genetic Alliance)  
<http://www.geneticalliance.org/counseling.guide>

Genetics FAQs [link:  
[http://www.nsgc.org/client\\_files/providers/cancer/PatientGeneticsFAQ.pdf](http://www.nsgc.org/client_files/providers/cancer/PatientGeneticsFAQ.pdf)]

Guide to Understanding Genetics (Genetic Alliance)  
<http://www.geneticalliance.org/understanding.genetics>

NSGC Guide to Genetic Counseling:  
[http://www.nsgc.org/client\\_files/GuidetoGeneticCounseling.pdf](http://www.nsgc.org/client_files/GuidetoGeneticCounseling.pdf)

For general information about genetic counselors, go to  
[http://www.nsgc.org/consumer/faq\\_consumers.cfm](http://www.nsgc.org/consumer/faq_consumers.cfm)

To find a genetic counselor: <http://www.nsgc.org/resource/link.cfm>

NCI: Cancer genetics professional finder: For a directory of professionals who provide cancer genetics services, go to <http://www.cancer.gov/search/geneticsservices/>

### **Genetic Testing for patients**

NCI: Understanding cancer genetic testing (a slide show):  
<http://www.cancer.gov/cancertopics/UnderstandingCancer/genetesting>

ACS Genetic Testing: What You Need to Know: [www.cancer.org](http://www.cancer.org) (search for “Genetic Testing”)

NSGC’s Five questions to ask before having genetic testing:  
[http://www.nsgc.org/consumer/NSGC\\_Five\\_Questions.pdf](http://www.nsgc.org/consumer/NSGC_Five_Questions.pdf)

### **General Cancer Genetics**

ACS Heredity and Cancer: [www.cancer.org](http://www.cancer.org) (search for “Heredity and Cancer”)

Genetics Home Reference: Help Me Understand Genetics:  
<http://ghr.nlm.nih.gov/handbook>

### **General Cancer Prevention**

ACS Cancer Prevention & Early Detection:  
[http://www.cancer.org/docroot/PED/ped\\_0.asp](http://www.cancer.org/docroot/PED/ped_0.asp)

NCI’s Cancer Prevention: <http://understandingrisk.cancer.gov>

### **Hereditary Cancer Syndromes**

To learn more about a specific cancer from the American Cancer Society, go to [www.cancer.org](http://www.cancer.org) and choose “Choose a Cancer Topic” (has info about syndrome in details about specific cancers)

To learn more about a specific cancer from the National Cancer Institute:  
<http://www.cancer.gov/cancertopics/alphalist/a-d>

Genetics Home Reference: Your Guide to Understanding Genetic Conditions:  
<http://ghr.nlm.nih.gov/BrowseConditions>

## **Support groups/Organizations**

### **Breast Cancer/HBOC**

#### **Breast Cancer Network of Strength**

<http://www.networkofstrength.org/>

*Mission: to ensure, through information, empowerment and peer support, that no one faces breast cancer alone.*

#### **National Breast Cancer Coalition**

<http://www.natlbcc.org>

*Mission: to eradicate breast cancer, by focusing the administration, U.S. Congress, research institutions and consumer advocates on breast cancer. NBCC encourages all those concerned about this disease to become advocates for action and change.*

#### **Susan G. Komen for the Cure**

<http://www.breastcancerinfo.com>

*The world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. The Komen Foundation answers questions from recently diagnosed breast cancer patients and provides emotional support. Information is available in Spanish.*

#### **Breastcancer.org**

<http://www.breastcancer.org/>

*A nonprofit organization dedicated to providing the most reliable, complete, and up-to-date information about breast cancer. Our mission is to help women and their loved ones make sense of the complex medical and personal information about breast cancer, so they can make the best decisions for their lives.*

#### **Breast Cancer Options**

<http://www.breastcanceroptions.org>

*Mission: to educate breast cancer patients about effective treatment options, to advocate for and support informed patient choice and to promote public awareness regarding cancer risk reduction.*

#### **Bright Pink**

<http://www.bebrightpink.org>

*Bright Pink is a national non-profit organization that provides education and support to young women who are at high risk for breast and ovarian cancer.*

#### **Facing Our Risk of Cancer Empowered (BRCA carriers)**

<http://www.facingourrisk.org>

*To provide women with resources to determine whether they are at high risk for breast and ovarian cancer due to genetic predisposition, family history, or other factors. To*

*provide information about options for managing and living with these risk factors. To provide support for women as they pursue these options. To provide support for families facing these risks. To raise awareness of hereditary breast and ovarian cancer. To represent the concerns and interests of our high-risk constituency to the cancer advocacy community, the scientific and medical community, the legislative community, and the general public. To promote research specific to hereditary cancer. To reduce disparities among underserved populations by promoting access to information, resources and clinical trials specific to hereditary breast and ovarian cancer.*

#### Genetic Information to Stop Breast and Ovarian Cancer, Inc.

<http://www.jacobintl.org>

*To educate Ashkenazi Jewish women about their hereditary risk for breast and ovarian cancer and the benefits of genetic testing.*

#### Inflammatory Breast Cancer Research Foundation

<http://www.ibcresearch.org>

*To assist scientists and researchers in their quest to determine the definitive causes of inflammatory breast cancer. The Inflammatory Breast Cancer Research Foundation seeks to assist them in their work so effective and meaningful detection and diagnosis, prevention and treatment can be pursued and achieved.*

#### Young Survival Coalition

[www.youngsurvival.org](http://www.youngsurvival.org)

*Young Survival Coalition (YSC) is the premier international organization dedicated to the critical issues unique to young women and breast cancer.*

#### Sharsheret

[www.sharsheret.org](http://www.sharsheret.org)

*Linking young Jewish women in their fight against breast cancer.*

#### NCI: BRCA1/2 cancer risk and genetic testing

<http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>

## Ovarian Cancer

#### Conversations!

<http://www.ovarian-news.org>

*The International Newsletter For Those Fighting Ovarian Cancer!*

#### Gilda Radner Familial Ovarian Cancer Registry

<http://www.ovariancancer.com>

*Our goals are to identify new genes associate with familial ovarian cancer, thereby improving genetic and psychological counseling for individuals and families and to characterize lifestyle choice that reduce ovarian cancer risk in women who may be more susceptible to the disease.*

#### National Ovarian Cancer Coalition, Inc.

<http://www.ovarian.org>

*To raise awareness and promote education about ovarian cancer. The Coalition is committed to improving the survival rate and quality of life for women with ovarian cancer.*

#### Ovarian Cancer National Alliance

<https://www.ovariancancer.org>

*Our mission is to conquer ovarian cancer by uniting individuals and organizations in a national movement.*

#### Colorectal Cancer/Lynch Syndrome (HNPCC)/FAP

#### Collaborative Group of the Americas on Inherited Colorectal Cancer

[www.cgaicc.com](http://www.cgaicc.com)

*Provides education regarding the clinical management and molecular genetics of inherited colorectal cancer to physicians, allied health-care professionals, patients and their families. Also provides access to clinical and chemoprevention trials.*

#### C3: Colorectal Cancer Coalition

<http://www.fightcolorectalcaner.org>

*A national, nonpartisan organization whose mission is to eliminate suffering and death due to colon and rectal cancer through advocacy. C3 pushes for research to improve screening, diagnosis, and treatment of colorectal cancer; for policy decisions that make the most effective colon and rectal cancer prevention and treatment available to all; and for increased awareness that colorectal cancer is preventable, treatable, and beatable.*

#### Colorectal Cancer Network

<http://clickonium.com/colorectal-cancer.net/html//index.htm>

*Survivors and their loved ones standing up to say "Not one more person should die from this cancer!" Our plan includes: A support network so that no one goes through this alone anymore; aggressive awareness, screening, and early detection programs; and legislative actions.*

#### Colon Cancer Alliance

<http://www.ccalliance.org/>

*Provide support for those affected by this disease, helping patients and caregivers, inform the public about screening guidelines; support research for new treatments, and, advocate for legislation to support efforts to eliminate colorectal cancer.*

#### Minnesota Colorectal Cancer Initiative (last updated on 7/05/08)

[http://www.surg.umn.edu/surgery/Divisions/General/C\\_and\\_R/MCCI.html](http://www.surg.umn.edu/surgery/Divisions/General/C_and_R/MCCI.html)

*A non-profit, community and professional resource that provides information regarding colorectal cancer; personal risk assessment and individual, risk-specific screening recommendations.*

#### Johns Hopkins Gastroenterology & Hepatology Resource Center

<http://www.hopkins-coloncancer.org/>

*This site is provided to educate and inform people about hereditary colorectal cancer. You can find information about the basic causes of colorectal cancer, how colorectal cancer is diagnosed, what surgical therapies are available, and complications of hereditary colorectal cancer. Specific information on Familial Adenomatous Polyposis*

(FAP), Hereditary Nonpolyposis Colorectal Cancer (HNPCC), and a gene mutation called APC I1307K

#### Yahoo! Groups FAP/Gardners Syndrome

<http://groups.yahoo.com/group/gardnerssyndrome/>

*Yahoo! Groups runs an online support group for people with FAP.*

#### Intestinal Multiple Polyposis and Colorectal Cancer Foundation

E-mail: [impacc@epix.net](mailto:impacc@epix.net)

*A support group for families with FAP and/or hereditary colon cancer. Offering professional counseling, medical referrals, peer support, matching individuals/families. Providing educational materials, registry of affected individuals, and linking researchers and families. Based in Pennsylvania.*

#### UOA (United Ostomy Association)

<http://uoa.org>

*A national volunteer-based organization. More than 500 chapters are made up of people with ostomies whose goal is to provide mutual aid, moral support, and education to those who have had colostomy or ileostomy surgery. Check the telephone directory for your local chapter.*

#### Other

#### The Association for Multiple Endocrine Neoplasia Disorders (AMEND)

[www.amend.org.uk](http://www.amend.org.uk)

*AMEND is a UK-registered charity committed to supporting all those affected by multiple endocrine neoplasia (MEN) and its associated endocrine growths.*

#### National Endocrine and Metabolic Diseases Information Service

<http://endocrine.niddk.nih.gov/pubs/men1/men1.htm>

#### Pancreatic Cancer Action Network

[www.pancan.org](http://www.pancan.org)

*A nationwide network of people dedicated to working together to advance research, support patients and create hope for those affected by pancreatic cancer.  
877-272-6226*

#### The Carcinoid Cancer Foundation

[www.carcinoid.org](http://www.carcinoid.org)

*This non-profit organization encourages and supports research and education on carcinoid and related neuroendocrine cancers.  
888-722-3132*

#### Be Strong Hearted: A Network for Gastric Cancer Patients, Survivors and Families

[www.BeStrongHearted.org](http://www.BeStrongHearted.org)

*A charitable organization whose mission is to expedite education and research for early diagnosis, screening, treatment and prevention of Hereditary Diffuse Gastric Cancer (HDGC) and other diffuse gastric cancers and their related health risks, and to provide a network of support for affected families.*

### National Childhood Cancer Foundation Children's Oncology Group

<http://www.curesearch.org/>

*CureSearch unites the world's largest childhood cancer research organization, the Children's Oncology Group, and the National Childhood Cancer Foundation through our mission to cure childhood cancer. Research is the key to the cure.*

### National Organization for Rare Disorders

[www.rarediseases.org](http://www.rarediseases.org)

*NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and service.  
203-744-0100; toll-free 800-999-6673*

### Genetic Alliance

[www.geneticalliance.org](http://www.geneticalliance.org)

*An organization that provides support to individuals and families with genetic conditions. A helpline is available for people with genetic questions.  
(202) 966-5557*

### VHL Family Alliance

[www.vhl.org](http://www.vhl.org)

*Provides information and support for families and physicians. The VHL Family Alliance is dedicated to improving diagnosis, treatment, and quality of life for individuals and families affected by VHL.*

### Kidney Cancer Association

<http://www.kidneycancer.org/>

*"Your source for information and support for living with Kidney Cancer." The KCA is a charitable organization made up of patients, family members, physicians, researchers, and other health professionals globally. We fund, promote, and collaborate on research projects. We educate families and physicians, and serve as an advocate on behalf of patients at the state and federal levels.*