*Perspectives in Genetic Counseling*
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# President's Beat

## Provider Outreach: Reaching More Patients Through Collaboration

"What do physician assistants and nurse practitioners need from us, genetic counselors?" asked 2009 NSGC President **Steve Keiles** of Michael Rackover, physician assistant and Michelle Mott, nurse practitioner, both speakers at the 2009 Annual Education Conference (AEC) Professional Issues Panel entitled, "Genetics in Primary Care: The Role of Genetic Counselors and Primary Care Providers." The purpose of the panel was to start a dialogue between genetic counselors and leaders of other professions, like physician assistants and nurse practitioners, about how to best serve the genetic needs of the general population.

Mr. Rackover and Ms. Mott asked for basic genetics education and technology tools that will help them decide when to refer patients for genetic counseling and/or genetic testing, in addition to cooperation on policy and advocacy efforts to protect or help patients. "It's not a turf issue," Mr. Rackover stated. He went on to say that they don't want to replace genetic counselors, but need help integrating genetics into their practices. Specifically, they need to know which cases to refer and what the primary care provider, who has access to patients who could benefit from genetic counseling, should do to prepare cases for genetic counseling. "What do you need the person who is referring to you to do?" he finished.

The AEC plenary session was just one example of ongoing conversations with other healthcare professionals about how to increase patients' access to genetic counseling services. There are many others:

**The Genetic Counseling Foundation pursues "Summit" of health care professionals**
The Genetic Counseling Foundation (GCF) is currently seeking funding for a project proposal, a Summit of healthcare professionals. This Summit would convene professionals from different specialties to discuss integration of genetic services into primary care. The GCF is an arm of the NSGC led by **Vivian Weinblatt**, which allows members and others to make tax-deductible donations to pursue its mission to "serve as the catalyst for the integration of genomic information and genetic counseling services into healthcare through philanthropic support of education, research, and public policy." Members who wish to support projects like this can donate to the GCF by contacting the

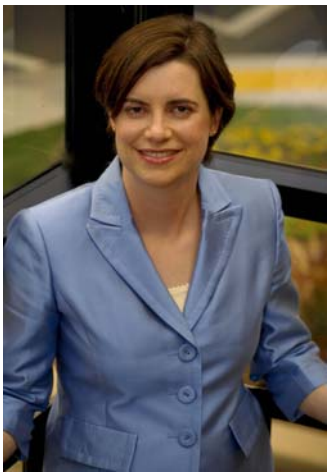
NSGC Executive Office at nsgc@nsgc.org or through the NSGC's online donation form at www.nsgc.org/payments/general/general.cfm; type "GCF donation" into the "description of payment" field.

**Access and Service Delivery Committee**
NSGC Member Stephanie Cohen is leading an effort to examine existing models for delivering genetic counseling services and evaluate their effectiveness in improving patient access to these services. One aspect of this effort will consider models using collaboration with other health care professionals. Stephanie says, "Collaborating with other health care providers gives genetic counselors an exciting opportunity to improve identification of at-risk patients, increase access and efficiency of genetic services, utilize existing local resources with whom patients are familiar, and maximize the unique skill sets of each provider." Look for upcoming surveys and focus groups to participate in this exciting discussion. This group has also submitted a proposal to the AEC Sub-Committee to offer an educational session on the topic of Alternate Service Delivery Models.

**Education Committee**
As the AEC speakers' comments, above, suggest, one of the most important resources other healthcare professionals need from genetic counselors is education about genetics as it specifically applies to their practices. The 2010 Education Committee is exploring options for offering educational programs to other health care providers. Benefits from these potential programs include 1) increased visibility for the profession 2) positioning genetic counselors as the experts in genetic services, and 3) developing additional revenue sources to fund the NSGC's numerous other strategic initiatives.

**Branding**
As discussed in numerous entries on the NSGC President's Blog (http://nsgcpresident.blogspot.com/) and in the NSGC's Branding FAQ (http://www.nsgc.org/Branding_FAQ_FINAL.pdf), the NSGC is undertaking efforts to develop an NSGC "brand" with physicians as the target audience. High-quality promotion of the genetic counseling profession requires a deep understanding of physicians' frustrations and needs when it comes to providing genetic services to their patients. The efforts described above – educational programs, exploration of service delivery models, and the GCF Summit – will all help the NSGC better understand these needs and consistently communicate to physicians how they can benefit from utilizing genetic counselors in their practices, or appropriately referring their patients to genetic counselors.

As you can see from these examples, the NSGC is reaching out to our colleagues in several other specialties to better understand how we can work together to meet the ultimate goal of providing appropriate genetic counseling services to as many patients as possible. This may best be summarized by quoting Dr. Alan Guttmacher and **Wendy Uhlmann** in their 2001 article in the *American Journal of Medical Genetics*, "...the expansion of non-genetic specialist providers' use of genetics will not relegate genetic specialists to the dustbin of medical history, but instead will redefine their roles." (Volume 106(3):216-22. Fall 2001).



Elizabeth Kearney, MS, CGC, MBA
2010 NSGC President

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## Leaders Among Us

*By Deepti Babu, MS, CGC and Kirsty McWalter, MS, CGC*

*Perspectives in Genetic Counseling* continues the **new series** highlighting genetic counselors who are exemplary contributors to the field and the NSGC. We hope this series will facilitate communication, show our appreciation of the countless hours of volunteer work donated by our members, and also illustrate that true leadership can be found everywhere within the organization. If you feel that a genetic counselor you know (including yourself) deserves mention in this series, please contact Deepti at deepti.babu@albertahealthservices.ca or Kirsty at kirsty@hawaiigenetics.org. We look forward to learning more about the different contributions made by genetic counselors throughout the NSGC!

We are pleased to announce the leader chosen for the Spring 2010 issue of *PGC*: **Monica Marvin, MS, CGC**. Monica was nominated by one of her work colleagues and she answers our questions, below.

1. Please list your current position and include a short description of your role(s).

*I currently function in two different roles at the University of Michigan. First, I serve as the Assistant Program Director of the University of Michigan Genetic Counseling Training Program. In this role, I oversee the clinical training of genetic counseling students, teach several classes, participate in curriculum development, and mentor genetic counseling students in clinical and research activities. I also serve as a clinical genetic counselor in the University of Michigan Cancer Genetics Clinic. In this role, I provide genetic counseling to individuals and families with a wide spectrum of hereditary cancer syndromes, while also teaching and supervising genetic counseling students, medical students, residents, and fellows. I couldn't ask for a better job! I am blessed to be able to work closely with outstanding students, unique patients, and great colleagues.*

2. What was your first volunteer activity with the NSGC? How and why did you get involved?

*My first involvement in the NSGC began shortly after receiving my genetic counseling degree and was the direct result of the encouragement of my Program Director,* ***Diane Baker,*** *and clinical supervisor,* ***Wendy Uhlmann****. Diane and Wendy exemplify what it means to be vital, active members of the NSGC. At that time, I served as a member of the Education Committee and then as member of the Steering Committee of the newly formed Cancer SIG. Just as there were role models for me, I hope that I too can be a role model and that my involvement in the NSGC inspires current students to become engaged in professional activities.*

3. What is your current involvement/role with the NSGC?

*In 2010, I was appointed to the role of Vice Chair of the NSGC Genetic Counseling Access and Service Delivery Committee. The charges for this Committee are numerous and relate to assessing the ability of various service delivery models to create access to genetic counseling; educating members, legislators and key stakeholders regarding licensure; educating members regarding CPT coding issues; developing and expanding*

*relationships with third party payors; and overseeing the NSGC Practice Guidelines proposal and development process. The work of this Committee is truly critical to our profession's ability to adapt to the changing healthcare landscape. During my short time in this new role, I have been thoroughly impressed with the collaborative, organized, and deliberative work of the Committee Chair* ***Janet Williams****, Past Chair* ***Leslie Cohen****, and the other Committee members.*

4. What has been your best role or experience with the NSGC?

*My most rewarding role in the NSGC was serving as the inaugural President of the Michigan Chapter of the NSGC (the Michigan Association of Genetic Counselors, or MAGC). As one of the first two state chapters of the NSGC, there was much I needed to learn about establishing such an organization. I navigated developing by-laws and filing articles of incorporations. Most importantly, I facilitated developing and executing a vision, mission, and goals for our small organization. I have also been actively involved in our state's licensure efforts, including drafting our bill, developing supportive documents and meeting with legislators, members of the Michigan State Medical Society, and other stakeholders. The MAGC also launched educational activities like annual conferences, website development, and outreach efforts. It has been gratifying to see what our group of genetic counselors within the state has been able to accomplish! Finally, my role in the leadership of our state chapter helped me develop the confidence to assume a leadership role at the national level.*

5. How can volunteer experiences with the NSGC be improved? How can volunteer involvement be encouraged in general within the NSGC, and for traditional leadership roles?

*I strongly support efforts the NSGC has made in recent years to identify new volunteers and to mentor new leaders, including the Pilot Project Mentor Program, the volunteer database, and the leadership development workshops held at Annual Education Conferences. Transparency is critical to these efforts, such that all members are aware of the multitude of opportunities for involvement and the process by which one can get involved. I think it is also important to recognize that genetic counselors can contribute to the growth of the profession at multiple levels, including at a local level. Being involved locally can be as simple as working with local advocacy groups, introducing yourself to a new group of health care providers in your community, or speaking at local schools. I am hopeful that by profiling genetic counselors contributing both nationally and locally, this "Leaders Among Us" series will demonstrate the we can ALL help advance the roles of genetic counselors in health care.*

6. How has your NSGC leadership experience enhanced your career?

*My professional activities within the NSGC have fostered new relationships with colleagues in the state and around the country. These new relationships have led to an increased understanding of the expanded roles genetic counselors are playing in healthcare, the challenges that face us, and the alliances that must be built. I also think that my service in state and national organizations was an asset when I was considered for and received a faculty appointment last year. Finally, my professional involvement has allowed for tremendous personal growth, including increased confidence in my leadership skills, expansion of my knowledge base, and the development of wonderful relationships with remarkable colleagues.*

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## Sarah Lawrence College Hosts First Annual Genetic Counseling "Summer Camp"

*By Caroline Lieber, MS, CGC*

On June 29, 2009, faculty from the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College hosted eighteen undergraduate students from the northeast region for a "Summer Camp" designed to teach attendees more about the field of genetic counseling. Information about the camp was distributed through an e-mail to the Northeast Association of Advisors to the Health Professions. Attendees came from as far north as Maine and as far south as Delaware. There was no fee to register. The camp was supported financially by a small grant from the Bloomberg Foundation.

***Faculty of the 2009 Sarah Lawrence College "Summer Camp" – Back Row:*** *Kelli Mayfarth, Khalida Liaquat, Kathleen Berentsen, Caroline Lieber, Lavanya Misra, Ushta Cantanweela;* ***Front Row:*** *Monique Simard, Sara Gilvary, Jamie Speer, Andy Faucett*

Faculty consisted of ten genetic counselors, including alumnae/i of the genetic counseling program, current faculty, clinical supervisors and the Director and Associate Director of the program: **Kathleen Berentsen, Ushta Cantanweela, Andy Faucett, Sara Givalry, Khalida Liaquat, Caroline Lieber, Kelli Mayfarth, Lavanya Misra, Monique Simard,** and **Jamie Speer**. Many different aspects of the profession were represented, including clinical roles in prenatal, cancer, pediatrics, assisted reproductive technologies, in addition to non-clinical roles in public health, health policy, international outreach and educational outreach.

The curriculum aimed to provide as broad and diverse a perspective on the genetic counseling field as possible. The agenda included a panel discussion highlighting the various genetic counseling roles, a Q&A session with the entire group, case presentations with discussion during lunch, and five "speed sessions," consisting of fifteen-minute small group meetings with individual counselors.

The majority of attendees had some familiarity with the genetic counseling field, and indicated that the main reason for attending was to learn more about it. While most of the participants were Biology majors, other disciplines included Psychology, Genetics, and Mathematics. All of the participants were enthusiastic in their comments following the camp. When asked about their overall reaction to the program, comments included the following:

- *This program was very informative and helpful.*
- *I was delighted about the fact that the faculty was proud of the program and happy/satisfied in their career.*
- *Was able to get a more in-depth perspective of a career as a genetic counselor.*
- *The professors are great, and I love the diversity in fields.*
- *I have wanted to be a genetic counselor since tenth grade. This was what I needed.*
- *This seminar caused me to like genetic counseling a whole lot more.*
- *Cleared up a lot of questions about the genetic counseling field.*
- *Made genetic counseling seem like an available, attainable field – very promising.*

When asked what they felt the faculty did especially well, participants had this to say:

- *They were very friendly and open to all questions.*
- *Answering questions and making sure we know what genetic counseling is about.*
- *They were all really knowledgeable and willing to help us.*
- *Very open and thoroughly informative.*
- *Very clear, friendly, intelligent.*
- *Very thorough; brought up many aspects of genetic counseling I didn't know existed.*
- *Loved hearing about cases.*

Suggestions for next year include more case discussions, and perhaps some role-playing exercises. Overall, both the students and faculty left with a very positive feeling about this kind of programming, and the faculty members have all enthusiastically signed on to participate in the camp again this year.

For more information on the upcoming 2010 camp, please contact Graduate Program Director **Caroline Lieber** at clieber@sarahlawrence.edu or (914) 395-2605.

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# The Jain Foundation
## Limb Girdle Muscular Dystrophy:  2B or not 2B?

*By Laura E. Rufibach, PhD, Esther Hwang, and Bradley Williams, PhD of the Jain Foundation*


The Jain Foundation is a non-profit foundation that focuses specifically on Limb Girdle muscular dystrophy type 2B (LGMD2B) and Miyoshi myopathy (MM), which are both caused by mutations in the dysferlin (*DYSF*) gene. The Foundation was founded in 2005 by the Jain family after their son was diagnosed with LGMD2B. The goal of the Foundation is to expedite the development of a cure/therapy for LGMD2B/MM, an orphan disease that receives little or no funding from traditional sources. The Jain Foundation is fully funded by private donors and does not request financial contributions from patients or physicians.

The Foundation's efforts fall into two main areas – patient advocacy and supporting research:

***Patient advocacy*:** The Foundation maintains an LGMD2B/MM Patient Registry and helps registered patients confirm their diagnosis by gene mutational analysis, the gold standard for diagnosis of LGMD2B and MM.

***Research*:**  The Foundation funds research projects in a large variety of areas, such as the role of dysferlin in muscle, the pathology of dysferlin deficiency, and approaches to treatment.

Limb-girdle muscular dystrophy (LGMD) refers to a group of hereditary muscle diseases with autosomal inheritance. In all types, the first muscles to show symptoms are generally those around the shoulders and hips. LGMD is genetically heterogeneous, with eighteen genetic forms identified to date, transmitted in either autosomal dominant or autosomal recessive inheritance patterns (about 90% of cases are the recessive types). The classification scheme for the limb-girdle dystrophies is as follows:  the diseases are

specified as LGMDNL, where "N" designates the inheritance pattern (1=dominant, 2=recessive) and "L" is a letter assigned in alphabetical order within each inheritance pattern, following the chronological order in which the locations of specific mutations were discovered. LGMD2B is the recessive type of limb-girdle muscular dystrophy caused by mutations in the dysferlin gene.

Miyoshi myopathy (MM) is a form of muscular dystrophy first described in the medical literature by Miyoshi in 1967. Although first identified in Japan, it occurs worldwide. MM is usually caused by abnormalities in the dysferlin gene, although two other genetic loci have been identified. MM is in the category of distal muscular dystrophies, which means that the muscles most strongly affected are in the calves, forearms, hands, or feet. In order to help facilitate the diagnosis of LGMD2B and MM, we have included a short clinical summary of each disease and recommendations for diagnosis. You can find additional information at https://www.jain-foundation.org/diagnostic.php .

Typical symptoms of LGMD2B/MM include the following:

- A recessive inheritance pattern, so typically a negative family history
- In LGMD2B, the proximal muscles are usually affected first, particularly the quadriceps and hamstrings. In MM, the first muscles to be affected are typically the gastrocnemius (calf muscles in the back of the legs used to stand on tiptoe).
- Onset of symptoms is generally between the ages of 15 and 30 years. However, there are exceptions to this age range. Genetically confirmed cases have been reported in the literature with onset ranging from congenital to as late as age 73.
- Levels of CK (creatine kinase, a muscle enzyme) in the blood are very high. CK values typically found in LGMD2B/MM patients are several thousand units/L, compared to a normal amount of 100 units/L or less.

Physicians face a number of challenges when trying to determine whether their patient has LGMD2B or MM. The most significant is pinpointing the specific type of LGMD or MM. For most forms of LGMD, this can be easily accomplished by antibody staining of muscle tissue biopsies for the various LGMD-related proteins (e.g. $\alpha$, $\beta$, $\gamma$, $\delta$, sarcoglycan, dysferlin, caveolin) or direct DNA sequencing of genes known to be involved in LGMD (e.g. *FKRP*, *CAPN3*). For LGMD2B and MM specifically, the level of dysferlin protein can be analyzed in either a muscle biopsy or a blood sample. An absence of dysferlin protein is highly indicative of a diagnosis of LGMD2B or MM. However, because reduced dysferlin can sometimes be a secondary effect, a finding of reduced dysferlin by itself does not necessarily indicate a diagnosis of LGMD2B/MM, so other possibilities also need to be considered. In order to obtain a definitive diagnosis of LGMD2B/MM, the dysferlin gene must be sequenced to identify specific pathogenic mutations. Due to the dysferlin gene's large size (6.9 kB of cDNA) and the cost involved, sequencing is generally only undertaken after a dysferlin protein deficiency is found via muscle biopsy.

The LGMD2B/MM Patient Registry is intended to identify patients who can participate in research studies and future clinical studies, and to document the natural history and incidence of the disease. Patients can self-register for the Jain Foundation LGMD2B/MM Patient Registry at https://www.jain-foundation.org/patients.php. The Registry is open to all patients who have been diagnosed with, or suspected to have, LGDM2B or MM. In addition, we sponsor dysferlin mutational analysis for qualifying patients who have not had genetic analysis of the dysferlin gene. All patient information is kept strictly confidential and will not be disclosed without prior consent of the patient, unless required by law or for legal process.

Patients who become part of the Registry will have access to the following services:

- Financial support for gene mutation analysis (approximately a $2000 value) for U.S. patients in cases where this diagnostic step is warranted (e.g. confirmed absence/reduction of the dysferlin protein)

- Information about ongoing or upcoming research studies or clinical trials relevant to the disease

- A source of knowledge about treatment options that are under development

- General information about LGMD2B and MM

Currently, the Jain Foundation is funding approximately 25 research projects. A summary of each project can be found on our website at www.jain-foundation.org. The Foundation's funding of research has so far led to 21 publications in peer-reviewed medical journals. Our approach to sponsoring research is to encourage collaboration between research groups worldwide, including development and sharing resources, such as animal models, protein antibodies, and specialized equipment.

To facilitate communication between researchers, the Foundation has sponsored a research conference focused specifically on dysferlin since 2007. The 2009 conference, held in Boston, included 37 oral presentations and 41 poster presentations, as well as a satellite session devoted to organizing a natural history study of dysferlin deficiency. A summary of the 2009 conference was published in the medical journal *Neuromuscular Disorders* and a summary of all our conferences can be found at https://www.jain-foundation.org/conferences.php. The 2010 conference will be held in Seattle, Washington from September 11-14, 2010.

For additional information about the Jain Foundation and/or the LGMD2B/MM Patient Registry, please contact Dr. Laura Rufibach by email at Lrufibach@jain-foundation.org or by phone at 425-882-1659. Thank you very much for your consideration and your efforts on behalf of these patients and their families. Our ultimate goal is the accurate diagnosis and best care for all patients.

# What Can the NSGC Learn from TV?

*By Elizabeth Kearney, MS, CGC, MBA – 2010 NSGC President*

As a recent contributor to *Perspectives,* I wrote about the importance of branding an association (http://www.nsgc.org/members_only/perspectives/Winter09/04_NSGCBranding.cfm). When the NSGC Board decided several years ago to develop an NSGC "brand," the first step was to select a specific audience, or "target customer." To illustrate the selection of a target customer, I look to my favorite cable television station, TBS. A TV station has many similarities to an association, as it is service-based and depends heavily on support from external parties, namely advertisers. Attracting more advertisers means investment in the programming, which attracts more target viewers, which attracts more advertisers – a television version of the circle of life.

Some of you may remember, as I do, the TBS station from many years ago when it was the "TBS Superstation" and ran a hodge-podge of re-runs and movies typical of many cable channels. If you don't remember, you are reinforcing the reasons why TBS needed to change! At that time, the channel was not clearly differentiated from other stations as the place to go for a specific type of programming. In other words, TBS was not very memorable and potential viewers couldn't tell whether it was the station for them or not.

TBS underwent a re-branding effort beginning in 2005, and I was fortunate to hear the brand manager speak about the effort later that same year. The first step the management took was to analyze the different possible TV viewers and place them into categories. They considered many types of characteristics such as gender, age, employment status, household constitution (e.g., number and age of adults, children), hobbies, etc. Next, they identified the customer group, or target, that they could serve better than anyone: the busy adult who wants "comfort TV" that is a reliable release from daily demands of work and household responsibilities. The benefit the station thought it could provide was an escape with familiar friends on funny programs (think about shows like "Friends" and "Everybody Loves Raymond").

This process of identifying a target customer and the benefits an organization or product can bring to that customer better than anyone else can is the basis for creating a brand. The NSGC went through a similar process. Board members determined that the best way for the NSGC to serve genetic counselors was to promote the profession itself, an activity that no other organization is likely to undertake. To do so, the NSGC Board chose to target physicians, who are key gatekeepers for patients' access to genetic counselors and repeated beneficiaries of the value genetic counselors bring to their patients. After all, who will hear about the patient's satisfaction after having received helpful, easy-to-understand translation of genetic information to facilitate decision-making? The physician who referred! And who might potentially discourage a patient who has heard about genetic counseling and asks whether it is appropriate for her? Again, the physician

– at least one who hasn't heard from the NSGC's brand campaign yet and therefore doesn't know the value the patient and physician both receive from a genetic counseling consultation.

Once the target customer and key benefits to that customer are determined, the next stage of branding is tactical, meaning that all the creative development occurs, such as designing a new logo, choosing colors, and developing key phrases about benefits. If you aren't a tbs viewer, you can see an example of its creative work on its website, www.tbs.com. The tbs logo, with its casual, lower-case letters, half-circle "smile," and the phrase "very funny," says it all! The result is that the target customer can consistently count on finding that welcome "release" when tuning to tbs.

Did it work? The station's management faced some initial challenges changing to advertisers seeking its new target customer. I recall seeing an advertisement in the fall of 2005 for "The Matrix." Very funny? I don't think so. However, a recent, quick review of its website demonstrates a line-up of character-filled, funny sitcoms as well as original programming that suggests success and the ability to invest in further development of its "very funny" brand. Also, its advertising likely appeals to the target viewer: Progressive.com's humorous online "store," a Pine-Sol queen with a handsome servant, and numerous time-saving products to manage the home such as Turbotax, Select Harvest Light soup, and Bounty paper towels.

What does tbs's branding success have to do with the NSGC's recently begun branding efforts?

Branding the NSGC will increase visibility and credibility for genetic counselors. This means the NSGC will attract more dollars through advertisers, collaborators, membership, and others – all allowing the NSGC to expand and enhance member services and increase investment in critical strategic initiatives like improving access to genetic counseling services. Physicians will recognize which patients will benefit the most and refer a larger number and/or more appropriate patients. Prospective students are more likely to learn about the genetic counseling profession to potentially increase the diversity of our field.

I hope this example has helped demonstrate why the NSGC is investing in creating a brand and how we will do so. I'm exhausted from writing this article and just want to relax in front of television… I wonder what's on tbs?

# For Your Practice

# Evolving Models of Cancer Risk Genetic Counseling

***Editors' Note:*** *This feature article will be the first in a series that describes a number of alternative cancer risk assessment models. The authors are a group of genetic counselors from across the country* ***(see footnote list of authors at end of article)*** *whose goals are to encourage colleagues to learn about the ideas and resources others have employed, and to open dialogue about the benefits and limitations of utilizing other models to approach patient care.*

The rapid translation of genetic discovery and direct-to-consumer marketing of predictive genetic tests are driving a surge in demand for cancer risk counseling and genetic testing services. As the field of cancer genetics continues to grow, it is increasingly evident that there are not enough genetic counselors to reach all of the at-risk individuals and families who can benefit from our expertise using traditional service delivery models. In March 2009, nine genetic counselors from a variety of practice settings across the country met with five genetic counselors in leadership positions with Myriad Genetic Laboratories (see footnote). The purpose of the meeting was to discuss the challenges faced by genetic counselors as the demand for counseling and testing services continues to grow, and to explore ideas about how we, as clinicians in the forefront of providing these services, can work progressively to help address these challenges.

During the meeting the participants voiced a shared recognition that the traditional counseling model that requires a genetic counselor to spend several hours face-to-face with each patient, often with a minimum of two visits, is not practical in many settings. We shared examples of how we have adapted non-traditional models of counseling to help streamline the cancer risk assessment process. Testing is already widely being performed by non-genetics providers and this was an opportunity to re-evaluate how we are utilized.

Leading genetics and oncology professional organizations, including the National Society of genetic Counselors (NSGC), American College of Medical Genetics (ACMG), American Society of Human Genetics (ASHG), American Society of Clinical Oncology (ASCO), and the Oncology Nursing Society (ONS) have served as widely-recognized voices of authority in the development of policy and practice in clinical cancer genetics (see references). But increasingly, professional societies representing medical professionals outside of the realms of genetics and oncology are encouraging physicians, nurses and physician assistants to consider cancer predisposition testing for their patients. For example, the American College of Obstetricians and Gynecologists recently released Clinical Guidelines to evaluate patients' risk for hereditary breast and ovarian cancer syndrome as a routine part of their practice (see references). A number of these physicians, especially those who have limited access to genetic counselors, are facilitating cancer risk assessment and testing without referring patients to a genetic

counselor. As in any practice setting, some of these cases are likely to be straightforward, and thereby may not require the specialized expertise of a genetic counselor. Others are more complex and would benefit from such expertise, such as cases with uninformative results, truncated or otherwise limited family histories, or patterns of familial disease warranting consideration of differential genetic etiologies.

With the increasing application of genetic testing provided outside of genetic clinics, our roles as genetic counselors need to evolve to meet the needs of a broader spectrum of healthcare providers and their patients. We would all agree as professionals that the focal point is the patient, and all efforts toward facilitating patient access to information that will improve their care should be supported. It is clear that different models are needed to suit different needs of patients as well as the different roles of other healthcare professionals. We are far more likely to have a positive impact on the quality of care provided to patients if we remain open-minded about alternative approaches to cancer risk assessment counseling and testing.

While it is often difficult to transition from a traditional service delivery model, genetic counselors are in the best position to test the benefits and limitations of alternative counseling approaches. The consensus among our group was that it is more important to evolve our clinical practice models and identify ways to support the interest in cancer risk assessment and genetic testing among other healthcare providers rather than to position ourselves as the exclusive gatekeepers of genetic information. Giving up "control" of genetic testing for hereditary cancer predisposition by supporting alternative service delivery models may actually help give us better visibility and influence with physicians. In fact, many of us have found that by remaining open to different approaches, most of our colleagues from other practice disciplines end up "running" cases by us for a second opinion and referring patients regularly with greater respect for what our expertise can add to the genetic counseling and testing process.

The following genetic counseling models, some of which we will discuss in more detail as this series progresses, are examples of the styles used by various counselors around the country. Many are using several different models in tandem, depending on their institutional resources and the needs of their community.

- **Direct Referral**: Traditional model for referral. Physician refers all patients to genetic counselor for pre-test counseling and results disclosure. Physician has no involvement with facilitating testing for the patient.

- **Modified Direct Referral:** Physician refers to community based genetic counselor, who then provides risk assessment and coordinates genetic testing in direct partnership with the referring physician. This model brings the referring physician into the genetic counseling process in the community where that patient is seeking care.

- **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.

- **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.

- **Group Education**: Patients are educated in a small group and some receive testing from a genetic counselor and some from their physician (often driven by insurance reimbursement).

- **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.

- **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.

- **Phone Counseling**: Used by traditional genetic centers mainly for results disclosure. Used by companies including Informed Medical Decisions and DNA Direct in combination with internet educational materials. Models include a partnership with the referring physician to provide "off-site" service and patient initiated and requested service (DTC).

- **Public Health Model:** Casting a very wide net for appropriate patients for testing. As more patients would be tested, the population as a whole would benefit. May come into play if chemotherapy regimens are decided based on genetic information.

Upcoming articles in this series will provide more complete descriptions about some of the service delivery models outlined above. In addition, in the near future, cancer genetic counselors will be invited to participate in surveys designed to ascertain their attitudes about cancer genetic practice models and genetic counselor experiences with alternative delivery models.

Finally, we hope this series will lead to a professional dialogue about delivery models across all genetic counseling specialty areas, which would be timely given that the NSGC's 2010-2012 Strategic Plan will be addressing genetic service delivery models, triage of genetic services, and workforce recommendations to support the triage plan.

References and Suggested Reading:

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# Licensure / Billing and Reimbursement

## The Coding Corner

*By Shanna Gustafson, MS, MPH, CGC and John Richardson, NSGC Government Relations Director*

The NSGC and *Perspectives in Genetic Counseling* are proud to present a new resource for practicing genetic counselors with **"The Coding Corner."** Coming soon, an on-line version will also be included in the NSGC's new and improved website. "The Coding Corner" is supported by the Coding Subcommittee of the NSGC and aims to assist NSGC members with the application and understanding of governmental regulations and guidelines regarding terminology and CPT/ICD coding in genetic services.

Navigating the complexities of compliant billing and coding for genetic services often raises questions that are applicable to the broad genetic counselor population, so we are taking these discussions to you, the practicing genetic counselor.

Most recently, the Center for Medicare & Medicaid Services (CMS) announced that as of January 1, 2010, they would no longer reimburse the consultation codes 99241-99245 and 99251-99255. This brought to the listserv the question "How will this affect billing for genetic services?" Although the American College of Medical Genetics (ACMG) released a statement to its membership, this does not directly address this question for those that are billing for genetic counseling.

First, it is important to note that the consultation codes still exist, and private payors may continue to recognize these codes. However, Medicare will not reimburse for consultation codes. Instead, they plan to increase reimbursement for office visit and inpatient codes to compensate for the inability to bill consultation codes. The effect of this change to the coding system will depend on what method is being used to bill for genetic counseling.

As this change currently only applies to Medicare patients and CMS does not recognize genetic counselors as providers who can directly bill for their services, this change may not impact genetic counselors who are currently billing in their own name. However, for genetic counselors who are billing incident to a physician provider, or where the center bills only for the physician provider time, the office visit codes 99201-99205 and 99221-99223 for outpatient visits or inpatient codes 99231-99233 may be the most appropriate codes for Medicare patients.

It is always best to speak with the billing officers at your own institution to determine how to respond to changes in billing practices. Additionally, the billing experts at your institution should have the best sense of how any changes may affect practices in light of institutional billing practices and local payor contracting.

The Coding Subcommittee would also like direct readers to the NSGC's recently released online coding course, "*Learn the 3 C's to Maximize your Service Delivery Model: Coding, Credentialing and Compliance"* as a good resource for learning the basics of billing and coding for genetic services. For more information about this course, please visit www.nsgc.org/conferences/CodingCourse2009.cfm and register today!

*We hope for "The Coding Corner" to be a resource from the NSGC membership for questions about coding and governmental regulations. If you have questions you wish to be considered for this section, please send them to* ***Shanna Gustafson*** *at gustafs@ccf.org or* ***John Richardson*** *at jrichardson@smithbucklin.com.*

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# NSGC News

## Announcing the 2010 Professional Status Survey!

*By Samantha Baxter, MS, CGC; Mary Freivogel, MS, CGC and Kami Wolfe Schneider, MS, CGC, Professional Status Survey Working Group Co-Chairs*

***"I was able to use the NSGC Professional Status Survey to negotiate an $8,000 raise last year. When I pointed out to my employers that my salary was well below the average in my region, they were able to 'locate' some money to ensure that I was being fairly compensated."***

We are excited to announce the availability of the NSGC's 2010 Professional Status Survey (PSS). The PSS has long been a tool utilized to collect important information about the NSGC membership and the genetic counseling profession. Both individual genetic counselors, as well as the NSGC organization, have successfully used data from the PSS advantageously, as illustrated by the above success story submitted by an NSGC member.

The timing of the 2010 PSS has changed to the first quarter of the calendar year, as opposed to the summer months when it was previously administered. This change was made primarily so that the data will coincide with calendar years to simplify data analysis and reporting.

As with the 2008 PSS, the 2010 PSS has a number of improved features that make it easier and faster to complete the survey. These include:

- An improved web-based format
- Skip logic that allows you to see only questions that are relevant to you
- In-survey definitions for terms that may not be clear or may have multiple definitions

Additional questions have been revised or designed specifically for:

- Genetic counselors who do not see patients
- Genetic counselors who work part-time
- Genetic counselors who practice in multiple specialty areas
- Collecting information about licensure and billing practices

**By now, you should have received a separate email from the NSGC Survey Coordinator (nsgcsurv@directsurv.net) with a personalized username and password that allows you to participate in the 2010 PSS.** If you have not yet received this email message, please contact Survey & Ballot Systems directly at surveys@directsurv.net or call 952-974-2339.

The survey will be available from February 22, 2010 through April 5, 2010 and will take approximately 30-40 minutes to complete. You do not have to complete the survey in one sitting; you can save your answers and return to it later. We encourage every member of the NSGC to complete this year's PSS and experience the many recent improvements that have been made.

Please feel free to contact the PSS Working Group Co-Chairs, **Samantha Baxter**, **Mary Freivogel**, or **Kami Wolfe Schneider**, with any questions or comments: psscomments@nsgc.org

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## Does Your Billing Department Need Help Billing for Genetic Counseling Services?

*By the NSGC Executive Office*

The NSGC has an online course specifically designed to be an educational tool for the complexities of compliant billing and coding of genetic services: *"Learn the 3 C's to Maximize Your Service Delivery Model: Coding, Credentialing and Compliance*!" Target audiences for the course include Professional Medical Coders, Health Information Management Administrators, and Genetic Counselors.

The course consists of three pre-recorded modules written by expert genetic counselors with experience in billing for genetic services: **Kimberly C. Banks**, MS, CGC; **Leslie**

**Cohen**, MS, CGC; **Shanna Gustafson**, MS, MPH, CGC; **Janet L. Williams**, MS, CGC; and John Richardson, the NSGC's Government Relations Director.

Module 1: Genetic Counselor Credentialing and Recognition
Module 2: Coding for Genetic Counseling Services
Module 3: Compliant Billing and Reimbursement for Genetic Counselor Services

Objectives: After participating in *Learn the 3 C's to Maximize Your Service Delivery Model: Coding, Credentialing and Compliance* online sessions, attendees will be able to:

- ⇒ 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

For more information about the coding course, please visit www.nsgc.org/conferences/CodingCourse2009.cfm and register today!

*The **National Society of Genetic Counselors** is authorized to provide **0.15** CEUs or **1.5** contact hours for this course. The American Board of Genetic Counseling will accept CEUs authorized by the NSGC for purposes of genetic counselor recertification.*

*This program/publication/subscription/etc. has prior approval of the **American Academy of Professional Coders** for **1.5** Continuing Education Units. Granting of this approval in no way constitutes endorsement by the Academy of the program, content or the program sponsor.*

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## Audrey Heimler Special Projects Award Deadline Approaching!

*By Erin Miller, MS, CGC*

The Audrey Heimler Special Projects Award (AHSPA) will provide funding to one or more genetic counselors for project(s) that focus on the future of the genetic counseling profession and/or the provision of genetic services. Projects will be reviewed on the basis of their merit and strength as well as on their vision of the future of the profession. Projects that may be appropriate for the AHSPA include:

- Pilot studies that could blossom into a more extensive future project
- Development of patient education materials
- Creation of tools for genetic counselors
- Development of ways to encourage leadership among genetic counselors

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| **Award** | Projects will be funded for one year, beginning January 1 of the year immediately following the year of application. Requests for renewals or extended study will be judged with other proposals in the year of application. Awards are available in amounts up to $5,000.00. |
| **Eligibility** | Applicants must be Full Members in good standing of the NSGC. |
| **Deadline** | May 14, 2010 |
| **Questions** | Contact **Erin Miller**, MS, CGC, Chair, AHSPA, by e-mail at Erin.Miller@cchmc.org |
| **Program Application & Guidelines** | Available at www.nsgc.org/members_only/funding/ahspa.cfm |

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# SIG/Committee Updates

## Public Policy Committee

### Position Statements and the NSGC – An Introduction

*By Cheryl E. Harper, MS, CGC, Chair, Public Policy Committee and Susan E. Hahn, MS, CGC, Vice Chair, Public Policy Committee*

Over the past year, there has been considerable discussion regarding the NSGC's position on a number of controversial issues such as reproductive freedom, gene patenting, and direct-to-consumer marketing of genetic tests. Recent events have triggered interest in these topics and bring to light the importance of the NSGC to have current and up-to-date Position Statements. Examples include the murder of Dr. George Tiller, along with the Association for Molecular Pathology, *et al*.'s lawsuit against the United States Patent and Trademark Office and Myriad Genetic Laboratories. The NSGC's Public Policy Committee is charged with creating and reviewing the organization's Position Statements to ensure that the views and expertise of genetic counselors are conveyed appropriately and concisely. This article serves as an introduction to the purpose of Position Statements, how they are developed, and the lessons learned by the Public Policy Committee in creating and reviewing these Position Statements.

### The Purpose of Position Statements

A Position Statement speaks on behalf of an organization to explain its unique perspective on an issue in a way that makes it easy for all audiences – other medical professionals, policymakers, patients, and the general public – to understand.

Here are some common ways in which a position statement may be used:

***Leadership:*** The NSGC leadership is frequently contacted by the media to speak out on issues related to the use of genetic information in medicine and society. The Statement allows the NSGC's leaders to respond easily on behalf of the membership. Without a formal Position Statement, the impact of the media encounter with our profession is diminished.

This particular use of Position Statements also clearly demonstrates the importance of brevity. The media typically captures positions with a single quote or sound bite.

***Other Organizations****:* Other professional organizations may look to the NSGC's Position Statements to see if we have a specific view on an issue. If our views are similar, an organization is more likely to reach out to the NSGC for coalition efforts to achieve shared policy goals.

***Potential Genetic Counselors:*** Individuals considering the genetic counseling profession are likely to research the NSGC, which includes reviewing our policy and positions on issues. Position Statements provide potential genetic counselors with examples of issues encountered by genetic counselors. Also, because many of these Position Statements are based on our Code of Ethics, they give potential members an idea of how we apply our professional expertise to form views on issues.

**The Position Statement Process**

Topics for new NSGC Position Statements may be generated by the NSGC Board members, Special Interest Groups, or Committees, and even individual members. The NSGC Board may ask the Position Statement Subcommittee (PSS) of the Public Policy Committee (PPC) to evaluate the need for a possible statement before approving. The PSS also makes suggestions regarding the review of existing statements. The NSGC Board of Directors must ultimately approve the development of a new official NSGC Position Statement or the revision of an existing one.

When a Position Statement needs to be created or reviewed, the process typically begins with the selection of Task Force members. A Task Force is assembled based on members' expertise and/or interest in the issue, and always includes at least one member of the PSS. If the issue is controversial, Task Force members are also chosen to represent diverse viewpoints on the issue. For example, when reviewing the Reproductive Freedom statement, the NSGC selected members who worked in a range of settings and had different views on the issue of abortion.

When an existing Position Statement is under review, the Task Force must determine whether the NSGC should reaffirm it as is, retire it, or revise it. A Position Statement is reaffirmed if it speaks on behalf of an issue that is within genetic counselors' scope of expertise and still reflects the current position of those in the profession. It is retired if the subject it addresses is outdated, or if it is a subject that is no longer relevant to the genetic counseling profession. Usually, Position Statements are revised, meaning that the Task Force feels that the organization still has the expertise to state a position on the subject,

but it may need to change it to reflect developments in the genetic counseling profession and current policy.

Starting the process of revising or crafting a new Position Statement can be overwhelming. A common pitfall is the belief that a Position Statement can always speak for the personal views of every member. With such a diverse membership, it is not uncommon for the NSGC to create one on an issue that many consider to be a personal issue as well. In this case, the Task Force must accept that the Position Statement is that of the organization; it may not satisfy every member's own personal perspective, including his/her own.

Professional organizations like the NSGC can address this problem by looking to their profession's Code of Ethics when forming a Position Statement. It only speaks on behalf of individual members in their capacity as genetic counselors. Focusing on how the Position Statement applies to the conduct and views of genetic counselors as outlined in the Code of Ethics helps the Task Force focus on those positions that can speak on behalf of the organization, not individuals.

The process is deliberative, allowing all points of view to be expressed. Members must be cognizant of their own biases and those of other members with regard to the issue at hand. Once a Task Force lays out all possible positions that an organization can take on an issue, they must start whittling these positions away to get to the most important aspect of the issue as it applies to the genetic counseling profession.

Many questions are pondered is this process:

- Why do we need this Position Statement?
- What is the potential influence of the Position Statement?
- What has been written about this issue, especially related to our perspective?
- Are there current misconceptions about our practice or view related to this issue?
- What current or pending public policy decisions exist related to this Position Statement?
- How does this issue impact our profession?
- What is unique about the genetic counseling perspective to this issue?
- Where does our expertise lie related to this issue?
- What should be included in the scope of the issue?
- What are all the relevant facets of the issue?
- What controversies exist over this topic, and why?
- Is there common ground to work from?

These are just a handful of the many questions that surface as part of the process.

If possible, the Task Force tries to determine the *one* position the organization should take. Even if the organization could logically support several views on an issue, a Position Statement should focus on the single strongest stance an organization can take

based on their common expertise. It should be noted that typically the process described above requires many conversations over several weeks to months.

The task force then submits a recommended Position Statement to the Board for review. If the Board approves the Position Statement, it goes out to the general membership for comment. ***This comment period is your way to participate in the process as an NSGC member.*** When the Position Statement goes out for comment, provide your thoughts on the proposed Position Statement. Following the comment period, the Task Force reconvenes to consider all comments and determine if changes should be made to the draft. Once this is complete, the Position Statement goes to the Board for final approval and adoption.

**Lessons Learned**

Members of the NSGC Public Policy Committee and Task Forces who worked on the Reproductive Freedom and Gene Patenting Position Statements will likely agree that the process is not easy. Several times, the group oscillated from one viewpoint to another to determine the best fit for the membership. A common pitfall was to drift away from the ***unique perspective*** of the genetic counseling profession on the issue to a more global viewpoint. It was also difficult at times to focus on our ***unique expertise*** related to the issue. For example, initially it was tempting to address patent law violations in the gene patent statement, but patent law is not where our expertise lies on this issue. Reminding ourselves of these two facts resolved some conflicts that arose within the group. Other conflicts were resolved by reviewing the NSGC's Code of Ethics. Once a Position Statement was agreed upon, editing occurred to ensure that every word had significance and precisely conveyed the intended position, minimizing the chance for misinterpretation. In addition, we searched for and removed jargon.

Ultimately, we would all agree that this is a fulfilling process. It challenges us to move outside of our personal views on issues to analyze them from the perspective of our profession. It challenges us to play devil's advocate – to consider all opposing views on our position to ensure that the NSGC Position Statement is as clear and strong as possible. We recognize that the NSGC is a diverse organization, so it is an achievement when two to three sentences can best represent the membership based on our common ground as genetic counselors.

***We encourage the membership to contribute to the development of the NSGC's Position Statements.*** Throughout the year, you will be invited to submit comments on draft versions of position statements as they are being reviewed. During these comment periods provide your thoughts, whether you agree or disagree, or have possible word changes. All comments are considered before a final recommendation is sent for Board approval. You can also find all of the NSGC's current Position Statements on the NSGC website (www.nsgc.org). If you have questions or comments about any Position Statement, we encourage you to contact the NSGC Executive Office.

*We would like to acknowledge **Barbara Harrison** and **Diane Baker,** 2009 Chairs of the Public Policy Committee, for their efforts to help create the NSGC's current Gene Patenting Position Statement.*

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# ABGC Update

## Two New Professional Activity Credit (PAC) Options For Those Recertifying

*By the ABGC Board of Directors*

The American Board of Genetic Counseling (ABGC) Board of Directors approved two new Professional Activity Credits (PACs) that are effective January 1, 2010. Certified genetic counselors who have paid their Certification Maintenance Fees and are recertifying may use up to five (5.0) PACs in lieu of Category 1 continuing education credits. For more information regarding recertification requirements, please visit the ABGC website at www.abgc.net. The new PACs are for participation in peer supervision groups or chronic disease specialty camps or other structured events or activities, as described below.

### Peer supervision groups

A maximum of one (1.0) PAC per year will be granted to Certified genetic counselors who actively participate in formal peer supervision groups. Effective January 1, 2010, one half (0.5) PAC will be granted for each 25 hours of participation in a peer supervision group for genetic counselors or other counseling professionals. The supervision group may have a designated leader or may be facilitated by group members, and should operate according to a contract or other written guidelines that outline the rules, procedures, fee structure (if applicable) and expectations for members' participation in the group. The group should meet on a regular basis according to a published schedule of dates, times and locations, and a sign-in sheet should be used to document attendance on each meeting date. If the supervision group meets in conjunction with a meal or other social event, the schedule should clearly distinguish group work time versus social time; PACs will only be granted for the group work portion of meetings.

Documentation: The name of the peer supervision group, dates, and hours of participation should be documented on the Continuing Education/Professional Activity Credit

Declaration form. For audit purposes, Diplomates should maintain a copy of the group's contract and/or written guidelines for operation, schedules of meetings, and dated sign-in sheets documenting attendance.

**Volunteer at a chronic disease specialty camp or structured event /activity**

A maximum of one (1.0) PAC per year will be granted to Certified genetic counselors who actively participate in a volunteer capacity to work directly with individuals with birth defects or chronic disease and their families at a specialty camp, and/or structured event or activity. Effective January 1, 2010, one half (0.5) PAC will be granted for each 25 hours of volunteer support time that involves direct interaction with participants of the specialty event (e.g., a PKU camp counselor, a ski trail guide for the blind, an event organizer/judge/referee for Special Olympics, etc.). These structured events or activities are highly variable, lasting as little as one day to up to several weeks. There must be a formalized agreement with the event organizer(s) as to the expectations of the genetic counselor's time commitment, roles and responsibilities; however, direct counseling is not required. Only scheduled activity hours with participants are to be included (i.e., sleep hours for overnight camps are not included).

Documentation: The name of the camp, its location and dates as well as the schedule of activities should be documented on the Continuing Education/Professional Activity Credit Declaration form. For audit purposes, Diplomates should maintain a copy of their volunteer agreement with the camp.

The following represent a few examples of various camps where genetic counselors could volunteer their time to gain personal and valuable insights into the perseverance, courage and abilities of individuals with varied chronic conditions and that of their families, siblings and peers.

www.campcamp.org/index.php?Itemid=65&id=48&option=com_content&task=view
www.holeinthewallcamps.org/Page.aspx?pid=356
www.kidsplastsurg.com/camp.cfm

The Board is currently reviewing and considering a PAC for conducting peer-review of manuscripts for scientific journals, which will go into effect on January 1, 2011 if approved.

# Student Forum

## Array CGH: Exploring a Controversial Issue as Students

*By Jilliane Miller, BS and Katharine Coles, BA*
*Boston University Genetic Counseling Program*

In the short time since the inception of array Comparative Genomic Hybridization (array CGH), it has been the subject of much interest and controversy. The technology detects microdeletions and microduplications using copy number variants (CNVs), which is achieved by labeling a test sample with fluorophores and hybridizing to several thousand probes derived from genes and non-coding regions of the genome. The ratio of the fluorescence from the test sample compared to a control sample is used to determine the CNV. Originally, this technology was used to detect microdeletions and microduplications in the general genetics setting. It has been both a powerful mechanism for determining etiology and also a frustrating endeavor, identifying many variants of unknown significance.

This technology has now moved into another arena. Adding to the already intricate world of prenatal screening and diagnostics, array CGH is being touted as the next tool in the obstetric arsenal. Signature Genomics Laboratories and Baylor College of Medicine are just two of many laboratories accepting prenatal samples for array CGH. Signature Genomics Laboratories has identified clinical indications where they believe this technology will be most helpful, including: advanced maternal age, abnormal serum screening, previous miscarriages, and abnormal ultrasound findings. While many recognize this technology will never replace karyotyping (e.g. array CGH cannot detect balanced translocations), they believe it should be used concurrently for added detection. This makes the significance of added detection the true question surrounding this controversial topic.

## Advantages of Array CGH in the Prenatal Clinic

The advantages of utilizing array CGH in the prenatal arena are both technical and psychological. The first main technical advantage is increased detection. Traditional karyotyping can only detect aneuploidies and CNVs that are microscopically visible, approximately 5 to 6 Mb at the 500 band level. Certain array CGH detects CNVs of less than 100 kb, revealing genetic abnormalities that may otherwise go undiscovered. A study performed by Kleeman *et al.*[3] confirmed previous findings, in which approximately 2% of fetuses with an structural anomaly and normal karyotype were found to have clinically significant CNVs. Parents interested in invasive testing may benefit from this added information during the course of the pregnancy for decision-making or anticipatory guidance.

The second main technological advantage of array CGH for prenatal care is that of turn-around time. Some labs do not require cultured cells for array CGH, which karyotyping does. Therefore, results are usually available in five to seven days. This faster turn-around time may be of the utmost importance when dealing with time-sensitive issues in the prenatal arena.

Psychologically, array CGH may also be able to provide parents with reassuring information. Although we know that no genetic test can look for all changes or guarantee a healthy baby, patients may derive additional comfort from reassuring results via array CGH as many already do from maternal serum screens, ultrasounds, and karyotypes.

There is no doubt that technologies, especially powerful diagnostic tools intended for use in pregnancy decision-making, have their limitations. However, when possible parental blood samples are always compared to fetal DNA to assess for inherited CNVs that may not be clinically significant. Additionally, patients must be counseled about the limitations of array CGH to detect variants of unknown significance, as well as the inability to detect other types of balanced rearrangements. Given proper counseling and patient understanding, it is each patient's personal decision whether to pursue such testing. It is our place as students and genetic counselors to make sure that we understand the new technology and its implications so that we can assist our patients in making a choice that is right for them.

## Disadvantages of Array CGH in the Prenatal Clinic

Array CGH was a popular topic at the NSGC's recent Annual Education Conference in Atlanta, Georgia. There were presentations on the technology itself, brochures were provided, and patient friendly flip books were available on request. Two abstract presentations also addressed the topic and conflicts over using this technology. An abstract by S. Jeddi *et al.*[2] discussed how genetic counselors determine the appropriateness of this technology in different situations. A variety of factors were identified that increased or decreased counselors' perceptions of appropriateness. While increased knowledge of array CGH decreased patient anxiety and providing more

comprehensive care were factors involved with increased appropriateness, working in a prenatal setting was associated with lower perceptions of appropriateness.

Another abstract by S. Lee *et al.* [4] explored actual practices of genetic counselors, emphasizing the experience and views of genetic counselors with experience in array CGH in the prenatal setting. The qualitative research found that genetic counselors were concerned with the relatively high frequency of variants of unknown significance and situations where pre-symptomatic or asymptomatic diagnoses were made. Additionally, the study uncovered that there was no consensus among the practice of genetic counselors.

These abstracts bring up the greatest concerns regarding the additional findings detected by array CGH. How do genetic counselors address the many possible test results with patients in the time given? What is the clinical significance of variants given the limited information provided by ultrasound and serum screening? When is it appropriate to offer this technology? Although the reliability of array CGH as a technology is high, can genetic counselors depend on the relatively new, and perhaps unreliable, clinical information that correlates with a finding? None of these questions has an organized answer at this time. The American College of Obstetricians and Gynecologists (ACOG) is currently the only professional organization to release recommendations regarding prenatal use of CGH. They state that conventional karyotyping remains the principal cytogenetic tool in prenatal diagnosis, and recommend that targeted array CGH be used in concert with pre- and post-test genetic counseling. ACOG also recommends that it be used as an adjunct tool in cases that have abnormal anatomic findings on ultrasound and a normal karyotype or in cases of fetal demise with congenital anomalies and the inability to get a karyotype.[1]

**What does this mean for students?**

Students are in an unusually privileged position in regards to this technology. Current training involves learning arrays, both CGH and single nucleotide polymorphism (SNP), together with other tools like Fluorescence In Situ Hybridization (FISH), Multiple Ligation Probe Assay (MLPA) and Polymerase Chain Reaction (PCR). We are well versed in the astounding diagnostic capabilities and the psychologically frustrating limitations of these tests. It is in our best interest to start asking ourselves now how we feel about these technologies and our comfort level in utilizing them in patient care.

As genetic counselors, we stand at the unusual intersection of providing for our patients' psychological well being and presenting them with medical realities. Technologies are thankfully going to continue to be developed, and array CGH is not the first controversial technique, nor will it be the last. It is important for us to develop our own sense of appropriate client care now, as we wade through our academic training and to reflect on our own thoughts, opinions, and backgrounds as they influence our practices. This way we can have a set of criteria with which to judge the coming waves of diagnostics and provide for both medical and psychological care. As we do that, we should also be cognizant of how we can help the profession to create much needed practice guidelines

and statements because we are the next generation of genetic counselors raised with the next generation of test technology. In this way, it is also our responsibility to ensure that the controversial technologies of today are on a safe path if they are to become the standard of care for tomorrow.

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# The New Graduate Life

## Perfecting the Art of Juggling

*By Kelly Z. Knickelbein, MS, University of Pittsburgh, Class of 2009*

Juggling has always been a favorite hobby of mine. I taught myself with a book called Juggling for the Complete Klutz that I received for my twelfth birthday. It came naturally to me; my dad was a recreational juggler, so I always assumed I had inherited the talent from him. I juggled trios of everything from the standard round beanbags to oranges, apples, handkerchiefs and tennis balls. Never the daredevil, I stopped short of knives and fire. Throughout my early teens, I perfected the techniques of circle juggling, overhand grabbing, juggling down low, the juggle exchange with a partner and blind juggling, the most difficult. Now, many years later, my beanbags have collected a fair amount of dust, yet I find myself using similar juggling techniques in a different setting. I am a recent genetic counseling graduate, and I juggle two part-time jobs, three different offices, multiple co-workers and bosses, as well as family, friends and, as of January 1st, studying for the Board exam.

I have a feeling that my story is not entirely unique. What genetic counselor is not juggling multiple tasks on a daily basis? I just sometimes wish that there were an instruction manual for those of us entering the field entitled, Juggling for the New Genetic Counselor to *Avoid* Being a Complete Klutz. We have all been excellently trained, of course, but nothing can quite prepare you for what the "real world" has in store. Only time and experience can really teach us what we need to know to feel confident and secure in ourselves both professionally and personally. That being said, I am sure that even the most experienced of genetic counselors find themselves blindly juggling every now and again. I am telling my story not to provide any advice or answers for new grads, but to let you know that if you feel klutzy and are struggling to keep many aspects of life up in the air without letting anything drop, you are not alone.

To begin, I am in a different location every day of the week and sometimes multiple places in the same day. Mondays, Fridays and every other Tuesday are dedicated to research. I consider this to be my "non-traditional" genetic counseling job. I coordinate a research study in the Department of Human Genetics at the University of Pittsburgh, which seeks to identify genes associated with the development of secondary lymphedema following breast cancer treatment. This is not a new role for me. A series of serendipitous events led me to the position as an incoming genetic counseling graduate student over two years ago. I was fortunate to be involved in this study from its inception, and my work as a student served as the basis of my Master's thesis.

From my office in the Graduate School of Public Health, I schedule research participants, enter data, maintain the Progeny database and brainstorm new ways to advertise and recruit women with breast cancer into the study. Approximately half a mile away from this office is Magee-Womens Hospital, where I meet with research participants, obtain their family histories, collect blood samples, and measure their arms and legs. Luckily, I enjoy walking because I can easily cover one to two miles in a day.

The remainder of my week is spent as a cancer genetic counselor, my "traditional" genetic counseling job. On the Tuesdays that I am not doing research, I counsel patients at Magee-Womens Hospital. On Wednesdays, I am located at the Hillman Cancer Center two miles away, and Thursdays begin at Magee for a case review meeting and end at the

cancer center. It is an elaborate schedule by anyone's standards and one that still has me questioning where to go each morning. I can proudly say that in the six months I have had this schedule, I have not once gone to the wrong office. I have, however, absentmindedly answered the research phone "Cancer Genetics Program, this is Kelly," and I sometimes take an embarrassing amount of time to write down my phone number for patients because I have four numbers to remember. The recent arrival of my business cards has helped to eliminate this problem, though. I also have four voicemails to check, three fax machines, three e-mail accounts and a pager that still startles me every time it beeps.

As you can imagine, advanced planning is critical. For example, a forgotten chart on a Thursday can create problems for the following Tuesday if a patient is to be seen in one location and the chart is two miles away. I admit to making late night or early morning visits on occasion to collect forgotten charts. It has been especially difficult for me to accept that when tasks are not complete in a day, it could mean waiting four to five days before finishing the task the next time I am in that particular office.

The stress of being a new genetic counselor and the additional challenges of working two part-time jobs took its toll on me in the beginning, both at work and at home. I had to write down everything from dates with my husband to planned nights for laundry. I was not accustomed to that kind of rigid scheduling, my brain was filled to maximum capacity, and I was terrified I would forget important tasks. The first few months my heart rate was consistently elevated, my cheeks were always flushed, and my mind raced at night when I closed my eyes with the overwhelming feeling that I had forgotten to do something. Does this sound familiar to anyone?

Now, with six months successfully completed, I find that I am exponentially gaining more confidence in my abilities and myself with each passing week. I remember how awkward it felt when I first learned to juggle, but also how, after persistence and practice, muscle memory kicked in. In fact, I can still juggle without concentrating and can simultaneously watch TV or hold a conversation. I am learning that it is the same with juggling life:  Keep at it and it will soon become second nature. My life still feels chaotic more often than not, but when I am sitting in front of a patient, whether it is for research or cancer genetic counseling, the surrounding chaos melts away, and I am able to be in the moment with them. I am proud of the improvement in my juggling skills over the past few months, which are crucial to being a competent genetic counselor. The patients are the reason I chose this profession, and my ability to be entirely present for them during every counseling session is my greatest accomplishment as a new graduate.

# Genetic Counselor Publications

*By Jamie C. Fong, MS*

**Featured Article**

**Rosenfeld JA**, Ballif BC, Martin DM, Aylsworth AS, Bejjani BA, Torchia BS, Shaffer LG. Clinical characterization of individuals with deletions of genes in holoprosencephaly pathways by aCGH refines the phenotypic spectrum of HPE. *Hum Genet*. 12 Jan 2010. [E-publication ahead of print]


Jill Rosenfeld

**Jill A. Rosenfeld**, MS, CGC, has at her fingertips a vast database of clinical and cytogenetic information that would be the envy of many a clinician or researcher. As Research Project Coordinator at Signature Genomic Laboratories in Spokane, Washington, Jill navigates the database to identify patients with interesting and often novel cytogenetic variants. She compiles accompanying clinical information, frequently turning to referring providers, who requested analysis of patients' blood samples via one of the company's proprietary SignatureChip microarrays, for more details that comprise the clinical spectrum. Together with colleagues, Jill then assembles all the pieces of the puzzle to craft a story that links the cytogenetic data with clinical features.

Such has been the research process for Jill during her relatively short one-and-a-half years at Signature Genomic Laboratories, time which has proven not too unproductive for Jill and her colleagues – a varied team of genetic counselors, medical geneticists, and research geneticists – under the direction of President and CEO Lisa G. Shaffer, PhD, and CMO Bassem A. Bejjani, MD.

Jill, who is a 2008 graduate of the Genetic Counseling Program at Indiana University, is first author on two recent scientific publications featured in this issue of *Perspectives*, and is co-first author with **Justine Coppinger**, MS, CGC, on a third publication. (See citations below.)

In an e-publication ahead of print in *Human Genetics*, Jill and colleagues took a "genotype-first" approach to characterize the presence or absence of holoprosencephaly in 136 individuals in their database (over 40,000 cases screened) in which array comparative genomic hybridization (aCGH) identified a deletion of one of 35 loci known to be associated with holoprosencephaly. They reported data to support previous research, with frank holoprosencephaly observed in most individuals with deletions of one of the four commonly associated genes. They also reported frank holoprosencephaly in a few individuals with deletions of putative loci and candidate genes, data which support the loci's/genes' association with forebrain maldevelopment. They noted, however, the absence of frank, or even microform, holoprosencephaly in some individuals with deletions of still other candidate genes, suggesting that deletions in holoprosencephaly-associated genes may not be sufficient to cause disease. Finally, they reported the presence of holoprosencephaly in two unrelated individuals with novel duplications of the GSK3B gene at 13q13.33. One had frank disease, and the other had a microform.

Confident that these data help refine the clinical picture of holoprosencephaly, Jill gladly contributes to the scientific literature. And despite feeling challenged by the laborious manuscript-revision process, Jill is genuinely excited about the nature of her work at Signature. She sees great potential in the impact of novel cytogenetic findings that SignatureChips have helped reveal, and believes that Signature's database represents a unique concentration of novel variants, otherwise infrequently observed at any given referring genetics clinic. Jill believes that by encouraging communication between the various referring genetics clinics, each seeking information that will help the families of their patients with novel variants, she might facilitate collaborative research about phenotypic associations. Crediting collaborative research with greater statistical power, Jill is optimistic that such research will lead to better understanding of chromosome abnormalities – understanding that, thanks in part to Signature technology, will ultimately offer patients better clinical care.

**Articles co-authored by genetic counselors from September 2009 to January 2010**
(Names of genetic counselors appear in bold)

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*Please send references of published articles by genetic counselors to **Jamie Fong** at jaf2025@med.cornell.edu.*

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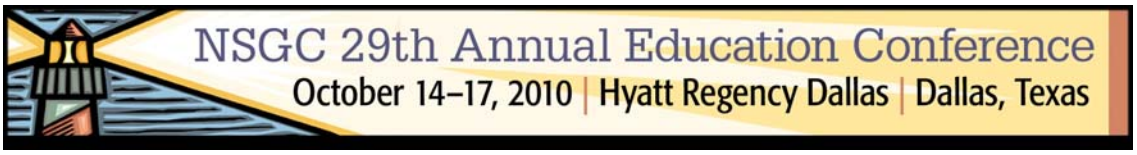
# AEC Update

## The NSGC Annual Education Conference Turns 29!

*By Shannan DeLany Dixon, MS, 2010 AEC Chair, and Elizabeth Wood Denne, MS, 2010 AEC Vice-Chair*




The Annual Education Conference (AEC) is turning 29! We are thrilled to invite you to join us in Dallas, Texas for the 29th Annual Education Conference. The Dallas area has so much to offer for attendees. Iconic structures by Frank Lloyd Wright and I. M. Pei, Dallas Museum of Art, Morton H. Meyerson Symphony Center, Campbell Center (home of the Dallas Opera), White Rock Lake Park, historic Fort Worth Stockyards, the Mesquite Rodeo, the Texas Rangers, the NBA Dallas Mavericks, and the Dallas Cowboys – all call the Dallas region home. You will soon receive your program brochure with all of the dates and deadlines for the AEC, which will be held **October 14-17, 2010.** We look forward to celebrating our 29th year with you.

**A New Look to the AEC**

The AEC debuted a new format for the 2009 meeting in Atlanta, Georgia. In response to the membership's desire to shorten the overall length of the AEC without cutting the number of continuing education unit (CEU) opportunities, the AEC will again begin on Thursday evening with the Student/First-time Attendee Orientation, followed by the Welcome Reception. There will be two full days of outstanding educational opportunities within the Plenary and Educational Breakout Sessions (EBS) on Friday and Saturday, followed by a shorter day on Sunday with the conference concluding in late-afternoon.

**Pre-Conference Symposia**

Based on the positive feedback from the 2009 AEC, we will again have six Pre-Conference Symposia on October 14, 2010, the day before the main conference. The Pre-Conference Symposia are high level, in-depth sessions for specific specialty practice areas, new issues in genetics and genomics or professional development topics. Each session will last six hours, allowing for a deeper review and discussion of a particular topic for genetic counselors with specific interests. We anticipate that the attendance at each symposium will be smaller than at the EBSs, which will allow for a more interactive experience. Each symposium will require separate registration from the AEC and will have limited space available. Sign up early!

**Continuing Education Units**

The NSGC is approved as an Authorized Provider for CEUs through IACET, the International Association for Continuing Education and Training. IACET requires that the NSGC document attendance at sessions for which attendees are requesting CEUs. Similarly, if you take a remote learning course, like the online course or the *Journal of Genetic Counseling* CEU program, participation is documented by the administration of a quiz that you must pass in order to earn CEUs. Based on feedback from the 2009 conference, we are looking into other ways to document attendance for future meetings.

**Program Book**
In an effort to reduce costs and "go green," handouts will again be available online prior to the conference for self printing. We recommend that you review the conference handouts prior to arriving in Dallas and print those you want to have on paper during the conference. Another option, if you have a laptop, is to download handouts for viewing on your laptop during the presentations.

**Accommodations**
The AEC will be held at the Hyatt Regency Dallas, which is about twenty-five minutes from the Dallas/Fort Worth International Airport (DFW). Attendees will receive complimentary access at the hotel's 24-hour StayFit Center, and will enjoy the hotel's Grand Bed™ and in-room iHome stereos with iPod docks. The Hyatt Regency Dallas, famous for its landmark tower in the Dallas skyline, is adjacent to the city's historical district and West End, featuring ample dining, shopping and entertainment. The hotel is also within walking distance of the John F. Kennedy Memorial Plaza and a short taxi or train ride from the Dallas Arts District with museums, galleries and grand performance venues.

Please check the NSGC Web site at www.nsgc.org/conferences/aec.cfm as we get closer to the conference for more details about hotel rates and reservation information.

**Dates to Remember**
The deadline for Early-bird Registration is **August 20, 2010.** Be sure to sign up on time to take advantage of this discount!

Abstracts for platform and poster presentations will be accepted from **March 22 to May 17, 2010**. See the NSGC Web site for more information.

The 29th NSGC AEC promises something for everyone. Mark your calendars to join us in Dallas, TX!

*For questions, please contact **Shannan DeLany Dixon** (smdixon@som.umaryland.edu) or **Elizabeth Wood Denne** (ewdenne@jhmi.edu).*

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## Call For Abstracts

Are you interested in presenting your abstract at the AEC and interacting with an appreciative audience of genetic counseling professionals? If so, consider submitting an abstract to the **Call for Abstracts** for a chance to be selected for a **Platform Paper** or **Poster** presentation.

Students, Full members, and non-members are encouraged to submit abstracts. Monetary awards will be presented for best Full member and Student member abstracts. A Best Poster Award will also be presented.

Call for Abstract Details:

- *Opens **March 22, 2010***
- *Closes **May 17, 2010***

Check the NSGC Web site at www.nsgc.org/conferences/abstract_index.cfm for submission details and guidelines.

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## Resources / Book Review

*Reviewed by Melody Perpich, MS, CGC, LGC*

### The Genome Book:
### A Must-Have Guide to Your DNA for Maximum Health

Authors: April Lynch with Vickie Venne
Publisher: Sunrise River Press, North Branch, Minnesota, 2009
Pages: 239
Retail paperback price: $14.95

The Genome Book: A Must-Have Guide to Your DNA for Maximum Health is written by April Lynch, a science author and journalist for the *San Jose Mercury News* and **Vickie Venne**, genetic counselor and Past President of the National Society of Genetic Counselors (NSGC).

The authors wrote this book so that the non-scientist, non-genetics professional could gain a better understanding of the concept of genomic medicine. They provide an easy-to-understand explanation of the medical benefits gained from the decoding of the human genome, and how knowing one's personal genetic information will impact an individual's health care.

The guide opens with a forward by **Catherine Wicklund**, also an NSGC Past President. She emphasizes that genetic technologies in everyday medical care can no longer be considered "futuristic" but, in fact, the time of genomic medicine has arrived. She states that The Genome Book will help prepare and guide individuals to interpret and use available technologies. She endorses genetic counseling services and guidance by medical professionals as she helps individuals think about their family histories, the appropriateness of available testing and "do-it-yourself" genetic testing options. As is made abundantly clear in this book, genetic counselors are being newly reinvented as "genomic counselors."

For the lay person, let alone the seasoned genetics expert, navigating the murky sea of available genetic tests can be daunting. The book's introduction specifically describes

that the primary goal for the reader ranges from creating a family medical history to finding a trained medical provider that is able to incorporate genomic information to improve individualized health care. The reader is able to gain a better understanding about how genes are involved in health concerns by the real-life stories sprinkled throughout the guide.

The ambitious task of describing the impact of genomics on individual personal health was accomplished in nine chapters and 230 pages. The first two chapters open with an overview of basic genetics and later chapters review disease-related topics including cancer, heart conditions, mental health, and the effects on insurability and privacy. The guide concludes with what lies ahead regarding what can and cannot be done once "dangerous DNA" is identified. Readers are encouraged to take responsibility for their personal health futures by learning their family's medical histories, considering appropriate genetic tests, and using this information to make healthier life choices. Vickie Venne provides real-life cases to help illustrate how people's lives have been reshaped by their genomic choices.

The reader is kept engaged by the "Did You Know" and "Red Flag" inserts woven into each chapter, which help underscore important points in the text. Each chapter concludes with "Frequently Asked Questions" and "Keep In Mind" sections, which serve to further summarize and punctuate key features. The conversational "counseling" style of this book helps to minimize misinterpretation of the salient information provided.

Chapter 2, " Reading Your Genetic Operating Instructions" begins by emphasizing and inspiring readers to learn how to compile a family medical history. This will help pinpoint potential health risks and allow readers to start making lifestyle and nutrition decisions tailored to their genes. Guidance is provided on what medical and family history information is important to obtain, including tools such as the website for the U.S. Surgeon General's "My Family Health Portrait" on how to construct a family history.

The humorously titled Chapter 4 "You Are What You Eat" covers nutrigenomics. Topics covered in this section include lactose intolerance ("Milk Drinkers Are Mutants"), celiac disease, obesity, diabetes, and phenylketonuria. This chapter cautions the reader about information that is directly marketed to the consumer. Common sense health care management strategies, such as not smoking, exercise, and choosing a healthy diet, are also highlighted throughout the book.

Chapter 5, "Your Genes and Cancer: Finding Your Risks, Boosting Your Options," does a nice job of broadly covering the complexities of genetic testing for hereditary cancer risk versus testing for cancer-related single nucleotide polymorphisms (SNPs), cancer profiling, and targeted treatments/pharmacogenomics. Upon completion of this chapter, the reader would be armed with enough general information to approach an oncologist with intelligent questions about how the new genomics might be helpful in a cancer management plan. However, there were several noteworthy omissions. Although not universally used, there is no mention of *CYP2D* genotyping as a pharmacogenomics tool to predict metabolizer status before initiating tamoxifen treatment; the selective use of

PARP inhibitors to treat *BRCA1* or *BRCA2* mutations carriers; or selection against certain forms of chemotherapy, specifically 5-FU, for treatment of mismatch repair deficient colon cancer in individuals with Lynch syndrome. Specific tests, such as Oncotype Dx testing, are good prototypes of how a gene profile can help determine whether or not there is benefit from hormonal therapy alone, or whether chemotherapy is needed to reduce the risk of recurrence. It would be useful to include these examples because they illustrate that personalized medicine tailored to a person's genome is already in use.

In chapter five's section on genomics and breast cancer chapter, the authors spend time "counseling" the reader about how to share information with relatives, including warnings of possible "surprised reactions to the news." They also give an example of how failing to share information with family members can be harmful to at-risk relatives. Surprisingly, the authors did not mention in the management section that prophylactic oophorectomy reduces the risk of breast cancer in addition to reducing ovarian cancer risk. Regardless, the information provided in this chapter and the book as a whole is likely far more thorough and accurate than what is generally covered during an appointment with a physician or in similar books. The "resource" section lists useful websites for more in-depth information. Unfortunately, when writing about rapidly evolving topics such as the genome, written information is almost obsolete the second the pen is put to paper.

It is refreshing to read a book that promotes the value of utilizing trained genetics professionals to gain an understanding into the benefits and limitations of the genomics world. The authors provide an extensive overview without bogging the reader down with difficult jargon. This understandably comes at the expense of being somewhat vague in areas and not detailed enough for a more sophisticated or scientifically educated reader. Therefore, this book would be appropriate for anyone without a scientific background who is interested in gaining insight and perspective on the nuances of genomic medicine. The Genome Book is thoroughly written in a voice that is comprehensible to all readers.

***Read any good books lately?*** *Would other genetic counselors benefit from knowing about these resources? Our Book Review column is interested in reviewing books that could benefit the counseling membership and the clients/patients they serve. Please send questions or potential books for review to "Book Review" Column Editor* ***Shelly Cummings*** *at scumming@myriad.com. You may also direct questions to* ***Deepti Babu*** *at deepti.babu@albertahealthservices.ca or* ***Kirsty McWalter*** *at kirsty@hawaiigenetics.org.*

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## Media Watch

*By Claire Noll, MS, CGC and Roxanne Maas, MS, CGC*

(names of genetic counselors appear in bold)

September 15, 2009 - *Woodbine House Publishers* (http://gifts2.segullah.org/)
"Change of Heart"
A compilation of writings about children with Down syndrome is called "Gifts 2: How People with Down Syndrome Enrich the World." **Lisa Johnson** contributed a story about how having a child with Down syndrome has changed her perspectives on genetic counseling.

October 26, 2009 – *Grand Rapids Press* (www.mlive.com/living/grand-rapids/index.ssf/2009/10/family_shares_how_hospice_prog.html)
"Family shares how hospice program prepared them for short time with daughter with fatal disorder"
A couple whose child was diagnosed prenatally with trisomy 18 described how they were supported by their hospital's perinatal hospice care program. **Trudy McKanna**, who makes referrals to the hospice program, stated "I don't think anyone can prepare for hearing the news that your baby has a severe or fatal condition… If there's nothing you can do to help the baby medically, you at least want to be able to take care of their emotional needs and their family needs."

November 3, 2009 – *The Health Care Blog*
(www.thehealthcareblog.com/the_health_care_blog/2009/11/as-you-know-each-year-at-health-20-we-present-launch-a-debut-of-new-products-and-services-that-generates-personalized-ge.html)
"Health 2.0 and AccessDNA"
Matthew Holt interviewed **Jordanna Joaquina** as part of a series of podcasts describing new health products and services. Jordanna compared her company's website content to that of other on-line genetics companies and discussed its business model and plans for the future. Topics discussed included the difference between testing for single gene disorders and complex traits, the shortage of genetic counselors and geneticists, and genetic testing for drug response.

November 18, 2009 – *The ACMG Channel*
(www.youtube.com/user/TheACMGChannel#p/u/1/ULXvN59Ub5s)
"Family Health History & Genetic Privacy"
In this YouTube video presented by the American College of Medical Genetics (ACMG), **Judith Benkendorf** explained the importance of family history, how to collect medical information from your family, and how the Genetic Information Nondiscrimination Act (GINA) protects genetic information.

November 18, 2009 – *Los Angeles Times*
(http://latimesblogs.latimes.com/booster_shots/2009/11/down-syndrome-treatment.html)
"Is a wonder pill necessarily wonderful for people with Down syndrome?"

A survey of Canadian parents of children with Down syndrome found that 27% would not cure their children of that condition if a cure were found, and 32% said they were not sure. For many parents, the reason was a concern for a change in the child's personality. **Angela Inglis** worked on the survey.

November 24, 2009 – *Long Island University* (www.cwpost.liu.edu/cwis/cwp/pr/press/2009/104.html)
"C.W. Post launches Long Island's first Master's degree in genetic counseling"
The C.W. Post campus of Long Island University announced the creation of a Master's degree program in Genetic Counseling. The program director will be **Bhuma Krishnamachari**, the former Director of Genetic Services at Edward Hospital in Naperville, Illinois, and an American Board of Genetic Counseling-certified genetic counselor.

December 2009 – *St Mary's Health Plans* (www.saintmaryshealthplans.com/downloads/pdfs/pqnl_4q_09.pdf)
"Hereditary cancer risk assessment"
In this newsletter article for physicians at a large local medical group, **Robbin Palmer** explained how a genetic counselor makes a risk assessment for hereditary cancer, including what constitutes a red flag in a family history and the types of cancer known to be heritable.

December 11, 2009 – US News and World Report (www.ihavenet.com/Health-Crucial-information-from-family-health-history-might-well-save-your-life-Katherine-Hobson.html)
"Crucial information from family health history might well save your life – The power of tracing your medical roots"
This Health column encouraged people to find out more about their family medical history than just the basic details. **Jennifer Bojanowski** shared her family history of cancer, revealed her experience with genetic testing, and explained how this influenced her decision to become a genetic counselor. **Steven Keiles** was also quoted, "Your family history is probably the best predictor of your own health."

December 15, 2009 – *The Wichita Eagle* (www.kansas.com/living/health-fitness/story/1098605.html)
"Genetic counselor helps people assess risk of disease, disorders"
**Shobana Kubendran** is the first genetic counselor that Wichita, Kansas has had for seven years. In this interview, she described how she came to be a genetic counselor, the importance of knowing your family history, and the types of clients she sees. "Most of the time, my job is telling them, 'Your risk is not as great as you thought it was,'" she stated.

December 21, 2009 – *Fox Toledo News* (www.foxtoledo.com/dpp/news/local/Factoring-in-genetic-counseling-kt-122109)
"Factoring in genetic counseling"

**Stephanie Cape** discussed prenatal testing within the context of genetic counseling in an interview for her local news channel. She highlighted the difference between screening and diagnostic testing.

January 12th, 2010 – *Channel 7 News*, Denver
**Melissa Gilstrap** was interviewed in this news segment about what cancer genetic counseling is and who can benefit from this service. She informed viewers that people desiring cancer genetic counseling can be referred for the service by a doctor or can find a genetic counselor on their own.

January 16, 2010 – *Hollywood Confidential*
(www.leezagibbons.com/slices/media/RadioInterviewwithAccessDNAJordanaJoaquina1.html)
January 30, 2010 - *Hollywood Confidential*
(www.leezagibbons.com/slices/media/RadioInterviewwithAccessDNAJordanaJoaquina2.html)
**Jordanna Joaquina** was featured twice on Leeza Gibbons' talk radio show to discuss the information available on her on-line company's website, what type of person might benefit from accessing the site, and how people who are adopted can obtain family history information. She also clarified details about *BRCA1/2* testing.

January 22, 2010 – *scienceblogs.com*
(http://scienceblogs.com/geneticfuture/2010/01/personal_genomics_is_getting_s.php#more)
"Personal genomics is getting serious: Counsyl emerging from stealth mode"
A blogger who has used Counsyl's tests found it remarkable that the company had been able to obtain insurance coverage for its carrier screening tests. He reprinted a press release from the company that included testimonials from the directors of several fertility centers, as well as physicians, parents, and community leaders with an interest in specific conditions. A comment from **Elena Ashkinadze** addressed the test's wide applicability. "Because Counsyl's test simultaneously covers diseases from many ethnic groups at a considerably lower cost than standard blood tests, it promises to make carrier testing affordable for previously underserved patient populations, including African-Americans and Hispanics," she stated.

January 22, 2010 – *The James Line*
(www.jamesline.com/viewer/Pages/index.aspx?P=538)
"Direct-to-consumer genomics: what should I do now, doctor?"
**Amy Sturm** prepared this primer on direct-to-consumer testing for doctors at her hospital. She compared the tests being marketed to physicians versus to consumers, described concerns about clinical validity and utility, reviewed the ACMG guidelines, and provided resources for finding a genetic counselor or geneticist.

January 28, 2010 - *New York Times*
(www.nytimes.com/2010/01/29/business/29gene.html)
"Firm brings gene tests to masses"

Another article discussed the direct-to-consumer carrier screening tests offered by Counsyl, which it described as a cost-effective way for couples to obtain carrier screening for conditions including cystic fibrosis, Tay-Sachs disease, spinal muscular atrophy, sickle-cell disease, and Pompe disease. “As a genetic counselor, I’ve been waiting for this for a really long time,” said **Elena Ashkinadze**.

January 29, 2010 – *hamptons.com* (www.hamptons.com/Outdoors-And-Fitness/Fitness/9919/Is-Genetic-Counseling-Right-For-You.html)
“Is genetic counseling right for you?”
This community webpage recognized that the addition of **Emily Smith** to the staff of a local hospital allows area residents to obtain cancer genetic counseling and testing without traveling. Emily’s counseling “assists individuals and their families in translating scientific knowledge into practical information,” it reported.

February 4, 2010 – *CNN.com*
(www.cnn.com/2010/HEALTH/02/04/baby.dna.government/index.html)
“The government has your baby’s DNA”
A parent’s surprise that newborn screening may include DNA testing started off this review of states’ practices with regard to storage of the actual newborn screening samples and their availability for medical research. One concern was whether the subject’s name was released to researchers along with the sample. **Amy Gaviglio**, a co-author of an article that found more than twenty published studies using data obtained from newborn screening samples, commented that states have operational policies in place with regard to such use.

February 8, 2010 – *UPI.com* (www.upi.com/Health_News/2010/02/08/Genetic-testing-should-involve-counselors/UPI-62001265610562/)
“Genetic testing should involve counselors”
**Elizabeth Kearney** discussed the added value brought to the genetic testing process by genetic counselors. “A trained genetic counselor can help prepare you for what you might learn and be there for you to interpret results. They can also help you decide if having a genetic test is a good choice,” she said.

February 8, 2010 – *suite101.com*
(http://humangenetics.suite101.com/article.cfm/genetics-and-genetic-counseling-answers)
“Genetics and genetic counseling answers”
In an online interview, **Sarah Kellman** described what a genetic counselor does, who might benefit from genetic testing, and some of the fears expressed by her clients.

February 10, 2010 – *WCMH channel 4, Columbus OH*
(www.youtube.com/watch?v=uWI4L3L8PIY)
Family history and genetics segment of “Matters of the Heart”
A local news channel broadcasted a four-part story on heart health and treatment. In the segment on family history, **Amy Sturm** provided information on the risk of hereditary

heart conditions. She made special reference to the program moderator, who had had a heart attack at age 32 years and was concerned about the risk to her children.

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## Research Network

*By Suzanna Schott, MS, CGC*

**Autoimmune Diseases in Pregnancy Project**
The Organization of Teratology Information Specialists (OTIS) is researching the effects of autoimmune diseases such as Crohn's disease, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, and psoriasis, as well as the medications used to treat these conditions during pregnancy. Participants will not be asked to take any medication as part of this study. We are also enrolling controls for this study (women who do not have an autoimmune disease, but who are pregnant). Visit the website to learn more about this study: http://www.otispregnancy.org/autoimmune-studies-s13049.
***Contact:*** Dee Quinn at **520-626-3547**, or e-mail dquinn@email.arizona.edu

**Genetic Epidemiology of Lung Cancer**
A consortium of six centers is collecting familial lung cancer cases for linkage analysis and genome-wide association studies. Eligible participants must have at least two or three blood related relatives with a diagnosis of lung cancer. Affected individuals must be from the same side of the family, and at least one must be living and willing to contribute a blood sample. No travel is necessary to participate in this study. Samples can be collected via pre-paid mail kit.
***Contact:*** Alicia Salkowski at **313-578-4311**, or e-mail salkowsk@med.wayne.edu
or Kelly Kennelly at **313-578-4296**, or e-mail kennellk@karmanos.org

**Genetic Factors in Charcot Marie Tooth Disease**
Researchers at the University of Miami are investigating genetic factors that contribute to Charcot Marie Tooth disease (CMT). Any individual with a diagnosis of CMT and his/her selected family members can participate. Participation involves providing a small blood sample, a family history interview, and a release of medical records related to CMT. Travel is not required. Find more information at http://www.mihg.org/weblog/study_participation/2009/07/charcotmarietooth-cmt.html.
***Contact:*** Susan Hahn at **1-877-686-6444**, or e-mail HIHGinfo@med.miami.edu

**Genetic Factors in Hereditary Spastic Paraplegia**
Researchers at the University of Miami are investigating genetic factors that contribute to Hereditary Spastic Paraplegia (HSP). Any individual with a diagnosis of HSP and his/her selected family members can participate. Participation involves providing a blood sample, family history information, and releasing medical records related to HSP. Travel is not required. Find more information at

http://www.mihg.org/weblog/study_participation/2009/07/hereditary-spastic-paraplegia-1.html.
***Contact:*** Susan Hahn at **1-877-686-6444**, or e-mail HIHGinfo@med.miami.edu

**Mayo Clinic Mitochondrial Disease Biobank**
Mayo Clinic is pleased to announce a new research resource: the Mitochondrial Disease Biobank. This is the first biobank in the country specifically developed to study mitochondrial diseases. Eligible participants include individuals with a mitochondrial disorder or disease affecting mitochondrial function. Their family members may also participate in some cases. Participants do not need to be Mayo Clinic patients. Enrollment and consent can be completed by mail. Please visit the website for more information: http://mayoresearch.mayo.edu/mitochondrial-disease-biobank/
***Contact:*** Ashley VanDenBoom at **1-877-594-2149**, or e-mail mitochondrialdb@mayo.edu

**MOMS - The Management of Myelomeningocele Study**
The Management of Myelomeningocele Study (MOMS) is actively recruiting pregnant women for a randomized clinical trial designed to compare prenatal surgery versus standard postnatal surgery for spina bifida. Screening begins by telephone and a review of medical records. Interested candidates who qualify are assigned to one of three MOMS Centers for a comprehensive evaluation: The Children's Hospital of Philadelphia, the Vanderbilt University Medical Center in Nashville, or the University of California San Francisco. Eligible candidates are randomized to the prenatal surgery group or the postnatal surgery group. Participants must complete enrollment by 25 weeks gestation. See http://www.spinabifidamoms.com for more information.
***Contact***: Jessica Ratay toll-free at 1-**866-275-6667**, or e-mail moms@bsc.gwu.edu

**Thrombotic Storm Study**
Researchers at the University of Miami are investigating a rare hypercoagulable state characterized by multiple, severe, life-threatening thromboembolic events, called Thrombotic Storm or Catastrophic Antiphospholipid Syndrome and Sepsis (CAPS). Individuals with two or more of the following findings at age 55 or younger are eligible to participate: more than two acute arterial or venous thromboemboli, and/or thrombotic microangiopathy; thrombosis in an unusual location (e.g., cerebral sinus); progressive/recent unexplained recurrence of thrombosis; refractory to acute therapy and/or an atypical response to therapy. Travel is not required. Additional study details are available at http://www.thromboticstorm.com and http://www.mihg.org/weblog/study_participation/2009/07/thrombotic-storm-ts.html.
***Contact:*** Susan Hahn at **877-740-7744** or e-mail HIHGTS@med.miami.edu

**Vaccines and Medications in Pregnancy Surveillance System (VAMPSS)**
The Organization of Teratology Information Specialists (OTIS) is researching vaccines and medications in pregnancy such as the H1N1 vaccine, seasonal flu vaccine, and antiviral medications. Participants will not be asked to take any medication or vaccines as part of this study. Eligible participants will be pregnant women who have already received the vaccines or taken antiviral medications. Pregnant women who have not

received the vaccines or antiviral medications are also eligible to participate as controls. Visit the website to learn more about this study: http://www.otispregnancy.org/vaccines-and-medications-in-pregnancy-surveillance-system-s13053.
***Contact**:* Dee Quinn at **520-626-3547**, or email dquinn@email.arizona.edu

**Validation of a Scale to Assess Stigma in Family of People with Mental Illness**
Researchers at the University of British Columbia are in the process of validating a new scale assessing stigma in relatives of people with mental illness. They hope to determine the usefulness of this tool for clinicians and researchers. First-degree relatives of individuals with schizophrenia, bipolar disorder, or schizoaffective disorder are eligible. Participation involves completion of a questionnaire.
***Contact**:* Emily Morris at **604-875-2000 ext. 4733,** or email mental.illness@ubc.ca

*Please send Research Network items to Emily Place at emily.place@gmail.com.*