Perspectives in Genetic Counseling - Volume 31, Number 1

President's Beat

Now is the Time for Strategic Thinking

So, here we are in our 30th year of existence under a new federal administration that is taking a hard look at how healthcare will be delivered in the future. As an organization, we are also trying to envision where the profession of genetic counseling is headed and what role genetic counselors will play in this new healthcare environment. Now is the time for everyone as individuals to be thinking strategically. This is the responsibility of the NSGC Board, and also the responsibility of every individual member.

For those of you who completed the recent vision survey, you had the opportunity to think strategically while answering questions. I want to thank those who took the time to provide the Board with your insight. This information was utilized at our recent Board meeting where we underwent our strategic planning session, and was vital in determining our organizational needs as we move forward.

Strategic thinking means asking, "Are we doing the right thing?" That is the key question we need to ask ourselves constantly as an organization and as individual genetic counselors. Where do we want to be and what can each of us do now to help get us there? Many issues are going to have an impact on the role of genetic counselors. At the same time, genetic counselors can and will have an impact on many of the issues facing the future of healthcare delivery.

We all want to have a proactive impact on the changes in healthcare delivery. It is not in our best interest to watch changes take place and then later have to react to ongoing changes by figuring out where we fit in, or even if we fit in. Several key issues facing genetic counselors in genomic medicine will include: reimbursement for services, state licensure, health information technology, education of primary care physicians in genetic and genomic medicine, and new and improved healthcare delivery models. We need to have input into these issues on the front end to ensure that we are not waiting for others to determine our role.

As an organization, our leaders have spent years trying to get us to the tables where these decisions are being made. This hard work has paid off as we are now recognized for our expertise and included in these processes. In June I will be representing the NSGC at a meeting sponsored by The National Human Genome Research Institute (NHGRI) of the NIH to develop a blueprint for primary care physician education in genomic medicine. This will be our opportunity to have input into identifying core educational needs as defined by primary care communities and to propose concrete strategies for primary care physician education. There is still a lot of work to be done and we will continue these efforts to carry our message to those who need to hear it. However, this is not something that can and should be pursued only by your leadership; this is really something for the entire membership to rally around. Where does one start?

It starts with thinking strategically. Think of how you want things to be in the future, and then figure out ways to get there. I did not say it was going to be easy, but it is certainly something everyone out there can be doing. As each of us strengthens our roles in the field of genetics and shares this information with our colleagues, we help build a stronger, more powerful organization.

As always, your feedback and comments are appreciated and valued. Please feel free to contact me directly at **skeiles@ambrygen.com**.

Meet the New *Perspectives* Editors

By Deepti Babu, MS, CGC

I was honored to be appointed the new *Perspectives* editor, but admittedly a little surprised. I don't have a typical NSGC pedigree. However, I have been a clinical genetic counselor for over a decade, all while honing my skills in writing and editorial work. Wherever I work, I manage to freelance in the background. At one point, I created a food column in a Wisconsin newspaper to help channel my family's foodie gene. While I'd like to think this was successful, in hindsight this may only have further fueled my obsession.

As an American living and working in Canada, this gives me the natural ability to observe genetic counseling in the U.S. from north of the border, and I'm hoping this will allow me to bring some international flavor to *Perspectives* that includes our international members, colleagues and their work.

After hearing more about this position and its three-year term, I was excited and thankful to hear that Kirsty McWalter would be appointed as Associate Editor. Jessica Mandell and those before her have given us a wonderful publication; I look forward to working with the dedicated *PGC* committee members and seeing where we can take it in the future. As always, we welcome any input, suggestions and comments as we go forward. Please contact me at **deepti.babu@capitalhealth.ca** at any time. Thank you to all of you for your continued support.

By Kirsty McWalter, MS, CGC

Aloha from the 50th state. I'm so pleased and honored to be the new Associate Editor of *PGC*. I've had a love of writing and editing since my Biology/English undergraduate degree, and am continually awed by the range of activities and experiences undertaken by genetic counselors. I can't imagine a better NSGC volunteer opportunity than to help publish genetic counselors' stories and facilitate communication within our profession.

I know it will be great to work with Deepti Babu on this undertaking. We'll make a well-balanced team – she's an American living and working in Canada; I'm a Canadian living and working in the United States. The PGC committee members are such a valuable resource, and I appreciate their continued support and hard work gathering articles. Please feel free to send me your thoughts and suggestions: **kirsty@hawaiigenetics.org**. I look forward to hearing from you and listening to your stories!

"From Whence We've Come": Historic Moments from the NSGC's First Thirty Years

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

In this, the thirtieth anniversary year of the National Society of Genetic Counselors (NSGC), *Perspectives in Genetic Counseling (PGC)* wishes to honor the history and achievements of our professional organization and its membership. *PGC's* Editors approached several respected leaders in our field for their reflections. Many of their responses, both thoughtful and thought-provoking, are included here for your enjoyment.

Thirty years ago this month, Audrey Heimler, President of the newly formed NSGC, contributed to the newsletter that would later become *PGC*. Her piece was entitled "From Whence We've Come," and her words still resonate today. Heimler later cited Beverly Rollnick's 1980 presidential address in her 1997 article in the *Journal of Genetic Counseling (JGC)* by saying, "'The 1970's were marked by discussions on licensing, certification, the process of genetic counseling and who should do it.'" Looking back on these historical moments, it is astounding how relevant they still are. As Wendy Uhlmann, another NSGC Past President, recently said, "…this quote summarizes issues that we are addressing today but from quite a different vantage point."

Genetic counselors initially needed to establish their identity, determine who should provide services, and define the process of genetic counseling. As Audrey Heimler recently described, "In the face of strong resistance from the medical profession, the decision to adopt the title of 'Genetic Counselor' as a distinct professional… was a brave step at that time. Establishing a national professional society… was key to empowering the profession for all future goals."

PGC's precursor was *A Newsletter of the NSGC*, which included an announcement of NSGC's incorporation. Deborah Eunpu, its inaugural Editor, invited members to contribute suggestions or articles. Contents included summaries of regional meetings and committee meetings, information from the Board of Directors, news from the various districts and job listings. The profession was relatively new and expectations of genetic counselors were being set.

In 1981, the NSGC held its first two-day Annual Education Conference in sunny San Diego. Robert Resta, a genetic counselor since the early '80s and past Editor of the *JGC*, feels the AEC is still "…key to a cohesive profession – it brings us physically together every year, reminding us that we are not alone out there." Michelle Fox, genetic counselor for over twenty-five years and past recipient of the Jane Engelberg Memorial Fellowship (JEMF) award agrees. She describes the first meetings as "very small (probably 100 [attendees] or so) but unbelievably exciting." The size and format of the AEC has changed dramatically over the years, evolving to meet the needs of an ever-changing membership.

The first published Professional Status Survey (PSS) also took place in 1981, a feat not typically accomplished so quickly by other professional organizations, but perhaps made possible due to the manageable size of the group at that time. The NSGC's PSS data have evolved and become more available to members over the years. "Having members able to easily access the PSS data has gone a long way to improving the status of genetic counselors…" says Ann Walker, former Director of the University of California, Irvine's genetic counseling training program.

In 1983, the NSGC solidified the profession in the field of medical genetics by adopting the definition of a genetic counselor's role based on that from the American Society of Human Genetics.

Responding to the growing pains of a larger membership, the NSGC set up an office and hired an Executive Director in 1987. "This allowed NSGC to centralize operations, increase and expand services offered…" explains Uhlmann. "Hiring an Executive Director brought a new knowledge base to our organization…" and this helped develop the NSGC beyond its membership.

As the membership grew, the NSGC created tools that fostered communication between members. Special Interest Groups and their listservs allowed "…for the successful expansion of genetic counseling services and wider roles for genetic counselors," says Uhlmann.

It became clear that funding was needed to help genetic counseling projects impact professional development. In 1991, the NSGC initiated the JEMF award, which was made possible because of a very generous endowment donation by Alfred Engelberg in memory of his wife. As Fox reflects, "JEMF continues to be the most prestigious award a genetic counselor can receive from NSGC. It is a privilege to be part of the process."

1992 marked the premiere issue of the *JGC*, increasing "professionalism, academic stature, recognition and visibility for our profession," says Uhlmann. Resta echoes these sentiments: "The vast majority of journals have a much shorter life span. The journal has served as a key outlet for publication of genetic counseling research."

The incorporation of the American Board of Genetic Counseling (ABGC) in 1993 was a key moment for genetic counseling. "When genetic counselors sat for the same general examination as medical geneticists and Ph.D. geneticists, it was clear that they were bona fide professionals of the medical genetics field," recalls Heimler. However, when non-physician or doctorate genetics professionals had to split off from the American Board of Medical Genetics due to requirements of the American Board of Medical Subspecialties, changes to the existing certification process were necessary to preserve the status of genetic counselors. The established nature of the NSGC was helpful in convincing our medical genetics colleagues that change was needed, and allowing for the ABGC to be formed. With the Board certification pathway appropriately modified, genetic counseling training programs began implementing standards and accreditation of the training programs began.

Increasing membership numbers again prompted change and the NSGC's transition to SmithBucklin for professional management. As Jessica Mandell, past Editor of *PGC*, says, prior management did "…a great job with limited resources for many years, but in order to fully achieve all that NSGC wanted and needed… having a team of business minded professionals on staff has allowed us greater opportunities…".

Over the years, *PGC* itself has gone through many evolutions. Thanks to the efforts of many, but specifically Mandell and Janice Berliner, past *PGC* Editor and a genetic counselor for twenty years, it is now available on-line in a printer-friendly format with color photos, features and recurring columns that highlight fundamental issues for genetic counselors. Reflecting our rapidly changing field, hard-copy job listings quickly became outdated and were replaced with electronic distributions.

Challenges for the NSGC and its membership will continue to arise in the future. Some challenges persist from thirty years ago, such as the need for more diversity within the field. Berliner advises, "This lack of diversity amongst our current membership may be a barrier to new recruits and may also be a barrier for consumers of our services." Walker suggests that "advocating for financial support for genetic counselor education (both for programs themselves and for more diverse students)…" may aid in increasing diversity.

Recognition of the genetic counseling profession continues to be a concern, but perhaps now with a different focus. Today it involves more education for the public and other medical professionals about genetic counselors – specifically, our services and the situations in which we excel. This is particularly important in the current environment of direct-to-consumer and direct-to-provider marketing. The NSGC's Genetic Counselors' Scope of Practice was finalized in 2007 and provides concrete information to those researching which services are potentially available and appropriate.

No list of challenges would be complete without mentioning billing and reimbursement, as well as licensure. Licensing is no longer "vague and general, it's state-specific and our efforts are bearing real fruit," says Berliner. The fact that only a minority of states have attained this goal speaks to its difficulty, but the NSGC has been a resource to those in the process.

Many leaders in our field feel that the NSGC will need to become a bigger player in order to meet the needs of the public, though it has already attained some degree of recognition by other organizations. As Resta suggests, this may only be accomplished if we continue to "maintain [our] relevance and utility to an increasingly growing and diverse field."

Over the past thirty years, charter NSGC members and leaders were instrumental in nurturing the evolution of the genetic counseling field. Advancements in medical genetics progressed at a dizzying pace, and genetic counselors have strived to strengthen our foothold as the face of medical genetics continues to change. The NSGC has been a dedicated advocate for genetic counselors since its inception, and there can be no doubt that it will remain so over the next thirty years and beyond.

For Your Practice

2008 Professional Status Survey Results Summary

By Troy Becker, MS, CGC and Sarah Parrott, PhD

Introduction
Over the 29 years since the Professional Status Survey (PSS) was first administered to the National Society of Genetic Counselors (NSGC), the results have been eagerly anticipated by the membership. Throughout the year, the NSGC receives inquiries about the PSS from both members and human resource professionals seeking information in order to adjust salaries and benefits for current and future genetic counselors. Given the continued small number of genetic counselors compared to other allied health professions, results of the biannual NSGC PSS are an important resource used by prospective and current employees.

Methodology
The 2008 PSS was administered online to full members (N=2130) of the NSGC via e-mail during the summer of 2008. A total of 1508 surveys were completed, which represented a 71.1% response rate, an increase of 21% over 2006. This was the highest response rate over the past four survey cycles, and the most individual responses received since the inception of the PSS in 1980.

To provide members with the most flexibility possible, a dynamic web-based survey instrument was used. Survey respondents were able to login with their NSGC ID and had the option to complete the PSS over multiple sessions. Respondents were able to answer questions in any order, review previous answers, and make corrections and modifications.

The online administration of the PSS was completed in August 2008. Responses were collected and complied on a secure server by Boston Information Solutions, a firm specializing in online data collection and management.

The comprehensive survey consisted of eight sections and 70 items, some of which were multi-part questions. The majority of questions remained unchanged from the 2004 and 2006 surveys; however, certain questions were edited for clarity and a number of new features were added. Frequencies and means reported are based on the number of respondents who answered the specific question. Interactions between variables were examined using Chi-Square significance testing.

Demographics & Ethnicity
The demographic composition of the 2008 respondents (Table 1) is not substantially different from previous surveys, although there has been a slight shift toward the younger age groups compared to 2006. Respondents continue to be primarily Caucasian women under age 40, with fewer than 10 years in the genetic counseling profession. The percentages of minority respondents (Table 2) are not substantially different from 2006.

Table 1: Demographics

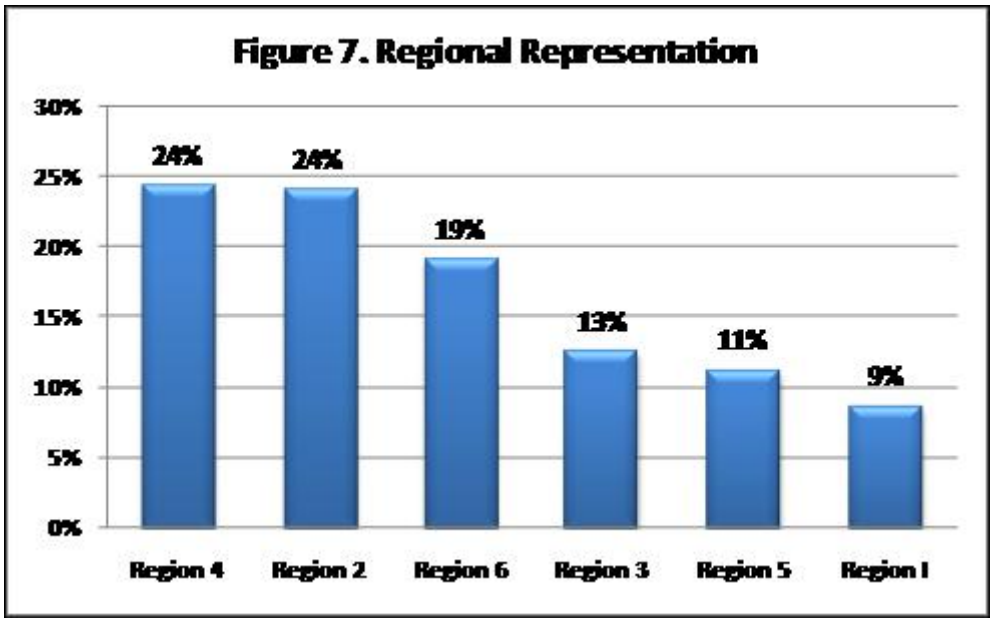
	Demographics of Respondents	
Gender	Male	5%
	Female	95%
Age	20-24	3%
	25-29	27%
	30-34	27%
	35-39	14%
	40-44	10%
	45-49	7%
	50-54	6%
	55-59	3%

	60-64	1%
	65+	0.4%

Table 2: Ethnicity

Ethnicity	Non-Hispanic or Latino	Hispanic or Latino
Native American	0.1%	
Asian	4.7%	
Black or African American	1.2%	4%
Native Hawaiian or Other Pacific Islander	0.2%	
White or Caucasian	93%	75%
Other	1.2%	21%
Total	**1473**	**24**

Regional Representation
Regional data (Figure 7) remain consistent with distributions in previous surveys. Nearly half of respondents continue to live and work in Regions II and IV. Region I continues to comprise the smallest regional group.



Training & Certification
Approximately two-thirds of genetic counselors surveyed have a Master's-level degree in Genetic Counseling, while one-fifth have a Master's-level degree in Human or Medical Genetics. These are slightly lower than the percentage reported by respondents in the 2006 PSS (75% and 25%, respectively). Only 2% of respondent have a PhD in a genetics-related field, and 3% have an additional Master's-level degree (MPH, MBA, MSN, MSW).

Regarding certification, 75% of respondents (N=1126) report being certified by either the American Board of Genetic Counseling (ABGC) or the American Board of Medical Genetics (ABMG). Of the 276 respondents who indicated they were not certified by either ABGC or ABMG, 210 (76%) were recent graduates who had not yet sat for their first ABGC exam. Only 3.6% of the non-certified respondents reported choosing not to take the ABGC certification exam, and 2.9% indicated they were not eligible to take the ABGC exam.

With regards to licensure of genetic counselors in the United States, approximately 7% of the total respondents reported holding either a full, provisional or temporary license. Respondents who were not licensed reported that this was primarily due to licensure not being currently available in their state.

Respondents who sat for the ABGC examination received a variable amount of reimbursement for expenses incurred in conjunction with the exam. Application fees were covered (complete or partial) for 55% of respondents, while 66% reported coverage of a Board review course. Twenty-four percent of respondents reported no employer reimbursement for any exam-related expenses.

Direct benefits related to passing the ABGC examination varied, with 27% of respondents receiving a salary increase, 4% receiving a promotion, and 9% receiving some degree of reimbursement for exam-related expenses upon passing the exam. Approximately 72% of respondents reported no benefits associated with achieving ABGC certification.

Employment Experience
Figure 2 shows the number of years that genetic counselors have been practicing. Nearly two-thirds have fewer than 10 years of experience working in the field.

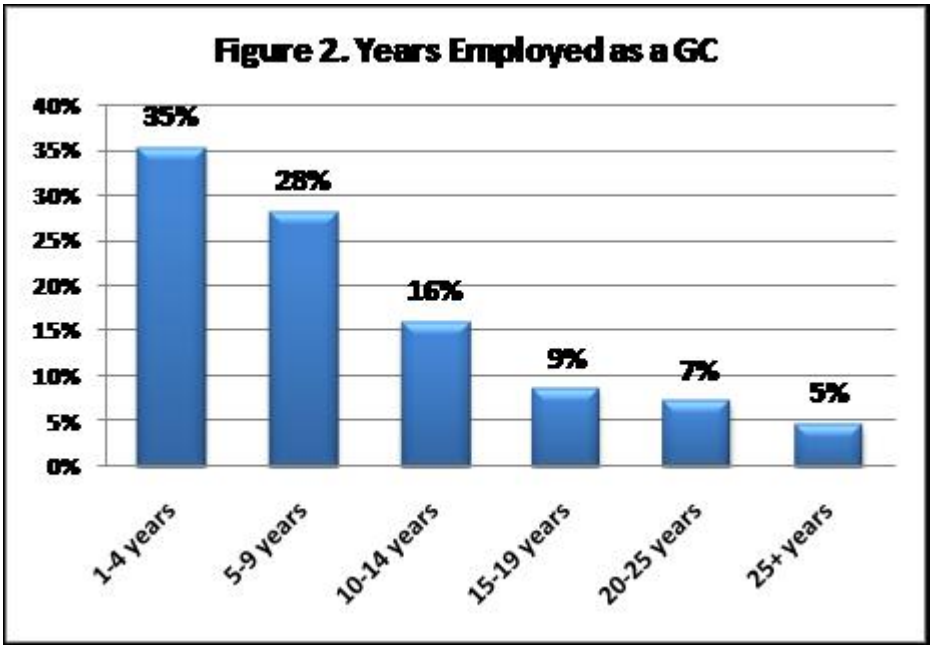


Table 5 shows that "word of mouth" continues to be the leading means of introduction to the genetic counseling profession amongst respondents completing their first PSS. However, this is closely followed by undergraduate coursework, which showed a substantial increase over 2006 and is now near parity with "word of mouth". The remaining categories remained similar to previous surveys.

Table 5: First Introduction to Genetic Counseling

First-time PSS takers	**N**	**Percentage**
Word of Mouth	116	31%
Undergraduate coursework	105	28%
High School coursework	58	16%
Internet Search	36	10%
Personal experience with a genetic counselor	20	5%
Other	35	10%
Total	**370**	**100%**

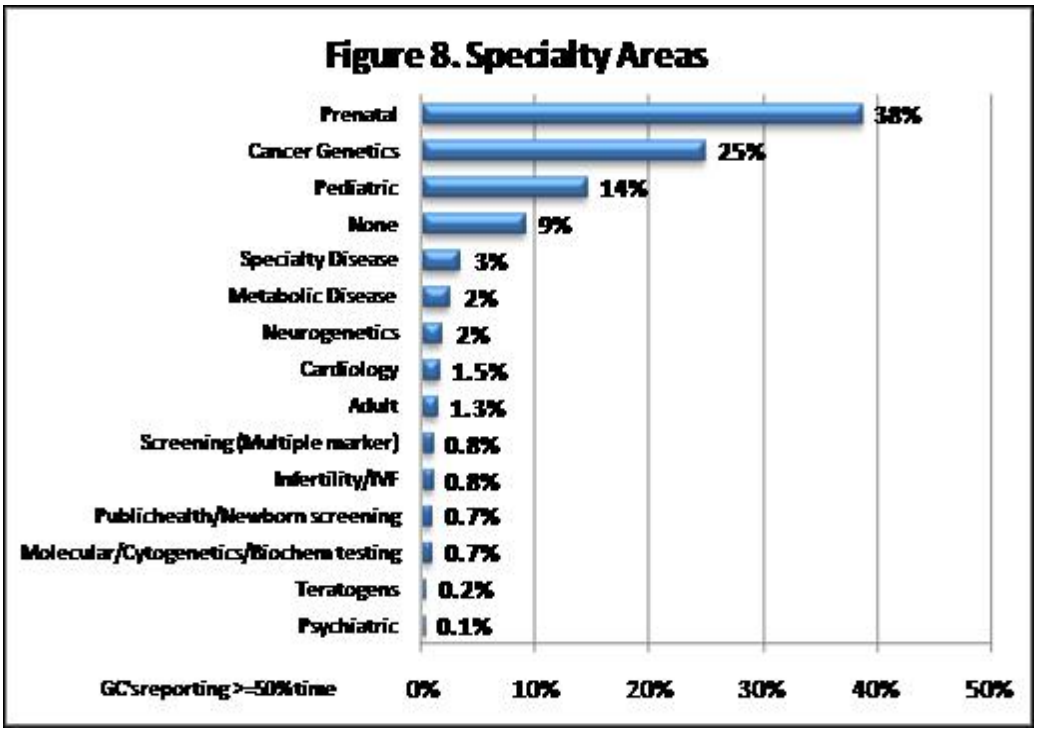
Work Environment

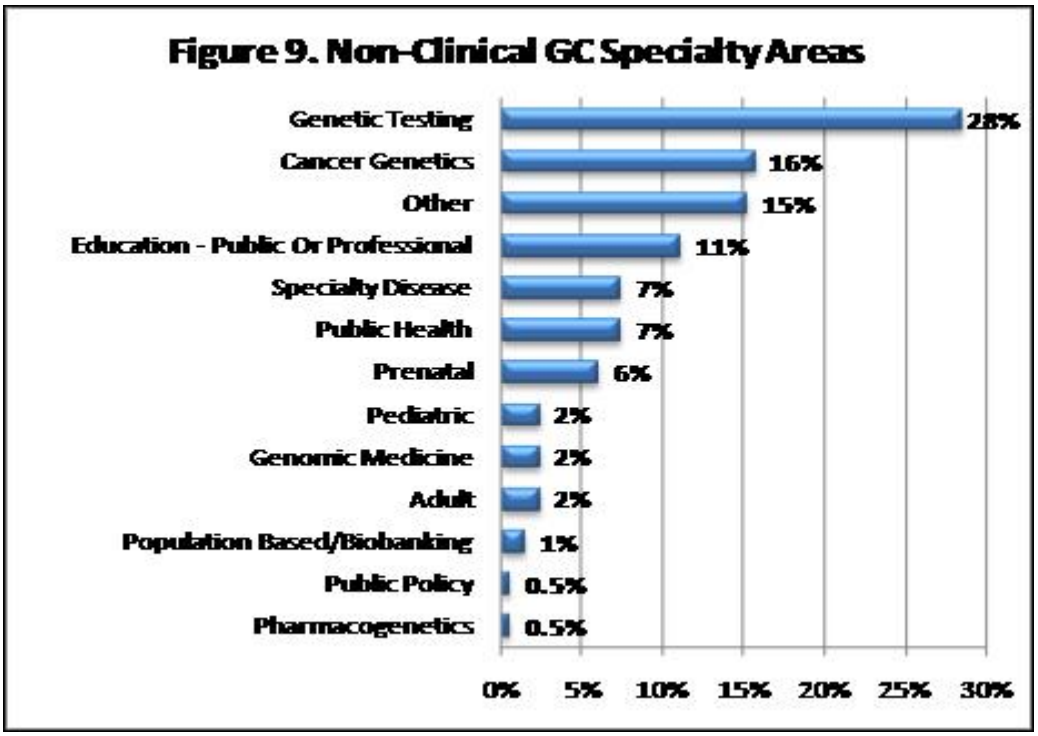
Primary Work Setting
Table 6 shows that the majority of respondents (37%) work in a university medical center. This is similar to the 2006 cohort (38%), but remains historically low compared to the late 1990s when this group comprised 47% of respondents.

Table 6: Genetic Counselors by Work Setting

Primary Work Setting	N	%
University Medical Center	524	37%
Private Hospital/Medical Facility	273	19%
Public Hospital/Medical Facility	205	14%
Diagnostic Laboratory	131	9%
Physician's Private Practice	86	5%
Health Maintenance Organization	60	4%
Not-for-Profit Organization	32	2%
University/Non-Medical Center	31	2%
Government Organization or Agency	24	2%
Federal/State/County Office	14	1%
Research Development/Biotechnology Company	10	0.7%
Pharmaceutical Company	9	0.6%
Private Practice/Self-Employed	6	0.4%
Bioinformatics Company	5	0.4%
Internet/Website Company	5	0.4%
Outreach/Satellite/Field Clinic	5	0.4%
Health Advocacy Organization	3	0.2%
Health Advocacy Organization	3	0.2%
Professional Organization	1	0.1%
Total	**1424**	**100%**

Specialty Area
Figure 8 and Figure 9 summarize the area of specialty in which genetic counselors reported spending greater than 50% of their time on a daily basis. The top three specialty areas for those who counsel patients (Table 7a) continue to be prenatal, cancer and pediatric genetics. Table 7b shows the specialty areas for those who do not counsel patients. As the 2008 PSS asked respondents to report only areas where they spent greater than 50% of their time, the percentages cannot be directly compared to previous surveys that asked for any specialty where respondents may have worked for any proportion of their time.





Primary Roles

Genetic counselors often fill multiple roles as part of their daily duties. New to the 2008 PSS, the primary role category is now divided according to whether or not respondents counsel patients. With increases in the diversity of the roles that genetic counselors play in the work environment, as well as an expansion of what have historically been considered "non-traditional" genetic counseling positions, this change will allow for a better direct comparison between genetic counselors whose daily responsibilities do and do not include direct patient counseling.

For the majority of genetic counselors who counsel patients (Table 8a), the primary role reported is clinical (83%). On average, these genetic counselors report seeing nine new patients and three return patients per week (the former being slightly lower than 2006), with patient load varying between specialties. When asked about the number of patients seen compared to 2006, nearly half (49.5%; N=534) reported that this number had increased, with an additional 23% reporting no change in overall patient load. The most common primary role for genetic counselors who do not counsel patients (Table 8b) is laboratory support (19%).

Table 8a: Primary Roles of Genetic Counselors		
Primary Role(s) - GCs Who Counsel Patients	**N**	**%**
Clinical	988	87%
Research/Study Coordinator	48	4%
Clinical Coordination	29	3%
Teaching/Education/Supervising Students	26	2%
Management	25	2%
Lab Support	13	1.1%
Customer Liaison	5	0.4%
Grant Management	2	0.2%
Healthcare Administration	2	0.2%
Total	**1138**	**100%**

Table 8b: Primary Roles of Genetic Counselors		
Primary Role(s) - GCs Who Do Not Counsel Patients	**N**	**%**
Laboratory Support	36	19%
Research/Study Coordinator	33	18%
Customer Liaison	26	14%
Teaching/Education/Supervising Students	18	10%
Project Management	14	7%
Clinical Coordination or Clinical Management	13	7%
Administrative	10	5%
Sales	10	5%
Management (For Profit/Not-for-Profit)	7	4%
Writing	7	4%
Other	7	4%
Marketing (Services, Products, etc.)	4	2%
Financial/Contract/Budget Development or Management	1	1%
Healthcare Administration	1	1%
Total	**187**	**100%**

Billing and Reimbursement

Billing and reimbursement for genetic counseling services continue to be significant priorities of the NSGC. While progress has been made since the 2006 PSS, data suggest that room for improvement remains. Nearly two-thirds (63%; N=401) of respondents who submit charges to third-party payors for genetic counseling services report that they bill using E&M codes in the name of their supervising physician, while only 6% bill in only their name using E&M codes. Following the 2006 PSS, the specific CPT code (96040) for genetic counseling services has been adopted; 24% of respondents (N=152) who submit charges to third-party payors for these services indicate that they bill in only their name using this code. The 2008 PSS did not assess the reimbursement rate when this code was used by genetic counselors.

Respondents were also queried as to whether they observed a change in reimbursement practices for genetic counseling services since 2006. Approximately 56% (N=591) were either unsure or reported this was not applicable to their practice. Ten percent reported an increase in reimbursement, while 31% observed no change.

Professional Status

Hours Worked
Approximately 71% of respondents reported being employed full-time in one position, with an additional 6% employed full-time through a combination of part-time positions. Nineteen percent of respondents reported that they held a part-time position, and 1% of respondents were unemployed. The latter three numbers are similar to the 2006 PSS, although the full-time, single position respondents made up a slightly lower percentage compared to the 2006 cohort.

Fifty-four percent of full-time respondents reported working overtime, with an average of 7.3 hours worked per week. Two-thirds of those genetic counselors reported receiving no compensation for the extra hours, although 19% reported receiving some degree of compensatory time off. Only 1% of those who reported working overtime hours (5 respondents) indicated that they were compensated financially through additional pay, bonuses or other incentives.

Data about respondents' current job and payment classifications are as follows:

Table 8c: Official Job Classification

Title	**%**
Genetic Counselor/Genetic Associate	66%
Senior Genetic Counselor/Supervisor/Coordinator	9%
Research/Study Coordinator	4%
Director/Clinical Director/Executive Director	3%
Genetic Counseling Program Director	3%
Manager	2%
Genetic Services Manager	2%
Genetic Specialist/Medical Specialist	2%
Project Coordinator/Project Director	2%
Cliniccal Coordinator	1%
Genetic Counseling Program Asst. Director/Coordinator	1%
Research Scientist/Assistant/Associate	1%
Public Health Worker (incl. State Genetic Coordinator)	1%
Genetic Counsultant	0.9%
Account Executive	0.9%
Patient Care Liaison	0.4%
Genetic Nurse Counselor/Nurse Geneticist	0.2%
Marketing Manager	0.2%
Product Manager/Product Specialist	0.2%
Total	**100%**

Faculty Appointments
Sixteen percent of respondents hold a faculty appointment, which is slightly lower than in 2006 (20%). Among those, 66% hold appointments at their institution of employment, with the remainder at another institution. Nearly two-thirds work at a School of Medicine, and an additional 21% work in a Genetics graduate program. Faculty appointment titles vary by institution (Table 9).

Table 9: Faculty Appointments

Faculty Appointment	**N**	**%**
Instructor/Lecturer	83	36%
Clinical Instructor/Lecturer	48	21%
Assistant Professor	36	16%
Clinical Assistant Professor	22	10%
Associate Professor	18	8%
Clinical Associate Professor	9	4%
Research Associate/Assistant/Professor	5	2%
Clinical Professor	4	2%
Professor	3	1%
Total	**228**	**100%**

Salary
To facilitate comparisons and benchmarking, all information regarding salary and benefits is based on residents of the United States and Canada who are working only one full-time position, and who have earned at least one graduate degree (N=1117). Of these, 977 respondents (87%) reported salary information. Statistical outliers (i.e. respondents who reported incomes greater than three standard deviations above or below the mean) have been omitted from the analysis. Canadian dollars were converted to U.S. currency at CAN 0.965 / USD 1. To protect confidentiality, data are not displayed for cells in which N<=5.

Table 10 shows the salary breakdown according to the NSGC region. Overall, the maximum yearly gross salary was $150,000. The average salary was $62,948, which represents an increase of 7% from 2006. Approximately 76% of respondents reported that their salaries were not dependent on grant funding, 13% were partially dependent, and 5% were completely dependent on grant funding.

Table 10: Salary by Region

Region	**N**	**Mean**	**25%**	**75%**
1	95	$61,986	$52,000	$68,000
2	271	$62,238	$50,505	$70,000
3	149	$57,147	$48,000	$62,067
4	266	$60,639	$50,000	$66,890
5	129	$63,581	$53,613	$71,394
6	198	$71,683	$62,000	$79,899

Regardless of region, 56% of respondents who have held their current position for more than 12 months and attempted to increase their salary since 2007 reported they were at least partially successful. Only 10% were unsuccessful in obtaining a salary increase. Thirty-four percent made no attempt to increase their salary.

Table 11 shows salary breakdown by years of experience. As expected, genetic counselors with the most experience reported the highest salaries.

Table 11: Salary by Years Experience

Years Experience	**N**	**Mean**	**25%**	**75%**
1-4	363	$53,666	$48,000	$57,900
5-9	247	$63,226	$55,000	$70,000

10-14	127	$72,320	$60,000	$80,000
15-19	75	$72,599	$62,232	$84,368
20-25	58	$78,136	$65,000	$85,500
25+	44	$85,563	$70,500	$96,723

Table 12 shows salary breakdown by primary work setting. Respondents with the highest average salary work in health maintenance organizations, while those in public hospitals/medical facilities and in federal/state/county offices report the lowest average salary.

Table 12: Salary by Primary Work Setting

Primary Work Setting	**N**	**Mean**	**25%**	**75%**
University Medical Center	367	$60,796	$50,000	$67,500
Private Hospital/Medical Facility	174	$60,680	$51,000	$66,900
Public Hospital/Medical Facility	114	$59,425	$51,000	$66,704
Diagnostic Laboratory	110	$71,191	$56,000	$83,500
Physician's Private Practice	58	$60,219	$52,175	$65,390
Health Maintenance Organization	30	$77,267	$66,000	$90,988
University/Non-Medical Center	25	$66,539	$58,000	$72,376
Not-for-Profit Organization	24	$60,057	$50,000	$69,500
Government Organization or Agency	18	$61,437	$50,372	$70,500
Federal/State/County Office	11	$59,935	$49,000	$79,500
Research Development/Biotech Company	9	$66,222	$56,000	$76,000
Other	15	n/a	n/a	n/a

Table 13 shows salary data by job classification. Directors/Clinical Directors/Executive Directors report the highest average salaries, followed by Managers.

Table 13: Salary by Job Classification

Job Classification	**N**	**Mean**	**25%**	**75%**
Genetic Counselor/Genetic Associate	589	$57,361	$50,000	$63,000
Senior Genetic Counselor/Supervisor/Coordinator	79	$70,057	$60,410	$77,500
Research/Study Coordinator	38	$61,306	$50,880	$70,000
Director/Clkinical Director/Executive Director	28	$88,361	$72,025	$102,738
Genetic Counseling Program Director	23	$81,673	$70,000	$91,000
Manager	21	$82,049	$72,500	$91,250
Genetic Services Manager	18	$74,557	$62,242	$94,000
Genetic Specialist/Medical Specialist	18	$71,695	$58,750	$77,821
Project Coordinator/Project Director	14	$75,760	$56,750	$88,000
Clinical Coordinator	12	$70,311	$59,258	$79,125
Genetic Counseling Program Asst. Director/Coordinator	10	$70,947	$56,000	$84,788
Research Scientist/Assistant/Associate	10	$55,671	$42,625	$64,861

Public Health Worker (incl. State Genetic Coordinator)	9	$57,701	$46,750	$69,000
Genetic Consultant	8	$61,892	$52,000	$69,329
Account Executive	6	$77,417	$67,125	$95,750
Other	10	n/a	n/a	n/a

Salary data are reported according to primary specialty area in Table 14. Genetic counselors working in Adult genetics clinics report the highest average salary, with those in the Pediatric genetics and Public Health specialties reporting the lowest average salary.

Table 14: Salary by Specialty Area (>50% time)

Specialty Area	**N**</td>	**Mean**	**25%**	**75%**
Prenatal	362	$60,787	$51,000	$66,000
Cancer Genetics	240	$62,887	$52,075	$70,000
Pediatric	155	$56,232	$48,464	$60,410
Specialty Disease	37	$64,190	$51,000	$76,984
Metabolic Disease	25	$59,874	$51,723	$67,500
Adult	17	$70,600	$54,000	$92,500
Cardiology	16	$61,591	$49,000	$71,000
Neurogenetics	16	$60,021	$47,150	$67,000
Multiple Market Screening	14	$62,827	$54,000	$72,000
Infertility/IVF	12	$69,054	$56,875	$81,500
Molecular/Cytogenetics/Biochemical	11	$59,711	$53,750	$67,625
Public Health/Newborn Screening	11	$56,341	$47,961	$65,250
Other (Teratogens, Psychiatric)	5	n/a	n/a	n/a

As in previous PSS studies, salaries were compared for both gender and race. Male genetic counselors earned a slightly higher salary than their female colleagues: $67,101 (N=62) compared to $62,688 (N=1054). These data continue to be consistent with previous surveys; however, the relative small number of male counselors prevents a conclusion that the difference is due to gender factors alone.

In the 2008 PSS, the salary gap between Caucasian and minority genetic counselors is slight, with minorities reporting an average salary of $59,590 (N=79), compared to the average Caucasian salary of $63,180 (N=1038). As with the gender salary data, due to the small number of minority respondents the salary differences between Caucasian and minority genetic counselors do not necessarily confirm that a racial gap exists.

In addition to their regular salaries, many genetic counselors report receiving additional income through other professional activities (Table 15). The most frequent supplemental income source is lecturing/honoraria, followed by teaching, consulting, and technical writing.

Table 15: Additional Income from 2007 Professional Activities

Income Source	**N**	**Mean**	**25%**	**75%**
Lecturing/Honoraria	149	$499	$200	$500
Teaching	59	$1,069	$200	$1,200
Consulting	43	$2,538	$500	$3,000
Writing	24	$1,099	$163	$1,000

Advisory Board	14	$693	$275	$1,000
Contract Work	11	$2,891	$200	$3,500
Royalties	7	$864	$200	$1,000
Private Practice	2	$3,250	$500	n/a

Benefits
As in previous PSS studies, respondents were asked about benefits packages. To facilitate comparisons, all information on benefits is based on residents of the U.S. and Canada who are working in a single full-time position, and who have at least one graduate degree (N=1117).

Table 16 shows various components included in benefits packages, and the percentage of respondents who report receiving those benefits.

Table 16: Benefits Packages

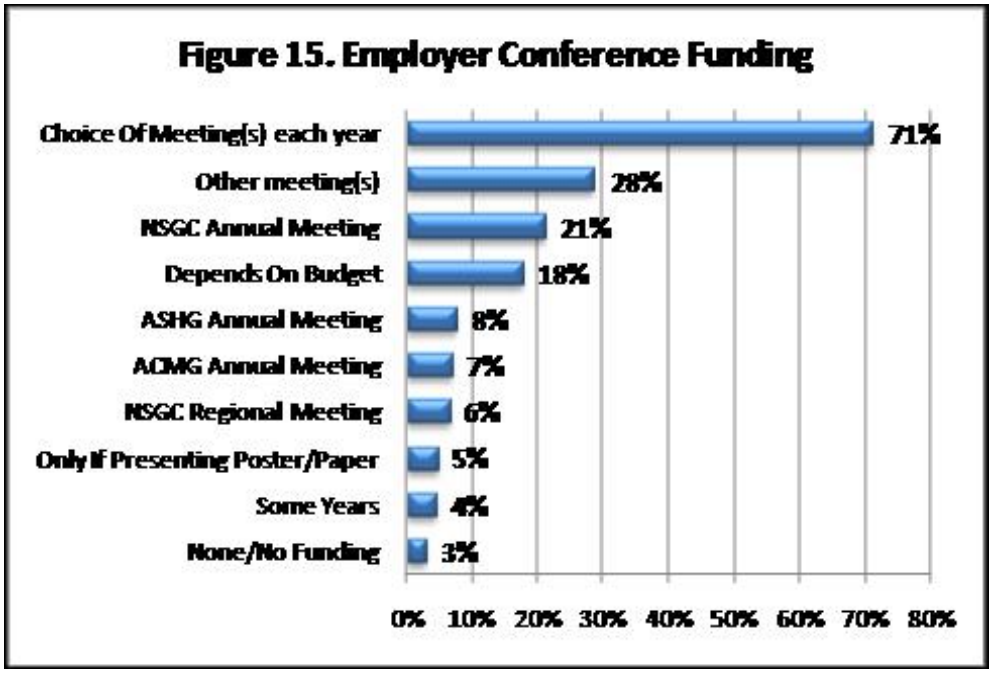
Benefit	**% Included in Package**
Health Insurance	99%
Retirement Savings	94%
Dental Insurance	94%
Disability (Short or Long term)	86%
Life Insurance	84%
Pre-tax Expense Accounts	78%
Vision Plan	73%
Stock options/purchase plan	16%
Profit sharing	7%

In addition to work-related benefits, other expenses that may be covered by employers were also assessed. Table 17 shows various expenses and the percentage reported by respondents as covered.

Table 17: Paid Expenses

Employer Compensation	**% Coverage**
Business-related phone/Internet access	70%
NSGC professional membership	69%
Continuing education credits	77%
Liability insurance	46%
Books/Journals	70%
Mileage/Transportation	62%
Other professional membership	45%
Home computer/laptop	26%
Interview expenses	27%
Moving expenses	30%
Foreign language classes	19%
Licensure	9%

Figure 15 shows the rates of reimbursement for professional meetings. Nearly three-fourths reported reimbursement for one meeting of their choice, while less than 10% reported either limited or no funding for conferences. Forty-one percent reported receiving a specific meeting budget annually, with an average budget of $1,512.



Professional Activities
As in the past, the majority of respondents are involved in professional activities outside of their work setting (Table 19). The most common outside activity reported was the creation of patient materials (N=851), followed by membership in an NSGC SIG (N=603).

Table 19: Professional Activities

Professional Activity	**% Involved**
Created patient education materials	62%
NSGC SIG member	32%
Advisory Board	32%
IRB research protocols	28%
Developed/organized a conference, etc. for health professionals	27%
Interviewed by media	26%
Developed genetics curriculum for students/teachers	25%
NSGC, ABGC or ASHG committee	22%
Wrote/contributed to funded grant proposals	20%
Developed/organized a conference, etc. for patients	16%
Worked to develop GC licensure in home state	15%
Local/state/national committee for GC delivery issues	15%
Wrote/contributed to nono-funded grant proposals	14%
Reviewer for journal submissions	12%
Resource for legislators on GC issues	11%
Committee to review grant proposals	6%
Worked to establish successful GC billing in home state	5%

Committee to review IRB research proposals	5%
Board of NSGC, ABGC, ASHG	4%
Editorial board for journal	3%
Site visitor for ABGC	2%

Job Satisfaction
Since 2000, the PSS has asked genetic counselors to rate their levels of satisfaction with both their current position and the genetic counseling profession. Responses were ranked on a four point Likert scale, and then combined into either "Satisfied" or "Dissatisfied" for purposes of data analysis. Table 20 shows the level of satisfaction with their current position reported by genetic counselors, compared to the 2004 and 2006 PSS results. While genetic counselors continue to report a high level of satisfaction with their autonomy, variety of patients and interactions with other staff clinicians, they generally continue to report the lowest satisfaction rates for salary, research and advancement opportunities.

Table 20: Satisfaction with current position, last three PSS cycles

Satisfaction with current position	**2008**	**2006**	**2004**
Autonomy	92%	90%	90%
Variety of patients/cases	91%	79%	80%
Interactions with other clinicians on staff	91%	84%	84%
Interactions with other GCs on staff	80%	77%	75%
Director's support	79%	79%	78%
Number of patients/cases	79%	66%	68%
Teaching opportunities	77%	76%	78%
Continuing education opportunities	76%	74%	74%
Administrative responsibilities	67%	65%	68%
Institutional support	66%	66%	64%
Secretarial/administrative support	64%	n/a	n/a
Research opportunities	59%	59%	62%
Salary	57%	60%	56%
Advancement opportuniities	41%	30%	39%

Genetic counselors continue to be satisfied with the learning opportunities, scientific content and personal growth they achieve, albeit at somewhat lower levels than in 2006 (Table 21). They remain less satisfied with advancement opportunities and earning potential of the profession.

Table 21: Satisfaction with the GC Profession, last two PSS cycles

Satisfaction with the GC Profession	**2008**	**2006**
Learning opportunities	93%	94%
Scientific content	92%	96%
Personal growth	81%	87%
Respect from medical community	65%	53%
Opportunity to develop/administer programs	65%	71%
Respect from business/other community	64%	n/a

Opportunity for advancement	45%	35%
Earning potential	40%	27%

Approximately 13% of respondents (N=183) indicated that they were considering leaving the genetic counseling profession, and an additional 10% (N=150) were undecided. Among the former respondents, the primary reasons cited included limited earning potential (68%), limited opportunities for advancement (56%), burnout (41%) and change in professional interests (37%).

Discussion

The NSGC's bi-annual Professional Status Survey remains a valuable tool for genetic counselors. The survey has remained generally consistent for over 20 years, although with each cycle the questions are examined anew and may be altered slightly to obtain additional data. In 2008, the ethnicity categories were further expanded to more closely match U.S. Census designations; other modifications included the addition of part-time salaries and a non-clinical track, expanded categories for primary work setting and specialty practices, and improved licensure and billing questions. The NSGC members continue to rate the PSS as a top member benefit. Each year, more genetic counselors report using the survey to negotiate starting salaries, merit increases and benefits. The published report is also reviewed by other allied health professionals, human resource specialists and individuals who may be considering a career in genetic counseling. The survey's consistency and final report establish a reliable benchmark for negotiation in many areas, including salary and benefits.

Survey Success

Improving upon its success in 2006, the 2008 PSS posted a response rate increase of more than 21% and included the highest number of surveys ever completed for a PSS since its inception in 1980. The 2008 survey, as in the previous three cycles, was completed online. Confidentiality was assured by members using their NSGC member ID to login and access the survey, but that ID number was not linked to the member's responses. Utilizing the NSGC member ID as the primary login requirement ensured that the survey was only completed by Full NSGC members.

Diversity

Consistent with previous surveys, the vast majority of genetic counselors are Caucasian females. As part of the NSGC's initiative to increase the diversity of the profession, additional categories within the ethnicity questions were added beginning in 2006, and were further expanded in 2008. Over the past 8 years, however, the distribution of ethnic groups in the NSGC (according to the PSS data) has changed little. Compared to 2006, the 2008 PSS showed little difference in the percentage of minority representation despite the increased overall survey response rate, although this does represent an increase in the actual number of minority NSGC members.

Expanding Roles and Specialization

The roles of trained genetic counselors continue to expand beyond the traditional specialty areas of prenatal, pediatric, cancer and adult genetics. In 2008, metabolic diseases and "none" were added to the list of specialty areas where genetic counselors work. Data from the 2008 PSS suggest that genetic counselors are working even more frequently in "non-traditional" areas of genetic counseling, with the four traditional areas all showing a decrease of up to 20 percentage points as compared to the 2006 PSS.

Billing and Reimbursement

Billing and reimbursement for genetic counseling services remain areas of significant focus for the NSGC. In 2006, a new CPT code (96040) for genetic counseling was approved, and the 2008 PSS is the first opportunity for the NSGC to systematically survey the rate of this code's adoption among its members. Data from the 2008 PSS show that, of genetic counselors who submit bills to third party payors for their services, 24% (N=152) submit the bill in only their name using the 96040 code, compared to 63% (N=401) who submit in the bill only in the physician's name using existing E&M codes. Reimbursement rates associated with use of the genetic counseling CPT code in clinical practice were not assessed.

Salary and Advancement

Consistent with previous surveys, genetic counselors continue to report high levels of satisfaction in their current position regarding areas of autonomy, variety of patients/cases and interaction with other clinicians on staff. Salary and opportunities for advancement continue to have the lowest satisfaction levels. Salary levels, however, continue to cover a very wide range, with the highest reported salaries in all Regions being well above $100,000. Many genetic counselors report success in negotiating an increase in salary or benefits by utilizing the PSS data. Respondents reported an average salary increase of 5.6% in 2007; this continues to be above national trends, as has been the case in previous PSS reports.

The ongoing advances in genomic medicine continue to demonstrate the need for individuals trained in genetics, and genetic counselors are uniquely qualified to meet those needs by virtue of their specialized training and expertise. As genetics and genetic counseling continue to become further integrated into the healthcare system, we would expect to see an increased demand for our services as well as a concurrent increase in overall salary levels.

In summary, the 2008 PSS was extremely successful and improved upon the excellent results obtained from the 2006 PSS. The 2008 PSS had the highest response rate ever recorded. Greater than 70% of respondents reported both their annual gross income and workplace ZIP code, which allowed for a more complete assessment of salaries stratified by region, experience, work environment and specialty. As this is one of the primary areas of interest among those who read the PSS, we are pleased to be able to offer this high quality assessment of salary data for our constituents. We are hopeful that the 2010 PSS will further build upon this foundation and offer improvements in the data collected.

References

National Society of Genetic Counselors, Inc. Professional Status Survey 2008, **www.nsgc.org**
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SIG Speak

Getting Started in Cardiovascular Genetics: A Follow-Up to the 2008 Short Course

By Colleen Brown, ScM and the Cardiovascular Genetics SIG

This article is intended as a follow-up to the 2008 NSGC Short Course: Taking Heredity to Heart: Cardiovascular Genetics, An Overview. We hope that the Short Course piqued your interest in cardiovascular genetics and that this article will provide the necessary conceptual and practical details to help you get the ball rolling.

Why get into cardiovascular genetics?

The need for genetic counselors specializing in cardiology is growing rapidly. Hereditary conditions that affect the heart are at least as prevalent as hereditary cancer syndromes. The number of genetic tests available has expanded such that a clinically useful test is available for the majority of single-gene hereditary heart conditions. Cardiologists are increasingly interested in incorporating genetics into their evaluations of patients with such conditions and are eager to work with genetic counselors to do so. While the number of genetic counselors specializing in cardiology is increasing, many more genetic counselors are needed to meet the needs of families and our cardiology colleagues.

In addition to clinical care of cardiovascular patients, genetic counselors are well positioned to make valuable contributions in the research arena. Cardiovascular genetics research is a rapidly expanding field of study at individual institutions, as well as part of NIH-funded multi-center studies. Genetic counselors, who have training and expertise in family risk assessment, soliciting informed consent, and interpreting and explaining genetic test results in a research and/or clinical setting, are well-suited to be clinical research associates or study coordinators. A study coordinator job may also lead to a clinical position, as more institutions are interested in developing cardiovascular genetics clinics as part of patient care.

What services will you provide?

Service models for cardiovascular genetics vary widely. A more traditional approach may involve a genetic counselor working in a genetics department, focusing on cardiology and taking referrals from cardiologists. An inter-disciplinary model may involve a genetic counselor who is employed by cardiology and integrated into the practice of one or more cardiologists. The type of service you develop will depend on the interest, resources, and needs of your institution.

Not all hospitals have a cardiologist who specializes in hereditary disease. However, all hospitals have patients with hereditary heart conditions who would benefit from genetic counseling. If the climate isn't right at your institution to develop a specialized multi-disciplinary clinic, you can still make a significant contribution by becoming the "go-to" genetic counselor for cardiology cases.

Who are your partners?

No matter what service model a cardiovascular genetic counselor practices in, it is common to have a majority of cases referred from just a handful of cardiologists. Often, these are electrophysiologists (cardiologists who specialize in arrhythmias), who see people with conditions like long QT syndrome, or heart failure specialists who care for patients with cardiomyopathies. Seek out these cardiologists and present yourself as a resource. They will be excited to work with you and eager to send you cases.

How do you market yourself to cardiologists?

Many cardiovascular genetic counselors have found that cardiologists respond best when the genetics piece is "brought to them" and they feel some sense of ownership over it or direct connection to the genetic counselor. Make it easy for them to contact you and to refer patients to you. Have a presence in the cardiology clinic, at Grand Rounds or other cardiology meetings.

Try to describe your role and your services from their point of view. What will you add to their practice? This may mean emphasizing certain aspects of a genetic counselor's role in which they are interested, such as coordinating send-out genetic testing or family outreach. Point out how ascertainment of at-risk family members through genetic counseling will increase referrals for family screening[1]. Share guidelines and literature that establish a genetics work-up as standard-of-care for many hereditary heart problems[2,3] and genetic counselors as an important part of a specialized service for hereditary heart conditions[4].

How to get started:

Get connected:

- Join the NSGC Cardiovascular Genetics SIG, sign up for the SIG listserv, and check out the various materials available on the SIG's website.
- Shadow a cardiologist who sees relevant cases to learn more about the evaluation and management of hereditary heart conditions.
- Check what type of research projects are going on at your institution, and which cardiologists do genetic research or might be interested in doing it. Many institutions have web pages listing research opportunities.
- Connect with a genetic counselor who is already practicing cardiovascular genetics. If possible, spend a day or two shadowing in a cardiovascular genetics clinic.
- Identify another genetic counselor at your institution who has set up a specialty clinic and can act as a mentor.
- Seek out other individuals that you will need to work closely with, such as: cardiac pathologists, cardiac nurses and nurse practitioners, psychologists or social workers who specialize in cardiology, local support groups, and local representatives of relevant genetic testing labs.
- Get to know the relevant advocacy and support groups, such as the Hypertrophic Cardiomypathy Association (**HCMA**) and the Sudden Arrhythmia Death Syndromes Foundation (**SADS**).

Learn:

- Invest in a few good books, such as Clinical Cardiology Made Ridiculously Simple[5] and Cardiovascular Genetics and Genomics for the Cardiologist6. See the SIG site for a more thorough list.
- Start your foray into the literature with a few good reviews[7-9].
- Find out which clinical testing laboratories offer testing for the disease(s) you see and connect with their genetic counselors or representatives.
- Browse the **AHA website** and read the Patient Pages in the journal Circulation.
- Attend a national cardiology conference. The **Heart Rhythm Society** annual meeting is one conference that includes many sessions on hereditary conditions.

Find cases:

- Identify key people who will be making referrals, such as nurse coordinators. Help them learn which cases are appropriate for referral.
- Spend some time in appropriate cardiology clinics (electrophysiology, congenital heart defects, heart failure) to help the cardiology team identify which patients should be referred to you.
- Start attending cardiology case conferences and grand rounds. This will help you learn cardiology, build relationships with cardiologists, and identify cases.
- Offer to teach residents or fellows by providing a lecture on cardiovascular genetics. Trainees are often the best referral sources.

Get the word out:

- Work with your marketing department to develop brochures and referral guides, and set up a website.
- Arrange for leaders in cardiovascular genetics to speak at cardiology or medical Grand Rounds.
- Give lectures to cardiologists at other institutions.
- Attend and present at cardiology conferences and advocacy and support group meetings.
- Volunteer to review a genetics topic at a cardiology journal club or equivalent venue.

Watch out for more learning opportunities put on by the cardiovascular genetics SIG.

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Thank You to Jessica Mandell

By Deepti Babu, MS, CGC

I first met Jessica Mandell during my genetic counseling training in New York, she being a recent graduate of the same program. She was a guest speaker, introducing a unique opportunity to us – student coordinator positions for Dr. Mary-Claire King's New York Breast Cancer Study. Even then, I could see Jess's infectious vibrancy and enthusiasm for genetic counseling. The fact that Jess still works closely with Dr. King today, over ten years later, speaks to her dedication and loyalty to hereditary cancer families and the profession as a whole.

It was five years ago that Jess was appointed as Editor of *Perspectives*, having previously chaired NSGC Committees. Through this time she took the publication on-line and transitioned it through numerous other changes, shaping it tremendously while maintaining its timeliness. Kirsty McWalter and I thank Jess for her enthusiasm, tireless work she has put into Perspectives and her availability to us as we begin our own transition. It really will take two people to fill her shoes!

NSGC News

2009 Audrey Heimler Special Projects Award (AHSPA) Submission Deadline

By NSGC Executive Office Staff

The deadline for the 2009 Audrey Heimler Special Projects Award (AHSPA) is May 15, 2009, so start thinking about your proposals today! Some types of projects that might be appropriate for the AHSPA include:

- a pilot study that can blossom into a bigger future project;
- developing patient education materials;
- creating tools for genetic counselors;
- developing ways to encourage leadership among newer genetic counselors.

Awards are available in amounts up to $5,000.00 for the purposes of supporting projects that focus on the future of genetic counseling or the provision of genetic counseling services. Additional details can be found in the Members Only area of the NSGC website. Select the "funding opportunities" link for details regarding the application process. All proposals must be submitted to the Executive Office by May 15, 2009 for consideration. If you have questions about a proposal, please contact the Chair of the Audrey Heimler Special Projects Award Committee for 2009, Leigha Senter, MS (**Leigha.senter@osumc.edu** or 614-293-7369).

2009 JEMF Information

• **Objective:**	To promote the professional development of individual genetic counselors and to improve the practice of genetic counseling, by providing support for scholarly investigation of any aspect of the profession. Recipients may wish to explore new interests, enhance present skills, answer a specific research question or develop expertise in areas related to genetic counseling. Results must be of sufficiently broad interest and high caliber to warrant professional publication or presentation.
Award:	One-year, $ 60,000 award to an individual genetic counselor (or more than one genetic counselor who will share the award).
Eligibility:	Board-certified (ABMG or ABGC) genetic counselor who is a Full member in good standing of the NSGC. Genetic counselors who have been granted Active Candidate Status by the American Board of Genetic Counseling are also eligible to apply.
Program Application & Guidelines:	Available at **www.nsgc.org**. Follow links to the Members Only area and "**Funding Opportunities**" dropdown box. Abstracts of previously funded projects are also available at this site.
Deadline for Receipt of Proposals:	May 4, 2009
Questions?	Contact Jill Stopfer, MS, CGC, Chair, JEMF Advisory Group, **stopfer@mail.med.upenn.edu**

ABGC Update

New Eligibility Requirements for the ABGC Certification Examination, Beginning with the 2010 Examination Cycle

By the ABGC Board of Directors

The American Board of Genetic Counseling (ABGC) recently approved several new changes to the Active Candidate Status (ACS) qualifications that will be implemented for examinations beginning in 2010. Some of the highlights of these changes are:

- New graduates can choose to apply for the examination in the year they graduate.
- The Logbook of Clinical Training will be eliminated.
- While training programs will still require students to complete a logbook of clinical cases, the ABGC will not review this logbook to determine eligibility for the certification examination. The ABGC will require documentation that the applicant has graduated from an ABGC-accredited genetic counseling training program.
- All new graduates will have 3 attempts at certification within five years after graduation.
- Individuals who did not become certified for any reason by 2007 and are not taking the 2009 certification examination will have a new, time-limited opportunity to become ABGC certified by taking the certification examination by 2014.
- New eligibility changes have been developed for individuals re-attempting the certification examination in 2010 and for individuals formerly certified by the ABGC whose certification has lapsed.

Check out the ABGC website for more detailed information at: **www.abgc.net**. The full policy document on the website includes detailed information and timelines for every category of exam candidate who may take the ABGC certification examination beginning in 2010. We will review the new criteria for two of the exam candidate categories, below.

New graduates of an ABGC-accredited training program

Graduates of an ABGC-accredited training program after October 1, 2008 are eligible to apply for ACS for up to three examination cycles within five years of graduation. Eligibility for ACS expires following the first five examination cycles with application deadlines occurring after the graduation date or the third examination failure (examination failure includes failure to sit during a cycle for which ACS was granted), whichever comes first.

For those who lose ACS eligibility by failing (or not sitting for) three examinations within the five year timeframe, eligibility will be granted for one more examination attempt if an individual demonstrates an active commitment to continuing education by obtaining five category 1 CEUs as defined by ABGC (no Professional Activity Credits, or "PACs", may be substituted) within the one year period following expiration of the third period of ACS or following the fifth examination cycle with application deadlines occurring after the graduation date. If approved, the individual may sit for the examination but will not have the ACS designation during the interim period up until administration of the examination. If certification is not achieved for any reason during this final examination cycle (including withdrawal prior to the examination), no future attempts at the ABGC certification examination will be allowed unless the individual newly enters and completes all requirements for graduation from an ABGC-accredited training program.

Individuals who have never become ABGC-certified genetic counselors

The Board of Directors is aware of the increased recognition of ABGC certification by state licensure boards. In order to support genetic counselors who may have previously decided not to become certified and who work in states that currently or soon will require a license to practice, the Board unanimously approved one final opportunity to take the ABGC certification examination. These individuals will have up to three total attempts to take and pass the certification examination between 2010 and 2014. Please note: this opportunity is only available through the 2014 examination administration and will not be re-opened. The ABGC certification examination will be offered annually during this five year period.

To apply and sit for the ABGC certification examination, these individuals must submit:

- five Category 1 CEUs as defined by ABGC (no PACs accepted) collected during the year immediately prior to applying for the next available examination cycle

- three recommendation letters from ABGC- or American Board of Medical Genetics (ABMG)- certified genetics professionals (at least two of these must be from ABGC or ABMG certified genetic counselors)
- a transcript documenting coursework and a graduate degree awarded by an ABGC-accredited or historical genetic counseling training program recognized by the ABGC
- a signed "verification of training" form completed by the program director (please contact ABGC for special instructions if the graduate program is no longer in operation).

If approved, the individual may sit for the examination but will not have the ACS designation during the interim period up until administration of the examination.

Accrual of Category 1 CEUs, as defined by ABGC, may begin on January 1 of the year before the examination cycle to be attempted and must be completed before the deadline for application for that examination cycle. For instance, if the deadline to apply for the 2010 exam were July 1, 2010, the five CEUs must be obtained between January 1, 2009 and June 30, 2010. Note: the five Category 1 CEUs obtained within a one-year window only need to be collected once to allow for the three exam attempts between 2010 and 2014.

Please let your colleagues and friends who are not currently certified know about these exciting new opportunities. The ABGC website (**www.abgc.net**) has more detailed information.

Student Forum

Perspectives from Male Genetic Counseling Trainees, 'Y' Not?

By Barry Tong, BA, University of Michigan

With contributions from Beau Amadeus Crabb, BA (University of Colorado, Denver), Jeff Kopesky, BS (University of Minnesota), Christopher Lauricella, BS (University of Pittsburgh), Justin Leighton, BS (Arcadia University), Dr. Kunal Mahesh Sanghavi, (Boston University), Ian A.A.D. Wallace, BS (Boston University), Spencer Michael Wood, BS (University of South Carolina), and Jamie Zdrodowski, BS (Northwestern University)

Imagine being a male researching genetic counseling as a potential career, and realizing from Professional Status Surveys that only 4% of respondents share your gender. A mere 50 males exist in the field to serve as gender-concordant role models[1]. Furthermore, a 2005 published survey of all enrolled students in training programs revealed only six male respondents, 2.6% of the sample, in a research article no less aptly named, "Who are the Next Generation of Genetic Counselors."[2]

Sure, these statistics might seem striking to individuals who believe there is an inherent difference between the way males and females practice genetic counseling, though in reality, this may not be the case. However, my interviews for genetic counseling programs seemed to suggest otherwise. Much to my frustration, I remember the need to justify, at each interview, every permutation of the same question regarding my gender relative to the predominantly female field of genetic counseling. From that point on, I vowed to explore the issue of gender and to what extent it was truly a concern over the course of my training at the University of Michigan.

I now believe that the perception of an underlying difference between genders and gender disproportions are issues that only trainees and professionals in genetic counseling observe. Our clients, who are the primary purpose of our discourse, may fail to notice the imbalance. As any other good student in science, however, I needed more data.

To explore this, I questioned a few of my fellow male trainees in various programs. Did they have experiences where gender compromised their ability as genetic counseling interns to appropriately counsel their clients? Has gender even been an issue? What do other male genetic counseling students have to say?

Why do I want to work with all females?

A theme that immediately surfaced in my colleagues' responses involved questions posed to us even before we matriculated – either during the interview process or while inquiring about programs in genetic counseling. "During each of [my interviews], without variation, I was asked to discuss how I felt going into a predominately female field. I was asked how I felt my gender could affect schooling and further down the road, my career," says Spencer Wood of the University of South Carolina, Greensboro.

He continues, "To be honest, I really had only given it much thought probably a month earlier, and almost solely due to the fact that I saw this question coming."

Jamie Zdrodowski of Northwestern University remembers, "Just about every person I interviewed with asked at least one question about being a guy going into this field." Upon reflecting the question back to his interviewers, "No one had an answer other than to say that it doesn't really matter, just something different."

If no difference exists, why was this emphasized for these students when it should really be a null point? Was there, in fact, a clinical impact when a genetic counselor happened to be male rather than female that I failed to notice?

To patients, why does a genetic counselor's gender matter?

To our benefit or not, it seems that other factors often preclude a client's comfort with the gender of their genetic counselor. Opinions that surfaced from this exploration were that our clients' general lack of knowledge of genetic counseling often meant they were unaware that the field was predominantly female. Beau Amadeus Crabb of the University of Colorado, Denver states, "I don't think many people outside of the profession know about the disproportionate gender distribution. Clients that I work with have little understanding of genetic counseling, so they tend not to have any preconceived notions about a genetic counselor."

In the prenatal setting, patients often recognize that "many doctors are male… so [clients] don't see it as strange at all that we [genetic counselors] are guys," says Zdrodowski.

However, not all clinical situations are completely gender-neutral. Ian Wallace from Boston University has experienced "patients from certain cultures [who] prefer to talk to another woman about pregnancy or female-related issues." Commenting on an experience he had with a female client of Lebanese descent, Wallace continues, "Interestingly, while [she] would not converse with me regarding her pregnancy or medical history, her accompanying husband would only talk to me and would not speak to the female [genetic counselor] in the room."

It is unclear whether such an example is solely the result of the provider's gender, but it is apparent that many cultural factors also play into how our clients respond to gender.

And of our male genetic counseling supervisors?

Justin Leighton at Arcadia University had the opportunity to have both male and female supervisors in a clinical rotation. He comments, "From my experiences with them and with patients, I can honestly say that I did not notice any difference in their interactions with patients."

My rotation with both male and female supervisors mirrors those of Justin's opinions. The University of Michigan allowed me to travel to a summer rotation site of my choosing, and with that ability, my main concern was to explore this potential, underlying difference between male and female genetic counselors. I decided to choose my rotation solely based on the availability of a male genetic counselor to be one of my supervisors. I soon realized this was not necessary.

Although I observed scant differences in mannerisms, accountable by individual counseling styles, I gained an incomparable and valuable rotation experience from both my male and female supervisors alike during this rotation. Indeed, I couldn't find a difference and, fortunately, learned a lot more about genetic counseling in general.

"It also makes it near impossible to go absent unnoticed."

If there is little gender significance in the clinical setting, do our roles as males in genetic counseling training programs warrant the degree of questioning we receive during interviews?

"Usually it is in the context of a discussion about gender differences, and I am expected to speak for the entire male gender," says Crabb. He continues, "There were multiple times when our teacher was discussing gender differences and had to preface her statement with, 'Now we all know Beau wouldn't do this or say this' then proceed to discuss the failings of the male gender."

Christopher Lauricella of the University of Pittsburgh recalls, "The only times where I feel singled out is during classes, because I am the only guy in many of them. Not that it's a negative thing. It also makes it near impossible to go absent unnoticed."

"Men in genetic counseling will bring to the table perspectives and first-hand expertise on what makes men tick," says Wood. "Male patients often require different strategies, have different issues, make decisions differently, and perceive risk … differently."

"If anything, being a male allows you to bring different aspects to the field," says Jeff Kopesky of the University of Minnesota.

"No one has really commented on my gender," says Zdrodowski, "aside from jokingly pointing out that I have never had an amnio, and I don't really know what it's like to have breasts."

His clients are correct: we will never understand what it is like to experience the sensation of an amniocentesis or the connection a woman's breasts may have with her identity, but the tenets of our genetic counseling training do not require personal experience for us to do our job effectively and empathetically. Let's remember that many of our female counterparts have never had an amniocentesis, been faced with the decision to pursue prophylactic surgery, had the experience of being pregnant, becoming a parent, or losing a child. Male and female genetic counselors alike must use empathy to connect with their clients.

Therefore, what we truly bring to the table as males is an understanding of ourselves within our social and physical environments, which is equally significant to the experiences of any other individual in our training programs.

Cease and Desist

These results may not be surprising, but from what I can tell, the concern of a gender bias is purely an artifact of demographics, regardless of which specialties we, as male genetic counseling trainees, choose to pursue.

As future genetic counselors, we perceive our contributions as males to clinical practice as no less than, nor significantly different from, those of our female role models and colleagues. As such, let us encourage other men to pursue their interests in genetic counseling and cease creating barriers to interviewing males regarding their intention to enter this field.

Kopesky concludes, "My training focused on preparing me to be the best genetic counselor, not the best male or female genetic counselor." If our training programs are already taking this position, why suggest to interested male applicants that there may be differences between male and female genetic counselors?

My advice to other males wishing to pursue genetic counseling: don't let a profession pursued predominantly by women deter you. They may ask you questions to justify your intentions beyond the average applicant, and there may be comments regarding your gender, as well as being singled out in casual conversation throughout training, but the end result is no different. The skills we gain as males are just as valuable, and we will become great genetic counselors, whether we have Y chromosomes or not.

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Genetic Counselor Publications

By Deborah McDermott, MS, CGC

Featured Article

Pollin TI, Damcott CM, Shen H, Ott SH, Shelton J, Horenstein RB, Post W, McLenithan JC, Bielak LF, Peyser PA, Mitchell BD, Miller M, O'Connell JR, Shuldiner AR. A null mutation in human APOC3 confers a favorable plasma lipid profile and apparent cardioprotection. *Science*. 322:1702-5. 2008.

It's fair to say that when you have a paper published in the journal Science, you are likely to get a lot of attention. That has certainly been the case for Toni Pollin, M.S., Ph.D. over the last few months. Her work, which highlights a specific mutation in the *APOC3* gene among a subset of Old Order Amish, has been profiled in a variety of venues including the *New York Times*, as well as in the online newsletter *Today's Science*, which is geared to introducing real scientists to high school students. This does not begin to touch on all of the speaking engagements and conferences that have also kept her busy. When speaking of her groundbreaking paper, Pollin states, "This is why I went into genetics."

Pollin is an Assistant Professor of Medicine in the Department of Medicine, Division of Endocrinology, Diabetes and Nutrition and the Program in Genetics and Genomic Medicine at the University of Maryland School of Medicine. She received her M.S. in Genetics and Genetic Counseling from the University of Minnesota in 1997. Her passion for statistics and genetics started with her Master's degree project, an investigation of recurrence risks and pregnancy outcomes in families with Miller-Dieker syndrome due to chromosomal translocations. While working at the Alliance for Genetic Support Groups (now the Genetic Alliance), her desire to work in statistical genetics remained. She investigated a job posting in the *Washington Post* classifieds, a position looking for someone to manage databases and perform some basic statistical genetics. Not only was Pollin hired, but she put her skills as a genetic counselor to work, securing a reclassification of the job and a raise in compensation. Her boss, Dr. Alan R. Shuldiner, had a longstanding interest in working with the Old Order Amish in order to gain a better understanding of complex diseases like diabetes and cardiovascular disease.

Pollin ultimately earned her Ph.D. in Human Genetics from the University of Maryland in 2004 and continues to collaborate with Dr. Shuldiner and others there on many projects. Despite the fact that most of her work focuses on statistical genetics, Pollin is not averse to rolling up her sleeves and performing some of the molecular biology that needs to be accomplished as part of her work. Additionally, she and her colleagues often meet with Amish liaisons when they are planning new studies. Since part of their current published work involved brachial artery ultrasound, it was important that sonographers have easy access to the arms of subjects. In order to respect the modesty important to Amish women, the liaisons were critical in designing and making dresses that could be kept in the Lancaster clinic so that women could wear them during the ultrasounds. These dresses were crafted in the Amish tradition of not using buttons, which are considered worldly.

In addition to her research, Pollin can often be found writing grants or teaching in a number of settings at the University of Maryland, including the genetic counseling training program. She is the course master for an innovative seminar series for graduate students in the Human Genetics program, as well as the genetic counseling program, where discussions may follow the themes of "Name that disorder" or "Genetics in Hollywood." Pollin also currently serves on the NSGC-affiliated Jane Engelberg Memorial Fellowship Advisory Group.

Pollin's current work could have major implications in understanding how to better develop pharmaceuticals to address the major public health problems impacting so many in the US. There is little doubt that we will continue to hear more about her and her important work in the years to come.

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(names of genetic counselors appear in bold)

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Please send references of published articles by genetic counselors to Deb McDermott at **dam2001@med.cornell.edu**.

AEC Updates

28th NSGC Annual Education Conference: Overview

By Sarah Noblin, MS, CGC, 2009 AEC Chair and Shannan DeLany Dixon, MS, CGC, 2009 AEC Vice-Chair

Whether or not you are a fan of the Pittsburgh Steelers, Super Bowl XLIII Champions, the 2009 Annual Education Conference (AEC) Subcommittee is looking forward to welcoming all of you to the 28th NSGC AEC in Pittsburgh, Pennsylvania. Soon you will receive your program brochure with the dates and deadlines for the AEC, which will be held **November 12-15, 2009**.

A new look to the AEC

The AEC has a new look, which will debut in 2009. In response to the membership's desire to shorten the overall length of the AEC without cutting the number of CEU opportunities, the overall conference format has been modified. First, the conference has been shortened to a total of three days. There will be six hours of plenary sessions, including the Janus series, Beverly Rollnick lecture, and other sessions appropriate for a wide audience. There will be three Educational Breakout Sessions (EBS), with four offerings at each session. In the future, we hope to clearly identify an EBS as beginner, intermediate or advanced so there is something that appeals to everyone. As in 2008, we plan to have two concurrent paper sessions, for a total of three contact hours. This will allow you to attend more platform presentations by your colleagues. We are planning to close the conference with a late-breaking session.

Pre-conference symposia

Another exciting change for 2009 is the introduction of pre-conference symposia on the day before the main conference. You may be familiar with this format, as many other organizations do this as well. These will be high level or in-depth sessions for specific specialty practice areas, new issues in genetics and genomics or professional development topics. Each session will last approximately 4 hours, allowing for a deeper dive into a particular topic for

genetic counselors with specific interests. We anticipate the attendance at each symposium will be smaller than at an EBS, which will allow for a more interactive experience. Each symposium will require registration separate from the AEC and will have limited space available. Sign up early!

CEU changes

The NSGC became an approved provider for CEUs last year through the International Association for Continuing Education and Training (IACET), which is different from the previous organization. As a result, some of the requirements of the NSGC and its members have changed. One new requirement is that we must document that people actually attended the sessions for which they request CEUs. If you take a remote learning course, like an online course or the JGC CEU program, participation is documented by the administration of a quiz, which you must pass in order to earn CEUs. For the 2008 AEC, the Scantron forms that you filled out for each session served as documentation of your attendance. Based on feedback from the conference, we may look into other ways to document attendance for future meetings.

Program book

In an effort to reduce costs and "go green," another change that began in 2008 involved speaker handouts; instead of being printed in the program book, handouts were available online prior to the conference for self printing. We recommend that you review the conference handouts prior to arriving in Pittsburgh and print ones you want to have on paper during the conference. If you have a laptop, another option is to download them for direct viewing on your laptop during the presentations.

Accommodations

The AEC will be held at the Hilton Pittsburgh, which is about 25 minutes from the Pittsburgh International Airport. Attendees staying at the hotel will receive complimentary hotel Fitness Center access, as well as complimentary internet access in the sleeping rooms. The Hilton Pittsburgh is adjacent to Point State Park, which features a fountain, riverfront promenade and bike trail. The hotel is also within walking distance to PNC Park (home of the Pittsburgh Pirates), Heinz Field (home of the Pittsburgh Steelers), Majestic Star Casino, theatres, museums and shopping.

Dates to remember

The Early Registration deadline for the 28th NSGC AEC is **September 18, 2009**. Be sure to sign up on time to avoid late fees. Abstracts for platform or poster presentations will be accepted from **March 20, 2009 to May 15, 2009**. See the NSGC website for more information.

The 28th NSGC AEC promises something for everyone. Mark your calendars to join us in Pittsburgh!

*Please contact Sarah Jane Noblin (**Sarah.J.Noblin@uth.tmc.edu**) or Shannan DeLany Dixon (**SMDixon@som.umaryland.edu**) with any questions or comments.*

28th NSGC Annual Education Conference: Call for Abstracts

Abstracts that are of interest to the genetic counseling profession and related fields are being accepted for consideration as platform or poster presentations from **March 20, 2009 to May 15, 2009**. Students, Full members and non-members are encouraged to submit abstracts. Monetary awards will be presented for best Full member and best Student member abstracts. Beginning March 20, 2009, guidelines and instructions for submission of abstracts can be found on the NSGC website (**www.nsgc.org**).

*Please address questions to the Executive Office at nsgc@nsgc.org or the Abstract Committee Chair, Courtney Sebold (**seboldc@uthscsa.edu**) and Vice-Chair, Kirsty McWalter (**kirsty@hawaiigenetics.org**).*

How the Abstract Workgroup Reviews Abstracts: An Update

By Jehannine Austin, PhD, CGC and Courtney Sebold, MS, CGC

Several years ago, an article detailing the NSGC Abstract Workgroup's review process appeared in *Perspectives in Genetic Counseling* (Dickerson, 2001). This article describes recent revisions to this original framework.

The goal of the NSGC Abstract Workgroup is still to select high quality abstracts for oral and poster presentations at the Annual Education Conference (AEC). We strive to select abstracts that will enhance patient care, justify the time and expense that genetic counselors put into attending the conference, and enhance the professional reputation of genetic counselors.

As a profession, genetic counselors are engaged in a wide range of activities. To better reflect the diversity of these activities, the NSGC Abstract Workgroup has broadened its scope and now welcomes the submission of abstracts in a wide range of areas. In addition to encouraging abstracts documenting original research, we also encourage case reports and abstracts describing novel perspectives or experiences that, by being shared with colleagues, may contribute to the continuing development of the profession. We define the acceptable categories of abstract below, and describe the evaluation criteria used by the NSGC Abstract Workgroup.

Definitions of abstract categories

Three categories of abstracts will be considered for presentation at the AEC:

1. Original research - Original research may be quantitative or qualitative in nature. In general, quantitative research tests hypotheses whereas qualitative research generates hypotheses. While case reports can be considered original research, the abstract workgroup has chosen to define them in a separate category, as the manner in which they are evaluated may be significantly different.
2. Case reports - Case reports should address observations of patients or families that add to the knowledge of the etiology, pathogenesis and/or delineation of the natural history or management of the condition described.
3. Professional issues - These abstracts are brief vignettes of experiences or tools that might be useful for genetic counselors to learn about for the purpose of continuing the development of our profession. Examples of acceptable abstracts might include a description of the development of a relationship between a genetics clinic and another organization, a summary of a state's experiences in obtaining licensure, or a report on the experience of providing genetic counseling services in unusual circumstances.

Basic evaluation criteria

All submitted abstracts will be evaluated according to the following basic criteria:

1. The abstract should have a clear message of original work and include only one or two major points. If there are more, an additional abstract should be written.
2. The work should not have been previously published as a manuscript.
3. The abstract should not be based on anticipated data. Abstracts stating that "results will be presented" or some variation thereof will be rejected.

In addition to these basic criteria, the following evaluation criteria are applied in a category-specific manner.

Evaluation criteria for original research abstracts

Original research abstracts should be structured using the following headings: Introduction, Hypothesis (for quantitative research) or Purpose (for qualitative research), Methods, Results and Conclusions.

Authors should consider the following questions when writing their original research abstract, as they reflect the evaluation criteria used by the Abstract Workgroup:

1. Does the title summarize the abstract and grab the reader's interest?
2. Does the introduction clearly state what is currently known based on previous research, as well as what is currently unknown? Does the introduction clearly state the importance of the research?
3. Are the objectives of the study clear? In general, only one sentence should be dedicated to describing the study's objectives. A quantitative abstract should describe the hypothesis being tested. A qualitative abstract should describe the data that was generated by the study.
4. Are the methods used in the research clearly defined? This section should usually comprise one-third to one-half of

the abstract. Not every research study has a theoretical framework. However, if one was used either to frame the research or to interpret results, this should be stated.

5. Is the study population (and control group) defined, along with how it was identified and selected? Authors should also consider the following questions regarding methodology:
   a. Is the study population (and control group) defined along with how it was identified and selected?
   b. Does the abstract define what was measured?
   c. Does the abstract describe the tools used to measure the variable(s)
   d. Do the authors use tools that measure the variables appropriately?
   e. If it is a new tool, does the abstract briefly describe its development?
   f. If it is a new tool, does the abstract assess the validity/reliability of the tool?
   g. Do the authors use an appropriate method of data analysis, considering the intent of the study?
6. Do the results or findings reflect the hypothesis or purpose of the study?
7. Are the data presented in a clear, concise and consistent manner?
8. Is the order in which items are described retained throughout the document?
9. Are the statistics presented appropriately? The University of Washington has created a document discussing the presentation of statistical results (see the Resources section below). This article can also be found on the NSGC Abstracts page of the website.
10. Lastly, does the conclusion directly relate to the stated hypothesis? Is the conclusion well-supported by the data?

Evaluation criteria for case report abstracts

Case report abstracts should be concise, focused, and structured using the following headings: Introduction, Case Report(s), and Discussion. Reports that involve cytogenetic observations should include the molecular cytogenetic definition of the aberration.

Authors should consider the following questions when writing their case report abstracts as they reflect the evaluation criteria used by the Abstract Workgroup:

1. Is the nature and significance of the case adequately described?
2. Is the confidentiality of the patient/family maintained? Abstracts from which an individual's identity may be deduced will be rejected.
3. Does the discussion of the case provide a systematic and thoughtful interpretation of the case, as well as an informative and useful discussion of its implications for genetic counseling?

Evaluation criteria for professional issues abstracts

Professional issues abstracts should be concise and focused, but need not be structured using subheadings.

Authors should consider the following questions when writing professional issues abstracts as they reflect the evaluation criteria used by the Abstract Workgroup:

1. Is the material relevant to the genetic counseling profession? Submissions that are not relevant will be rejected. Submissions that are of relevance to a large proportion of genetic counselors may be rated more highly than those which are relevant only to a small minority.
2. Does the abstract provoke thought in a new direction, inspire new avenues for research, or have implications for new clinical approaches?

Conclusion

In this article, we have provided an overview of the abstract review process. We hope to encourage the submission of high-quality abstracts that will contribute to the ever-growing professionalism of our organization and the AEC.

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Resources

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Resources/Book Review

Reviewed by Shelly Cummings, MS

Breast Cancer: The Complete Guide (Fifth Edition) by Yashar Hirshaut, MD, FACP and Peter I. Pressman, MD, FACS. A Bantam Trade Paperback, New York, New York, 2008.

432 pages/ $17.00

Breast Cancer: The Complete Guide has been a valuable resource for women diagnosed with and fighting breast cancer since its first edition in 1992. The authors, a medical oncologist and a surgical oncologist, have made several revisions to the current version in order to incorporate the advances and updates that have taken place since their last version, four years ago. This resource is deficient in a few areas but, overall, I found it to be extremely informative.

The Guide opens with a foreword by Jane Brody, the "Personal Health" columnist for *The New York Times*, who shares her personal experience with breast cancer and the care she received from one of the book's authors. Her enthusiasm and excitement about the advances that have been made in breast cancer diagnosis and treatment are contagious and immediately set the tone for the book. The step-by-step guide provides a clear and thorough explanation of the diagnosis and management of breast cancer, with scattered anecdotes explaining various situations. Anonymous stories from women help readers know and feel that they are not alone and that others have walked this path before them.

The book is divided into four sections. Book I describes the time from initial suspicion to diagnosis. It explains the medical personnel that need to be assembled during this time period and outlines how cancer occurs and its pathology. Book II discusses what happens after the diagnosis and the probable course of treatment, including surgical procedures, radiation, chemotherapy, hormone treatment and breast reconstruction. Book III covers what happens after initial treatment and medical follow-up and management, as well as recurrence. This section also discusses areas of new research and prevention. Book IV focuses on the emotional impact of the disease and draws heavily from the experiences from women whom the authors have treated.

Chapter 7, a new addition to the book, is on genetics and is, disappointingly, only five pages long. This section mentions that a "genetics counselor" is uniquely qualified to help women through the testing process and that "she" (my apologies to our male genetic counselor colleagues) can explain all aspects of testing and the implications of testing. In reality, genetic counselors inform women of their screening/management options, but ultimately patients consult with their physicians, when a more detailed discussion of the various options may occur based on one's diagnosis and future risk(s). This section states that genetic test results take "several weeks" when, in reality, they may be available sooner, thus making it much easier for women to make surgical decisions in a timely manner. The authors caution that "it is not wise to have testing done by someone who uses a prepared sheet to outline risks and benefits of testing". However, many genetic counselors use these exact resources, in the form of a flip book or other visual aid, to show and explain complicated concepts because some people are visual learners. It would have been nice to have included a comment that genetic testing and the decisions following it are extremely individualized, and may be different even for those within the same family.

The expansive section discussing treatment nicely overviews the range of options and a chart helps explain what treatments the oncologist might recommend based on nodal status, tumor grade, size, menopause status and receptor status. This section nicely delineates why an approach might be suggested, as well as any drug-related side effects that could occur when "he" (the physician) proposes one over another.

Chapter 15, on prevention, does a nice job of outlining the various cancer risks associated with BRCA1 or BRCA2 mutation in males and females. The portion that discusses tamoxifen for the reduction of breast cancer risk only states that it can be used prophylactically for unaffected mutation carriers, but fails to mention that studies have proven tamoxifen to be beneficial for BRCA mutation carriers in reducing the risk for second primary breast cancer. Several pages discuss and graphically demonstrate the various options for prophylactic surgeries. This section also emphasizes the importance for women to not feel hurried when making decisions about treatment but, rather, stresses the importance of working with their health care providers and "genetics counselor."

"New Directions" in chapter 16 provides a nice summary of current treatment options. The section begins with a primer in molecular biology and the biology of breast cancer, and segues nicely into the significance of participation in clinical trials and how breakthroughs in clinical trials have lead to drug development.

One of the strengths of this book is the wealth of resources for patients and their families. The "Resource" section at the end of the book provides a comprehensive state-by-state listing of the NCI-designated cancer centers with contact

information. This section also includes a description of some of the major breast cancer organizations and a means for contacting them. This additional list of resources and websites is the most impressive and comprehensive of any patient-focused book I have read, and demonstrates the authors' level of compassion and understanding for women fighting breast cancer.

Several components could be improved. The "Insurance and Financial Issues" does not address health insurance coverage for genetic testing or protection from genetic discrimination but, rather, focuses on monetary assistance for a broad range of needs, including housing, transportation, utilities, medical payments and insurance deductibles. The "Family Support" section briefly mentions the impact that a mother's diagnosis can have on children and the authors emphasize the importance of speaking openly and in appropriate language about the disease and "without being overwhelming, being evasive or making them think there is a terrible secret." However, they do not provide resources for guidance on how to talk to children about cancer. Since such tools exist and the authors admittedly discuss the importance of communication with children, this seems to be an obvious resource to include.

Breast Cancer: The Complete Guide, 5th Edition covers a wide range of topics associated with breast cancer and is a comprehensive compendium. Overall, this is an excellent resource for women going through their journey of breast cancer diagnosis, treatment and recovery. One major deficiency I found was the lack of references at the end of each chapter. There are many statistics and "studies" mentioned to support them, but no references noted. This fact will make this book's usefulness for genetic counselors limited, as we tend to like to see the source documents supporting claims. However, the easy-to-read and descriptive narration may help many who are not familiar with preventing, diagnosing, and treating breast cancer in women to walk away with a clearer and more compassionate understanding of this disease.

Media Watch

By Claire Noll, MS, CGC and Roxanne Maas, MS, CGC
(names of genetic counselors appear in bold)

September/October 2008 issue – American Health Insurance Plans on-line magazine, *Genetically Speaking*

This article cited the growing complexity of genetic testing as a reason to expect an increasing demand for genetic counselors. **Angela Trepanier**, **Heather Pierce**, and **Heather Shappell** described the changes they have seen in their practices and how this has affected the services they offer. Alternate methods of providing genetic counseling, such as the telephone genetic counseling that Heather Shappell's company provides to Aetna members, were highlighted. A sidebar described **Janet Talbert's** experience with a new telephone genetic counseling program for familial pulmonary fibrosis that was launched in February 2008.

October 7, 2008 – *Woman's Day* magazine, "The experts weigh in"

Shivani Nazareth was interviewed as part of a round table discussion about how to reduce the risks of breast cancer. She advocated for genetic counseling: "There are some rare genetic mutations that predispose you to several types of cancer; in counseling, you'll get more information that will help you decide if you should get tested for any of them." She added, "Ideally, it's best to test the people in your family who have had cancer before testing anyone else... If that's not possible, I recommend sitting down with a genetic counselor to review your family history in more detail."

November 8, 2008 – *Los Angeles Times*, "Genetic testing under the microscope"

In an interview during the recent NSGC AEC, **Angela Trepanier** provided information about the risks and benefits of genetic testing, as well as concerns about equal access to genetic testing.

November 2008 – **www.parents.com**, "Health 101: Genetic testing before & during pregnancy"

This article provided basic aspects of prenatal genetic testing, including who should consider it, what information the tests can provide, and how to obtain testing. **Angela Trepanie**r was interviewed about the risks and benefits of testing, the optimal timing for testing, and the importance of genetic counseling.

December 2008 – Discovery Channel, "Mystery Diagnosis"

In this episode, LuAnn Weik presented a mystery diagnosis case resulting in a diagnosis of Ehlers-Danlos syndrome.

December 11, 2008 – *US News and World Report*, "Best Careers 2009: Genetic Counselor"

This article described the genetic counseling field as an exciting and topical way to provide medical support and education. The description of a typical day in the life of a genetic counselor was a somewhat misleading composite of the tasks faced in prenatal, adult, and specialty clinics. Although the article fairly accurately represented the topics addressed within each type of practice, some of the descriptions of how genetic counselors communicate downplayed the attention we give to confidentiality.

December 28, 2008 – *The Advocate* at **www.2theadvocate.com)**, "Procedure an emerging tool in preventing and treating such diseases as cancer"

This article described a case of familial breast cancer in which BRCA testing occurred. This is contrasted with direct-to-consumer testing, including "markers" for cancer rather than single-gene testing. Angela Trepanier was interviewed about the differences between the two types of testing, including the type of information each can provide and the challenges in interpreting test results. In a companion piece to this article titled "Experts: Record family medical history," **Trepanier** discussed how to take your own family history, with particular reference to cancer.

December 30, 2008 – National Public Radio, "Family struggles with ambiguity of genetic testing"

NPR's Health and Science segment followed a couple's decisions to both undergo BRCA testing based on family history on both sides. The husband was found to carry his mother's mutation and the wife was found to carry a variant of unknown significance. **Beth Peshkin** discussed some of the benefits of BRCA testing, as well as the emotional and medical uncertainty that can result when a variant is detected. She identified a person's tolerance for risk as a key factor in determining whether or not to test, as well as how to proceed when the results are ambiguous.

*Please send Media Watch items to Claire Noll (**Claire.Noll@uth.tmc.edu**) or Roxanne Maas (**rruzicka@gmail.com**)*

Research Network

By Suzanna Schott, MS, CGC

Mechanism of Chromosome Breakage in Subtelomeres

Patients with identified subtelomeric rearrangements are encouraged to enroll in a study at Emory University in the Department of Human Genetics. The lab of Dr. Katie Rudd is researching the mechanisms of DNA breakage at the subtelomeric ends of chromosomes. Participants will be requested to give a blood sample and subtelomeric breakpoints will be identified by high-resolution array CGH.
Contact: Katie Rudd (404-727-9486) or **krudd@genetics.emory.edu**

Genetic Causes of Ocular Conditions

The Children's Research Institute is enrolling individuals and families affected with ocular conditions including Peters-plus syndrome, Axenfeld-Rieger anomaly and syndrome, anophthalmia/microphthalmia, Peters' anomaly, anterior segment dysgenesis, glaucoma, cataract, optic nerve hypoplasia/atrophy, and high myopia. Genes screened include *PITX2, PITX3, FOXE3, B3GALTL, SOX2, OTX2*, and other candidate genes as they are discovered. Participation involves a blood or saliva sample and completion of clinical/family history questionnaire. Results can be confirmed in a CLIA laboratory for use in diagnosis/family planning.
Contact: Linda Reis (414-955-7645), or **lreis@mcw.edu**

Genetic Study of Hirschsprung Disease

Researchers at Johns Hopkins University are seeking participants for an investigation of the genetic basis of Hirschsprung disease (HSRC). The study aims to find new HSRC genes and further characterize known HSRC genes and the interactions between them. Participation includes completion of a medical and family history questionnaire, review of surgical and pathological records, and submission of a blood sample. Genetic testing results are not currently disclosed to participants, except when an MEN2-associated mutation in the *RET* gene is identified.
Contact: Courtney Nichols (410-502-7541), or **hirschsprung@igm.jhmi.edu**

Study of Intermediate and Premutation FMR1 Alleles

The Institute for Basic Research and Genzyme Genetics are examining the factors that influence *FMR1* allele stability and repeat size distribution in families. Individuals with an *FMR1* allele of 45-200 CGG repeats are eligible to participate. First-degree relatives and at-risk family members may subsequently enroll. Test kits and analysis are provided at no cost; families pay blood draw costs. Results are disclosed through the participant's health care provider

in 1-2 months. Prenatal samples are not accepted, and international cases require special review.
Contact: Marcia Jodah (813-250-0588), or **marcia.jodah@genzyme.com**

GenTAC Registry

The National Institutes of Health sponsors the national Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions (GenTAC) registry. The goal is to collect data and biologic samples to enable research on best clinical management practices. Participation is open to people of all ages and ethnicities with: Marfan syndrome; Turner syndrome; EDS; Loeys-Dietz syndrome; Shprintzen-Goldberg syndrome; genetic mutations in *FBN1, TGFBR1/2, ACTA1 or MYH11*; a family history of aneurysm or aortic dissection; certain congenital heart defects; and other less common conditions. Website: **http://www.gentac.rti.org**
Contact: Call the coordinating center at 800-334-8571, Ext. 24640, or **gentac-registry@rti.org**

Seeking Families with a History of Alzheimer Disease

The Genetics Program at the University of Washington Alzheimer's Disease Research Center is collaborating with other Alzheimer disease research centers on a new initiative sponsored by the National Institute on Aging to better understand genetic factors in late-onset familial Alzheimer disease. Families with two or more living affected individuals with onset of dementia at age 60 years or later are being sought. Participation involves a phone interview, review of medical records, and a blood sample.
Contact: Malia Rumbaugh (800-821-7967), or **maliarum@u.washington.edu**

Please send Research Network items to ***sschott@cpdhealth.com***