nsgc

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President's Beat

Education, Education, Education…How Can We do It Better?

According to our most recent Membership survey, the majority of NSGC members selected educational offerings as the most important aspect of their membership. When asked about changes or improvements that could be made to NSGC overall, a key topic was "enhancing the annual education conference."

Having identified how important education is to our increasingly diverse members, and always looking for ways to increase member benefits, the Board of Directors has included education in our strategic plan. Specifically, strategic initiative #2 is, "…to promote an organizational culture that will enable NSGC to adapt to the evolving needs of genetic counselors, which includes engaging the membership to ensure that the Society's leadership understands and meets their needs through high quality education and will meet the needs of its members in relation to the increasing specialization of the profession…"

Educational Planning Summit

So we began. In July we held an Educational Planning Summit to critically examine our educational offerings. The goal was to use the collective insight and knowledge of the NSGC volunteer leadership and membership to shape and prioritize our education plans and learning strategies.

The Summit was facilitated by an educational expert and spearheaded by our Education Chair, **Sue Schmerler**. The committee itself was comprised of ten invited genetic counselors with varied years of experience and practice specialties/expanded roles.

Prior to the Summit, NSGC surveyed members who had not attended the AEC in the past few years to find out reasons why. The Summit committee was provided these surveys as well as information about how other professional organizations have structured conferences, trends in education, trends in the NSGC membership (from the Professional Status Survey) and results of past AEC conference evaluations.

Stages of Discussion

The first stage of the Summit was to look critically at the needs of our primary target audience - you, the members - with regard to length of time in the profession and primary work roles. The group also examined the educational needs of NSGC's extended target audience, now and in a future in which genomic medicine will evolve. We asked ourselves what is working within our current offerings and what is not. We recognized that we need to consider the interests of those who just graduated as well as those practicing for 20-30 years. It also is important to provide more high-level education in a variety of methodologies that benefit the traditional prenatal, pediatric, cancer and neurogenetic genetic counselors as well as those working in industry, public health, advocacy, research and administration.

We considered other audiences that may benefit from NSGC educational offerings. We looked at other professional societies, genetic and unrelated, to get a different view of how their major conferences work. From this we were able to step back and think about rebuilding the AEC, based on our members' needs today. We discussed the Regional Conferences and how best to offer education to our geographically diverse membership. Finally, we brainstormed about other educational products and services that would be of value to our members.

Exciting Changes to Come

The next steps for the Summit committee will be to evaluate the summary of the meeting and make recommendations to the Board. Since planning is already underway for 2008, the majority of changes will be developed during 2008 and implemented in 2009. We are really excited about the future of our educational programs, and we hope you are too!

Cathy Wicklund, MS
NSGC President

Evolution, Creationism and the National Society of Genetic Counselors

In repsonse to a recent listserv debate on evolution and creationism in the classroom, and in preparation for an Educational Breakout Session to be held at the 2007 NSGC Annual Education Conference in October, two genetic counselors provide insight into this age-old discussion and how it involves our profession.

Response 1: Respect First

By Brianne E. Kirkpatrick, MS

Last fall (2006), you may recall a discussion on the listserv: A genetic counselor was invited to speak to a junior high science class but was instructed to avoid mentioning evolution or cloning. This situation sparked a flurry of reactions. Some genetic counselors were outraged about the restrictions; others expressed support for avoiding these controversial topics.

At the 2007 Annual Education Conference in Kansas City, the discussion will continue during the Educational Break-out Session (EBS), "The Evolution/Creationism Debate: Ways of Thinking and Talking About It."

This EBS, submitted by the Ethics Subcommittee, presents an opportunity for attendees to expand their understanding of the core issues. Seeing this in the program book though, may cause some genetic counselors to run in the other direction. Those who expect the EBS to focus on ways to explain the logic of Darwinian evolution to "non-believers" may remain silent to avoid criticism or humiliation if they have different viewpoints. Yet this EBS should open a dialogue, not a debate. A debate ends with a victor and a loser; a dialogue welcomes diverse viewpoints in the context of a sensitive discussion.

A Question of Macroevolution

In a way, all genetic counselors believe in evolution, even those who self-describe as creationist. Microevolution, variation *within* a species, is the genetics we work with daily – point mutations, variant alleles at a locus and the like.

Macroevolution on the other hand, as **Charles Darwin** described in *The Origin of Species,* is not as central in general genetic counseling or in our daily lives. A minority of NSGC members do not believe in macroevolution, preferring the idea of Biblical creation. Unfortunately, those who expressed such views on the listserv last year received some pretty strong responses. It is not surprising that these genetic counselors may not feel "safe" sharing their beliefs out of fear of professional slander.

One doesn't have to believe in macroevolution to excel as a genetic counselor. In fact, a genetic counselor comfortable discussing issues of faith and religious beliefs when asked by a patient may be a more valuable resource than one who can list the supporting points of Darwinian evolution.

Valuing Different Beliefs

Genetic counselors are not a homogeneous group, nor should we aim to be. Just as we are expected to recognize and respect the diversity of beliefs and opinions in our clients, respecting the beliefs of our colleagues is equally important. How incongruous that we accept with little judgment the differing values and beliefs of our patients while avoiding diversity in our profession.

At the same time, in formal schooling situations, children who are denied the opportunity to learn the basics of evolution are at a significant disadvantage as adults. One cannot claim and defend an informed stance on the evolution/creation debate without understanding each side of the issue. Genetic counselors have a professional responsibility to be willing to discuss evolution, cloning and other hot button topics, as well as a responsibility not to perpetuate misunderstandings of scientific terminology such as "scientific theory."

Reconciling Spirituality with Science

Many people find it possible to reconcile spiritual beliefs with scientific theory so that beliefs do not have to fall into an either/or category. In his recently published book, *The Language of God,* **Francis Collins** shares his own personal struggle with the challenges of aligning religious and scientific beliefs. In regard to this topic, he writes:

> *Evolution, as a mechanism, can be and must be true. But that says nothing about the nature of its author. For those who believe in God, there are reasons now to be more in awe, not less.*

I urge us as a Society to approach the AEC, and particularly the Ethics Subcommittee's EBS, with a goal of recognizing and appreciating diverse viewpoints. As we are dedicated to valuing our patients, no matter how they are different from ourselves, may we also never chase colleagues away from our Society due to differing beliefs that are peripheral to our daily work.

Response 2: Talking with Students; Talking with Each Other

By Sarina Kopinsky, MS

Evolution occurred yesterday in my backyard, when the fastest, cutest squirrel won the heart of his ladylove. This is modern natural selection. However, within NSGC and the wider scientific community, the creationism debate addresses not modern but ancient evolution: Was natural selection of random mutations responsible for originating new species, including humans, from primordial soup?

Is Evolution "The Truth"?

Since we weren't present to observe, we cannot prove either the sequence or randomness of historical events. All we can ask is, "CAN evolutionary theory explain the origin of species?" Evolutionary theory depends on circumstantial evidence, even if it succeeds as an intellectually satisfying interpretation of biological facts and themes. Normally in science this level of certainty would suffice.

So why such animosity about presenting evolution to students? Perhaps it's because the concept of Biblical revelation raises the stakes, or because of (perceived) attempts by evolutionists and creationists to control curriculum by force, excluding the other view. Opposing factions accuse each other of being anti-rational, anti-intellectual, bigoted, closed-minded, ignorant (e.g., misunderstanding the term "theory"), defensive (aka "fanatic") or Godless.

Communicating with Goodwill

Witnessing these factions arise among genetic counselors propels us to encourage friendly discussion. How can we dialogue with such diverse opinions and irreconcilable differences? First, with goodwill – courtesy, tolerance and integrity. Second, by seeking clarity rather than agreement. Since each approach rests on premises whose validity is unproven, the key is in respectfully analyzing each viewpoint's underlying assumptions.

Let's also consider the impact on students of our style of disagreeing. The way adults dialogue is itself an educational message. For children maturing in a world filled with violence, learning how to disagree successfully is an essential life skill. Some might almost value it more than getting the science right.

Genetic counselors are trained to be role models for communication. We have aptitude for blending boundary lines as we educate about genetics, statistics, ethics, emotions, family and society. Our profession can show leadership, to other scientists and to our youth, about harmonious dialogue.

Different Values, Different Assumptions

What are the assumptions of creationism and evolution? (Please forgive the generalizations, but we need a way to talk about this…)

Creationists assume that God exists, that the Bible is true, that a creative time once occurred and/or that God revealed Himself to humankind with an eyewitness account of earth's early history. Creationists cannot prove these things; they believe as a matter of faith.

In contrast, evolutionary theory assumes that natural processes were similar then and now and that shared, or conserved, DNA sequences imply common ancestry. See, for example, a quote from NSGC's recent listserv discussion on evolution versus creation:

> "If humans are not evolved from apes, how do you explain the overwhelming percentage of genomic DNA sequence we share with primates? If we take this as evidence of evolution of other species, on what basis do we make an exception for humans (other than a religious basis)?"

A problem with this reasoning is that the causative link between shared genomic sequences and shared ancestry is an *a priori* assumption, not a consequence, of evolutionary theory. Though we habitually see them together, shared ancestry is not philosophically PROVED by shared sequence. For those who see God's intelligent hand in "random" events of evolution, odds are not so overwhelmingly against identical sequences arising independently more than once. It becomes rational for believers to ask if God could have chosen to handle humans differently than other species, whether biologically or morally.

Mutually acknowledging assumptions on each side, a successful evolution-creation conversation might conclude:

Evolutionist: Given that you're convinced God revealed Himself at Sinai, you're logical and intellectually consistent to try reconciling The Word with science. I respect that.

Creationist: Given that you're convinced God's existence and revelation are irrelevant, which no-one can disprove, it makes sense that you confine yourself to rational, non-miraculous interpretations. I respect that.

Evolution and Creation in the Classroom

Individual citizens have the autonomous right to abstain from the debate, even if this leads to a different career, e.g., genetic counseling over evolutionary biology. However, educators must not abstain.

The problem is, teaching evolution begs that one at least mention creationism. Given the separation of church and state, however, science-based opinion is welcome in tax-funded public schools; faith-based is not.

Being honest, what if both evolution and creation have some truth? What if there actually was a magical, creative historical time? What if science isn't the whole way to elucidate the origin of species? Couldn't students in holistic classrooms dissect this conundrum?

Are we teaching science or teaching children? In other fields, we value interdisciplinary teaching. What is our risk in biology? If we are secure in our science and honest in interpreting its assumptions and limitations, why suppress diverse opinions?

Reconciling Faith with Science

The discrepancy between evolution and creation challenges open-minded believers to reconcile their views. Examples include:

- God's hand is in random events; God used evolution to create species (Francis Collins' BioLogos theory, as I understand it).
- God mostly used evolution, with occasional miracles.
- The Bible is sometimes metaphorical, not literal. (Note how even Genesis 2 contradicts Genesis 1!)
- The Oral Torah (in Judaism) interprets the Bible compatibly with science.
- Intelligent design then, evolution now; creativity changed when God rested on the seventh day.

Fervently rejecting either scientific evidence or religion is blindly one-sided. Both extremes undermine students' acquisition of the cognitive background to develop critical thinking skills and arrive at their own truth. As such, both risk keeping students ignorant, anti-intellectual and anti-rational.

Teaching only science yields good technicians, but risks churning out products with uniformly secular-humanist viewpoints, lacking philosophical sophistication. On the flip side, excluding both evolution and creation to avoid debate leaves students uneducated.

It is not necessary to add religion chapters to biology books or require teachers to declare, "God created" – only to permit educators to present evolution in cultural context. We may be amazed how far a simple acknowledgment could go in calming the turmoil between strident "God-believers" and the staunchly scientific.

For Your Practice Special Series:

Cases in Expanded Metabolic Screening

This is the third article in a series presented by the Metabolism/Lysosomal Storage Disease SIG in response to the expanded newborn screening panel developed in 2005 by the American College of Medical Genetics' Newborn Screening Expert Group. The expanded panel comprises 29 conditions to be tested by all state newborn screening programs. Perspectives *is highlighting several lesser-known genetic conditions now included in newborn screening to help both metabolic and non-metabolic genetic counselors as they come face-to-face with these diseases.*

CASE 3: Deficiency of 3-methylcrotonyl-CoA carboxylase (3-MCC)

By Dawn Laney, MS

Disease Review

Biochemistry: 3-methylcrotonyl-CoA carboxylase (3-MCC) is an enzyme involved in the breakdown of leucine. Reduction or elimination of the activity of 3-MCC results in the build-up of the toxic byproducts of leucine processing, damaging the brain and nervous system. The enzyme is located in the inner membrane of the mitochondria in the liver and kidney. 3-MCC is classified as an organic acid disorder.

Genetics: Autosomal recessive. 3-MCC is caused by mutations in MCCA or MCCB that code for the two protein subunits of the enzyme. MCCA is located at 3q25-q27, MCCB at 5q12-q13.1. Sequencing of MCCA/MCCB is available, but no common mutations have been identified.

Incidence: Currently estimated at 1 in 50,000.

Natural History: In 1970, **L. Eldjarn** et al. reported a new inborn error of metabolism in a patient with excess urinary excretion of beta-methylcrotonylglycine. The main clinical features included muscular hypotonia and atrophy, suggestive of a neurologic defect. Now known as 3-MCC, this condition can be variably expressed, from asymptomatic to a progressive disorder starting in early life.

The characteristic presentation involves infants that appear normal at birth but develop symptoms during the first year or in early childhood. Symptoms include feeding difficulties, recurrent episodes of vomiting and diarrhea, lethargy and hypotonia. If untreated, 3-MCC can cause delayed development, seizures and coma. Early detection and lifelong management consisting of a low-protein diet and carnitine supplements may prevent many of these complications.

Genetic Counseling - Positive Newborn Screening in the Case of an Open Adoption

A two-week old Caucasian male was seen in metabolic clinic following abnormal newborn screening results indicating an elevation of 3-hydoxy-glutaryl carnitine. The differential diagnosis included: 3-methylcrotonyl-CoA carboxylase deficiency (3-MCC), 3-hydroxy-2-methylglutaryl-CoA lyase deficiency (HMG), multiple carboxylase deficiency (MCD), 2-methyl-3-hydroxybutyric acidemia (2M3HBA) or 3-methylglutaconic aciduria (3MGA).

Diagnostic testing included plasma amino acids, urine organic acids and plasma acylcarnitine. The plasma amino acids were normal. The urine organic acids revealed a large amount of 3-hydroxyisovaleric acid and a smaller amount of 3-methylcrotonylglycine. The plasma acylcarnitines showed that free carnitine was significantly reduced, total carnitine was slightly reduced, esterifed carnitine was normal and the AC/FC ratio was slightly elevated. These results confirmed the diagnosis of 3-MCC.

The parents reported that the baby had thrived in the newborn period. He fed well and gained weight on formula. He had good muscle tone and was not floppy. The baby had jaundice, which resolved after phototherapy, and congenital unilateral hydronephrosis. The parents were counseled by metabolic nutritionists about the natural history of 3-MCC, dietary recommendations and carnitine supplementation. The parents wanted more information about predicting the severity of the condition in the baby. We discussed that there is no good test to determine future severity.

Although the case seemed straightforward, discussion of genetics revealed that the baby was adopted through an open adoption. The newborn screening follow-up program had contacted the biological mother when the baby was born and had disclosed the abnormal newborn screen. The adoptive parents said that the biological mother previously reported having chronic fatigue and muscle aches and pain. She also had two older children with the same father as the affected baby. As expanded newborn screening was not performed at the time of the other children's births, it is unknown if these siblings were affected by 3-MCC.

The metabolic clinic staff provided information on 3-MCC and genetic testing to the adoptive parents to give to the biological mother. The genetic counselor then called the biological mother, who agreed to come to clinic and bring her other two children. However, she did not show up for that appointment. Subsequent phone calls were not returned. At a later date, the genetic counselor met with the adoptive parents in the clinic for follow-up and asked about the biological mother. The adoptive parents said the biological mother refused to talk to them about the 3-MCC diagnosis or the health of her other children. The adoptive parents felt that the biological mother was being defensive, as if they were blaming her for the baby's 3-MCC condition.

Teaching Lessons

1) Limited Knowledge of Natural History

As with several of the other disorders on the expanded newborn screening panel, it is difficult to predict the severity of symptoms based on current knowledge of the disease. Genetic counseling is complicated by this limitation. Hopefully with the increased number of children undergoing expanded newborn screening and diagnosis, longer term natural history information from metabolic clinics will clarify the natural history of 3-MCC.

2) Challenges of Adoption

An age-old problem with children adopted by other families is how to recontact the biological family when a genetic disease is discovered. Although it was fairly easy to contact the biological mother in this particular case, closed adoptions make it difficult to reach at-risk family members. In addition, as the biological family is not considered the immediate patient, duty to warn is questionable. Under HIPAA restrictions, are you allowed to recontact the biological family? How much effort should be expended to ensure a biological family understands the condition and testing options?

3) Risks to Parents and Siblings

When an autosomal recessive genetic condition is diagnosed in a family, the genetic counselor's role is challenged when a parent refuses to test other at-risk siblings. If the risk for a life altering condition is high and a treatment is available, is refusing to test considered parental negligence? Do you call Child Protective Services? The best path to follow is further complicated in conditions with a clinical presentation that may range from mild with no associated harm to medically devastating.

Career Watch

Since 1980, the National Society of Genetic Counselors has conducted a Professional Status Survey (PSS) of the membership every other year. The PSS is a comprehensive survey, which focuses on eight primary areas of interest: Background Information, Work Environment, Professional Status/Job Description, Faculty Appointments, Board Certification, Salary and Benefits, Professional Activities and Job Satisfaction. Below is a summary of the 2006 PSS, which can be found in full on the NSGC Web site.

2006 Professional Status Survey

By Maria Del Vecchio, MS, Chair, Professional Issues Committee and Sarah Parrot, MS, Boston Information Solutions

Introduction

In the 27 years since the Professional Status Survey (PSS) was first administered to the NSGC, results have been a top benefit, anxiously anticipated by the membership. Throughout the year, NSGC receives many inquiries about the PSS from members engaging in their own research and from human resource professionals seeking to adequately adjust salaries and benefits for both current and future genetic counselors. Given the small number of genetic counselors compared to other allied health professionals, the results from the PSS are a critical resource used by prospective employees.

Methodology

The 2006 PSS was administered online, although paper copies also were available. The survey was administered to full members of the NSGC (n=1829) via email during the summer of 2006. A record 1,245 completed surveys were received, resulting in a 68.1% response rate. This was the highest response rate among the last three survey administrations and the highest number of individual respondents ever recorded.

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

The online administration of the PSS was completed in August, 2006. Of the 1,245 surveys received, all but one was completed online. Responses submitted online were collected and compiled 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 multipart questions. The majority of the questions remained unchanged from the 2002 and 2004 surveys. However, certain questions were edited for clarity, and the ethnicity items were expanded.

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

The demographic composition of the 2006 survey respondents did not differ substantially from previous surveys, although it appears respondents are slightly more mature in age and in years working in the genetic counseling profession. Respondents to the survey are predominantly Caucasian women under the age of 40 with fewer than ten years in the genetic counseling profession

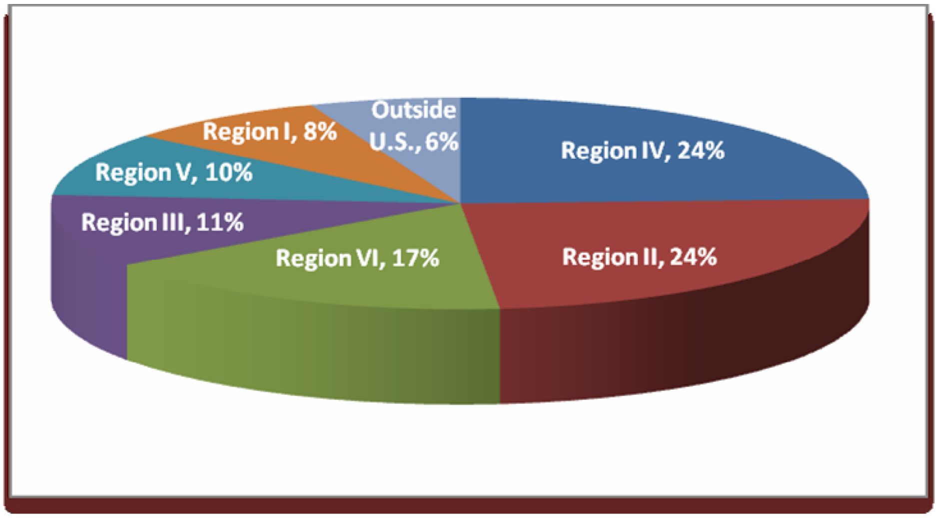
Table 1. Demographics

Demographics of Respondents	
Gender	
Female	96%
Male	4%
Age	
20-29	29%
30-39	42%
40-49	18%
50-59	9%
>60	2%
Ethnicity	
Caucasian	91%
Asian	5%
African American	1%
Hispanic	2%
Native American	0%
Other	2%

Regional Data

Regional data is consistent with previous surveys. Nearly half of the respondents live and work in Regions II and IV. Region I has the fewest genetic counselors (Figure 1).

Figure 1. Genetic Counselors by Region



Training and Certification

Nearly three-quarters of the genetic counselors surveyed hold an MS or MA in Genetic Counseling, while another quarter hold an MS or MA in Human or Medical Genetics. Only 2% of NSGC members hold a Ph.D. in a genetics related field. Overall, 8% of genetic counselors hold an additional Masters degree (MPH, MBA, MSW, etc.).

Regarding certification:

- 14.3% of respondents are certified by the American Board of Medical Genetics (ABMG)
- 65.8% of respondents are certified by the American Board of Genetic Counseling (ABGC)
- 15.9% of respondents are planning to take the ABGC certification exam
- 2.5% of respondents have no plans to take the ABGC certification exam
- 1.5% of respondents are not eligible to take the ABGC certification exam.

Genetic counselors who previously sat for the ABGC examination received a variable amount of reimbursement by their employers. Application fees were covered for 46% of respondents; a board review course was covered for 57% of respondents, while 31% of the respondents received no monetary compensation for the board examination or review course.

The direct benefit of certification also was variable among respondents to the 2006 PSS. One-quarter of respondents received a raise, 4% received a promotion, 16% were reimbursed for the costs associated with the exam and 61% received no obvious benefit from passing the certification examination.

Employment Experience

Table 2 details the number of years genetic counselors have been practicing. More than half of the respondents have fewer than 10 years of experience working in the field. The mean is eight years of experience, and the median is five years. The majority of genetic counselors have been in their current positions for less than five years. A small percentage of respondents have been in their current position for more than 15 years (Table 3). The overall mean is five years in the current position, with a median of three years. Table 4 shows the number of positions respondents have had since graduation from a genetic counseling program. The mean number of positions is two, and the median number of positions also is two.

Table 2. Years in Field

Years	%
0-5	38
5-10	29
10-15	13
15-20	8
20+	12

Table 3. Years in Current Position

Years	%
0-5	61
5-10	15
10-15	5
15-20	4
20+	2

Table 4. Positions Since Graduation

No. of Positions	%
1	38
2	30
3	18
4	8
5+	6

Survey respondents were asked about their experience obtaining their first position after graduation from a genetic counseling program. The majority of respondents (69%) were employed in a genetic counseling position within one month following graduation (Figure 2).

Figure 2. Time to Find First Position

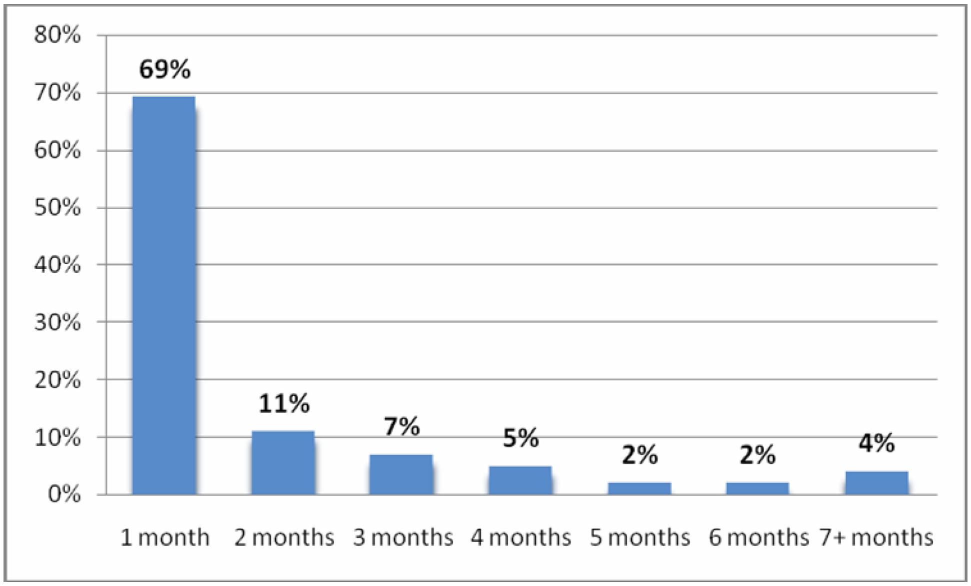
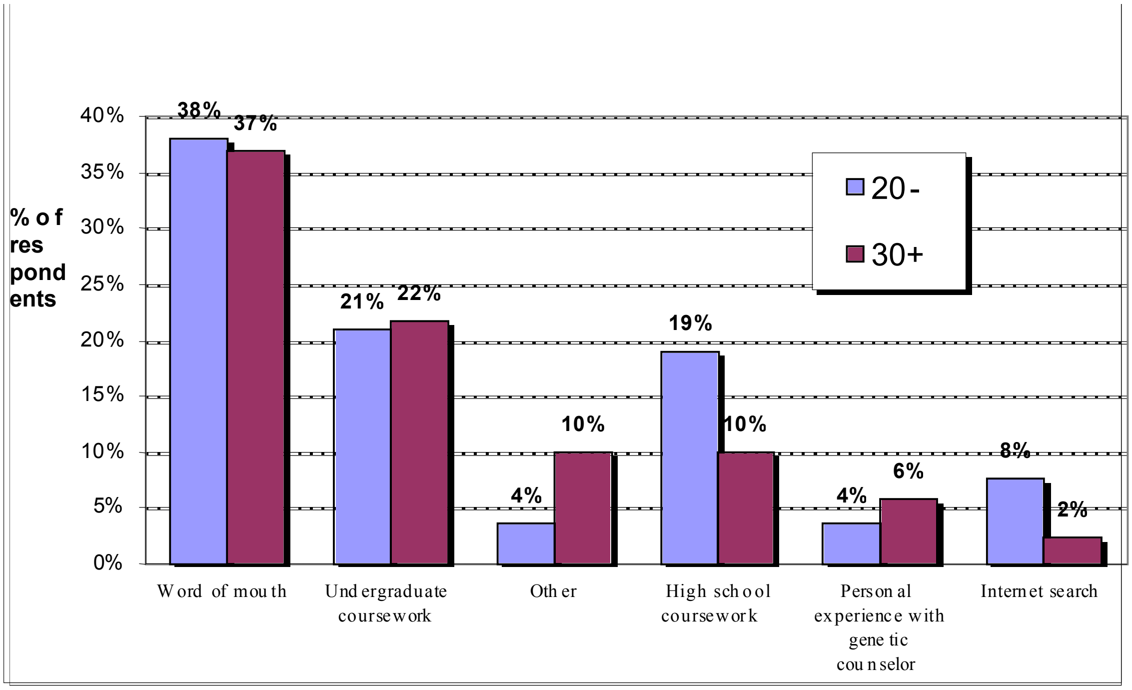


Figure 3 shows that "word-of-mouth" is the most common introduction to the profession of genetic counseling; however, differences exist depending on the age of the respondent. Among those aged 20-29 (29% of respondents), significantly more report being introduced to the genetic counseling profession through high school or undergraduate coursework compared to their counterparts 30 years of age and older. This reinforces the findings in 2002 and 2004, indicating that information about the profession of genetic counseling may be more of a staple in coursework that lends itself to the genetic counseling profession.

Figure 3. First Introduction to Genetic Counseling



Work Environment

Primary Work Setting

Table 5 shows that the majority of respondents work in a University Medical Center. This percentage has declined through the years, from 47% in 1998 to 38% in 2006.

Table 5. Genetic Counselors by Setting

Setting	N	%
University Medical Center	474	38
Private Hospital/Medical Facility	252	20
Public Hospital/Medical Facility	134	11
Diagnostic Laboratory	95	8
Physician's Private Practice	58	5
HMO	43	3
University/Non-Medical Center	39	3
Federal/State/County Office	27	2
Private Practice	12	<1
Research Development/Biotechnology Company	10	<1

Pharmaceutical Company	7	<1
Outreach/Clinic	4	<1
Internet Company	2	<1
Health Advocacy Network	1	<1
Other	38	3

Specialty Area

Table 6 shows the area of specialty reported by respondents. (Note: Percentages do not add to 100% since respondents were able to select more than one specialty area.)

Several trends are noted compared to historical PSS data. There is a 6% drop in prenatal and pediatric genetic counseling since 2000. Cancer genetic counseling has remained steady since 2000. Genetic counselors offering multiple marker screening and information about teratogens reached a peak of 44% and 40% respectively in 1994, yet in 2006 reflected only 6% and 8%.

Cardiology is a new specialty added to the 2006 survey. It will be interesting to track the growth in this area in future surveys.

Table 6. Genetic Counselors by Specialty Area

Specialty	%
Prenatal	54
Cancer	39
Pediatric	34
Adult	24
Specialty Disease	13
Molecular/Cytogenetic/Biochemical Testing	9
Teratogens	8
Multiple Marker Screening	6
Infertility/ART/IFV	6
Public Health/Newborn Screening	6
Neurogenetics	6
Cardiology	4
Psychiatry	1

Primary Roles

Genetic counselors often have multiple roles within a given position. The majority of NSGC members who responded to this survey indicate that their primary roles include clinical practice and teaching. The percentage reporting clinical practice, teaching and research as their primary roles has remained steady over the last several surveys (Table 7).

Table 7. Primary Roles of Genetic Counselors

Primary Role	%
Clinical	84
Teaching	55
Clinical Coordination/Administration	28
Research	27

Marketing	12
Health Administration	6
Public Policy	3

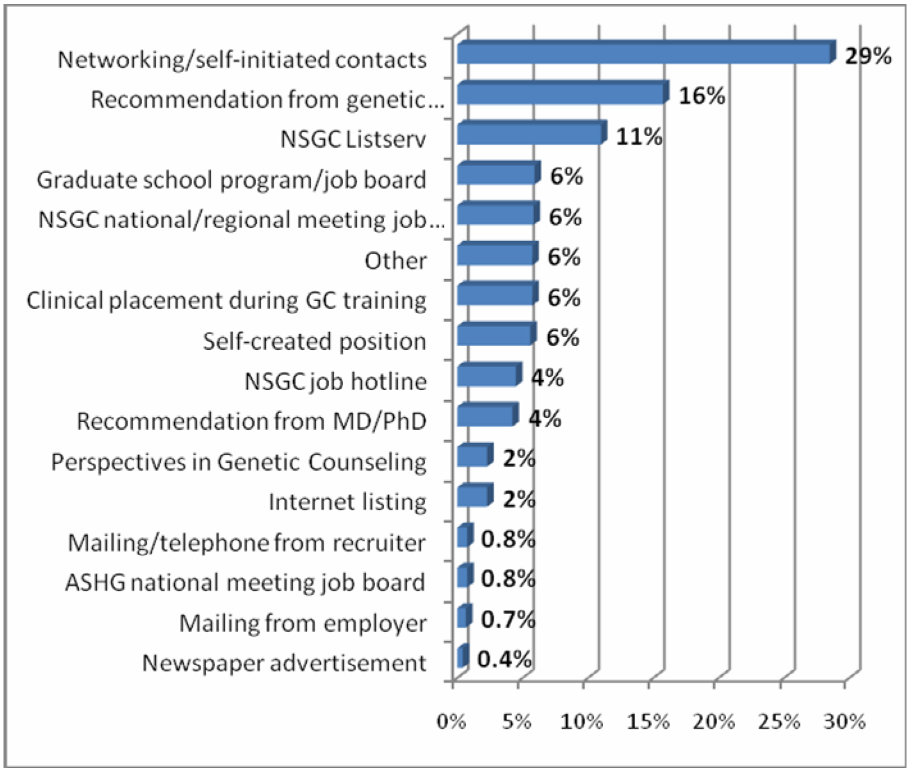
Clinical practice remains the role of more than three-quarters of respondents. The survey data indicates that 51% of respondents saw an increase in patient load in the year leading up to the survey. In the same time frame, 48% of respondents indicate that no change in office or clinical staffing was associated with the increased patient volume.

Patient load, including both new and returning patients, varies between specialties. Overall, survey respondents indicate seeing an average of 10 new patients per week and three returning patients per week.

Current Position

Genetic counselors have several opportunities to find available positions. National meetings, job boards and networking are all viable options. In 2006, nearly 30% of respondents indicate that networking was the most useful way to learn about available positions (Figure 4). Sixteen percent of respondents learned about their current position from another genetic counselor. Just over 10% learned about their current position from the NSGC listserv.

Figure 4. Learning About Current Position



Billing and Reimbursement

Billing and reimbursement for genetic counseling services has remained a top priority of the NSGC. Data continue to indicate that improvement in this area is needed. Almost half

(42%) of respondents indicate that they bill in the name of their supervising physician, while 2% bill only in their name. Roughly 8% of respondents bill in both their name and the name of the supervising physician.

Respondents were also asked whether they had seen a change in reimbursement for services during 2005. Nearly half of respondents are unsure if a change had occurred. Eight percent report an increase in reimbursement during 2005, while 38% saw no change in the level of reimbursement for genetic counseling services.

Professional Status

Hours Worked

Three-quarters of respondents held a full time position in 2005. Of these, 6% were able to work full time by combining at least two part time positions. As in previous studies, roughly 20% of respondents indicate that they held a part time position. This number has been steady since 1994. Only 1% of respondents were unemployed. This number has fluctuated very little over the last 12 years.

Seventy-five percent of genetic counselors working full time report working overtime in 2005. Of those reporting overtime, 31% report 1-4 hours of overtime per week, 40% report 5-9 hours of overtime per week and 17% report 10-14 hours of overtime per week. Two thirds of genetic counselors reporting overtime receive no compensation for the extra hours, and 21% report that they received compensatory time off.

Of respondents working part time, 14% state that they chose to work part time temporarily for personal or family reasons, while 72% indicate that they chose to work part time long-term for the same reasons. Only 8% state that they chose part time status because a full time position was not available in their geographic location.

More than half (52%) of genetic counselors who report being unemployed state that they chose to remove themselves from the work force for personal or family reasons. The remainder of those unemployed during 2005 cite other reasons (retirement, no position available within geographic location, position eliminated.)

Official Job Classification

Job classification varies between institutions (Table 8). The most common titles are Genetic Counselor and Genetic Associate. The titles Genetic Consultant, Public Health Genetic Counselor and Genetic Education Specialist are less common, comprising 1% each of respondents' titles. Genetic Social Worker and Genetic Nurse Counselor make up less than 1% each of respondents' titles.

Table 8. Job Classification

Title	%
Genetic Counselor/Genetic Associate	63
Senior Genetic Counselor	14
Director	4
Clinical Coordinator	2
Research Assistant/Associate	2
Genetic Consultant/Public Health Genetic Counselor/	

Genetic Education Specialist	1
Genetic Social Worker/Genetic Nurse Counselor	<1

Faculty Appointments

Twenty percent of respondents hold a faculty appointment. Among these, almost two-thirds (64%) are at their institution of employment, and the rest are at another institution. Just over half of those with faculty appointments (58%) work at a school of medicine, and another 23% work in a graduate program for genetics. Faculty appointment titles vary by institution (Table 9).

Table 9. Faculty Appointments

Faculty Appointment	**%**
Instructor/Lecturer	32
Clinical Instructor/Lecturer	23
Assistant Professor	13
Clinical Assistant Professor	7
Associate Professor	5
Research Associate/Assistant	3
Clinical Associate Professor	3
Professor	1
Clinical Professor	<1
Other titles	12

Circumstances of Faculty Appointment

Respondents were asked about the circumstances of their faculty appointment. (Respondents could check more than one reason, so responses do not add up to 100%.)

- 34% received a faculty appointment due to supervision of genetic counseling students.
- 33% received a faculty appointment at time of hire.
- 32% received a faculty appointment due to supervision of other genetic counselors.
- 19% received a faculty appointment based on self-request.
- 13% received a faculty appointment due to supervision of medical students.
- 11% received a faculty appointment after a specified service period.
- 10% received a faculty appointment after board certification.

Salary

To facilitate comparisons and benchmarking, all information presented in the sections on 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=924). Of these, 880 (95%) reported salary information. Statistical outliers (for example, the few respondents who report incomes greater than three standard deviations above or below the mean) have been omitted from the analysis so they do not skew the results. Canadian dollars have been converted to U.S. currency at CAN 1.13/USD 1. To protect the confidentiality of survey respondents, data are only displayed for cells where N>=5. For salary information in greater detail, NSGC members may view the NSGC Web site.

Overall, the yearly gross salaries reported by survey respondents range from $20,000 to $150,000, with an average of $58,975. This is an overall increase of 9% ($5,598) from 2004, where the average salary was reported at $53,377. Over two-thirds (71%) of respondents report that their salaries were not dependent on grant funding, 20% were partially dependent on grant funding, and just 9% were completely dependent on grant funding.

Table 10 demonstrates that regardless of years of experience, the average salary reported by respondents in Region 6 (AK, CA, HI, ID, NV, OR, WA and British Columbia) is significantly higher than salaries reported by respondents from the other five regions (p<.01). This is consistent with past survey results.

Table 10. Salary by Region

Region	**N**	**Median**	**Min**	**Max**
1	68	$53,615	$22,000	$92,000
2	224	$55,000	$37,132	$136,000
3	107	$51,854	$36,000	$110,750
4	210	$55,062	$32,760	$150,000
5	90	$55,000	$35,000	$125,000
6	140	$67,500	$20,000	$115,000

Regardless of region, 88% (n=392/447) of respondents who have held their current position for more than 12 months and attempted to increase their salary report they were at least partially successful since 2004. Only 12% (n=55) who tried were unsuccessful at obtaining an increase. 306 respondents made no attempt to increase their salary. The average increase for those who report "success" at achieving a salary increase is 7.7%. Respondents reporting "partial success" average increases of 4.9%, while those who report "no success" average increases of 3.4%. Interestingly, respondents who did not try to increase their salary received a 3.9% increase on average. Overall, regional data demonstrate an average increase in salary of 5.3% nationwide (n=901).

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

Table 11. Salary by Years of Experience

Years of Experience	**N**	**Mean**	**Min**	**Max**
1-4	351	$51,750	$22,000	$97,900
5-9	247	$61,268	$38,879	$150,000
10-14	86	$65,849	$36,000	$128,234
15-19	64	$70,739	$49,100	$115,000
20-25	59	$72,315	$20,000	$137,000
25+	34	$78,434	$57,000	$136,000
Total	841	$59,858	$20,000	$150,000

Table 12 shows salary breakdown by primary work setting. Respondents with the highest average salary work in the biotechnology industry, while those in public hospital settings report the lowest average salary.

Table 12. Salary by Primary Work Setting

Work Setting	N	Mean	Min	Max
Univ. Med. Ctr.	374	$57,153	$34,895	$137,000 Private
Hospital	181	$57,013	$22,000	$105,000
Public Hospital	105	$54,480	$35,000	$88,500
Diagnostic Laboratory	82	$68,562	$40,000	$128,324
MD Private Practice	45	$57,245	$41,000	$80,000
University/Non Med. Ctr.	31	$58,944	$40,000	$119,000
HMO	26	$71,956	$52,100	$115,000
Federal/State/County	20	$60,775	$37,132	$120,000
Biotech/R&D	10	$94,111	$47,000	$150,000
Other	26	$61,944	$40,000	$107,500

Mean salaries by job classification are reported in Table 13. Genetic Counseling Program Directors report the highest average salaries, followed by Senior Genetic Counselors.

Table 13. Salary by Job Classification

Job Classification	N	Mean	Min	Max
Genetic Counselor/Associate	570	$53,613	$20,000	$92,560
Senior Genetic Counselor	107	$63,174	$35,000	$88,500
GC Program Director	11	$67,464	$56,273	$78,983
Clinical Coordinator	20	$60,232	$36,000	$84,000
Research Assistant/Associate	17	$59,032	$37,900	$93,000

Salary data stratified by primary specialty is shown in Table 14. Genetic counselors working in infertility clinics report the highest average salary, while those working in the public health area report the lowest average salary.

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Table 14. Salary by Primary Specialty Area

Specialty Area	N	Mean	Min	Max
Prenatal	313	$55,180	$22,000	$92,560
Pediatric	120	$53,840	$38,000	$111,405
Adult	14	$64,895	$44,000	$90,000
Cancer	176	$59,313	$20,000	$108,000
Specialty Disease	39	$57,869	$37,000	$93,000
Public Health	18	$51,255	$37,132	$71,988
Newborn Screening/ Serum Screening	6	$51,814	$44,000	$65,000
Molecular/Cyto/ Biochem Testing	26	$58,815	$40,000	$97,000
Neurogenetics	14	$53,219	$47,000	$63,806
Infertility	5	$67,800	$52,000	$90,000
Cardiology	13	$55,027	$44,000	$82,000
Other	27	$66,903	$44,000	$137,000

As in previous studies, we were able to compare salary between gender and race. Male genetic counselors (n=47) earned an average of $63,871 compared to $58,722 for females (n=876). This data is consistent with earlier studies, but given the small number of male genetic counselors participating in the survey, it is difficult to conclude that the difference is due to gender alone.

The salary gap between Caucasians and minorities is almost nonexistent, with minorities reporting an average salary of $59,009 (N=88), compared to Caucasians (N=833) who report an average salary of $59,005. Again, conclusions based on these data must be made with caution due to the relatively small number of minorities in the genetic counseling profession who responded to the survey.

In addition to salary, many genetic counselors report additional income through other professional activities. The most frequently reported activity is lecturing (n=167), followed by teaching (n=54), consulting (n=39) and technical writing (n=24). These activities result in additional income ranging from $25 to $20,000 per engagement (Table 15).

Table 15. Additional Income

Income Source	N	Average	Range
Lecturing	167	$713	$25-$15,000
Teaching	54	$1,774	$50-$11,000
Consulting	39	$3,756	$150-$20,000
Writing	24	$1,117	$100-$7,000
Private Practice	7	$7,900	$300-$15,000
Other	20	$2,715	$70-$12,000

Benefits

As in previous studies, respondents were asked about benefits. To facilitate comparisons, all information presented is based on residents of the U.S. or Canada who are working one full time position and have earned at least one graduate degree (n=741).

Table 16 lists items included in benefits packages and the percentage of respondents receiving each benefit. Respondents also were asked about vacation time. A quarter of respondents receive more than four weeks vacation and personal time per year, 30% have four weeks of vacation and personal time per year and 42% reported between two and three weeks vacation and personal time per year.

Table 16. Benefits Package

Benefit	% Included in Package
Health Insurance	97
Dental Insurance	91
Retirement Plan (401K/403B)	85
Life Insurance	84
Disability Insurance	84
Pre-Tax Accounts	79
Pension Plan	44
Stock Option	13
Other	10

In considering total compensation, one must consider all compensation related to a particular position. As in previous surveys, work-related reimbursement was investigated. A list of covered expenses is listed in Table 17 with the percentage of respondents receiving at least partial reimbursement for the expense.

Table 17. Paid Expenses

Expense	**% Receiving Coverage**
NSGC Membership	67
Other Professional Memberships	36
Journals/Books	65
Tuition Reimbursement	48
CEU Credits	44
Interview Expenses	31
Moving Expenses	27
Laptop/Home Computer	27

Meeting/Conference Reimbursement

Table 18 shows the reimbursement for professional meetings. Over half of respondents report reimbursement for one meeting of their choice per year.

Table 18. Professional Meeting Reimbursement

Meeting	**% Reimbursed**
One meeting Per Year/My choice	52
NSGC Annual Meeting	28
NSGC Regional Meeting	16
ASHG Annual Meeting	12
ACMG Annual Meeting	9
Budget Dependence	25
Only if Presenting Poster/Paper	6
No Funding	5

Professional Activities

The majority of respondents are involved in professional activities outside of their work environment (78%). The most common outside activity is speaking to community groups (n=726). All activities are listed in Table 19.

Table 19. Professional Activities

Professional Activity	**% Involved**
Spoken to lay/community groups	63.0
Served on committee of NSGC, ASHG, ABMG, CORN	29.7
Developed/organized a conference/workshop for health professional	29.7
Involved in support group (advisory board, developed, etc.)	25.9
Developed genetics curriculum for students/teachers	23.6
Served on committee(s) dealing with delivery of health/genetic services	22.4
Quoted/appeared on television, radio, newspaper, magazine, etc.	20.4
Worked to develop licensure for GC in my state	19.1

Developed/organized a conference/workshop/symposium for patients	15.2
Served as a reviewer for journal submissions	12.2
Served as a resource for local/regional/national legislators on GC issues	10.8
Worked to establish successful billing as a GC	8.0
Served on Board of NSGC, ASHG, ABMG, CORN	4.5
Served on editorial board for journal	2.2
Served as a site visitor for ABGC	1.9
Other professional activity	5.8

Job Satisfaction

In PSS surveys administered since 2000, genetic counselors were asked to rate their level of satisfaction with their current position and the profession of genetic counseling. Respondents to the 2006 survey were asked to rate their satisfaction on a four point Likert scale, and the scale was combined into the categories “Satisfied” and “Dissatisfied” to facilitate data analysis. A large percentage of genetic counselors (90%) report satisfaction with their current job. Figure 5 shows that genetic counselors are significantly more satisfied with their autonomy and interactions with other clinicians on staff than they are with their salaries, research and opportunities for advancement. Table 20 shows job satisfaction over the past six years.

Figure 5. Level of Job Satisfaction

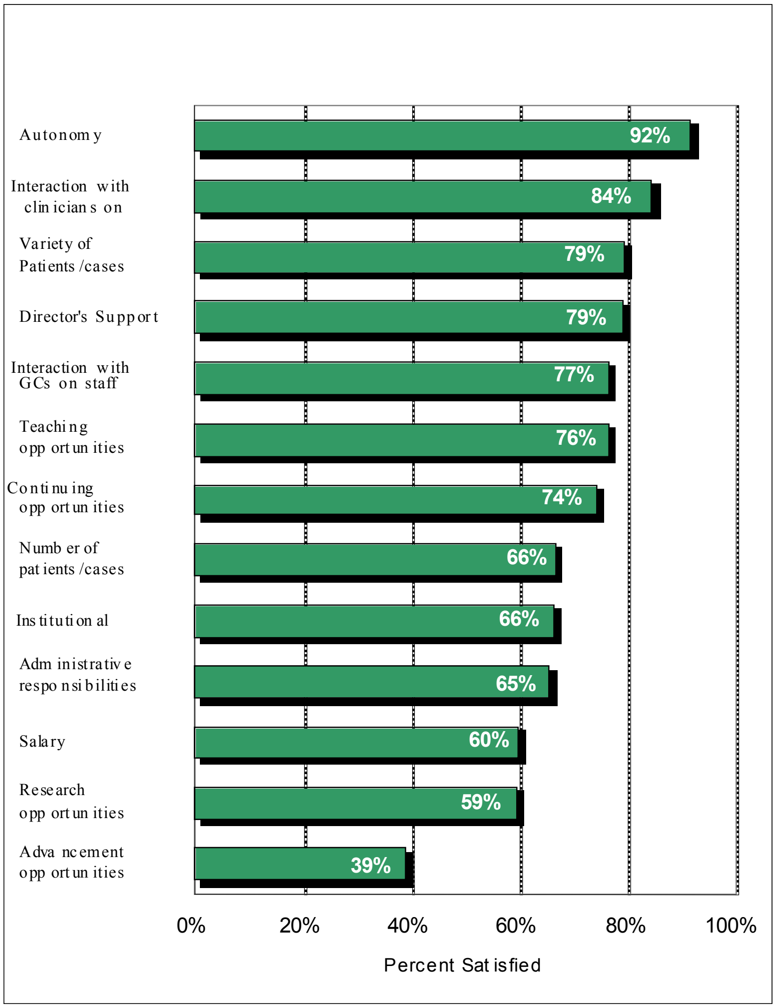

Table 20. Job Satisfaction

Satisfaction with Current Position	***Percent Satisfied***		
	2002	***2004***	***2006***
Autonomy	*92.5*	*90.2*	*91.5*
Interaction with other clinicians on staff	*84.1*	*84.4*	*84.3*
Variety of patients/cases	*83.3*	*80.0*	*79.1*
Director's support	*78.2*	*77.9*	*79.0*
Interaction with other GCs on staff	*75.3*	*75.0*	*76.5*
Teaching opportunities	*78.4*	*77.9*	*76.3*
Continuing education opportunities	*72.6*	*74.1*	*73.8*
Number of patients/cases	*68.1*	*68.1*	*66.4*
Institutional support	*62.5*	*63.5*	*66.1*
Administrative responsibilities	*67.6*	*68.3*	*65.4*

Salary	*59.2*	*56.1*	*59.6*
Research opportunities	*61.3*	*61.9*	*59.4*
Advancement opportunities	*39.7*	*38.9*	*39.1*

Although genetic counselors are satisfied with the scientific content, learning opportunities, patient counseling and personal growth they receive, they are far less satisfied with the opportunities for advancement and the earning potential that the field offers. The percent satisfied with each item is listed in descending order in Table 21.

Table 21. Satisfaction with Field

Aspect	**% Satisfied**
Scientific content	96
Learning opportunity	94
Patient contact/counseling	94
Personal growth	87
Opportunity to develop/administer programs	71
Professional growth	65
Respect from medical community	53
Opportunity for advancement	35
Earning potential	27

Discussion

The biannual Professional Status Survey (PSS) of the NSGC is a valuable tool for genetic counselors. The survey has remained consistent over more than 20 years. Every other year the questions are examined and may be altered slightly to obtain additional data. For example, in 2006 we expanded the ethnicity categories and added cardiology as a specialty option.

NSGC members continue to report the PSS as a top member benefit. Each year more genetic counselors report using the survey results to negotiate starting salaries and merit increases and benefits.

The published report is also reviewed by other allied health professionals, human resource representatives and those who may be interested in the field of genetic counseling. The consistency of the survey and the final report establish a benchmark for negotiation in many areas including salary and associated benefits.

Survey Success

The 2006 survey was the most successful survey to date. We saw an increase in the percentage of full NSGC members completing at least part of the survey. Most notable was the number of genetic counselors who reported salary information. Confidentiality has been cited in the past as a reason for omitting salary information. The 2006 survey, as with the previous two surveys, was completed online. However, the 2006 survey was the first in which respondents did not enter their social security number. Upon accessing the survey Web site, through the members only section of the NSGC Web site, respondents were asked for their NSGC member ID number. Once the ID number was entered, the survey appeared. This insured that only full NSGC members completed the survey. The ID number was not linked to the responses, and no unique identifiers were obtained as part of the survey.

Diversity

As with previous surveys, the majority of NSGC members are Caucasian females. Several years ago, NSGC began an initiative to increase diversity within the profession. To track the progress of these efforts, we added additional categories in the ethnicity questions to the 2006 survey. However, we have seen almost no change in the ethnic makeup of NSGC members. Since 2000, we have seen a 2% drop in Caucasians, a 1% increase in Hispanics and a 1% increase in the "other" category.

Expanding Roles and Specialization

With the completion of the human genome project and the expansion of pharmacogenetic research, the roles of properly trained genetics professionals will continue to increase. NSGC is proactively working towards positioning genetic counselors for the changing field of medical genetics. Each year we see new and experienced genetic counselors expanding their focus within the research and clinical areas. In 2006, we were able to add cardiology to the list of specialty areas in which genetic counselors work. The increase in genetic counselors choosing expanded roles allows us to stratify the data in new ways each year.

Billing and Reimbursement

Billing and reimbursement for genetic counseling services remains a top concern for the NSGC and its members. In 2006, a CPT code was approved and is currently in the early stages of utilization. As such, it is too early to determine the long-term success of this code. The 2008 PSS should begin to provide data to determine the frequency with which the code is being used and the reimbursement rate associated with the code in clinical practice.

Also in 2006, the NSGC Board of Directors approved a strategic plan for improving the outlook for billing and reimbursement. This involves a three-pronged approach with remedies on state and federal levels and with third party payors. Full details on this plan are available at the NSGC Web site (www.nsgc.org).

Salary and Advancement

As in previous surveys, genetic counselors report being satisfied with their current position in terms of scientific content, autonomy and staff interactions. Salary and opportunities for advancement remain the two areas in which genetic counselors report the least satisfaction. We continue to see a wide range in salary, especially between geographic locations, and the highest reported salary was $150,000. Armed with data from the PSS, many genetic counselors have reported great success in increasing their salary in their current positions as well as having the ability to negotiate a much higher salary in new positions. In 2005, genetic counselors reported an over 5% increase in salary, which is higher than the national average increase during the same time period.

Advances in genomic medicine are increasing the needs for individuals with experience in genetics. Clearly, genetic counselors are trained to meet these needs within the fields of medical genetics and genomic medicine. As genetic counselors become more integrated within the healthcare delivery system, we should see an associated increase in demand for our services as well as an increase in salary.

In summary, the 2006 PSS was extremely successful. We had the highest response rate overall, and more than 75% of respondents reported their salary and zip code, which has allowed for a more thorough examination of salaries stratified by region, experience, work environment and specialty. We are hopeful that even more data will be collected with the 2008 PSS.

References

National Society of Genetic Counselors, Inc. Professional Status Survey 2006, www.nsgc.org

National Society of Genetic Counselors, Inc. Professional Status Survey 2004, www.nsgc.org

National Society of Genetic Counselors, Inc. Professional Status Survey 2002, www.nsgc.org

Acknowledgements

We would like to thank **Elinor Langfelder-Schwind** and **Nancy Callanan** for critical review of this document. We also would like to thank the Professional Issues Committee for their long time dedication to the Professional Status Survey.

Liaison Report

Developments Advance the American Board of Genetic Counseling

By Robin E. Grubs, PhD, ABGC President

The American Board of Genetic Counseling (ABGC) now has a new partner in its mission to establish the standards of competence for clinical practice and advance the role of genetic counselors in healthcare through accreditation of graduate programs in genetic counseling and certification of genetic counseling professionals. Applied Measurement Professionals (AMP), the association management company headquartered in Olathe, KS, is now handling ABGC's management needs, as of July 1.

ABGC Acquires a Management Company

Like many credentialing organizations, ABGC is supported by a network of committees, bylaws, processes and procedures. While the organization has experienced a remarkable evolution in the 14 years since its inception - growing from 495 certified genetic counselors to more than 2,000 - the administrative and information technology needs of the organization became greater than what the staff, shared with the American Board of Medical Genetics (ABMG), could provide. The ABGC Board of Directors considered various staffing models that would allow for planned growth of the organization - a journey that led to the selection of AMP as its management company. Allowing AMP to handle tasks such as Board and committee meeting facilitation, Web site administration and database maintenance will allow ABGC to manage accreditation and certification more efficiently and to focus on setting standards for the profession.

About Applied Measurement Professionals

AMP is a wholly owned subsidiary of the National Board for Respiratory Care (NBRC) and is accredited by the Association Management Company Institute. The company's Management Services division boasts nearly 20 years of experience and is made up of 20 team members with expertise in association management, meeting planning, public relations, public policy, marketing, technology and other fields. AMP is uniquely qualified as a service provider for management of certifying agencies and a consumer, as it provides both testing and management services to its parent company, NBRC. This talented team will proactively oversee ABGC and work with the Board for continued growth of our organization and the genetic counseling profession.

Meet the New Executive Director

Executive Director, **Sheila O'Neal**, who has 14 years of multi-association management experience, will lead AMP's efforts for ABGC. Sheila has worked with professional societies and trade associations, but her main focus for the past seven years has been management of health care related certification boards. She has experience with various testing and research methodologies, strategic planning, board and organizational management, volunteer management, legislative initiatives, examination accreditation processes and recertification policies and has done extensive work with educational program accreditation processes.

Sheila maintains her current knowledge of nonprofit association management through membership in national and local societies such as the American Society of Association Executives (ASAE) and the National Organization for Competency Assurance (NOCA).

"ABGC is an organization that is preparing to evolve into the next stage of its life cycle. I'm excited to work with an organization at this particular point in time because there are so many opportunities and pathways to explore," Sheila said. "The Board is a wonderful group of individuals with such dedication and commitment to the profession – it is refreshing to see. I look forward to meeting as many of you as possible at the NSGC national conference, either at our booth (#410) or during the annual ABGC business meeting."

Future Directives

With the change to a management company, the Board can now focus its attention on such initiatives as streamlining applications for programs and professionals, updating information technology and reconsidering the certification examination frequency in light of state licensure. For more detailed information about new directions that ABGC is considering, attend the ABGC business meeting at the NSGC Annual Education Conference on Saturday, October 13 at 1:30 p.m. in the Shawnee Room of the Westin Hotel, Kansas City, MO.

Current ABGC Board

The members of ABGC's Board of Directors are: **Robin E. Grubs**, Ph.D, President; **Troy A. Becker**, MS, Secretary/Treasurer; **Carol S. Walton**, MS, Credentials Chair; **Leslie Cohen**, MS, Accreditation Chair; **Anne E. Greb**, MS, 2005-2006 President; **Lisa Amacker North**, MS, Director; **Heather Hampel**, MS, Director; **Barbara Pettersen**, MS, Director; **Cathi Rubin Franklin**, MS, Director; and **LuAnn Weik**, MS, Director. In addition, ABGC welcomes two newly elected members to the Board: **Janice Berliner**, MS and **Debra Lochner Doyle**, MS. They will begin their five-year terms January 1, 2008, replacing Troy

Becker and LuAnn Weik, who will complete their service on the ABCG Board as of December 31, 2007.

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Legislation Update

Achieving Licensure in Tennessee

By Amy Crunk, MS and Martha Dudek, MS

The Genetic Counselors' Licensing Act was passed this spring by the Tennessee General Assembly and signed by the Governor on June 7, 2007. The journey toward achieving licensure in Tennessee started in 2004 via discussions between the 23 genetic counselors in the state at that time. The general consensus was that licensure was something we wanted to pursue, but questions kept coming up about the details, i.e. supervision, ordering tests and continuing education. It was decided a draft bill would help facilitate our conversations.

Getting Down to Business

We formed a Licensure Working Group to draft a licensing bill. Language was developed using the NSGC Recommended Bill Language as well as other Tennessee allied health professionals licensing bills. We created an email list to communicate with all of the counselors in the state. The draft language allowed us to discuss specific issues among ourselves as well as with other individuals and organizations.

In October 2004, we created the Tennessee Genetic Counselors Association (TGCA) and inducted all Tennessee genetic counselors as members. Creating this organization allowed us to represent ourselves as a cohesive group when talking with individuals, organizations and legislators. Although the TGCA is not incorporated, it has officers, a Web site and letterhead. The officers (Table 1) were the individuals spearheading the efforts towards licensure, and the Licensure Working Group became part of the TGCA.

Table1

Inaugural Officers of the TGCA	
President	Amy Crunk
Vice President	Martha Dudek
Secretary/Treasurer	Kelly Taylor

The Licensure Working Group created information sheets to educate individuals and groups about genetic counselors and the need for licensure. A grant in 2005 from NSGC paid for associated costs including copying, official TGCA folders, the TGCA Web site and conference calls for the Working Group.

The Benefits of a Lobbyist

Since Nashville is the capitol of Tennessee, the majority of the work for licensure was done by the genetic counselors located in Nashville, eight of nine who worked at Vanderbilt University Medical Center (VUMC). Early in the process, they gained the support of the supervisors, faculty and administrators at VUMC, allowing us to devote extra time to our endeavor and recruit instrumental - gratis - help from a VUMC lobbyist. In the beginning, the lobbyist only outlined the key pieces and players we needed to be successful. However, once we had backing from sponsors, he guided us through the maize of "legislation making." He helped us find our way through committee meetings and talking with legislators before votes. We did the work, but his direction was invaluable. Additionally, because he is well respected and well recognized by legislators, his involvement made our many trips to the Hill go smoothly.

Gathering Reinforcements

While drafting the bill and before talking to potential legislative sponsors, we collected 60 letters of support from prominent individuals. One of the most important things we did was to approach key state organizations (Table 2). The approval of the Tennessee Medical Association (TMA) was crucial. The legislators, state organizations, potential sponsors, Senate and House committee members and the Governor's office with whom we spoke about licensure all asked if the TMA was in favor of our bill.

Table 2. Organizations and individuals contacted by TGCA prior to introducing licensure bill

Organizations	Prominent Individuals
Tennessee Medical Association	Other Allied Health Care Providers
Children's Hospitals Alliance of TN	Directors of State Genetic Centers
TN Chapter of the American Academy of Pediatrics	Members of the Governor's Genetic Advisory Committee
Vanderbilt University Medical Center	Tennessee Governor
Tennessee Family Physicians Group	Deans of Medical and Nursing Schools
Tennessee Nurses Association	Our Patients
Tennessee Psychological Association	Directors of Cancer Centers

Amy Crunk, the TGCA president, had multiple conversations with the TMA's president and lobbyist. Once we completed a draft bill, they reviewed it carefully. At their request, we added the requirement of a referral from a physician for a genetic counselor to see a patient. This compromise was reached after consulting with the NSGC and other genetic counselors in states that passed genetic counselor licensing bills.

In the summer of 2006 we completed our final draft bill, and by the fall we were approaching legislators in our home districts to ask for support and inquire about possible sponsorship. These legislators included the new Speaker of the House, a constituent of **Debbie Pencarinha** whose bipartisan support was important.

The Question of Governance

One-on-one conversations with legislators were key to learning more about the laws and politics specific to Tennessee. We were put in touch with a contact in the Tennessee Department of Health to review our language and ensure it conformed to other licensing bills. We also learned of the expense to have our own Genetic Counseling Licensing Board. In the state of Tennessee, all licensing boards must be financially self-sufficient, carrying enough reserve funding to cover any litigation that may occur. Due to our small numbers, this would make our licensing fees several thousand dollars per licensing cycle. Other possibilities included being overseen by an already established board with no genetic counselor representation or having our own genetic counseling committee within an established board. Having our own committee was appealing but still meant high licensing fees.

After much discussion, the TGCA decided that we wanted licensure even if it meant being overseen by another group. Licensure, we expected, would help to increase our numbers, so we could form our own committee or board in the future. Accordingly, our bill states that we are regulated by the Board of Medical Examiners. We made certain that all details related to the licensing of genetic counselors were in the bill, hopefully leaving nothing unspecified for when the rules and regulations are written. Each step of the way we tried to involve all of the Tennessee genetic counselors through emails, phone calls and meetings to ensure that we were in agreement with moving forward and there was opportunity to voice concerns.

The Legislative Process

Once our bill was introduced in February 2007, the process moved quickly. We had politically prominent sponsors who were able to move the bill along at critical times. We did have to endure the committee process in both the House and Senate. The TGCA had a member present at the dozen or more committee meetings, during which, most of the time, our bill was deferred to the next meeting or passed without discussion. Although we were never called on to testify during committee, our presence with our well-recognized lobbyist was noticed.

With two minor amendments of language, our bill passed first in the Senate 31 to 0 on April 25, 2007. One Senator gave testimony on the floor about how impressed he was when genetic counselor constituent, **Kami Wolfe Schneider**, visited him in his home office. One month later on May 24, the bill passed in the House 95 to 2. These were two very thrilling days to hear the gavel fall.

While the Tennessee Genetic Counselors’ Licensing Act is not perfect, we were successful in passing a strong bill that will allow for licensing the 28 genetic counselors currently in the state. As our numbers grow, we hope to make changes to the bill to allow for more self-governing. For now, we look forward to the hearing on the rules and regulations in mid-September, with licensure hopefully implemented soon after.

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Student Forum

What it Takes to be a Lab Genetic Counselor

By McKinsey Goodenberger, BS and Angela Tess, BS

This summer, 13 genetic counseling students from eight different graduate programs participated in the Genetic Counselor Laboratory Rotation at Mayo Clinic in Rochester, MN. Rotations lasted for one or two weeks and included shadowing laboratory genetic counselors in cytogenetics, biochemical genetics and molecular genetics. This is the second year that Mayo has offered this rotation, and once again, it was a great success. The experience enhanced our understanding of the genetic counselor's role in a clinical laboratory and also increased our knowledge of the molecular genetics, biochemistry and cytogenetics behind many genetic conditions.

A Busy Schedule

On the first day we reviewed the laboratory genetic counselor's role, toured the labs, spoke with the lab directors and worked through hands-on exercises illustrating the variety of issues counselors face in each laboratory. While many of us could probably guess the basic jobs performed by laboratory genetic counselors, we were all surprised at how many hats these professionals wear everyday.

For the next three days, students were assigned to the cytogenetics, biochemical genetics, or molecular genetics laboratories. All of the counselors and lab personnel were very helpful and informative. We learned about tests that are inappropriately requested and why this happens, the importance of knowing clinical information to ensure that correct testing is ordered and the decision-making process for orders that are questionable. It was very interesting observing result disclosures with the counselors and discussing sign-off of completed cases with directors. In each laboratory we had an opportunity to see the more technical aspects, such as the role of the microarray technical specialist in cytogenetics, the revolutionizing importance of tandem mass spectrometry in biochemical genetics and the difficulties of variants of unknown significance in molecular genetics.

The final morning of the rotation was spent learning about maternal serum screening, witnessing first-hand the details of a clinical service that many of us are counseling about in our prenatal rotations. That afternoon, we each presented a case-report or project to the laboratory genetic counselors, showing what we had learned in our rotation.

The Value of Counseling

One of the misconceptions we had about laboratory genetic counselors is that they do not typically use "counseling skills" as a part of their job. We quickly learned that this is not the case; lab counselors educate other professionals about genetics so the professionals can then explain these concepts to patients. Lab counselors are cognizant of word choice so that other professionals with whom they interact (and who often work directly with patients) are careful with words and phrasing. Lab counselors work closely with the ordering clinician to ensure that the test ordered is the best for the patient in terms of sensitivity, specificity and result availability.

For Those Who Like Variety

Lab counselors have a fast-paced job, with each day different from the next. This variety is one of the appealing aspects of the job, and each counselor talked about how the job was a great fit for them. Many of the lab counselors also work in the clinic setting about one day a week, and they find this a satisfying balance between traditional and non-traditional counseling. One of the greatest features of this rotation was the lab counselors' enthusiasm to teach. Their patience was endless, despite their busy schedules, as we bombarded them with multiple questions.

The Mayo laboratory rotation has increased our knowledge of the testing techniques of many genetic conditions and our understanding of the job description of a laboratory genetic counselor. Since training programs generally lean toward the clinical genetic counseling role, this rotation was invaluable. It clarified how genetic counselors are a crucial part of a laboratory and how a career in a clinical laboratory can be both interesting and fulfilling.

For more information on the Genetic Counselor Laboratory Rotation at Mayo Clinic, contact: Teresa Kruisselbrink, MS, 507.538.2344, kruisselbrink.teresa@mayo.edu

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Genetic Counselor Publications

By Deborah McDermot, MS

Featured Paper

Matloff ET, Shannon KM, Moyer A, Col NF. Should menopausal women at increased risk for breast cancer use tamoxifen, raloxifene or hormone therapy? A framework for personalized risk assessment and counseling. *Cancer Educ.* 22(1):10-4. 2007.

> *To exist is to change, to change is to mature, to mature is to go on creating oneself endlessly. -**Henri Louis Bergson**, French scientist, philosopher and psychologist (1859–1941)*

Echoes of HL Bergson can be heard when speaking with **Ellen Matloff** about her recent publication on the role of genetic counseling in decision-making surrounding medication use for menopausal women who are at increased risk for breast cancer. Ellen, an Associate Research Scientist in the Department of Genetics and the Director of the Cancer Genetic Counseling Program at Yale University, is quite modest when asked about the $250,000 grant she received from the Susan G. Komen Foundation that funded this work. The current paper is the second publication generated from this study, and both are co-authored by fellow genetic counselor, **Kristen Mahoney Shannon**, Program Manager, CCRA, at Massachusetts General Hospital (see Matloff et al., J *Women Health*, 2006).

While Ellen found it challenging to write the original grant application, the fundamental idea of incorporating the skill set of a genetic counselor into the decision algorithm faced by so many women seemed a natural extension of the profession. She states that when the FDA approved tamoxifen for chemoprevention, it became clear that existing models, like the GAIL model, had significant limitations for guiding appropriate use. There was little difficulty recruiting potential subjects for the study, and referring physicians were equally enthusiastic and eager for input on incorporating genetics when trying to decide between hormone replacement and breast cancer chemoprevention options.

From her studies, Ellen and her colleagues have developed a counseling model to provide to both doctors and patients. The advantage of the new model is its adaptability: it is designed to be easily updated to remain current with the rapid discoveries in this complex area of clinical care. The counseling model reflects Ellen's overall professional philosophy that genetic counselors themselves must always be willing to adapt to advances in order to continue growing as a profession.

Articles Co-Authored by Genetic Counselors, June - August 2007

(names of genetic counselors appear in bold)

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Welch KO, Marin RS, Pandya A, Arnos KS. Compound heterozygosity for dominant and recessive GJB2 mutations: Effect of phenotype and review of the literature. *Am J Med Genet*. 143A:1567-1573. 2007.

Contact: Deborah McDermott, dam2001@med.cornell.edu

AEC Update

Kansas City, Here We Come!

By Karen Potter Powell, MS and Courtney Rowell, MS, 2007 AEC Co-Chairs

It's almost here, and excitement is building! You don't want to miss the 26th NSGC Annual Education Conference (AEC) in Kansas City, MO, October 12-16 and the Short Course, "Survival Skills for the 21st Century: How to Shape Your Future as a Genetic Counselor," October 11-12. In addition, we are pleased to offer something new this year - an Advance Session, "Emerging Technologies for Genetic Teaching and Learning," held on Friday, October 12, before the AEC begins. To view a complete conference schedule, go to www.nsgc.org/conferences/aec.cfm.

Sharing with Students

Also on Friday, NSGC has coordinated an Outreach Event to "give back" to the local host community. Students in the Kansas City area are invited to attend a special presentation to expose them to the global picture in the field of genetics. Speakers include:

- photographer, **Rick Guidotti**, presenting, "Positive Exposure: Celebrating the Spirit of Difference" (www.positiveexposure.org)
- genetic counselor, **Diane Baker**, discussing the role of genetic counselors in the Katrina crisis
- a panel of teenagers with genetic conditions sharing information about their particular disorder and how it affects their lives.

A question and answer period will follow. Please join us if you are in Kansas City on Friday.

A Savant in our Midst

The AEC itself will commence with a special Dr. Beverly Rollnick Memorial Lecture, "We Share the Same Shadow," featuring **Kim and Fran Peek**. Kim, a savant with a photographic memory, was the inspiration for the character, Raymond Babbit, played by **Dustin Hoffman**, in the Oscar®-award winning movie "Rain Man."

Described by some as the world's most famous savant, Kim was born in Salt lake City, Utah in 1951, diagnosed with macrocephaly, an encephalocele, an absent corpus callosum, no anterior commissure and damage to the cerebellum. Despite these birth defects, Kim could memorize every book read to him from the age of 16-20 months. Kim reads a book in about one hour and remembers approximately 98%. According to some sources, he can recall about 12,000 books from memory! Kim and his father, Fran, travel across the world to share Kim's story, skills and message. We look forward to welcoming Kim and Fran Peek to the AEC.

Something for Everyone

The AEC, Short Course and Advance Session planning committees have worked hard to organize events to appeal to our ever-growing and diverse profession. There is still time to register (www.nsgc.org/conferences/2007/registration07.cfm) and reserve your room at our host hotel, The Westin Crown Center (www.nsgc.org/conferences/2007/travel07.cfm).

We look forward to seeing you in Kansas City, the City of Fountains (www.kumc.edu/gec/kc/)!

SIG Activities

Legal SIG Calls For Topics of Discussion

The Legal SIG would love to hear from you regarding medical/legal issues for which you would like more information. Topics could include: legal advocacy and legislation issues, public health issues, reproductive technologies, etc. Discussion of such topics is beneficial for the entire NSGC membership. The Legal SIG is available to share their expertise.

Please send topics of interest to Sandy Factor, MS, JD, Legal SIG Chair, at ENGRAVITAS@aol.com.

Familial Cancer Risk Counseling SIG Reports Three Public Opportunities

Professional Status Survey (PSS) 2006: Cancer Genetics Analysis Available on the NSGC Web site

The Cancer Genetics Analysis has become the standard among cancer genetic counselors in establishing benchmarks for salaries and benefits as well as gauging job satisfaction. Some highlights from the analysis include:

- The number of genetic counselors concentrating on cancer genetics is increasing.
- There has been a 33 percent increase in patient volume since 2002. The average caseload is now in the range of other subspecialties, with the exception of prenatal.
- Cancer genetic counselors earn a competitive salary when compared with the other subspecialties.

The entire PSS 2006, "Cancer Genetic Analysis on the Familial Cancer Risk Counseling SIG," can be found on the Web site www.nsgc.org/members_only/sig/sig_familial_crc.cfm.

Now Online - "NSGC Comments on Breast Cancer Screening with MRI Recommendations"

In the 2007 *Perspectives* summer issue, the Familial Cancer Risk Counseling SIG reported submitting an electronic Letter to the Editor (eLetter) in response to the article, "American Cancer Society Guidelines for Breast Screening with MRI as an Adjunct to Mammography" (*CA Cancer J Clin*. 57:75-89. 2007). The eLetter has since been posted online and can be viewed at http://caonline.amcancersoc.org/cgi/eletters/57/2/75.

Cancer SIG Co-Chair, Nancie Petrucelli, Quoted in *Journal of the National Cancer Institute*

Nancie Petrucelli was interviewed for an article by **Mary Beckman** titled, "Genetic Nondiscrimination Legislation Could Improve Cancer Prevention - If it Passes" (*JNCI.* 99:993-995. 2007). Beckman's article speaks about the Genetic Information Nondiscrimination Act (GINA) of 2007, which passed the U.S. House of Representatives in late April but is currently being held up in the Senate. If passed, GINA would provide a uniform standard to fully protect the public from discrimination by both health insurers as well as employers, allowing individuals to take advantage of genetic testing, clinical trials and research without the fears of discrimination. To view and download the article, please go to http://jnci.oxfordjournals.org/cgi/content/full/99/13/993.

Contact: Nancie Petrucelli, MS, CASIG Co-Chair, petrucel@karmanos.org or Joy Larsen Haidle, MS, CASIG Co-Chair, joy.larsen.haidle@NorthMemorial.com

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Research Network

Four Studies by the Organization of Teratology Information Specialists (OTIS)

1) The Autoimmune Diseases in Pregnancy Project

PIs: Tina Chambers, PhD, MPH and Ken Jones, MD

Abbott Laboratories, Amgen, Apotex, Aventis, Barr, Bristol-Myers Squibb, Par Pharmaceutical, Sandoz and Teva are participating in this research study to evaluate the potential teratogenic effects of medications used to treat various autoimmune diseases during pregnancy including rheumatoid arthritis, psoriasis, ankylosing spondylitis and psoriatic arthritis. Leflunomide, Humira (adalimumab), Enbrel (etanercept) and Orencia (abatacept) are specific medications being studied. Participants must be pregnant, have a diagnosis of one of the listed conditions or have exposure to one of the medications.

Contact for Professionals: Diana Johnson, 877.311.8972, d4johnson@ucsd.edu
Contact for Potential Subjects: 877.311.8972

2) Discontinuation of Antidepressants During Pregnancy

PI: Anick Berard, MD

This study is investigating the effect of discontinuing gestational use of antidepressants on maternal behavior during pregnancy as well as on the cognitive and behavioral development of infants. Women who call OTIS and who are taking an antidepressant prior to the 14th week of pregnancy are eligible to participate in the study.

Contact for Professionals: Nadia Ceccotti, 514.343.6111 ext. 15485, nadia_ceccotti@hotmail.com
Contact for Potential Subjects: 514.343.6111 ext. 15485

3) Postmarketing Surveillance for Safety of Adacel, Menactra and Fluzone in Pregnancy
PIs: Tina Chambers, PhD, MPH and Ken Jones, MD

This study explores a variety of potentially effective methods for identifying vaccine-exposed pregnancies and will establish baseline numbers of exposed pregnancies. The study also will provide preliminary data on pregnancy outcome for a subset of women exposed to Adacel, Fluzone or Menactra during pregnancy. To participate, women must be pregnant and have had exposure to influenza, meningitis or pertussis vaccines during their current pregnancy.

Contact for Professionals: Diana Johnson, 877.311.8972, d4johnson@ucsd.edu
Contact for Potential Subjects: 877.311.8972

4) OTIS–MOD iPledge Isotretinoin Pregnancy Prevention Survey
PIs: Rich Miller, MD, Tina Chambers, PhD, MPH and Dee Quinn, MS

This study is a continuation of a previous OTIS investigation that attempted to uncover why women become pregnant following participation in pregnancy prevention programs. This particular study is looking at the new, more stringent program, iPledge, which was instituted in January of 2006. Women are being recruited who became pregnant within one month of discontinuing the use of isotretinoin. The study involves three telephone surveys during and after the pregnancy.

Contact for Professionals: Dee Quinn, 866.626.3547, dquinn@email.arizona.edu
Contact for Potential Subjects: 866.626.6847, button #2

Public Eye

Media Watch

January –April, 2007 - *Northern Nevada Family Life*
Robbin Palmer has been busy advocating for genetic counseling services in her community. She wrote an article, “Document Family Health Histories,” in the January issue of *Northern Nevada Family Life (NNFL)*, where she described how family gatherings during the holidays are a good time to gather and record family history to assess one’s health risks. The February issue of *NNFL* ran her article, “Genetic Counselors: Translating Science into Clinical Practice,” which explained what a genetic counselor is and what happens in a genetic counseling appointment. For the April issue, Robbin wrote, “Genetic Testing for Hereditary Breast Cancer,” which included case scenarios of probable HBOC, information

about genetic testing for hereditary cancer and the role of the genetic counselor.

May 16, 2007 – Duke University Medical Center Web site (www.mc.duke.edu), "Thymus Transplants Give Hope to Babies with Fatal Immune Disease"
This article told the story of the 31st baby to have a thymus transplant at Duke to correct immune system deficiencies caused by DiGeorge syndrome. The results of Duke's experience with thymus transplants, published in the journal, *Blood*, show that 75% of the babies who received a thymus transplant were alive after one year, whereas all would have died without the transplant.

May 21, 2007 – ABC News, ABC-TV, "Who's Your Daddy? Paternity Battle Between Brothers"
Identical twin brothers who both slept with the same woman battled to determine which is the father of her baby to avoid paying child support. Paternity testing indicated both men had over a 99.9% probability of being the father. This story points to one limitation of DNA evidence in determining paternity.

May-June, 2007 - Dairy Queen television commercial
A man in a lab coat behind a desk with a plaque saying "Genetics Counselor" meets with a female ice cream and a male waffle cone. The counselor tells the couple that he has received their test results, and the couple can have children together because the waffle cone is not "lactose intolerant." The waffle cone and ice cream then run out of the office together, blissfully happy.

July 8, 2007 - *The New York Times*, magazine section, "The Gregarious Brain"
This article discussed Williams syndrome, which is described as a "small genetic accident" leading to a deletion of about 25 genes out of 30,000. Citing research being done on the personality attributes of people with Williams syndrome, the article explains the cognitive deficits associated with the syndrome, the "exuberant gregariousness and near-normal language skills" often exhibited and the social savvy and lack of social fear.

July 25, 2007 – *The Indianapolis Star* Web site (Indystar.com), "Genetic Counselor Looks at Cancer's Hereditary Ties to a Patient"
Cindy Hunter described the career path and interests that led her to the field of genetic counseling and what her job entails in cancer risk assessment counseling. The article explained the schooling necessary to become a genetic counselor and the main specialties in which genetic counselors work.

July 30, 2007 – BBC News, "Inherited Cancer Fear 'Unfounded'"
Results of a UK survey suggested that people worry unnecessarily about cancer in their family because they do not realize that only a small number of cancers are hereditary. The survey indicated that 91% of more than 1,000 people "falsely" believed that if a relative has had cancer they are at a greater personal risk, when in fact, the likelihood of an increased risk is small, as nine out of ten cancers appear by chance. A quarter of people surveyed thought that between 50% and 100% of cancers are hereditary, and 60% of people thought family history was the biggest risk factor for cancer. The information nurse manager at Cancer Research UK was quoted as saying, "While most cancers are not strongly linked to family history, if people are worried they should speak to their GP for advice." There was no mention of genetic counselors.

July 31, 2007 – The Hallmark Channel, *"New Morning"*

Caroline Lieber, Director of the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College, was interviewed on this morning TV program. She discussed the importance of family history and reviewed the profession of genetic counseling.

August 13, 2007 – *The New Yorker*, "An Error in the Code"
A very interesting, sensitive article explained the mystery of Lesch-Nyhan syndrome. The writer interviewed **Dr. Nyhan** and included the stories and symptoms of several patients. The article accurately explained X-linked inheritance and mentioned a few other genetic conditions associated with "profound behavioral changes."

Contact: Roxanne Maas, rruzicka@gmail.com

In Remembrance

By Heidi Cope, MS

Marcy Carlson Speer, 47, died Saturday, August 4, 2007 in Duke Hospital following a valiant battle with breast cancer. She was born October 1, 1959 in Indianapolis and was raised in Indiana and Illinois. Marcy graduated from Indiana University and received a Master's degree in genetic counseling from Sarah Lawrence College. She obtained her Ph.D. in genetics from Duke University. A Durham, NC resident since 1985, Marcy was a long-term faculty member at Duke in the Center for Human Genetics. She was named Director of the Center this past year.

Marcy was an accomplished researcher with international acclaim. She published 124 papers on 24 different diseases and was actively working on at least eight more manuscripts. She received 24 research grants and was an authority on the genetics of neural tube defects such as spina bifida and anencephaly.

Marcy was a devoted mother whose energies were always directed toward her children. Marcy is survived by her husband of 24 years, Kevin P. Speer, MD, her daughters, Kira and Casey, her mother, Marsha Carlson, and her brothers, Ned, Eric and Kris. She was predeceased by her father, Milton Carlson, this year.

Donations in Marcy's memory may be made to: Komen for the Cure, 2314 S. Miami Blvd. Ste 154, Durham, NC 27703; www.komen.org

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Region II Update

Region II Representative
Ellen Schlenker, ellen.schlenker@genzyme.com

A Message from Your Representative

This is my last update as your regional representative to the NSGC Board of Directors. It has been my honor and pleasure to represent you to the Board. I encourage each of you to *get involved with NSGC. I am sure you will find it to be as rewarding and educational an experience as I have.*

This is an exciting time for NSGC and for the profession of genetic counseling. We are making great inroads in our billing and reimbursement efforts. You will also hear more about the upcoming changes in our governance structure, which I believe will make NSGC a stronger, more powerful organization.

I would like to thank Vicki Lyus and Flavia Facio for co-chairing the Region II Annual conference. Unfortunately, I was unable to attend but I heard it was wonderful! I also extend a big thank you to all of the volunteers on the planning committee.

Thank you again for the honor of being your representative. - Ellen Schlenker

Annual Region II Education Conference

The annual Region II education conference titled, "New Developments in Genetic Counseling: Implications and Growing Opportunities for Our Practice," was held on April 27 at the NIH in Bethesda, MD. The meeting was preceded by the "Genetic Counselors' Day on the Hill," when several counselors visited the offices of their representatives and senators. The counselors were very well received and learned a great deal about the challenges of policy making. Thank you to all who helped make the day a success.

The Region II conference was attended by nearly 100 genetic counselors and genetic counseling students from the region. The conference was kindly sponsored by the National Human Genome Research Institute Genetic Disease Research Branch, Myriad, Lenetix and GeneDX.

The meeting started with an introduction titled, "Genomic Science and Public Policy," by **Francis Collins**. Subsequent topics included: The CETT Program, Regulations of Genetic Testing, Billing & Reimbursement, GINA, New Developments in Hereditary Cancer Counseling, Cardiovascular Genetics, Prenatal Screening for Aneuploidy and Psychiatric Disease. Speakers included genetic counselors and physicians from around the region. For a complete list of topics and speakers, please go to www.nsgc.org/conferences/Regions/2007/Region_2.cfm.

Genetic Counseling Programs

Howard University

Howard University Genetic Counseling Program is proud to announce the graduation of several students for spring and summer 2007. Their names and thesis projects are below:

> **Brandi Blaisdell**: X-Linked hydrocephalus and LICAM: Mutation detection and its implications
>
> **Heather Collins**: A qualitative study of opinions of sickle cell patients regarding cord blood banking and use for a potential treatment for sickle cell disease
>
> **Tiffiney Greer**: Hyperthermia combined with lipoxygenase inhibitors as potential treatment for metastatic prostate cancer

Adriana Malheiro: Erythrocyte carbonic anhydrase in African-American obese children

Tejani Mendiz: Psychosocial concerns of women with epilepsy in the Black community

Kim Morrison: Assessing urban school district high school teachers' and guidance counselors' awareness of genetic counseling as a career choice

Kim Muse: A survey of genetic counselors on their knowledge and views about the genetics of alcohol dependence: Counseling at-risk individuals and their relatives

Oluwatosin Olaleye: The effect of the written newborn screening letter on mothers of newborns with sickle cell trait on understanding and subsequent follow-up in an urban district

Please join us in congratulating these fine women. We look forward to their future contributions to the genetic counseling community.

McGill

McGill congratulates its 2007 genetic counseling graduates! **Marilyn Richard** has taken a maternity leave position in prenatal diagnosis at the Jewish General Hospital in Montreal. **Jennifer MacLean**, **Nassim Taherian** and **Teresa Tiberg** are job hunting - Nassim in London, UK and Teresa following a two-month trip to Europe this fall.

University of Montreal

The Master's in Genetic Counselling Program at the **University of Montreal**, which opened its doors in the fall of 2004, is the first North American program in which the language of instruction is French. **Gail Ouellette**, PhD, MSc, will assume the position of Program Co-Director. Both the McGill and University of Montreal programs welcomed students from the genetic counseling program in Marseille, France for rotations this summer.

2007 graduate, **Isabelle Gosselin**, took on a new position at CHUM-Hôtel-Dieu in Montreal as a counselor for cancer genetics research projects. A second graduate, **Josianne Leblanc**, joined the Genetic Counselling Service at the Centre Hospitalier de la Sagamie in Chicoutimi.

Arcadia University

The Genetic Counseling Program at Arcadia University has a new home, moving to a new house on Limekiln Pike in January. Now the faculty offices, administrative office, two classrooms, kitchen and student lounge with computer workstations are under one roof. In May, a "grand opening" celebration was held in the new house. It also served as a marvelous home base for a very successful recruiting cycle. Arcadia welcomes 13 dynamic new students in the fall, bringing our total enrollment for the year up to 26. We welcome visitors to come and see us anytime.

The 2006-2007 academic year finished on a strong note. Eight students graduated, most already employed in places ranging from Canada to California. This group was recognized for the high quality of their research projects with several platform and poster presentations scheduled for the NSGC AEC in Kansas City. Those not able to attend their thesis presentations last April will get another chance to see what they have accomplished.

Arcadia is working on the re-accreditation process for the ABGC. Many of you have helped by completing surveys, updating clinical site forms and reviewing materials. Once again we are reminded to express our gratitude to all who participate in the process. This program is truly community based and you are an essential element in that community.

Virginia Commonwealth University (VCU)

Virginia Commonwealth University's Master's in Genetic Counseling program achieved re-accreditation by ABCG this spring until 2015. VCU also is enrolling our first dual degree student for a Master's in Genetic Counseling and a Human Genetics PhD.

Regional Practice News

The New York State (NYS) Genetic Counselors Group is participating in preparations for the upcoming direct-to-consumer (DTC) advertising campaign for BRCA testing. NYS Genetic Counselors have been invited to discussion groups and planning committees. This is a unique opportunity for genetic counselors to advocate for their role in risk assessment and guidance in genetic testing. They have done a fantastic job coordinating a response fro the Department of Health to the DTC campaign to let the public know about the availability of genetic counselors in the state. In addition, NYS Genetic Counselors have been asked to assist the Genetic Alliance in their WikiGenetic Project. This August, NYS Genetic Counselors introduced a new communication tool to facilitate working groups. We are looking forward to a busy fall. For more information contact **Luba Djurdjinovic**, MS and **Randi Zinberg**, MS, Co-Chairs, NYS Genetic Counslors Group.

Member News

Karlene Australie is the new President of the Quebec Association of Genetic Counsellors. Congratulations, Karlene!

Veteran genetic counselor, **Lola Cartier**, was awarded the Montreal Children's Hospital Foundation Award of Excellence in the Professional category this spring, and her colleagues are very proud.

Linda Nee recently had an article published: Nee LE. Genetic Counseling and Presenilin-1 Alzheimer's Disease: "Research Family" Members Share Some Thoughts. *Am J Alzheimer's Disease and Other Dementias*. 22(2):99-102. 2007.

Deanna Steele, genetic counselor at Magee Women's Hospital spoke at the Malignant Hyperthermia Association of the United States Diagnostic Test/Hotline Workshop on September 7, 2007 at Children's Hospital of Philadelphia. Deanna works with the University of Pittsburgh to coordinate genetic testing for malignant hyperthermia.

Genzyme Genetics in Philadelphia is excited to welcome several new counselors to their group: **Meagan Corliss**, **Beth Jiorle**, **Christen Pulicare**, **Laura Monaco** and **Joanne Gablik** have all joined since January.

In the fall of 2006, **Stephanie Fox** assumed a new full time position in Medical Genetics at the Montreal Children's Hospital.

Lidia Kasprzak returned to her post in the cancer and adult genetics clinic at the Montreal General Hospital after her maternity leave. She joined **Laura Palma**, who was hired in July of 2005.

Elizabeth Kramer joined a private perinatal practice, Maryland Perinatal Associates, in January 2007. She is enjoying the challenge of being a part of a rapidly growing new practice.

After a very extended maternity leave, **Susan Levine** returned to work at New Jersey Perinatal Associates in Livingston, NJ.

Best wishes to **Laura Thomson** who will be leaving Syracuse, NY and Region II to move to Children's Mercy Hospital in Kansas City, MO as a Senior Genetic Counselor.

Jessica Vega and **Lindsay Warner** have joined the genetic counseling staff of Reprogenetics. Jessica is in the lab in Livingston, NJ, and Lindsay is in the lab in California. The new contact number for the New Jersey PGD counselors is 973.436.5003.

Region VI Update

Region VI Representative
Fiona Field, Fiona.field@csun.edu

State Representatives
Alaska - Christy Le Blond, cleblond@health.state.ak.us
California (Northern) - Kerstin Spangner, kspangner@hotmail.com
California (Southern) - (vacant)
Hawaii - Alison Taylor, ataylor@queens.org
Idaho - Anne Spencer, SpencerA@dhw.idaho.gov
Nevada - (vacant)
Oregon - Cori Feist, feistc@ohsu.edu
Washington - Darci Sternen, darci.sternen@seattlechildrens.org
British Columbia - Kim Gall, kgall@cw.bc.ca

We are looking for new State Reps for the following vacancies: Southern California and Nevada. Please contact Fiona Field at fiona.field@csun.edu or 818.677.6259 if you are interested in serving.

Region VI Education Conference

Stayed tuned for further information on upcoming educational offerings from the NSGC.

Genetic Counseling Programs

California State University Northridge (CSUN)

Congratulations to the 2007 Graduates of the CSUN Program. Many of the graduates will present their thesis work at the upcoming 2007 NSGC AEC – hats off to a job well done!

Tonya Harrel accepted a position at Southwest Washington Medical Center. Tonya's thesis topic was, "Recontacting former patients regarding BART."

Bret Hutchinson will be working for the California State AFP Screening Program in Sacramento. Bret's thesis topic was, "Opinions of university students on ethical use of blood and tissue samples in genetic research."

Claudia Hernandez will be working for Dr. Linda Cowan's private office in Los Angeles. Claudia's thesis topic was, "X-AFP test knowledge and anxiety in minority women."

Carin Huzienga will be working for Children's Hospital in Los Angeles. Carin's thesis topic was, "Genetic discrimination and genetics professionals."

Mitchel Pariani will be working for Cedars Sinai Medical Center in Pediatrics and Adult Genetics. Mitchel's thesis topic was, "C-KIT system in testicular germ cell tumors: An immunohistochemical analysis."

Lindsay Warner will be working for the Reprogenetics in South San Francisco as a PGD genetic counselor. Lindsay's thesis topic was, "Knowledge, opinions and practices of PGD and HLA typing."

Erin Yokoyama will be working for Kaiser Permanente in Panorama City. Erin's thesis topic was, "QOL in Women who carry a BRCA1/BRCA2 mutation."

University of California, Irvine (UCI)

UCI congratulates the 2007 graduates of the Genetic Counseling Program.

Sandra Brown accepted a position with Genzyme Genetics in Orange County. Her thesis topic was, "Health literacy, numeracy and interpretation of graphical breast cancer risk estimates."

Elaine Chen accepted a position with Genzyme Genetics in Los Angeles. Her thesis topic was, "Knowledge and perception of diabetes causes and risk factors in a Southern California Chinese cohort."

Lauren Ann Dennis accepted a position with the UCSD Prenatal Diagnosis Center. Her thesis topic was, "Screening for heteroplasmic mitochondrial DNA mutations with Surveyor Nuclease; Investigation of complex I nuclear modifying genes in a family with Leigh syndrome."

Julia Platt accepted a position with UC Irvine in Mitochondrial Medicine. Her thesis topic was, "Investigation of prior preterm birth and early third trimester CRH levels."

Stephanie Rosemberg accepted a position with Genzyme Genetics in Los Angeles. Her thesis topic was, "Does genetic variation in *IRS1*, *IRS2* or *SHC1* alter susceptibility to developing breast cancer in *BRCA1* and *BRCA2* carriers?"

UCI Program Director, **Ann Walker**, has announced she will be resigning her position as director as of January 1, 2008 and retiring later in the spring. She hopes to remain involved in teaching and patient care to a modest degree. A search committee is being formed to identify a new program director, and suggestions are welcome.

New GC Programs in California

Two new genetic counseling programs are in the works in the Northern California area and hope to be accepting students for admission in the fall of 2008:

- California State University Stanislaus hopes to offer a Master's of Science in Genetic Counseling tract under the direction of **Laurie Nemzer** and **Dr. Janey Youngbloom**.
- Stanford University welcomes new Director, **Kelly Ormond**, from Northwester University. Kelly and Medical Director, **Dr. Louanne Hudgins**, are excited to be developing the Master's in Human Genetics and Genetic Counseling Program for Stanford.

Upcoming Education Opportunities

The Genetic Counseling Program at California State University Northridge will host a one-day conference on September 29, 2007 entitled, "The Changing Face of Muscular Dystrophy." Speakers include **Dr. Timothy Miller** and **Dr. Perry Sheih**. Genetic counselor CEUs wil be offered. For more information, contact: 818.677.3611.

Regional Practice News

New Collaboration between Genzyme and Children's Hospital of San Diego

The San Diego Perinatal Center, which was previously partnered with Children's Hospital of San Diego to provide prenatal diagnostic services, became affiliated with Genzyme Genetics in May 2007. Of the four counselors who were part of the original Perinatal Center, only **Tara Shea** remains and is now a Genzyme employee. Two new counselors at the new Perinatal Center are **Kaori Onozuka** and **Ashley Badgwell**.

Liesl Mestre and **Diane Masser-Frye** remain at Children's Hospital but now are focused on pediatric counseling, including counseling for the hemophilia, muscle disease and cystic fibrosis clinics. Children's Hospital of San Diego also launched a Genetic Counseling Clinic and is preparing to open a comprehensive Down Syndrome clinic, which Diane will coordinate.

Kim Kopita, formally of the San Diego Perinatal Center, continues to be employed at Children's (after a brief period of employment by Genzyme) but is under a contract with the state to do CF counseling as part of the Newborn Screening Program.

Member News

Kristen Anstrom has left Nevada to start medical school at Ohio University in Athens, OH. The hospital where she worked, St. Mary's in Reno, will not be hiring a replacement as they are phasing out Maternal and Fetal Medicine.

Michelle Applegarth joined the genetics staff at the San Diego Naval Medical Center.

Colleen Brown is a recent transplant from Region II to Region VI. Colleen is working on starting a new Program in Cardiovascular Genetics at UCSF. The new program is a collaboration between Genetics (Colleen and geneticist **Dr. Robert Nussbaum**) and Cardiology. The program is aiming to provide multidisciplinary care for families with hereditary cardiovascular conditions including Marfan syndrome, cardiomyopathies, arrhythmias and congenital heart defects. Contact Colleen with family referrals or questions about the new program at Colleen.Brown@ucsf.edu.

Kaiser Santa Teresa in San Jose is happy to welcome the following new staff: **Megahn Beck**, newly graduated from the University of Pittsburgh, and **Catherine Tipps Vendola**, newly graduated from the University of Texas.

Heather Hussey has joined St. Luke's Hospital in Boise/Meridian, ID, bringing the total number of genetic counselors working in Idaho to six. She is a recent graduate from the University of Utah Genetic Counseling Program, in their first graduating class.

Jessica Kushner has taken a new position at Oregon Health and Science University (OHSU) as a Study Coordinator for the National Registry of Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions (GenTAC). The purpose of GenTAC is to create a data and biospecimen repository of patients with or at risk for genetically induced thoracic aortic aneurysm, which will be available to researchers interested in improving the diagnosis and management of such patients. Patient and health professional resources (e.g. brochures) are being created at this time. There is also a Web site for more information at http://gentac.rti.org. Enrollment is expected to begin October 2007 at the five participating centers in the U.S., including OHSU.

Franchesca Liao began with California Pacific Medical Center's Prenatal Diagnosis Center in June. CPMC is currently 12 counselors strong and growing. Franchesca is fluent in Mandarin and is one of eight bilingual counselors.

Hawaii welcomes **Melissa Ortiz** to the Fetal Diagnostic Institute of the Pacific.

Teri Richards recently retired from the University of California at San Digeo.