Perspectives in Genetic Counseling

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Special Report: Hurricane Katrina Efforts Continue

In the last issue of Perspectives, *we learned of two genetic counselors who forged a relief team in Texas to assist a large family that had escaped Hurricane Katrina. In the two articles below, the tremendous efforts of genetic counselors continue, as students and seasoned professionals volunteer their time and devotion to reunite families and identify missing persons. NSGC commends all of our colleagues who helped better the lives of the victims of this natural disaster.*

Ringing the Bell: The Louisiana Family Assistance Center

By Barb Biesecker, MS and Holly Peay, MS, NHGRI/NIH

National Human Genome Research Institute (NHGRI) investigators, **Drs. Joan Bailey-Wilson** and **Les Biesecker,** served on the advisory group to the post 9/11 identification efforts. One of the lessons learned from these efforts was that collection of accurate family relationships is essential when DNA from relatives is to be used in the victim identification process. When Katrina and its subsequent floods hit, the doctors volunteered again as advisors to the DNA identification efforts.

In this capacity, Dr. Bailey-Wilson traveled to Baton Rouge to the Louisiana Family Assistance Center. There she helped **Dr. Amanda Sozer,** a DNA forensics expert, and **Tammy Pruet Northrup,** manager of the Louisiana State Police Crime Laboratory DNA Unit, with organize and document the ways genetic professionals could assist in finding missing persons, taking pedigrees and supporting in DNA collection efforts. Upon her return to Maryland, Dr. Bailey-Wilson identified genetic counselors and clinical geneticists interested in traveling to Baton Rouge to help in these efforts. The NHGRI also continued to play a leadership role by identifying geneticists around the country willing to volunteer.

The Bell of Hope

Genetic counselors at NHGRI were in an ideal position to help because funds were secured to support assistance efforts by staff geneticists. Many NHGRI genetic counselors and clinical geneticists traveled to Baton Rouge, as well as two classes of Johns Hopkins

University/NHGRI genetic counseling graduate students. There is consensus that this is some of the most important work any of us have ever done.

During our first trip in early January, many of the thousands of missing persons were being found. Many people had been displaced after the storm and were unable to re-connect with their relatives, some who were also displaced. Since the hardest-hit areas were economically disadvantaged, it was even more difficult for family members to locate each other. Every time we found someone, we were invited to ring the bell in the Center. The bell reminds everyone working hard to chase down obscure leads that hope remains.

Counselors and Detectives
Genetic counselors served several roles at the Center. We worked with devastated family members who witnessed relatives drowning or who had reason to believe their loved one was dead. We collected accurate family histories to assist in the identification of appropriate relatives to target for DNA collection, and we facilitated the sample collection from those family members by answering questions related to the collection and testing process. Genetic counseling skills were vital for this work; research proficiency, internet savvy, grief counseling, family history-taking and overall sensitivity.

Upon our second volunteer visit to Baton Rouge in March, the majority of the missing persons had been found alive. Those left on the missing persons list were much harder to locate or to confirm dead. We worked more as detectives than as counselors, but it was rewarding nonetheless, as each identification was a victory.

Future Roles of Genetic Counselors
Our group at NHGRI plans to pursue efforts to ensure that specifically trained genetic counselors are available in the wake of future national or international disasters. We could be called upon in varied circumstances when our counseling, genetics and inquiry skills may help families who are missing a loved one or in cases where the identity of remains is unclear.

For an in-depth report of genetic counselors' efforts in Baton Rouge, listen to NPR's story on DNA Identification of Katrina Victims click here.

GC Students Gain a Special Education from Hurricane Katrina

By Ira Lu, MS

During spring break this past March, a group of five first-year and two second-year genetic counseling students from Sarah Lawrence College traveled to Baton Rouge to assist the Louisiana Family Assistance Center. We were volunteers responding to an email request for students to help identify deceased victims of Hurricane Katrina. **Dr. Siobhan Dolan,** our public health genetics professor and a geneticist and OB/GYN at Montefiore Medical Center in the Bronx, supervised us on this journey.

Work to Be Done
The large-scale damage of the hurricane washed away items that would normally be used as reference samples, such as biological materials from hairbrushes and toothbrushes. For recovered bodies too degraded to assess pathology and dental records, kinship analysis was the only means for DNA identification. This work involved close association with the Louisiana State Police, forensic specialists and the family history unit. When our group first decided to go to Baton Rouge, the task before us seemed inevitably challenging. Still, we

were hopeful to use our counseling skills to help the survivors of this natural disaster and possibly bring them some closure.

Finding Missing Persons
Upon arrival at the Center, we were each given a stack of missing persons files. Our job was to contact family members, collect family history information and initiate the process of setting appointments for DNA collection. Since it is difficult to put families through this process, we investigated every possible lead before attempting to contact the families.

In our searches, we learned that many missing persons were actually relocated during evacuation and were alive and well. We are happy to say that each of us found at least one missing person alive during our stay, and thus, we were able to close their case. We also were able to reconnect families and friends. In one instance, a newborn screening record led Dr. Dolan to a pregnant woman reported missing because she gave birth after the storm. When a missing person was found alive, a bell rang in the office, and everyone stopped and clapped for the accomplishment.

Noteworthy was the dedication and teamwork of every volunteer at the Center. Many have been away from home for several months to work in Baton Rouge. The chaplains who assist there and the stress management team, Louisiana Spirit, were also essential, offering emotional and psychological nurturing to the volunteers working painstaking hours.

A Life Changing Experience
On the last day of our stay, we were treated to an authentic Louisiana crawfish boil and a tour of New Orleans led by **State Trooper Officer Neale.** We walked among debris of some of the hardest hit areas, such as Lakeview, the Lower Ninth Ward and St. Bernard's Parish. We saw broken levees, water lines over eight feet tall, mold-covered walls of torn-apart houses and markings on homes that had been searched for bodies. Many of us recognized street names from the missing persons files and felt a strange connection to the places we visited. Our trip to Louisiana was immensely rewarding and eye-opening for us all. We came away from the experience with a greater appreciation of the role for genetic counselors in public health, forensics and disaster relief.

Point-Counterpoint

Prenatal Chromosome Microarray Analysis

In November 2005 at the NSGC Annual Education Conference, one particular Educational Breakout Session created a buzz. The topic: chromosome microarray analysis (CMA), a test that enhances quantitative genome analysis, compared to standard chromosome studies. The controversy: use of CMA in the prenatal setting. ***Sandra Darilek, MS,*** *and* ***Dr. Aurthur Beaudet*** *from Baylor College of Medicine, led the EBS and reviewed data from their study on the benefits of prenatal CMA. In the point/counterpoint below, Sandra re-opens last year's discussion, and* ***Monica Marvin, MS,*** *the Assistant Director of the Genetic Counseling Graduate Program at the University if Michigan, who attended the meeting, offers a varying view on the use of this technology.*

Point: The Value of CMA in Prenatal Screening

By Sandra Darilek, MS

Chromosome microarray analysis (CMA), also known as array-CGH, combines chromosome and FISH analyses to detect aneuploidies as well as all known microdeletion and microduplication disorders including telomere rearrangements. Since 2003, this testing has been available for postnatal evaluation of individuals with suspected genomic disorders. The application of CMA in the prenatal setting is now gaining consideration.

CMA Research

To understand the risks and benefits of CMA in the prenatal setting, Baylor College of Medicine undertook a study of couples at increased risk of chromosome abnormalities due to abnormal fetal ultrasound findings or advanced maternal age. Couples were informed of CMA and the risks and benefits of testing during a genetic counseling session. Ninety-eight couples with high-risk pregnancies agreed to participate, and their fetal samples were analyzed by karyotype and CMA.

In this group of 98 pregnancies, four cases of Trisomy 21 were detected by both methods. An unbalanced translocation involving chromosomes 3 and 7 also was detected by both methods; however, CMA provided more detailed and clinically relevant information regarding the translocation breakpoint. Copy number variants detected by CMA were in most cases familial, with only 1% of cases having an unresolved variant. Couples were more likely to proceed with CMA testing if their fetal ultrasound showed abnormalities or if they desired as much information as possible about their pregnancies.

Improved Detection

The major benefit of this new prenatal testing is the discovery of an abnormality that previously may not have been detected. Most of the well-characterized microdeletion and microduplication disorders are difficult to detect with prenatal ultrasound alone, and most are sporadic conditions. As such, CMA can provide expectant parents with valuable information for making decisions about a current pregnancy or the baby's medical care after delivery.

With CMA, there is the possibility of results of uncertain significance, which may lead to increased anxiety in a pregnancy. However, this risk exists with all prenatal testing, including chromosome analysis and fetal ultrasound. In the near future, large-scale prospective studies may help directly compare CMA and karyotype. Until that time, prenatal CMA is available after comprehensive genetic counseling about its limitations and benefits.

Counterpoint: Cautions Against Routine Prenatal CMA

By Monica Marvin, MS

Chromosome microarray analysis (CMA) is a promising technology for detecting constitutional chromosome abnormalities. While CMA is likely of utility in prenatal cases with an identified anomaly, it is premature to use this technology on routine prenatal specimens.

A 2000 report from the Secretary's Advisory Committee on Genetic Testing states, "No test should be introduced to the market before it is established that it can be used to diagnose and/or predict a health-related condition in an appropriate way." Four recognized objectives to assess in considering genetic tests include:

- analytic validity
- clinical validity
- clinical utility

- social consequences

Potential Ambiguity
In considering the use of CMA in routine prenatal specimens, the analytic validity, or how well a test performs in the lab, is high. However, the clinical validity, clinical utility and social consequences are ambiguous. Preliminary data from Dr. Arthur Beaudet's laboratory, presented at NSGC's 2005 Annual Education Conference, suggest that the majority of abnormalities detected using this technique in routine prenatal samples will be "obvious" abnormalities that are already detected with traditional cytogenetic techniques.

Furthermore, about 10% of prenatal CMA results will require blood samples from both parents for appropriate interpretation (not always an easy task). The same preliminary data suggest that approximately 1% of samples will be of low clinical utility due to the detection of de novo variants that remain difficult to interpret.

Effects on Society
There are a number of potential negative social consequences of CMA in routine prenatal diagnosis including unequal access, stigmatization and anxiety surrounding the diagnosis of fetuses and parents with de novo variants of uncertain significance. And let's not forget the threat of a "slippery slope" by allowing prenatal testing for inherited "traits" rather than medical conditions.

CMA has the potential to be a powerful diagnostic technique. However, until additional data is available to clarify its clinical validity and utility and its possible social impact, prenatal use of CMA should be limited to research protocols and to pregnancies with identified ultrasound abnormalities.

For Your Practice

Do You Know Your NPI?

By Peter Levonian, MS, Billing and Reimbursement Subcommittee

The National Provider Identifier (NPI) is a number that grants a unique identifier for a health care provider. The National Plan and Provider Enumeration System is the agency that provides the NPI. As of October 2005, genetic counselors have been included on the list of providers eligible for an NPI. As NPIs are mandated and maintained by the United States federal government, they are only available for genetic counselors that practice in the US.

The NPI had its origins in the HIPAA administrative code. HIPAA mandated the adoption of standard unique identifiers for health care providers, with the purpose of improving the electronic transmission of health information, and CMS thus developed the **National Provider** Identifier. Don't let the terms "electronic transmission of health information" turn you away; NPIs are important for our efforts in billing and reimbursement. NSGC's Strategic & Analytic Billing & Reimbursement Advisory Group (SABRAG) recommends that every genetic counselor apply for an NPI well in advance of the end of 2006. Any individual attempting to bill for health care services after January 1, 2007 will be required to submit an NPI.

How do you get an NPI?
Signing up for your NPI is stunningly easy. First it is a good idea to check with your institution to make sure that they have not signed up for you. Assuming not, then you're ready to begin the short process:

1. Go to this URL: https://nppes.cms.hhs.gov/NPPES/Welcome.do
2. Click on "If you are a healthcare provider…"
3. Click on "Need an NPI? Apply online for an NPI." (The instructions state that it will take 20 minutes from this point. That's only if you're using an untrained monkey.)
4. Click "Begin application."
5. The first screen asks you for your user name and password. There is no magic user name or password here. You are selecting it right now.
6. Simply follow the on-screen instructions from here. Early in the process you will be asked to confirm that you are applying as an individual versus as an organization. Click "individual."
7. There is only one other place where you might get tripped up: At one point you will be asked for your "taxonomy number" (corresponding to a particular field of work). When you scan the list, you won't find "genetic counselor." Click on "#17-Other Service Providers." When you click "next", this will take you to another list. "Genetic counselor" will be on this list (just above "funeral director" - honestly). Everything else should go smoothly.
8. After you register, you will get a confirmation e-mail. Congratulations! You now have an NPI.

Conclusion
You should apply for your NPI. Will having this number assure that you will be able to bill and get appropriately reimbursed for your services? No, there are several other factors at play as well. However, one thing is certain: After January 1, you will not be able to bill if you do not have an NPI. Do it. Do it now. It's quick and easy.

There are a number of potential negative social social consequences of CMA in routine prenatal diagnosis including unequal access, stigmatization and anxiety surrounding the diagnosts of fetuses and parents with de nova varients of uncertain significance. We must also be careful of the threat of a "slippery slope" by allowing prenatal testing for inherited "traits" rather than medical conditions.

CMA has the potential to be a powerful diagnostic technique. However, until additional data is available to clarify its clinical validity and utility and its possible social impact, prenatal use of CMA should be limited to research protocols and to pregnancies with identified ultrasound abnormities.

Licensure Update Series, Part 1

The NSGC Licensure Subcommittee is pleased to present a new series addressing the controversial obstacle encounter when applying for licensure. This first article addresses whether or not to include the ability for genetic counselors to order genetic tests in a licensure law.

Should Genetic Counselors Seek Licensure to Order Genetic Tests?

By Cheryl E. Harper, MS, Licensure Subcommittee Co-Chair

When applying for genetic counseling licensure, each state must determine the importance of genetic counselors' ability to order genetic tests independently. The states that have been successful in their licensure efforts thus far have not included this ability. Whether genetic counselors are qualified to be involved in ordering genetic tests is neither controversial nor in dispute. The question is if we are the appropriate professionals to be taking full and complete responsibility for ordering tests, and if this is in the best interest of the public. States that feel strongly about having this ability will need to be prepared to counter the opposition's arguments, to negotiate in some areas and possibly to decide if this issue is important enough to "make or break" licensure itself.

How to Begin

First, one should determine the level of support for including the ability to order genetic tests among the state's genetic counselors, clinical (MD/DO) geneticists and Medical Society. The licensing laws of the state's other mid-level professionals should be reviewed to determine if this activity is allowed and, if so, what limitations/restrictions are placed on this activity. For instance, there may be a requirement for a contract/document signed by both the provider and the supervising physician specifying which tests can be ordered without a physician counter-signature. It may be advantageous to model licensure language similarly to that used in other licensure laws in the state.

Reasons to Support

The strongest reason for including the ability to order genetic tests is that many genetic counselors are already routinely involved in this activity. Genetic counselors who work with physicians not trained in clinical genetics may be the only ones familiar with test applicability, interpretation and follow-up. One can argue that it is neither effective nor efficient for physicians to order genetic testing for unfamiliar conditions. Furthermore, if genetic counselors in private practice were able to order genetic tests instead of requiring the patient be seen by a physician, there would be a decrease in health care dollars spent and an increased respect for both the patient's time and genetic counselor's expertise.

Reasons to Oppose

The strongest reason to oppose inclusion of ordering tests is that it may be considered part of the practice of medicine and reserved for physicians; the most vocal opponent is often the state's medical society. One argument is that since ordering tests is so intertwined with making diagnoses and medical management decisions, it should not be done without physician involvement. There may be particular concerns about counselors in private practice, since the potential is higher for a medical mistake in that setting versus working as part of a larger health care team. Opponents may stress that licensure is intended to protect the public, and since genetic counselors are not trained in medicine, they could miss a significant health problem, regardless of its genetic significance.

Other Considerations
Defining what is considered a genetic test is critical in determining which tests a genetic counselor would be able to order independently. Whether this includes all DNA or RNA-based tests, chromosome analyses, hemoglobin analysis, metabolic tests and others will need to be specified. Many states have recently passed genetic privacy/discrimination bills that define a genetic test. An existing definition should be reviewed to determine whether it would suffice for licensure purposes. Broad definitions will give the most flexibility and be more adaptable to future trends in genetic testing, but they also may face considerable opposition. Narrow definitions are less likely to be opposed but may be too restrictive, especially in the long term. Another alternative is to leave the definitions to the licensing board, since the rules developed by the board are more easily amended than the law itself.

In the next issue, Licensure Update Series, Part 2: The effects of language in the new Oklahoma licensure bill.

President's Beat

I am always glad for an opportunity to provide updates and insights into NSGC activities. Moving from our familiar systems to a large management company has been quite an experience for the Board of Directors and NSGC leadership, and I expect the impact has been felt at all levels of the membership as well. Over the past few months, the Board has enjoyed working with our new Executive Director, **Kristen Smith,** who brings a great deal of experience to this position.

Leveraging our Resources
NSGC is actively using the resources available to us through our association with SmithBucklin. We worked with the Director of Marketing and Communications to develop an initial marketing plan, and we look forward to developing a longer-range strategic marketing plan later this year. We solicited input from the Government Relations team in developing an immediate and long-range strategy for the Billing and Reimbursement Task Force, which is chaired by **Leslie Cohen**. The Conference Management team has been working very closely with the AEC Subcommittee on the upcoming AEC and Short Course. The Information Technology Services (ITS) group worked closely with the Communications Committee on integrating the NSGC website with the membership database, allowing for real-time updates and greater ease with on-line membership renewal, meeting registration, nominations and voting, etc. The ITS group also helped design and implement this updated, online format for *Perspectives.*

Strategic Focus
As we gear up to develop our next strategic plan, we remain focused on meeting the goals of the 2003-2006 strategic plan. The Scope of Practice Task Force has completed their work and a final draft of their report is currently under review. In addition, the Evaluation Work Group, headed by **Elinor Langfelder-Schwind** and **Jen Farmer**, has developed an objective and comprehensive tool to evaluate the services provided by SmithBucklin. Input will be actively solicited in a number of ways including a subset of specific, evaluative questions on the full membership survey that will be conducted later this summer.

Kelly Ormond and the Long Range Executive Office Planning Task Force recently conducted telephone interviews with current and former NSGC leadership and other stakeholders. This information will be used to develop a set of questions that also will be included in the

upcoming membership survey. It is increasingly clear to me that our long-range executive office needs are very closely related to the goals we identify through the strategic planning process (i.e. the administrative and/or professional staffing needs and situations that can best support our strategic goals). As such, we will consider these needs in the context of the strategic planning process and implementation.

Let Your Voice be Heard
One of the most important responsibilities of membership is to voice your opinions about the strategic priorities and directions of NSGC. This summer, every NSGC member has two important opportunities to let your voice be heard.

- The first is by considering the nominations for the Board of Directors and casting your vote. NSGC needs leadership that is both visionary and strategic in guiding the direction of our organization and our profession into the future.

- The second is by completing the membership survey that will be distributed later this summer. Please take time to complete the survey to let us know your views about member services and NSGC strategic initiatives. This is YOUR professional organization, and your voice does count!

It is hard to believe that summer is here already. I hope that all of you get to enjoy the nicer weather and any vacations that you have planned.

Nancy Callanan, MS
NSGC President 2006

Student Corner

Immigrant Culture: A Genetic Counseling Population with Unique Needs

By Donnice Michel, BA, University of Cincinnati

Throughout my training in genetic counseling, there has been an emphasis on unique issues related to cultural background and diversity. Last summer, I encountered a culture I had not previously considered that brought up distinct psychosocial issues. I counseled many Hispanic patients in Dallas who were immigrants to the United States. They varied in the length of time that they had been here, their acculturation and their legal status, but they tended to have similar personal concerns. I attributed this to a cultural influence related to being an immigrant, and I reflected on how genetic counseling could better serve this population.

Exploring Psychosocial Issues
In genetic counseling sessions, the concerns that were repeatedly raised included limited access to health care, low socioeconomic status and education levels, potentially limited support systems, limited access to relatives and fear of deportation. Health care access and socioeconomic status certainly are obstacles for many groups in the United States. The

psychosocial issues of support and deportation surrounding immigration are a little more unique.

Support systems were non-existent for many of these patients. Most individuals traveled to the United States without any family members. I found myself empathizing with their loss and loneliness. Suggesting a visit or phone call would only worsen the issue, as most families didn't have the monetary resources to travel or make long distance calls. I learned that sometimes it was better just to listen and help them identify their own sources of support related to their new lifestyles.

The issue of deportation was most pressing in the counseling sessions. It was difficult for patients to disclose information about their families or their living or employment situations. They often were concerned that while their children were legal citizens, we would discover during their medical visit that they were not citizens and we would report them. It helped to emphasize that the information we obtained was for their children's health care and that it was kept confidential in their medical records.

Multicultural Genetic Counseling

When I first started this summer internship, I felt unprepared as a student to anticipate and manage the needs of the Hispanic immigrants who were my patients. Much of it seems obvious looking back, but perhaps including immigrant culture in our cultural awareness training would bring these issues to mind more readily. Encountering patients who have recently immigrated is becoming more common. To effectively serve this population, we should begin to familiarize ourselves with their unique issues before we enter the counseling session.

Sign Up for NSGC's Mentor Match: 10th Year Welcomes New Leadership

By Stephanie Herbert, MS and Melissa Stillberger, MS

The Mentor Match Program, sponsored by the Membership Committee, recently completed its 10th year and is making plans for the 2006 match under new leadership. The program has been a past success due to the enthusiasm and direction of **Troy Becker**. A hearty thank you goes to Troy for all of his efforts. **Stephanie Herbert** and **Melissa Stillberger** will spearhead the 2006 Mentor Match.

Benefits on All Sides

Mentor Match allows professionals and students to exchange ideas and information about their current interests or experiences in genetic counseling. The program runs over six months and will begin in August. Mentors and students are asked to contact each other every four to six weeks, with the focus determined by individual interests.

For practicing genetic counselors, Mentor Match offers contact with students which may not be present in their daily activities. For students, the program provides a chance to discuss a variety of issues and concerns with an experienced counselor and an entrance to the process of networking. The outcome and success of the Mentor Match is directly related to student participation; those more active in the program have the best experiences. Less active students tend to have poorer experiences and may create frustration for the genetic counselors who have volunteered.

Praise From Participants

"The greatest benefit of the mentor program was the opportunity to speak candidly with a genetic counselor about my personal and career goals and how to achieve those within the scope of the profession."
Jessica Hooks, UNCG, Class of 2005.

"The Mentor-Match program put me in contact with a genetic counselor that had similar interests as I did. I was able to email her throughout my second year and get her perspective on things like my thesis and job hunting."
Eleanor Rees, Brandeis, Class of 2006.

"I have always tried to participate in the Mentor Match because it is an important part of the growth of a genetic counseling student. Networking is critical to our field and being a mentor provides a connection for students outside of their training facility. This is important if a student is looking into a particular field of genetic counseling or wants to work in a specific area of the country. The time commitment required to participate is reasonable."
Michelle Moore, MS, Memorial Hospital, Colorado

Sign-Up is Open
To join the Mentor Match, sign up via email (below) by **Monday, July 10**. Include your name, email address and the US or Canadian postal address where you will be receiving mail in June when the registration questionnaires are sent. Mentors must have graduated prior to July 2004; students are eligible if they will graduate after January 2006. Those who participated in previous years will not be automatically re-entered in the program, so sign up again if you still would like to participate as a mentor or student.

Contact: Stephanie Herbert, allele44@hotmail.com
Melissa Stillberger, mstillberger@mail.com

SIG and Committee Update

The Professional Status Survey: An Important Tool for Genetic Counselors

By Maria Del Vecchio, MS, Professional Issues Chair and Susan Manley, MS, NSGC Treasurer

For more than 20 years, the NSGC has conducted a biannual Professional Status Survey (PSS). The PSS is a comprehensive survey aimed at obtaining data in eight areas:

- Background Information
- Work Environment
- Professional Status/Job Description
- Faculty Appointments
- Board Certification
- Salary and Benefits
- Professional Activities
- Job Satisfaction

Traditionally, nearly 70% of full members complete at least some part of the PSS (we hope that, in the future, all members will complete the entire survey). While there is a high completion rate throughout most sections of the survey, the salary and benefits questions are often left unanswered. Speculation exists as to why this section is skipped by nearly half of those who complete the other seven sections, but without supporting data, the reasons are unclear.

Why is Salary Data Important?
Genetic counselors around the United States and Canada are using the PSS results to negotiate fair starting salaries and merit increases and benefits such as travel and book allowances. All salary data remains confidential, and data points with less than five respondents are NOT used in order to keep data private. The more data NSGC can collect, especially in certain geographic areas, the more powerfully counselors with a range of years of experience and backgrounds can use the PSS analysis to successfully negotiate their salaries.

PSS Success Stories
The following testimonials verify how the PSS benefits our profession:

“I used the PSS in 2005 to negotiate salary for a position I was offered. I was given exactly what I asked for which was supported by the PSS data. The figure I negotiated was $9,000 more than the original offer. It certainly worked for me.”

“Our project is hiring a genetic counselor, so I was able to look at the PSS and determine a salary for this counselor. I ended up using the average salary for a genetic counselor, rather than the average for our region (region III - a very low salary region). People did not question it! Yeah!”

“I, like many others I'm sure, have used the PSS to justify salaries, both for my own job and for posting a new job. Because I live in New Mexico (poor state) and work for a public institution, the GCs here have had to struggle to get parity, and the PSS has been a BIG help. In fact, as I am being considered for a faculty position, I am looking forward to the next PSS to help with salary negotiations!”

“Last year the job title "genetic counselor" at our institution was successfully elevated a grade, which came with a nice pay increase. The PSS was crucial.”

“I was offered a position, but the salary was significantly lower than the average salary for my region according to the PSS. I explained this to the HR department and stated that I had documentation for them to review if they wanted and asked if they would consider the salary again. And they did! I got a much better offer and took the job and am very happy.”

“I am currently a second year student. I have referenced the PSS multiple times, even before I was in graduate school. As an undergraduate student exploring the field of genetic counseling, I used the PSS to gain a better understanding of the field. While I was considering in which regions to look for a job, I also used the PSS. Finally, and most importantly, I was able to use the PSS to set an acceptable salary range for myself based on what other counselors were earning in Region IV. Although I did not have to, I was prepared to bargain for that salary because I had the data from the PSS to reference.”

What Can You Do?
Look for an E-blast announcing the next PSS. **The PSS is scheduled to be online from June 19 through August 14, 2006**. As in the 2004 PSS, this year we would like to report

salary data for major metropolitan areas - ***but we need you to provide this data***. We need a sample size of at least five to report data for a specific area. Do your part. Complete the survey in its entirety, and encourage your colleagues to do the same. Perhaps you will be using the PSS data to successfully obtain a merit increase with your next performance review.

National Society of Genetic Counselors – 25th Annual Education Conference

Kick Up Your Heels in Music City, USA!

By Nicole Teed, MS, Kelly Taylor, MS and Martha Dudeck, MS, AEC Logistics Committee

The 2006 NSGC Annual Education Conference is headed to Nashville, TN, a city famous for its musical heritage. In the 1950's, the city gained recognition with "The Nashville Sound," a blend of country and pop music originating from the radio show, the Grand Ole Opry. More than just a music source, however, the city is home to fourteen universities, sweeping parks, museums and renowned restaurants. Pull up a porch chair, sip some sweet tea and read on to learn what this year's host city has to offer.

Accommodations
The AEC will be hosted by one of the largest and most unique hotels in the southern United States. The Gaylord Opryland Resort is in northeast Nashville, 15 minutes from the Nashville International Airport. A small city unto itself, the hotel contains 2,881 guest rooms and multiple options for entertainment, shopping and dining. Nine acres of indoor gardens boast winding rivers, walking paths, a 44-foot waterfall and laser-light and fountain shows. The Relache Spa offers salon services, massage therapy and a fitness center.

Music and Nightlife
Nightlife is no surprise in Nashville. The Bluebird Café has an international reputation for presenting original country and acoustic music seven nights a week. The Grand Ole Opry offers country, bluegrass and gospel, performed by platinum-selling artists and newer musicians. In downtown Nashville, you'll find restaurants, coffeehouses, nightclubs and shops, many in renovated warehouses. You can line-dance at the Wild Horse Saloon or enjoy local bands while honky-tonkin' on Broadway.

Shopping
The Opry Mills Mall is walking distance from the hotel and offers more than 200 retail outlets and a 20-screen movie theater. Hillsboro Village, a collegiate neighborhood near Vanderbilt University, offers locally-owned boutiques, cozy restaurants, an artisan bakery, a bookstore, an art gallery and the Pancake Pantry, a Nashville institution for Sunday brunch (be prepared for lines).

Historical Sights
History buffs will have their fill of sightseeing in Nashville. Tour the Hermitage, home of President Andrew Jackson and Fort Nashborough, the early settlement of Nashville, located in Riverfront Park. Fans of Scarlett O'Hara can tour the Belle Meade Plantation, where Union and Confederate forces skirmished in the front yard and bullet damage can still be seen in the mansion's stone columns.

Museums and Family Entertainment
A trip to Nashville is not be complete without visiting the Country Music Hall of Fame - with exhibitions including costumes, music memorabilia, instruments, photographs, manuscripts and film. Nearby you'll find the Ryman Auditorium, a unique concert hall with tours during the day and performances at night. Stop by the Hatch Show Print, one of the oldest working letterpress print shops in America, whose posters have featured performers like Hank Williams, Johnny Cash, Garth Brooks and Shania Twain.

For some of the world's greatest art, visit the Frist Center for the Visual Arts or Cheekwood, a 30,000-square-foot mansion with an indoor collection of early American, decorative and contemporary art and an outdoor display of Japanese, herb and flower gardens.

The young and young-at-heart also will enjoy the Nashville Zoo at Grassmere and the Adventure Science Center.

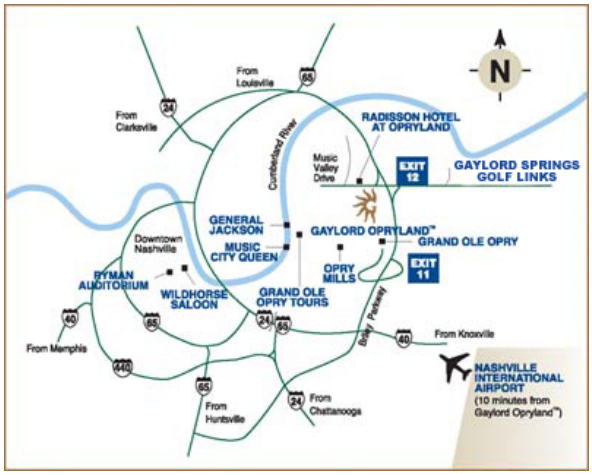
Side Trips
Consider renting a car and visiting one of the many destinations nearby Nashville. The Jack Daniels distillery in Lynchburg is about an hours' drive. Elvis's Graceland is west in Memphis. For hiking and spectacular views, visit Burgess Falls or Falls Creek State Park.

We look forward to seeing ya'll in Nashville!

Contact: Martha Dudek, AEC Logistics Chair, martha.dudek@Vanderbilt.Edu

Helpful Web sites

www.gaylordopryland.com
www.bluebirdcafe.com
www.oprymills.com
www.thehermitage.com
www.countrymusichalloffame.com
www.bellemeadeplantation.com
www.ryman.com
www.adventuresci.com
www.jackdaniels.com
www.elvis.com/graceland
www.state.tn.us/environment/parks/
www.lapetite.com
Nashville Convention and Visitors Bureau: www.nashvillecvb.com
Citysearch Nashville: www.nashville.citysearch.com
Downtown Nashville: www.nashvilledowntown.com



Media Watch

By Angela Geist, MS and Roxanne Ruzicka, MS

December/January, 2006 – *Fit Pregnancy*, "Early Warning"
A discussion of "new" first trimester screening reviewed the differences between AFP screening and first trimester screening, including various screen-positive rates. The article stated that first trimester screening is performed at 11-12 weeks gestation. CVS and amniocentesis were accurately explained as diagnostic testing options.

Winter, 2006 – SistaGirls.org
Genetic counseling was added to the career section of this website for teen girls after the site featured NSGC Diversity Subcommittee member **Kisha Johnson** and the 2005 Genetic Counseling Student Diversity Scholarship award winners, **Elaine Chen** (UCI) and **Stephanie Herbert** (Brandeis). SistaGirls.org gives teen girls from all over the world the opportunity to express themselves, read about their peers, learn about careers and health topics and see themselves represented on the web.

March 6, 2006 – *Reno Gazette Journal*, "Your Turn" section
This op-ed column published an article written by **Robbin Palmer** entitled, "Laws against genetic discrimination are essential." On April 22, KRNV-TV news also aired an interview with Robbin about her experience as a volunteer with the Find Family National Call Center in Baton Rouge, LA.

March 12, 2006 – *The New York Times*, "A Wrongful Birth"
Controversy surrounding wrongful birth lawsuits was highlighted via the context of a family who has a child with Wolf-Hirschhorn syndrome. The author shared her knowledge of genetic counseling from her personal experience of terminating a pregnancy with congenital CMV. Genetic counselors were described as "20-something," "biased toward termination" and providers of "mini-science lectures."

March 22, 2006 – *The New York Times,* "Flaw Seen in Genetic Test for Breast

Cancer Risk" and *Wall Street Journal*, "Test for Breast Cancer Risk Could Miss Mark"
Two news articles (that sparked a brief rash of emails on the NSGC listserv) reported the findings of a study by **King, et al** as published in *JAMA.* The articles reported that "as many as 12% of women with strong family history get inaccurate reading" from the BRCA1 and BRCA2 testing commercially performed by Myriad Genetics and that "without appropriate education, people may take a negative test to mean they don't have to worry." One of the articles mentioned genetic counseling as a "long-term relationship" with the client but did not clearly indicate that genetic counselors do discuss the limitations of available genetic testing with patients.

April 12, 2006 – *The New York Times*, "Seeking Ancestry in DNA Ties Uncovered by Tests"
A health story reviewed the increasing popularity of DNA ancestry tests and how individuals are using these results for college admission, financial aid and government entitlement.

April 13, 2006 – *The New York Times*, "A Crystal Ball Submerged in a Test Tube"
A commentary discussed whether new, expensive diagnostic tests use genetic information to determine the best course of treatment for a patient. The author explored several controversial issues of this testing, such as having only one lab performing a particular test, the need for FDA approval and poor reimbursement by insurance companies.

April 19, 2006 – Reuters, "Effort to Photograph Dying Children Helps Families"
In a program called, "Now I Lay Me Down to Sleep," professional photographers offer parents of dying children a series of portraits without charge. The newswire article featured the family of a baby with type 2 Gaucher disease. The disease was described as an enzyme deficiency in which the body can't break down a type of fat and stores it on organs, tissues and the brain stem.

May 12, 2006 – Fox-TV, "Evening News"
This NY-area newscast aired a segment on breast cancer services offered by the Weill Cornell Breast Center. The story included a shot of **Shivani Nazareth** and mentioned genetic counseling at part of the multi-disciplinary approach and breast cancer treatment.

Star/Rosen Media Highlights

NSGC in the Media: January-May 2006

From commenting on prenatal testing or direct to consumer testing, NSGC members have shined in the media spotlight. Star/Rosen, NSGC's PR agency, has worked with many genetic counselors to promote the Society and its goals. Below are highlights of recent media placements that included NSGC members.

- **Sarah Noblin, Jennifer Hoskovec** and **Nancy Callanan** drafted a letter to the editor at *The New York Times* in response to an article that discusses wrongful birth lawsuits and genetic testing.

- **Scott Weissman** was interviewed by a reporter at *HealthDay.com* and commented on a study published in *Cancer.* The article ran on February 15 and was picked up by *Forbes.com*. The article included a link to the NSGC website for further information.

- **Kelly Ormond** was interviewed by *The Associated Press* about direct to consumer testing. The piece was picked up by over 20 media outlets including *Forbes, Washington Post, Boston Globe*, *ABC News.com, Contra Costa Times, The Biloxi Sun Herald, Commercial Appeal.com, Redding Business News* and *Deseret Morning News*, with a circulation to date of 3,775,076.

- **Jill Allen** was interviewed for a story on prenatal testing for *ePregnancy* magazine which ran in the April issue.

- **Nancy Kramer** was quoted in an article in *B.A.B.Y.* (a publication of *LA Parent magazine*) about prenatal testing. The article listed the NSGC website as a resource for expecting parents who have questions about genetic testing and counseling.

- **Nancy Callanan** was interviewed for a *Consumer Reports* health newsletter that looked at the profession of genetic counseling. The article ran in the May issue and included the NSGC website as a resource for readers.

If you have any additional media opportunities or story ideas, please contact your SIG chairperson, and they will relay the information to Star/Rosen.

Resources

Book Review: *Designing Our Descendants, The Promises and Perils of Genetic Modifications*

Edited by: ***Audrey R. Chapman, PhD and Mark S. Frankel, PhD***
Published by: The Johns Hopkins University Press, 2003; 370 pps with appendices and index; $32.00 paperback
Reviewed by: ***Laura L. Dudlicek****, MS*

Are genetic engineering and designer babies “things of today” or “things of tomorrow?” Science is definitely progressing; but are medical ethics, the law and public policy keeping up? The book, *Designing Our Descendants, The Promises and Perils of Genetic Modifications*, fully addresses the idea of genetic modification, from practicality to practice.

An In-Depth Review
This well-organized, non-fiction text includes three main sections:

- technology and its availability
- ethics and religion
- policy

Each section contains essays from experts and a list of references. While the book lacks any graphics, the authors succinctly explain technical terms and processes. The book seems geared for readers who have a background in genetics.

The book poses numerous questions as well as many reasonable and thought-provoking answers provided by noted physicians, scientists, philosophers, theologians, lawyers and

policy analysts. Topics include alternatives to genetic modification, the issue of justice and discrimination, policy and marketing, access to technology, views from the Catholic and Jewish religions and the notion of "playing God."

For Your Library
Genetic counselors are not mentioned anywhere in this text, though we will likely be involved in the counseling of these patients and the informed consent process, if and when this technology is available. (Incidentally, an example consent is provided in the appendix.) Unless you work in an IVF/PGD clinic or a related field, you most likely won't be using this book in practice. Still, genetic counselors with an interest in genetic modification may want to add this to their collection.

Bulletin Board

Recertification News from the ABGC

Genetic counselors certified by ABGC in 1996 are required to recertify by the end of this year. Individuals certified before are encouraged to voluntarily recertify. Recertification shows a commitment to lifelong learning and helps to ensure that knowledge and skills are maintained in a rapidly evolving field. Recertification will become even more significant for licensing, professional advancement, employment, hospital credentialing and insurance reimbursement. The ABGC Administrative Office will begin accepting recertification applications on July 1. The ability to complete all recertification documents directly on the new ABGC Web site will be available soon. Stay tuned for further details.

Contact: Sharon Robinson, srobinson@genetics.faseb.org

International Society for Gastrointestinal Hereditary Tumours (InSiGHT) 2nd International Conference

March 27-30, 2007
Pacifico Yokohama Conference Center
Yokohama, Japan

InSiGHT, a combined organization between the International Collaborative Group on Hereditary Non Polyposis Colorectal Cancer (ICG-HNPCC) and the Leeds Castle Polyposis Group (LCPG), is seeking abstracts and attendees for its 2nd Biennial Scientific Meeting. The conference will focus on hereditary gastrointestinal tumours, including basic science, genetic epidemiology, research and registry information, case reports, nursing and counseling issues. The meeting is intended for international medical professionals, patients and family members dealing with hereditary gastrointestinal tumours.

To submit abstracts: www.insight-group.org/
To register: www.kyoundo.jp/insight
For information: **Takeo Iwama, MD,** iwama@po.kyoundo.jp

Sharpen Your Professional Edge - New Certificate Programs at Sarah Lawrence College, Bronxville, NY

Sarah Lawrence College has created two Advanced Certificate Programs for health professionals looking for career-related knowledge, skills and credentials. The certificate programs are: Public Health Genetics/Genomics and Applied Research Ethics. Both certificates offer flexible enrollment and participation in discrete modules without committing to the full program. CEU credit is available. Classes begin June 5, 2006 at Sarah Lawrence.

For details and curricula:
www.slc.edu/index.php?pageID=3909 for Applied Research Ethics
www.slc.edu/index.php?pageID=3910 for Public Health Genetics/Genomics

For a print brochure email: atakano@sarahlawrence.edu

Member News

By Jessica Mandell, MS, Perspectives Editor

A Colleague We Will Miss

It is with great sadness that we announce the death of NSGC member, **Mary-Jo Rosenblatt.** Mary-Jo died of cancer on April 10 at the age of 40. She is survived by her husband, Michael, and her two sons, Joshua and Zachary. Mary-Jo received her BA in 1987 from SUNY Albany and her Master's degree in genetics from the University of Cincinnati in 1991. At the time of her passing, she was a genetic counselor at the Albany Medical Center.

In the words of long-time friend and colleague, **Luba Djurdjinovic,** "It does not seem possible that this vibrant woman will no longer grace us with her laughter, willingness to help at a moment's notice and readiness to champion the genetic counseling profession. Many of us had the opportunity to witness her love and devotion for her family, to whom we send our deepest sympathies. We are grateful for the professional contribution and memories. She will be missed."

As a gift to her husband and sons, Luba is coordinating a collection of remembrances about Mary-Jo from her genetic counseling colleagues. Photos, stories and cards are welcome. Please send all contributions to: Luba Djurdjinovic, 124 Front Street, Binghamton, NY, 13905.

In addition, a scholarship fund is being set up in honor of Mary-Jo at her high school. For more information on donating, please contact Julie Lundberg at LundbeJ@mail.amc.edu.

Sarah Lawrence Names the Human Genetics Program in Honor of Joan Marks

On April 4, Sarah Lawrence College officially dedicated its Graduate Program in Human Genetics in honor of the program's first director and a creator of the genetic counseling field, **Joan H. Marks, MS.**

At a special ceremony and reception, colleagues, family and friends gathered for the renaming. Sarah Lawrence President, **Michele Myers,** and current Human Genetics Program Director, **Caroline Lieber,** offered opening remarks. Newswoman **Barbara Walters,** Joan's roommate at Sarah Lawrence as undergraduates, spoke of their long-time

friendship. World-renowned stem cell expert, **Dr. Irving Weissman,** from Stanford University Medical Center, presented the lecture, “Stem Cells: Science, Medicine & Politics.”

Joan started the Sarah Lawrence genetic counseling program in 1972, the first of its kind in the nation, and served as director until her retirement in 1998. In 1979, she also founded the Graduate Program in Health Advocacy at Sarah Lawrence, the first to train advocates working within the health care industry to ensure patients' rights.

Currently, Joan serves on several advisory groups including the American Board of Internal Medicine, the American Academy of Physicians and Patients and the Women's Health Initiative of the National Institutes of Health. She is a co-director of The New York Breast Cancer Study and is the author of, *The Genetic Connection: How to Protect Your Family against Genetic Disease.* In 2003, Joan was the first woman and first non-MD to receive the Excellence in Human Genetics Education Award, presented by the American Society of Human Genetics.

Congratulations, Joan, from all of NSGC!
