# *Perspectives in Genetic Counseling*

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## President's Beat

### The Role of Governance in NSGC

Governance has been the hot topic of conversation of the Board of Directors for at least the past three to four years. In fact, it has been discussed at some level since the beginning of NSGC's existence. The size and structure of the Board has been examined many times to determine if it is meeting our needs. The current Board and NSGC members felt this topic was so important that we included it in the most recent strategic plan.

What does governance mean? There are several different definitions, depending if you are talking about the private, public or non-profit sector. When talking about a professional association such as NSGC, governance can mean the process of decision-making and implementing (or not implementing) decisions of the volunteer Board with respect to establishing and monitoring the long-term direction of the organization.

So how can we structure our Board and organization to ensure that we are thinking strategically, acting quickly and utilizing our volunteer leaders effectively? Luckily there is research on governance to help us determine the best size and structure of our Board, our committee structure, liaison program, nominations process and volunteer and staff utilization. All of these pieces are critical when thinking about governance and how our association operates.

#### Size and Structure of the Board of Directors

There is a definite shift towards smaller Boards so that the entire Board feels engaged and on the same page. In general, Boards tend to start out large, reduce in size as the organization ages and then possibly increase in size again if the profession continues to grow and become more specialized. In addition, the Board composition must represent the interests of the core membership, not the interests of individual Board members. The Board is responsible for setting the direction of the organization with loyalty, care and obedience.

There are three types of Boards:

- ceremonial (no dialogue, no discussion)
- liberated (active engagement, dialogue, consensus, inconsistent information, time spent waiting to talk, not always listening)
- progressive (discussion, debate, consensus, "one voice" representation).

NSGC seeks to create a progressive Board; one that looks to what they can agree on and goes forward with the thought to agree. A progressive Board understands that their role is to guide the success of the organization and not their self-interests. All Board members agree upon the information flow, and the Board trusts the core workgroups or task forces without having to repeat their work in order to move forward. There is continual evaluation of the Board culture, the performance of the Board as a whole and the performance of individual Board members.

**Committee Structure**

Along with the size and structure of the Board, it is important to assess how we get things done within NSGC. What does it mean to serve on a committee, task force or working group? As a volunteer, are you given a specific task to accomplish in a given time frame? Do you know exactly what is expected of you? Do you know how to work with the staff of NSGC and what can they do to help you accomplish your task? When you join a committee, are you called upon to work on a project? Are you held accountable?

We want to make volunteering for NSGC a rewarding experience. We want to best utilize the skills and talents of volunteers by assessing the work to be done and then matching the people who have the needed skills with those positions. To this end, one of the options the Board is considering is to move towards appointing committee members and making sure that these members are assigned specific time-limited tasks that make the most of their skills, abilities and available time commitment. Several committees within NSGC are already utilizing this process.

**Mentoring Leaders within NSGC**

We also are evaluating ways in which members become involved in NSGC and how they are mentored through the process. We want to create more opportunities for members who are interested to learn about their organization and how to become strong and effective leaders. Our goal is to have a clear avenue for members to become involved so we can create a strong pipeline of leaders within NSGC.

Another important aspect of leadership is the nominations process we use to determine the slate of candidates for the Board. How can we encourage members to nominate candidates, and how can we encourage members to serve on the Board of Directors? Is it best to have candidates run against someone or to put forward an uncontested slate? An increasing number of professional organizations are using the uncontested slate option, and we are strongly considering this method for NSGC. I personally don't think the word "uncontested" accurately describes the process; it is contested at the beginning of the process rather than at the end when member input is more limited. Candidates are nominated by the membership, and it is the job of the Nominations Committee to choose the most qualified candidate by an application and interview process. The Committee would present a slate of candidates whose skills meet the needs of the current Board in terms of expertise and experience. A benefit of this process is that it helps reduce the attrition that can occur when strong volunteers decide not to run for office because of a previous lost election.

So the discussions continue, and we will spend more time on governance at our next Board of Directors meeting at the end of June. Evaluating our Board has been an exciting and informative process, and we look forward to implementing changes to ensure that NSGC continues to improve and grow in the future.

Cathy Wicklund, MS
NSGC President

# Case Report

## Prenatal Diagnosis for Huntington Disease: A Mother's Right to Know Without a Father's Knowledge

*By Rachel M. Barnett, MS*

### Huntington Disease Background

Huntington disease (HD) is a disorder of the central nervous system that causes progressive deterioration of involuntary and voluntary movement, cognitive decline and changes in personality. Symptoms usually appear in the third or fourth decade of life. Juvenile HD is relatively rare, with symptoms arising before age 21. Children with juvenile HD rarely live to adulthood.

HD is inherited in an autosomal dominant fashion. The gene was discovered in 1993 at chromosome 4p16.3, and the mutation involved is a CAG triple repeat expansion. There are four CAG categories:

- Normal allele: 26 or fewer repeats
- HD allele with reduced penetrance: 36-39 repeats, which may or may not produce symptoms
- HD allele: 36 or more repeats
- Normal mutable allele: 27-35 repeats; individuals do not develop HD but may have a child with HD.

It is possible to test at-risk individuals for the CAG repeat and to perform prenatal diagnosis. Adult onset HD usually results from 36 to 55 CAG repeats, whereas juvenile onset results from greater than 60 repeats[1]. HD exhibits anticipation, and large expansions occur mostly with paternal transmission[2,3,4].

Since there is no cure for HD, the decision to undergo genetic testing raises many legal, financial and personal issues. According to testing guidelines published in 1994, asymptomatic individuals under 18 should not be tested, but prenatal diagnosis may be performed by CVS or amniocentesis if a parent has a CAG repeat expansion[5]. Exclusion testing by linkage analysis can be used for fetuses at 25 percent risk when the at-risk parent does not wish to know his or her status.

### The Case

A 25-year old Caucasian female, six weeks pregnant, was referred for genetic counseling and prenatal diagnosis of HD. The patient's father-in-law, two of his sisters and his mother were diagnosed with HD. Her father-in-law developed symptoms in his 40s. Our patient was not aware of any genetic testing in this family.

Our client attended the appointment with her mother. Her husband did not know she was pregnant or that she wanted prenatal diagnosis. Her husband was reportedly aware of his

50 percent chance of inheriting HD and did not want to know his status. While the couple wished to be parents, our client did not want to bring a child with HD into the world. When she discovered she was pregnant, she decided to pursue prenatal diagnosis on her own. Her husband was 25 years old and asymptomatic.

**The Counseling**

We reviewed the fetus' 25 percent risk of having a disease causing allele. We stressed that, when possible, an affected individual should be tested first to confirm the diagnosis and verify the presence a CAG triple repeat expansion. CVS, amniocentesis and the option of exclusion testing by linkage were reviewed. Since exclusion testing would require cooperation by her husband's family, she felt this was not an option.

The bulk of the counseling focused on the potential impact of the test results. If the baby had an HD allele, the patient would know her husband was affected. In this case, she said she would terminate the pregnancy and not divulge any information to her husband. She wanted to protect her husband from the stress of learning his status, which could include emotional and psychological effects, altered relationships with his family and friends, difficulty obtaining long-term care, life and health insurance and potential discrimination in the work place.

If the baby did not have an HD allele, she would continue the pregnancy and tell her husband the results. She felt his joy at being a parent would eventually overcome any mistrust due to testing without his knowledge. She understood her husband would still be at 50 percent risk of developing HD.

We discussed at length other possible scenarios, such as:

- What if your husband suspects you are pregnant before the results are completed?
- If he responds in anger, would your safety be at risk?
- If your husband inadvertently found out he was positive, would he harm himself?
- Could you see yourself in a situation where you might use information about his status as a weapon?
- How would you cope with carrying the secret of your husband's status?
- Would a positive result impact your long-term commitment to your marriage?
- What would you do if we did not test the baby?

Our client had already thought about many of these scenarios. If her husband suspected she was pregnant, she would tell him, and if she terminated the pregnancy after a positive result, she would say she had a miscarriage. She did not feel her husband would hurt her or himself if he discovered he was positive for HD. Our patient and her mother assured us her husband's status would never be used against him. She felt it would be difficult to carry the secret of her husband's status, but she had a very supportive family and was prepared to undergo counseling. The couple's disagreements about asymptomatic genetic testing had created a rift between them, and our patient was more concerned about the effect on her marriage if she terminated the pregnancy without knowing the baby's status, an action she would take if we refused testing.

**The Literature**

After meeting with our client, we reviewed the literature and posted the case on the NSGC listserv. One response cited an article regarding the clinical, legal and ethical viewpoints on a hypothetical case similar to ours: a woman eight weeks pregnant who discovers that her

partner is at 50 percent risk of HD[6]. She seeks prenatal diagnosis, but her husband does not wish to know his status. In this article, the preferred action was to test the father first and offer prenatal diagnosis if he had the mutation, or perform exclusion testing.

Legally, the article cited Australian law, which holds that a mother can decide on prenatal diagnosis alone because the testing is performed on her body. Clinicians must provide the mother with information, advice and treatment, but not the father unless he also is a patient.

Ethically, the article determined that clinicians must offer testing to the woman in order to act in the patient's best interest. If both partners are present and their interests conflict, the authors suggested "maximization," promoting the interest with the greatest impact. For example, if the husband threatened to take his own life if he had HD, this harm may outweigh the harm to the woman if testing is not done.

**Professional Guidelines**

NSGC guidelines were established for prenatal and childhood testing for adult-onset disorders in 1995[7]. NSGC states that women who have an at-risk fetus should be informed of available testing, and that the decision to have testing must be the parents'. If prenatal testing could identify the status of relatives, attempts should be made to contact these relatives and obtain their testing permission. If the wishes of the parents and relatives conflict, consultation with an ethics committee or similar body is advised. Finally, if a genetic counselor feels uncomfortable providing a certain service, s/he may decline the case or refer it to another provider.

**The Decision**

The genetic counselor and perinatologists at our center decided that the patient's right to prenatal diagnosis for purposes of terminating an affected pregnancy outweighed the father's right not to know his status. Acting in the best interest of our patient meant respecting her autonomy and minimizing the harm of not testing, such as the termination of an unaffected pregnancy and psychological stress on the mother. While we were concerned about the father, he was not our patient, and legally we had no right to contact him (in the United States, HIPAA prohibits releasing medical information about our patient to her husband without her written consent.) We considered consulting with the hospital ethics board, NSGC and legal guidance. However, as there was no definitive guideline to follow, the ultimate decision would rest with our clinical team.

**The Testing**

Laboratories were contacted and notified of the circumstances of the case, and two were willing to perform the analysis. The patient returned at 10 weeks gestation with her parents, and CVS and maternal blood samples were collected.

Initial results revealed the fetus had one allele of 20 CAG repeats by standard PCR. This result could mean the baby had two alleles with 20 repeats each or the baby had one allele with 20 repeats and one allele with a large expansion (>60 repeats) not detectable by PCR. We requested the lab perform further analysis, and their protocol was to perform XL-PCR.

We contacted our patient to tell her we may never be able to rule out a very large expansion without knowing the repeat size in the family. Our client elected to tell her husband she had CVS to test the baby for HD. While initially shocked, he was pleased at the

prospect of being a father and expressed a desire to help clarify their baby's results. Arrangements were made for the couple to visit a local HD testing facility to discuss pre-symptomatic testing with a new genetic counselor. While he regretted the circumstances, the husband expressed his wish to know the baby's status even if it meant learning his own. The husband returned for a follow-up appointment to have his blood drawn.

**The Outcome**

One day later, the first laboratory completed XL-PCR and did not detect an expansion up to 130 repeats. At the same time, our client called the genetic counselors at both facilities to say that she learned her father-in-law was tested previously for HD and had 24 and 38 repeats. Given this information, the laboratory reasoned that an expansion from 38 to 130 repeats in two generations was highly improbable. They concluded that the fetus was homozygous for the 20 CAG repeat and did not have HD. At the time of this publication, the baby is three months old, and the family is happy with the outcome.

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## NSGC Ethics Subcommittee Response

The Ethics subcommittee of the NSGC had the privilege of considering this very interesting HD presymptomatic testing case. The subcommittee would like to first congratulate the author on so clearly laying out the case and what was at stake. We were impressed by the thoroughness and clarity in describing the case and the process the team followed.

The author provided great background for the case supported with a good review of the literature. This is necessary when considering any ethically challenging situation because, in some cases, what appears to be an ethical concern may be misinformation. Participants sometimes have a difference of opinion because the critical information is not well understood. Additionally, the author looked for similar cases in the literature, discussed the case with other genetic counselors and sought existing professional guidelines. These steps, too, are critical when faced with such a complex case.

### Confirming the Diagnosis

The Ethics subcommittee did have several points for consideration in addition to those outlined by the author. First is the uneasiness of having to go with the assumption that the diagnosis was correct with no real way to confirm it with records because the father's family could not be involved. This is of major concern given the serious decisions that were being made. If the disease turned out not to be HD or if the lab results could not be interpreted without additional information, then the outcome of this case may have been very poor. Not having a confirmed diagnosis to work with greatly raises the risk/benefit consideration for testing.

### The Family Unit

From a counseling standpoint, this case presents one of the ways genetic medicine can be more complex than traditional medicine. A patient's individual autonomy is usually considered to be of paramount importance in medical care, but genetics involves families, and this means that the needs of the family as a whole ought to be taken into account. In this case the interests of the mother, the father and the child-to-be were considered separately, but the interests of the family as a whole did not seem to come up in the discussion. While ultimately the mother may have the right to the information because of the baby, it is concerning that she should have knowledge about her husband's personal medical information without his consent within the context of a marriage. If she had found out that her husband was affected, there may have been damage to the marriage that could never have been repaired.

Also, it does not seem realistic to think she could get through the TOP without the support of her husband or without him ever finding out. We wondered if she was really prepared to live with the consequences of testing the fetus without him knowing. Was she able to make the decision about whose best interests were most important – the child's or her husband's? And even though the husband was not the primary patient, what about his rights as a member of this family? This case was particularly difficult because the genetic counselor was trying to balance the needs of everyone, as stated in our Code of Ethics, Section II: Genetic Counselors and Their Clients: "The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare and freedom." However, in some cases it may in fact be that the needs of the family as a unit trump any one individual's needs.

**Outside Consultation**

Lastly, consulting the ethics committees of NSGC and/or the counselor's institution may have helped the genetic counselors and maternal fetal medicine specialists identify alternate ways of thinking about this situation not previously considered. This might have resulted in recommendations of an alternate course of action. Often people outside of a discipline will think differently enough to come up with options not previously considered. Moreover, since this is such a challenging case, outside opinions often help clarify everyone's thoughts and better support the care plan for the patient.

This particular case ended successfully, but with the increasing levels of subterfuge, it may not have gone so well with a positive diagnosis. Therefore, we would argue for additional precautions:

1) an earlier and stronger attempt to involve the husband in a discussion with a genetic counselor and a mental health counselor
2) consultation with other professionals
3) consultation with a hospital and/or the NSGC ethics committees.

In summary, **Rachel Barnett** should be applauded for taking the time to share this article and a review of the literature with the genetic counseling community. Cases like this challenge us to clarify our thinking and help us appreciate the intricacy involved in the services we offer. We thank her for this opportunity.

***2007 NSGC Ethics Subcommittee:*** *Jehannine Austin, Dianne Bartels, Karin Dent, Sonja Eubanks, Bonnie LeRoy, Cate Walsh Vockley, Nancy Warren and Janet Williams*

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# For Your Practice Special Series

## Cases in Expanded Metabolic Screening

*This is the second article in a four-part 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 panel comprises 29 conditions to be tested by all state newborn screening programs[1], increasing the number of diseases on the test and requiring genetic counselors to determine the impact and recurrence risks of unfamiliar metabolic conditions.* Perspectives *is highlighting several lesser-known genetic conditions that are now included in newborn screening to help both metabolic and non-metabolic genetic counselors as they come face-to-face with these unusual diseases.*

## Case 2: Short-chain acyl-CoA dehydrogenase deficiency (SCADD)

*By Kelly Jackson, MS*

## Disease Review

**Biochemistry:** Deficiency of short-chain acyl-CoA dehydrogenase, an enzyme involved in the breakdown of short chain fatty acids. SCADD is classified as a mitochondrial fatty acid oxidation disorder.

**Genetics:** Autosomal recessive. The ACADS gene is located at 12q22-qter; one polymorphism in the gene causes ethylmalonic aciduria without SCAD deficiency (625G>A). The polymorphism in the SCAD gene, 625G>A, results in a more thermolabile enzyme. The polymorphism is estimated to be present in 35 percent of the general population in a heterozygous form and in seven percent in a homozygous form. The homozygous state leads to decreased catalytic activity of the enzyme.

**Incidence:** 1 in 40,000 to 1 in 100,000 newborns are homozygous for pathogenic *ACADS* mutations, besides the polymorphism mentioned previously.

**Natural History:** SCAD deficiency was first described in 1984 as a cause of secondary carnitine deficiency and lipid-storage myopathy. The classic presentation includes neonatal onset of metabolic acidosis and excretion of ethylmalonic acid (EMA) on urine organic acid analysis. Since the first cases were described, the presentation has been variable, with some patients presenting primarily a muscular phenotype of hypotonia and developmental delay and others having a severe neonatal course.

SCAD deficiency was originally thought to be rare. However, a study by **van Maldegem et al**[2] in The Netherlands suggested that the incidence is more common, with an estimate of 1/50,000 in the Dutch population. The phenotype in this population is nonspecific, generally uncomplicated and often transient with developmental delay, epilepsy, behavioral disturbances and hypoglycemia. Van Maldegem suggested that since SCAD deficiency did not meet major newborn screening criteria, it should not be included in the standard panel of screened disorders. However, newborn screening for SCAD deficiency is one of the 29 disorders recommended by the *American College of Medical Genetics' Newborn Screening Expert Group.*

## Genetic Counseling - Positive Newborn Screening and Testing of a Sibling

A one-week-old female of East Indian descent was referred due to an abnormal newborn screen showing elevations of C4 butyryl-carnitine. The differential diagnosis included isobutyryl-CoA dehydrogenase deficiency or SCAD deficiency. Confirmatory testing included urine organic acids which revealed marked elevations of ethylmalonic acid (EMA) of 164 mmol/mol creatinine (normal is less than 10). Urine acylglycines revealed a butyrylglycine level of 1.0 (normal is less than 0.1). Acylcarnitine analysis revealed a C4-carnitine elevation of 2.43 (normal is less than 0.62).

Mutation analysis of the ACADS gene revealed two copies of the 625G>A polymorphism AND two copies of a 136C>T mutation. There were other polymorphisms present in a homozygous state as well, suggesting that there may be a deletion of part or all of one copy of the SCAD gene in one allele (which is not detectable by sequencing) rather than two actual copies of each of these sequence changes. A deletion would look like homozygosity for whatever sequence changes exist on the non-deleted allele if sequencing was done. In

reality, if there is a deletion, the patient is hemizygous for the two sequence changes rather than homozygous.

The parents were counseled that their daughter's results suggested SCAD deficiency, which sometimes has biochemical lab abnormalities but no clinical symptoms. However, because of the risk of developmental delay and hypotonia, we recommended treatment with carnitine supplementation and avoidance of fasting. We also recommended testing their four-year-old daughter to see if she too could have SCAD deficiency. The four-year-old was reported to have had a seizure on day one of life, possibly related to low blood sugar. She had no other seizures and, other than occasional stomach aches, was in good health. The DNA testing on the sister revealed the same two sequence changes present in two copies. Again there were other "homozygous" polymorphisms, suggesting a deletion of part or all of one copy of the SCAD gene. Parental DNA analysis was recommended by the lab to clarify these results.

The father of the two patients was found to have the exact same results as his daughters: two copies of the 625G>A polymorphism and two copies of the 136C>T mutation, with other polymorphisms suggestive of a deletion in one copy of the SCAD gene. The father was 31 years old and in good health, with no history of hypotonia, developmental delay or problems with fasting. The mother of the two patients had one copy of the 625G>A polymorphism and one copy of the 136C>T mutation. There is no reported consanguinity between the parents. The results suggest that the father might carry a deletion of one copy of the SCAD gene (or portion of the gene) and then passed this deletion on to his daughters.

Counseling this family proved challenging because we wanted to treat both daughters for a condition shared by their father, though he had had no health problems. One could hypothesize that since the father had no medical issues related to SCAD deficiency, his two daughters shouldn't either. However, the complex nature of SCAD deficiency suggests that there are other factors involved in the presentation of symptoms, such as other genes interacting with the SCAD gene. There is no way to predict who will develop symptoms and who will not, with a given genotype.

The family moved back to India, and we referred them to a geneticist there for follow-up. However, there is a possibility that different geneticists will make different recommendations for treatment or that the family will not follow-up or continue the carnitine supplementation or avoidance of fasting.

## Teaching Lessons

### 1) Limited Knowledge of Natural History

There is controversy among biochemical genetics professionals as to whether SCAD deficiency is a real disorder or possibly a biochemical abnormality that does not cause symptoms. If the experts cannot decide, it is difficult for parents to believe what they are told regarding necessity for treatment.

### 2) Limitations of Confirmatory Testing after Newborn Screening

DNA testing through sequencing cannot detect large deletions or duplications in a gene; therefore, we often do not have all of the information regarding abnormalities in the gene in question. Patients can have biochemical changes on confirmatory testing but never develop symptoms of disease. SCAD deficiency is just one example of this phenomenon that is emerging from newborn screening data.

**3) Lack of Long-term Follow-up Information**
This family has moved to India, and we will never know the outcome of their daughters' "disorder." Long-term follow-up information is not yet available for many inborn errors of metabolism, which restricts our ability to know who needs treatment and who doesn't. The recommendation for disease registries has been made, and some progress toward this recommendation has occurred. However, it will be years before data from registries will provide a better understanding of the biochemical disorders that are part of newborn screening.

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# NSGC News

## Get to Know the NSGC Executive Office

*To better acquaint NSGC members with the Executive Office Staff,* Perspectives *is featuring profiles of those involved in the behind-the-scenes operations of NSGC. This issue features* ***Megan Barron,*** *Marketing Coordinator.*

**What are your primary responsibilities for NSGC?**
I am NSGC's Marketing Coordinator - I coordinate various marketing collateral with NSGC team members, designers and our print production manager on a day-to-day basis. While involved with all aspects of NSGC marketing, the main projects I oversee include the annual report, membership directory, AEC email blasts and the AEC Final Program Book.

**What experience do you bring to the Society?**
I graduated from Bradley University with a degree in Communications. While at Bradley, I worked in the Marketing & Communications Department for three years. Two years ago, before beginning my career at SmithBucklin, I interned in the communications and advertising sales department at *Teen People* magazine in New York. Working with various healthcare clients at SmithBucklin and in various marketing positions in the past has helped me to learn and bring new ideas to NSGC.

**What do you find interesting about NSGC?**
I find the entire profession to be very fascinating and admirable. Genetic counseling is a growing field and the public is becoming more and more educated on the contributions that the occupation offers, which is why I am excited to be associated with NSGC.

**What are your hobbies?**
Working out, going out to dinner with friends, traveling and shopping.

**What would people be surprised to learn about you?**
I was the top scoring bowler on our championship team this year.

# AEC Update

## The Cost and Value of the NSGC Annual Education Conference

*By Susan Schmerler, MS, JD and Juliann Stevens McConnell, MS*

Have you ever wondered how NSGC determines how much to charge for registration at the Annual Education Conference (AEC)? Establishing the registration fee involves consideration of several factors, the most important being the need to cover the cost of the conference. When NSGC puts on a conference, there are both fixed costs and variable costs. Fixed costs are the expenses that we have regardless of how many people attend, like audiovisual, speaker travel and honoraria, insurance and administrative and planning costs. Variable expenses are based on the number of people who come to the conference, and are incurred on a per person basis. Examples of variable costs include food, program books, bags and printed materials. The cost of registration is then determined by calculating the actual cost of the meeting per attendee. When NSGC sets the registration fees each year, the costs from prior years also are compared to the trends in registration.

### Financial Breakdown

A large portion of the registration fees covers costs for the food and beverages throughout the meeting. The remaining fees cover the education provided by the meeting, which is directly related to the CEUs earned. Below are some of the actual costs of meeting expenses, as well as the value per contact hour. The cost per contact hour for a member who registers early is $4.20. This is significantly lower than the cost per contact hour for similar organizations, which falls between $12 and $25.

**2007 AEC Registration Fees**

| Category | Early | Late | Includes |
|---|---|---|---|
| Member | $285 | $340 | Includes: 3.5 days (25 hours) of education, welcome reception, 4 breakfasts, 7 beverage breaks and 3 snacks |
| Student Member | $185 | $185 | |
| Non-Member | $400 | $450 | |
| Student Non-Member | $215 | $215 | |

**Value**

| Event | Per Item Cost | Total Cost per person |
|---|---|---|
| Welcome Reception (1) | $35 | $35 |
| Breakfast (4) | $22 | $88 |
| Beverage Break (7) | $6 | $42 |
| Break Snack (3) | $5 | $15 |
| **Total per person Food & Beverage portion of Early Member Registration fee** | | **$180** |
| | | **$105** |

**Education portion of Early Member registration fee ($105/25 = $4.20 per hour)**

Adding AV and facility expenses to the costs for refreshments, the actual cost to NSGC for each person who attends the entire AEC is $214. This means that for the 2007 AEC, 75 percent of each member's early registration fee will be going directly for food, beverage, A/V and facility expenses. This is before NSGC pays speaker honoraria and travel and other conference costs. These costs may seem high, but this is the reality of holding a conference in a hotel or conference center. We also don't cater the conference privately because hotels don't allow groups to bring in food and beverage without incurring a penalty.

**Subsidization**

The NSGC as an organization cannot absorb the total expenses for the AEC unless other revenue is available. Registration fees do not cover the entire cost of the conference. The AEC is heavily subsidized from the support of vendor partners through their exhibition booths and sponsorship. Without this vendor partner support, the AEC would not be possible. We encourage all attendees to take the time to visit the exhibit hall and thank NSGC's vendor partners for their ongoing support.

**Location and Timing**

An important way to control the expense of the AEC is the careful choice of the location. Locations must be selected several years ahead of the actual conference so that we can negotiate the best hotel rates and secure adequate space for all of our sessions and meetings. As a result, for example, the locations for the 2007 and 2008 AEC have been set for several years. To help control the costs to attendees and to NSGC, we specifically look at mid-tier cities so the conference can remain affordable to the membership. Hotel costs (both individual room rates and food and space costs) are higher for first-tier cities like New York, San Francisco or Chicago, but lower for cities like Nashville and Kansas City. We know that location is important to our attendees, but we also know that travel to and from the conference, along with registration fees, have to be affordable. For conferences in 2009 and later, we are looking for locations that will be enjoyable to visit, but that are also affordable and accessible.

Another cost consideration is the timing of the meeting. NSGC has typically held the AEC over a weekend to help reduce travel costs for attendees and to minimize the time away from work. As we select locations for 2009 and beyond, we will take all of these issues into account to determine the best locations for future AECs.

**Determining Value**

What makes a conference valuable? For some attendees, the education alone drives value. For others, it is a comparison of the number of tangible items compared to the dollars spent (e.g., food items, bags, CEUs, etc.). For others still, it is the networking and social opportunities. And for many, it is a combination of all of these things.

In addition to the "value" of food and beverage and the knowledge that NSGC is not making huge profits from registration fees, the value of earning CEUs, receiving cutting-edge education and networking with genetic counselors from around the country and the world

makes the AEC an essential forum for every genetic counselor. Putting a dollar amount on this type of value is impossible. And when comparing the AEC to other conferences offering a similar number of CEUs, NSGC is well below the average cost. Each individual, however, has to determine the value of the AEC for her/himself.

**Finding Balance**

When planning a conference, the NSGC aims to serve the best interests of our members while advancing the genetic counseling profession. The balance that exists between the individual and the organization is delicate, and we cannot sacrifice one for the other, or both will cease to benefit. Quality education at an affordable price is a necessity. NSGC is making every effort to ensure that our educational needs are met while still preserving the financial stability of the organization. It is helpful for the AEC planning committee to have your input. Please complete whatever survey comes your way. We really appreciate your point of view.

## The Heartland Beckons: Things to Do in Kansas City for the 2007 Annual Education Conference

*By 2007 Annual Education Conference Outreach Committee*

NSGC heads to the heartland for the 26th NSGC Annual Education Conference (AEC), October 12-16, and the 2007 Short Course, “Survival Skills for the 21st Century: How to Shape Your Future as a Genetic Counselor,” October 11-12.

Registration is now open – register online today at www.nsgc.org to take advantage of early registration prices. Hotel rooms go fast too, so reserve yours before October 9 at the Westin Crown Center in Kansas City by calling 816.474.4400 (mention the NSGC conference to receive discounted rates).

Check out the travel tips below to add some vacation to your conference education!

**Heartland History**

Kansas City is the largest metropolitan area in the heartland, straddling the border of two states - Kansas and Missouri. From its rural beginnings, Kansas City has combined culture with frontier history, making for many interesting outings.

Kansas City is home to a revitalized center of African American culture. Located at the **Historic 18th & Vine District,** you can learn about music at the **American Jazz Museum,** trace baseball history at the **Negro Leagues Baseball Museum** or check out the **Black Archives of Mid-America** for memorabilia from all aspects of community life – art, music, sports, religion and more.

You can learn about frontier history at **Fort Osage,** overlooking the Missouri River in Sibley, about 50 minutes from the Westin hotel. Tour the blockhouses, officers' quarters and soldiers' barracks on a site first surveyed by Lewis and Clark in 1804. Only 15 minutes away in Independence, you can ride in a covered wagon with **Pioneer Trails Adventures** and learn about the westbound settlers' lives at the **National Frontier Trails Museum** and the **Arabia Steamboat Museum.** Independence also was the home of the 33rd President of the United States, **Harry S. Truman.** Along with his papers, the **Truman Presidential Museum and Library** has a replica of his White House office.

**Activities for All Interests**

Kansas City has more fountains than any city in the world, aside from Rome. A fountain is incorporated into almost every commercial building project. The most famous fountains are found at the **Country Club Plaza,** within 10 minutes of the Westin hotel.

Aspiring financial whizzes will love the 150-year-old **Kansas Board of Trade.** Located one block south of the Country Club Plaza, the Board of Trade mostly deals in wheat commodities. Anyone high school age or older can tour the trade floor.

For art lovers, the **Kemper Museum of Contemporary Art** and the **Nelson-Atkins Museum of Art** both house great permanent and temporary displays.

**Harley-Davidson Vehicle and Powertrain Operations** is another good stop, the only location where Harleys are made from start to finish, and visitors get to watch. Children under 12 may visit the tour center and gift shop but may not go in the factory.

**Family Fun**

**Union Station,** home of Amtrak, is known for its museums, restaurants and shops. At the KC Rail Experience, sit in a vintage railroad car, watch a model train chug across 1,000 square feet of miniature terrain and hear stories of railroad ghosts. At Science City, visit 50 interactive exhibits, like riding a bike 30 feet in the air, timing baseball pitches and talking to a paleontologist in the Dino Lab.

**Kaleidoscope,** the brainchild of Hallmark Cards' **Don Hall,** lets kids "explore, create, imagine and do." In this magical atmosphere, you can create art from left over Hallmark materials. Sessions last 40 minutes and admission is free. Reservations are suggested.

Those who walk on the wet and wild side should head to **Worlds of Fun** amusement park or **Oceans of Fun** waterpark. In October, these favorites are open weekends only and highlight early Halloween festivities.

To catch a live performance, visit **Coterie Theatre,** rated by *Time* magazine and *Travel + Leisure* as one of the nation's top children's theaters.

Animal lovers should visit **Lakeside Nature Center,** Missouri's largest wildlife rehabilitation center. Lakeside is housed in Swope Park, off of Country Club Plaza. Overland Park's **Deanna Rose Children's Farmstead** also lets you feed the animals, go on a hayride and make crafts.

For more information on Kansas City and how to plan your trip, go to the Web site designed for AEC attendees at www.kumc.edu/gec/kc/.

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## Publications by Genetic Counselors

*By Deborah McDermot, MS*

*This feature highlights the publication activities of genetic counselors in peer-reviewed journals (other than the* JOGC*). Each issue of Perspectives lists the articles published during the previous quarter and spotlights one publication in which a genetic counselor served as first or senior author. Featured papers are chosen at the discretion of the* PGC *Editorial staff.*

## Featured Paper

(Names of genetic counselors appear in bold.)

**Multhaupt-Buell TJ,** Lovell A, Mills L, Stanford KE, Hopkin RJ. Genetic service providers' practices and attitudes regarding adolescent genetic testing for carrier status. *Genet Med*. 9:101-7. 2007.

One might say that a passion for policy is integral to **Trisha Multhaupt-Buell's** genetic make-up, so much so that she is not always conscious of it. During her interview for the genetic counseling training program at the University of Cincinnati, from which she graduated in 2004, Trisha expressed her intellectual interests in policy to the program director, **Nancy Steinberg Warren.** Nancy later reminded Trisha of this conversation when she selected her thesis topic, the practice of carrier testing in the adolescent population. This thesis culminated in the publication in *Genetics in Medicine*.

For Trisha, the general findings of the study were the biggest surprise. In practice, a significant number of health care providers are ordering carrier tests for adolescents despite the ASHG/ACMG statement that suggests deferring such testing until adulthood. This truth reflected what Trisha heard but did not want to believe as a student – that guidelines often do not direct clinical practice.

Trisha feels strongly that guidelines need to remain current and allow for real life scenarios in order to keep pace with the dynamic nature of genetic information. Even since the study was completed, a great deal has been learned about the clinical implications for carriers of conditions included in the study, namely cystic fibrosis, fragile X and Duchenne muscular dystrophy. Trisha also acknowledges a need for education and counseling models for the adolescent population. We are sure to hear more from her on these topics in the future.

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## Legislation Report

## Licensure Series, Part 3: Guiding Principles and Model Legislative Language for State Licensure Bills

*This is the third article in a four-part series by the NSGC Licensure Subcommittee addressing the issues involved in the licensure process. Below, the Licensure Subcommittee describes the newly developed Guiding Principles and Model Legislative Language for State Licensure Bills.*

As outlined in the Winter 2006 Issue of *Perspectives,* NSGC has developed a three-prong approach to address our profession's top priority: improving access to quality genetic counseling services.

- The first prong is to draft Federal legislation to amend the Social Security Act to add genetic counselors as providers under Medicare.
- The second prong is continued support of state licensure efforts.
- The third prong is to engage with third party payers.

### Prongs One and Two

The Billing and Reimbursement Task Force has already written an educational piece detailing NSGC's efforts in both Federal and State legislation and provides background on many of the issues involved; this document is now available on the Advocacy Section of the NSGC website.

The Board of Directors also charged the Licensure Subcommittee (LS) with developing Guiding Principles and Model Legislative Language to help states draft legislation that will be uniform nationwide and consistent with the Federal bill. This action addresses prong two, and the document is now available on the Advocacy Section of the NSGC Web site listed in the Licensure area.

### Guiding Principles

The purpose of the Guiding Principles is to provide a framework for all state licensure legislation so that laws regulating the practice of genetic counselors are consistent across the country. Although legislative language varies between states, the basic principles should be consistent. The outcome should provide flexibility in how genetic counselors practice while ensuring the greatest degree of public protection. Furthermore, the Guiding Principles and Model Legislative Language gives national guidance to the membership, something NSGC is committed to providing.

The LS also has developed a formal evaluation process to determine if specific state legislation is consistent with NSGC's policies and guidelines. The Guiding Principles will be the basis for this evaluation and will be used when states request NSGC assistance, as in a letter of support and/or grant funding for licensure efforts. Using the Guiding Principles will also enable states to gain support from the American College of Medical Genetics leadership, as they are in agreement with the Principles.

### Definitions

Many of the definitions in the Guiding Principles, such as the "practice of genetic counseling" (Scope of Practice) and qualifications for licensure, are based upon American Board of Genetic Counseling (ABGC) guidelines rather than those of NSGC. ABGC's accreditation of

training programs and provision of certification for genetic counselors sets national standards for the profession. ABGC certification is what truly separates certified genetic counselors from the "public." For these reasons, the provisions in licensure legislation are aligned with ABGC definitions as the basis for demonstrating the unique qualifications of genetic counselors. While these definitions are worded differently than NSGC principles, all are consistent with NSGC policies and guidelines.

**Supervision Issues**

The Guiding Principles address the supervision of genetic counselors. Supervision is one of the most highly charged issues among healthcare providers today, and there is no universally accepted practice applied throughout the country. For state licensure, this issue will be left to negotiation by local genetic counselors, members of the medical community and legislators. As such, the Guiding Principles provide specific definitions for supervision that reflect the varied relationships between genetic counselors and other medical providers.

In some states, licensed genetic counselors may practice under general supervision and in others they may operate with complete independence. Legislation should never require a licensed genetic counselor to practice under direct supervision. The goal is to ensure patient access to services without direct control by providers less experienced in genetics while maintaining high levels of public protection. If a state's political climate requires supervision that would impede patient access to genetic counselors, then it will be best to avoid licensure in that state.

Genetic counselors with temporary licenses (those with Active Candidate Status but not yet certified) are in a different situation than those with full licenses (certified counselors). Individuals with temporary licenses should have general supervision by a fully licensed genetic counselor or a licensed physician until certification is achieved. Ideally, the physician should be Board certified in genetics. Specific supervision or collaboration also should be considered when the genetic counselor's Scope of Practice includes activities within the practice of medicine, such as ordering genetic tests and/or making diagnoses. Here, language that includes relationships with a physician may be necessary to gain support for the legislation.

**License Administration**

Finally, the Guiding Principles address the administration of the license itself: either by the establishment of a specific Board ("Genetic Counselor Licensing Board") or another regulatory group ("Board of Medicine" or "Department of Professional Licensing"). If a specific Board is established, the majority of the Board should be genetic counselors so that the rules and regulations are controlled by members of the profession. The legislation can authorize the Board to determine the genetic counselors' Scope of Practice and qualifications for obtaining a license without having specifications written in the actual bill. However, if another regulatory agency will administer the license, the bill needs to contain specific language regarding the scope of practice, qualifications for obtaining a license and how the license will be administered. It is imperative that genetic counselors make the decisions that regulate their practice, rather than leaving these decisions up to others. Therefore, it is important to understand which type of licensing board your state will allow so you can write legislation appropriately.

**Model Legislative Language**

The Model Legislative Language for State Licensure is formatted to show how legislation is actually drafted. The first portion of this document contains a series of definitions that may be used within the text of the bill. The second portion contains the provisions indicating the qualifications for obtaining a license, practice parameters and establishment of an administrative agency. There is slightly different language if a Genetic Counseling Licensing Board is established versus if another regulatory group administers the license; these differences reflect the issues discussed above.

Model Legislative Language is the ideal to strive toward, but drafting this exact language may not be possible. As such, we offer this document as a starting place. We encourage you to review all of the materials available on the Licensure Section of the NSGC website and to contact the Licensure Subcommittee and/or NSGC's Government Relations Director, **John Richardson,** with any questions or issues regarding your state's pursuit of licensure. We also encourage states that have already drafted bill language to submit this to the LS for further review and input.

## NSGC Day on the Hill

*By Susan Manley, MS, NSGC Treasurer, Barbara Harrison, MS, Public Policy Committee Chair, and John Richardson, NSGC Government Relations*

On April 26, the day before the NSGC Region II Conference in Bethesda, MD, eight genetic counselors from the District of Columbia, Maryland, New York and Virginia took advantage of the locale of their meeting and participated in "NSGC Day on the Hill." The goal of the Hill day was to meet with 12 different congressional offices to discuss the importance of the Genetic Information Nondiscrimination Act (GINA) and the improvement of access to genetic counseling services.

### Legislation, Now and Future

GINA actually passed in the House of Representatives the day prior to our Hill day, so our presence offered an excellent occasion to thank those co-sponsors for their support and reiterate how legislation like GINA will help realize the promise of the Human Genome Project.

We also used this opportunity to stress that while GINA may help remove one hurdle (discrimination) for the consumer, access to appropriate genetic counseling remains an issue because legislation and regulation of genetic counseling services has not kept pace with scientific advancement. We reviewed NSGC's plans to introduce legislation to increase access to genetic counselors by Medicare beneficiaries and to attain genetic counselors' recognition as providers under the Social Security Act, the law that guides Medicare. We received positive feedback from each congressional office and some showed signs that they may like to become real champions for this cause!

### Careful Preparation

Our Hill experience was fun and educational for everyone involved, especially with the guidance of NSGC's Government Relations (GR) specialists. We were coached carefully ahead of our meetings, and every meeting included genetic counselors and a GR specialist to help lead the discussion. By the end of the Hill day, many of us felt we had really made an impact by educating people about genetic counseling.

### Special Thanks

We thank NSGC's GR specialists **John Richardson, Chris Krueger** and **Christine Perez** for their organization, expertise and coaching. Big thanks also go to **Rachel Gannaway, Flavia Facio, Emily Glogowski, Barbara Harrison, Jennifer Lieb, Susan Manley, Meg Menzel** and **Michelle Waite,** the genetic counselors who visited the Hill on behalf of NSGC. They were all great spokeswomen and represented NSGC well.

Further need for this type of grassroots effort will arise as NSGC progresses with its Billing and Reimbursement program. The Public Policy Committee, chaired by **Barbara Harrison,** along with our GR specialists, will lead these efforts. Watch for more opportunities to get involved.

**Contact:** Barbara Harrison, bwharrison@Howard.edu

## New York Needs Your Help

Show your support for New York state licensure! Please visit www.nysghpa.org to register and sign our e-petition demonstrating your support for genetic counselor licensure. Please forward our link to family members and friends in New York asking them to do the same. Thank you!

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# Committee & SIG Activities

## The NSGC Diversity Subcommittee Is Your Tool for Improving Cultural Competency in Genetic Counseling

*By John Quillin, PhD, MPH, on behalf of the NSGC Diversity Subcommittee*

In the later part of 2006, the U.S. population reached 300 million, in large part due to the increasing number of immigrants and others from groups historically categorized as minorities. The number of genetic counselors also continues to grow, although our cultural diversity does not yet reflect the richness of the clients that we do and could serve.

### Needs for Cultural Competency

The 2006 Professional Status Survey reveals that 91 percent of genetic counselors report being Caucasian, 5 percent Asian, 2 percent Hispanic and 1 percent African American. Compare this to the 2000 U.S. Census showing that 12 percent of the population reported African American race, and 12 percent reported Hispanic ethnicity. The demographics of the genetic counseling profession have remained static, while the numbers among minority and/or underrepresented populations have increased nationwide.

Beyond race, genetic counselors increasingly will be called upon with our clients to address differences in intellectual and physical abilities; spoken, signed, and written languages; gender; sexual orientation; spirituality; and cultural practices and traditions. The variety of

our clientele demands improvements in cultural competency, and diversity within our profession needs ongoing support.

### Diversity Subcommittee in Action

Recognizing these needs, in 2004 the Diversity Subcommittee (DSC) of the NSGC Membership Committee was organized. It is currently co-chaired by **Gloria Sanchez Araiza** and **Nancy Steinberg Warren.** Its mission statement continues to evolve: *"The Diversity Subcommittee is committed to promoting cultural diversity in the genetic counseling profession by increasing the number of minority genetic counselors and by providing cultural competency education to genetic counselors of all backgrounds."* Here are some highlights of DSC accomplishments:

- developed a Web site that includes a compilation of Spanish language counseling resources: www.nsgc.org/members_only/com_sub_activities/com_diversity.cfm
- awarded funds to support a graduate student thesis project, scholarships and student participation at the 2006 Annual Education Conference (AEC)
- attained a feature on genetic counseling on SistaGirls.org, a community-based Web site geared toward teen girls across the world
- partnered with nationally influential groups such as the Office of Women's Health in the U.S. Department of Health and Human Services
- hosted the Kijiji Village Community Outreach Event at the 2006 AEC, led by **Tené Franklin Hamilton** and co-sponsored by the NAACP, which introduced genetic counselors to local high school students, educators and community representatives.

Nancy Steinberg Warren, colleagues and students at the University of Cincinnati developed the NSGC minority recruitment brochure that was distributed at the Kijiji Village Community Outreach Event for review by the participants. Five thousand copies of this brochure have since been printed and are available for distribution from the NSGC. The brochure also can be downloaded from the NSGC Web site.

### Play Your Part

The energy and accomplishments of your DSC are growing, and there is still much work to be done. What else can we do to improve cultural diversity and enhance cultural competence among genetic counselors? Are there other diversity-related initiatives within NSGC that need leadership and coordination? Your help is needed to carry out the mission of the DSC. To join the committee or ask about its resources and activities, contact **Jolie Matheson,** Jolie.Matheson@bhs.org.

## Cancer SIG Takes Action for Awareness and Ethics

The Familial Cancer Risk Counseling SIG has been busy in recent months addressing issues of possible misconceptions and misuse of genetic testing for inherited breast and ovarian cancer.

### Clarifying Published Guidelines

This spring, the Cancer SIG, with the support of the NSGC President, **Cathy Wicklund,** wrote a letter to the editor of *CA: A Cancer Journal for Clinicians* in response to **Dr. Debbie Saslow's** article, "American Cancer Society Guidelines for Breast Screening with MRI as an Adjunct to Mammography," (*CA Cancer J Clin* 2007; 57:75-89). The Cancer SIG

congratulated the American Cancer Society on providing such a thorough review of the literature and discussion of the issues surrounding breast MRI. However, the SIG was compelled to dispel the misconception that hereditary risk cannot be inherited from the father, as this myth is still clinically prevalent. Our letter commented on the following two points:

1) When discussing *BRCA1* and *BRCA2* mutations, the author stated that, "These mutations follow an autosomal dominant pattern of transmission, which means that the sister, mother or daughter of a woman with a *BRCA* mutation has a 50 percent chance of having the same mutation." The Cancer SIG expressed their concern that this statement is misleading and gives the impression that men are not at risk to carry or transmit *BRCA* mutations.

2) The author further stated that, "Genetic testing for *BRCA1* or *BRCA2* mutations are generally offered to adult members of families with a known *BRCA* mutation, or to women with at least a 10 percent likelihood of carrying such a mutation, based on either validated family history criteria or one of the above-mentioned models." We explained that the appropriateness of genetic testing should be based on clinical judgment and not numerical thresholds as stated in the American Society of Clinical Oncology (ASCO) policy statement on genetic testing for cancer susceptibility.

We will report on responses to our letter in the Fall issue of *Perspectives*. Stay tuned!

**BRCA Testing for Minors**

In other news, the NSGC Executive Office sent a letter to the Chief Medical Officer of Myriad Genetic Laboratories, Inc., at the request of the Familial Cancer Risk Counseling SIG, pertaining to the SIG's concerns regarding the genetic testing of minors. This was motivated by a specific case that generated much discussion on the Cancer SIG listserv and involved the testing of a female minor for mutations in the *BRCA1* and *BRCA2* genes. Testing in this situation is seen as controversial, especially since our organization and others have standing policy statements that advise against routinely offering predictive genetic testing to minors.

In the letter, we encouraged Myriad to contact NSGC and the Cancer SIG to take advantage of our collective knowledge on this topic as Myriad develops a protocol and/or policy regarding this issue. A copy of the NSGC policy statement, "Prenatal and Childhood Testing for Adult-Onset Disorders," was provided for Myriad's review.

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# Resources

## Book Review

### *The Child Who Never Grew*

**Author:** Pearl S. Buck
**Publisher:** Woodbine House, 1992
**Reviewed by:** Katherine Young, MS, PhD

In 1950, **Pearl S. Buck** wrote an essay about her daughter with mental retardation that was published in *The Ladies Home Journal.* This was a time when mental retardation carried an enormous stigma, and she wrote the article to educate the public about mental retardation and ask for acceptance of all persons with disabilities.

In 1992, Woodbine House republished the article as the book, *The Child Who Never Grew*. This edition includes a forward by **James Michener,** who was a friend of Pearl Buck's, an introduction by **Martha Jablow,** who wrote, *Cara, Growing with a Retarded Child,* about her own daughter and an afterward by Pearl Buck's daughter, **Janice Walsh.**

**A Historical Journey**

Pearl Buck's first child, Carol, was born in 1920 in China. Carol had PKU, although this would not be diagnosed until many years later. Buck gradually realized that her young daughter was not developing normally and brought her to the U.S. for testing and, hopefully, treatment. *The Child Who Never Grew* focuses on Buck's relationship with her daughter as she learns to accept that her daughter will never be normal. She also writes about her decision to institutionalize her daughter. Finally, much of the essay is devoted to Buck's plea that people with mental retardation should be loved and valued.

**An Essay on Emotions**

The essay reads very differently than recent books by parents of children with mental retardation. Buck focuses on her emotions not on her search for a diagnosis. She does not list the clinics she visited or the tests that were done, and she does not distract readers with the names of doctors who gave the eventual diagnosis. She makes little to no mention of other family members, her husband or her unhappy marriage. She also never mentions that she had a hysterectomy after Carol's birth, when she was found to have a benign uterine tumor, She went on to adopt one child with her first husband and six more with her second husband.

**Required Reading**

This book should be required in all genetic counseling programs. Any counselor who will sit with a family when they are told that their toddler has mental retardation should read Buck's eloquent description as she fears that her daughter is not developing normally and then hears the diagnosis. Several points can lead to poignant discussions, including Buck's decision to institutionalize her daughter, the difference between Asian and Western attitudes toward disabled individuals and speculation on whether she would have chosen to have more children if she had not had a hysterectomy. Pearl Buck is a fascinating woman, and much more about her life and contributions can be found in **Peter Conn's** biography of her and her own fictionalized autobiography.

*Suggested Reading*
Buck, Pearl S. *The Time is Noon*, The John Day Company, 1966.
Conn, Peter. *Pearl S. Buck, A Cultural Biography*, Cambridge University Press, 1996.

## Student Network

## Graduating "First in Our Class" From the Boston University Genetic Counseling Program

*By Christina Choi, MS, Samantha Baxter, MS, Amy Lovelette, MS, Anya Revah, MS and Chandra Oksala, MS*

As the first students to graduate from the Boston University (BU) Genetic Counseling Program, we feel honored to have been the inaugural class. Over the last 20 months, we have grown from nervous and excited first-years to empowered second-years, ready to enter the field with the confidence and skills needed to thrive in this profession.

### A Strong Foundation

For the five of us, choosing to join the BU program was an easy decision. The curriculum, designed by Program Director, **MaryAnn Whalen** and Medical Director, **Dr. Jeff Milunsky,** ensured that we would receive a well-rounded education that prepared us for the future direction of genetic counseling.

In our first year, we learned the fundamentals of prenatal and human genetics as well as research training through lab methodology and biostatistics. Right away, we began observing genetic counselors in clinics, laboratories and research centers. During the summer and throughout our second year, we took on increasing roles at our clinical rotations throughout New England, including Boston Medical Center, Dana-Farber Cancer Institute, Baystate Medical Center, UMass Memorial Medical Center, The Lahey Clinic, Tufts-New England Medical Center and Dartmouth Hitchcock Medical Center.

Our second-year classes, including cancer, metabolic and quantitative genetics, helped bridge the gap between our books and the application of our knowledge base. We also attended the NSGC Region I meeting, where we met the genetic counseling students from Brandeis University and other genetic counselors in our area.

### Forging a Legacy

What we have loved most about our experience is that the directors and faculty at BU have encouraged us to be progressive. From day one, we have been treated as partners in the task of making our program successful. We each had the opportunity to leave our mark by designing "Legacy Projects" named after us, which will be completed by all students in years to come. These projects gave us a chance to contribute to the curriculum, such as a binder containing a list of support groups in Massachusetts or a project on developmental milestones. As the BU family grows, we are excited that we have helped enhance the education of future genetic counselors.

### A Welcoming Community

Although the idea of coming out of a new program felt overwhelming at first, the experience of representing our program over the last two years has taught us not only how to promote ourselves but our profession as well. Being located in a city like Boston, we were able to learn from many leaders in the medical field. As we graduate, we are confident that BU has given us the tools to make a smooth transition. So to all of you who have helped make our experience as educational, fun and challenging as it was, we thank you.

# Research Network

## Four Studies Open for Enrollment at the National Cancer Institute

The Clinical Genetics Branch in the Division of Cancer Epidemiology and Genetics at the National Cancer Institute (NCI) has four clinical genetics research protocols now open.

**1) Familial Testicular Cancer**
This study is seeking families with two affected male relatives or one male with bilateral cancer. *http://familial-testicular-cancer.cancer.gov*

**2) GOG-215**
NCI is an active site for GOG-215, the Osteoporosis Prevention Trial in women undergoing surgical menopause. This multi-center study is open at several GynOncology Group (GOG) sites around the country. *http://ovariancancer.gog199.cancer.gov/gog215/*

**3) Inherited Bone Marrow Failure Syndrome (IBMFS)**
This protocol is recruiting families with Fanconi Anemia, Dyskeratosis Congenita, Diamond Blackfan, Shwachman Diamond and related conditions. *http://marrowfailure.cancer.gov/*

**4) Urothelial Cancer**
We are seeking information on families with multiple cases of urothelial cancer (primarily bladder, renal pelvis, ureter) to evaluate whether there are enough such families in existence to warrant a formal study (no Web site available).

NSGC members **June Peters, Ann Carr** and **Mark Greene** are affiliated with all of these studies and can answer individual questions. To refer eligible families to these studies, contact our Family Studies Nurse for intake at 800.518.8474 or go to the Clinical Genetics Branch Web site at http://dceg.cancer.gov/cgb.

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# Public Eye

## Media Watch

*By Roxanne Ruzicka Maas, MS*

**March 18, 2007 – *The New York Times,* "Facing Life with a Lethal Gene"**
A young woman found to carry the gene mutation for Huntington disease (HD) tackled the question, "Is it better to know you will develop a disease, even if there is nothing that can be done?" Although most at-risk individuals reportedly decline predisposition testing, this woman felt she needed to know so she could plan her life. This experience also highlights the difficulties in families when some members want to find out if they carry a genetic predisposition and others don't.

**April 3, 2007 – *The Washington Post*, "For One Woman, An Unexpected Gift"**
Based on her enjoyable experiences with her nine-month-old daughter with Down syndrome, a mother expressed her dismay over the ACOG recommendation that all pregnant women "be screened for Down syndrome." She described how the most optimistic

version of her family's story starts today and the most pessimistic version starts with their "wretched" meeting with the geneticist in the hospital when the baby was born.

**April 5, 2007 – MSNBC, "Hatfield-McCoy Feud Blamed on 'Rage' Disease"**
A theory exists that "the most infamous feud in American folklore, the long-running battle between the Hatfields and McCoys, may be partly explained by a rare, inherited disease (Von Hippel-Lindau) that can lead to hair-trigger rage and violent outbursts." Some believe that increased adrenaline and other "fight or flight" stress hormones from pheochromocytomas may have contributed to the family's notorious behavior. However, some McCoys and doctors doubt this theory, as "there are a lot of underpinnings that are probably a more legitimate source of conflict."

**April 2007 - *Men's Health*, "Are You Raising Another Man's Child?"**
This article explored the painful but relatively common phenomenon of "paternal discrepancy" (PD). A 1992 article from *JOGC* indicating that most genetic counselors would not disclose PD was cited, and several genetic counselors (**Eriskay Burton, Suzanne Carter, Elsa Reich** and **Patrick Wilson**) were quoted in reference to the dilemma of whether to disclose PD to the father. The author clearly had an opinion as he wrote that men should "stick up for yourself" because "the medical establishment is not on your side."

**May 9, 2007 – *The New York Times*, "Prenatal Test Puts Down Syndrome in Hard Focus"**
Following ACOG's recent recommendation that all pregnant women be offered prenatal screening, concern arose that this ruling may increase termination of pregnancies with Down syndrome and other conditions. Parent advocates argued that the richness of the lives of children with Down syndrome is poorly understood and that better education would lead fewer women to undergo prenatal testing. However, the article stated, "Genetic counselors, who often give test results to prospective parents, say they need to respect patients who may have already made up their minds to terminate their pregnancy." The authors also stated that encouraging patients to read a flier written by parent advocates or spend a day with a child with Down syndrome may "unnecessarily complicate what is for many a painful and time-pressured decision."

**May 13, 2007 – MSNBC's *Dateline* online, "Open-fetal Operation"**
This video chronicled a fetal surgery at Texas Children's Hospital to remove a large cardiac tumor from a 20-week fetus. Without the surgery, the fetus likely would have died before delivery. The mother was at risk for uterine rupture due to the prenatal surgery and therefore was induced early. The surgery was a success, and the newborn was healthy.

**May 13, 2007 – *The Nation*, "Genetic Testing + Abortion = ???"**
This article reviewed the ethics of "choosing, or not choosing, certain kinds of children," given the availability of prenatal genetic testing for various conditions. Some people, both pro-choice and pro-life, interpret "the growing use of prenatal testing as a subtle form of eugenics." The article described how 90 percent of women who learn they are carrying a fetus with Down syndrome choose an abortion. It failed, though, to mention the proportion of women who choose not to undergo prenatal diagnosis, in part because they wouldn't terminate a pregnancy with an abnormality. The article pointed to the need for society to determine which conditions are severe enough to warrant a pregnancy termination.

**May 14, 2007 – *CSI: Miami,* CBS-TV, "Born to Kill"**
A serial killer was caught and identified as having an extra Y chromosome. One of the CSIs stated that the killer has "the criminal gene" and was "born to kill." Another CSI explained that outdated, flawed studies from the 1970s incorrectly suggested that men with an extra

Y chromosome tend to be more aggressive. In the end, the CSI team suggested that being falsely blamed for his sister's death as a child and being told throughout his life that he was predisposed to being a criminal - not his genetic makeup - were likely what contributed to him becoming a murderer.

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# Bulletin Board

## ASHG Updates

*By Flavia Facio, MS*

### Mark Your Calendars

The 57th Annual Meeting of The American Society of Human Genetics (ASHG) will be held in San Diego, CA, from October 23-27. Registration is open at www.ashg.org.

### Direct-to-Consumer Genetic Testing Position Statement

The Social Issues Committee of ASHG developed a draft statement on direct-to-consumer testing which was presented to the Board of Directors in October 2006, revised and then posted on the ASHG Web site for member comments. About 100 thoughtful comments were submitted. A further revised statement will go to the Board for approval. Stay tuned for more information.

For other news, see the ASHG Newsletter, *SNP-IT,* at www.ashg.org/genetics/ashg/snpit/.

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# Regional Updates

*Regional Updates is a new section added to Perspectives to address news specific to NSGC's six regions. This section replaces the bi-annual regional newsletters. In this issue, Regions I, IV and V are covered. Regions II, III and VI will be covered in the Fall issue. If you have information that may be of interest to your colleagues in your region, please pass it along to your regional or state representative. We're always looking for your input, so keep in touch.*

# Region I Update

**Regional Representative**
Reneé Chard, MS, CGC, chardr@mmc.org

**State Representatives**
Arizona - Zöe Powis, zoepowis@peds.arizona.edu
Colorado - Suzanne Davidson, sdavidson@myriad.com
Montana - Betsy Smith, smitelir@benefis.org
New Mexico - (vacant)
Texas - Colleen Buechner, Buechner@uthscsa.edu

Utah - Maureen Cantwell, maureen.cantwell@hsc.utah.edu
Wyoming - Rebecca Pollack, pollackrebecca@yahoo.com
Canada (Alberta, Manitoba, Saskatchewan) - Paulien van Galen, paulien.vangalen@calgaryhealthregion.ca

## Annual Education Conference

The annual Region I education conference titled, "The Evolving Field of Genetics: Implications for Genetic Counseling," was held on April 13 in Marlborough, MA. The meeting was attended by nearly 100 genetic counselors and genetic counseling students from the New England states and New York.

Topics included: Genetics and the Media; Genetics and Public Health; Newborn Screening: Past, Present, and Future followed by a panel featuring families affected by NBS expansion; Legal Protections for Gay and Lesbian Families; and Screening for Fetal Chromosome Abnormalities. The conference also included breakout sessions on Board exam preparation, starting and running a support group, pharmacogenetic testing and hereditary diffuse gastric cancer. In addition, there was a session devoted to professional issues (including a presentation on the results of the Professional Status Survey) and a working lunch on billing, reimbursement and licensure.

Speakers included genetic counselors from around the region, as well as physicians, research scientists, a social worker and an attorney. For a complete list of topics and speakers, please go to www.nsgc.org/conferences/Regions/2007/region_1.cfm.

Many thanks go to the members of the conference planning committee, led by Co-Chairs **Lisa Berry** and **Gretchen Schneider.**

## Genetic Counseling Programs

### Boston University

The Boston University Genetic Counseling Program is proud to announce the graduation of the first class of the program. **Samantha Baxter, Anya Revah, Chandra Oksala, Christina Choi** and **Amy Lovelette** are off to start their careers as genetic counselors. Meanwhile, the first year students have been working hard to follow in their footsteps and are embarking on their summer internships. Rotations include Lahey Clinic (MA), University of Rochester Medical Center (NY), Women and Infants Hospital (RI), Baystate Medical Center (MA), The National Institutes of Health (MD), and Alfred I duPont Hospital for Children (DE), in addition to the Boston Medical Center clinics.

The counselors and program directors at Boston University are working hard to ensure the program continues to be progressive and complete. While the program is sad to see the first-years go, everyone is looking forward to meeting the third class this fall! (See related article in Student Forum section of this *Perspectives.*)

### Brandeis University

Everyone is staying busy at Brandeis University. The second-year students worked hard on their Masters projects which culminated in a formal presentation May 10-11. The class of 2007 projects are:

**Pamela Blumenschein:** Challenges Prenatal Genetic Counselors Encounter When Counseling Adolescent Patients

**Kristen Dean:** Preimplantation Genetic Diagnosis: How are Patients Obtaining Health Insurance Reimbursement?

**Christa Haun:** An Examination of the Differences in Response, Coping, and Adaptation of Mothers and Fathers to Diagnoses of Genetic Conditions

**Jennifer Hume:** Genetic Counseling from the Rural Patient Perspective: Knowledge of, Interest in, and Accessibility to Services

**David Lieberman:** Development of a Web-Based Teaching Tool to Recruit Undergraduates into Genetic Counseling

**Irene Rainville:** Genetic Counseling Practices for Variants of Uncertain Significance in Whole-gene Sequence Analysis: a BRCA Case Study

**Sara Robinson:** Perceptions of Severity and Interest in Prenatal Diagnosis and PGD among Individuals with Hereditary Multiple Exostoses

**Jennifer Currier Tansey:** Parents of Children with Autism Spectrum Disorders: Assessing Interest in and Satisfaction with Genetic Services

Meanwhile, the first-year students started their first rotations this summer in the New England medical community and as far away as Hawaii, Atlanta and Montreal.

**Jason Carmichael,** a first-year student, has been selected as a 2007-2008 Boston Albert Schweitzer Fellow. The U.S. Schweitzer Fellows Program enables students in health-related professions to carry out direct service projects in underserved communities. Jason is collaborating with **Judy Jackson,** a prenatal counselor at Tufts-New England Medical Center and Lowell General Hospital, to improve the access of genetic health information, specifically alpha thalassemia, for Cambodian families in Lowell. Through the development of educational materials in Khmer and community outreach, this project aims to help the population make informed health care decisions.

## Upcoming Education Opportunities

Save the date for the NERGG, Inc. Annual Meeting (New England Regional Genetics Group), taking place November 29-30 at the New England Center in Durham, NH. Please consider becoming a NERGG member to receive the following benefits:

- access to the NERGG membership for collaboration on projects, finding speakers and networking
- participation in active committees, conferences and a Web site
- reduced registration fee for the Annual Meeting
- free job opportunity postings on the NERGG Web site

- a vote in the annual election for co-irector.

### Member News

The staff of Massachusetts General Hospital Cancer Center is excited to welcome **Lauren Carpiniello,** to the division of Cancer Genetics. Lauren is a recent graduate of Sarah Lawrence College.

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## Region IV Update

**Regional Representative**
Elizabeth Leeth, MS, CGC, eleeth@enh.org

**State Representatives**
Arkansas - Shannon Barringer, SNBarringer@uams.edu
Illinois - Melissa Dempsey, mdempsey@genetics.uchicago.edu
Indiana - Stephanie Cohen, sacohen@stvincent.org
Iowa - Jennifer Marcy, jennifer-marcy@uiowa.edu
Kansas - Lisa Butterfield, lbutterfield@kumc.edu
Michigan - Rebecca Zoller, zollerre@msu.edu
Minnesota - April Studinski, studinski.april@mayo.edu
Missouri - Jennifer Kussmann, kussmannj@health.missouri.edu
Nebraska - Gwen Reiser, greiser@unmc.edu
North Dakota - Mary Riske, mriske@medicine.nodak.edu
Ohio - Kate Lynch, lynchk2@ccf.org
Oklahoma - Jessica Mester, Jessica-Mester@ouhsc.edu
Ontario - Andrea Rideout, ARideout@mtsinai.on.ca
South Dakota - Quinn Stein, qstein@usd.edu
Wisconsin - Dania Stachiw, dstachiw@chw.org

### Annual Education Conference

The annual Region IV education conference titled, “RESPECT: Steps to a Fulfilling Career in Genetic Counseling – Research, Education, Students, Professionalism, Enthusiasm, Confidence, Technology,” was held April 13-14 in Skokie, IL. The meeting was attended by nearly 140 genetic counselors and genetic counseling students.

Our steps to RESPECT were met through several presentations including: Compassion Fatigue; a panel on Cystic Fibrosis addressing Newborn Screening and molecular testing; the Collaboration, Education and Test Translation (CETT) Program; Urea Cycle Disorders and Rare Diseases Clinical Research Network; Pompe Disease; A Glimpse of the World for Adults with Down Syndrome and Their Families; Securing the Future for Your Dependent with Special Needs; Chromosomal Microarray Analysis; Advocate Directed Biobanking; a panel on the Principles and Practice of Genetic Counseling Research, which included a student submitted abstract presented by University of Michigan winner **Amy Gaviglio;** and Genetic Testing: Bridging the Gap Between the Clinical and Laboratory Works. In addition, there was a working lunch presented by NSGC leadership on billing and reimbursement, the

planning of an education summit and licensure, as well as an evening of networking propelled by Genetic Counseling Bingo.

Speakers included genetic counselors from around the region, as well as physicians, research scientists, a social worker, a National Association for Down syndrome representative and a MetLife Financial Services representative. For a complete list of topics and speakers, please go to www.nsgc.org/conferences/Regions/2007/region_4.cfm.

Many thanks go to the members of the conference planning committee, led by Co-Chairs **Aimee Walter** and **Elizabeth Leeth.**

## Genetic Counseling Programs

### Indiana University-Purdue University Indianapolis (IUPUI)

Congratulations to the following graduates from the IUPUI Genetic Counseling Training Program Class of 2007. **Jake Massa** will be working at Kaiser Permanente in Fresno, CA; **Beth Hannan** will be working in Albany, NY; **Courtney Cummings** will be working at the Indiana State Department of Health; **Melissa Lehman, Lindsey Stephens** and **Candy Heyen (is there any info on these people?).**

The program also is pleased to announce the incoming students for the Class of 2009: **Angela Costa,** 2006 graduate of Hawaii Pacific University; **Damara Hamlin,** 2007 graduate of Washington University; **Anna McGill,** 2006 graduate of UC Davis; **Audrey Norby,** 2007 graduate of Iowa State University; **Jodie Rueger,** 2006 graduate of the University of Kentucky; and **Meredith Thompson,** 2007 graduate of Indiana University.

### University of Michigan

The University of Michigan Class of 2007 received their Masters of Science in Genetic Counseling on April 27. The class is poised to begin their genetic counseling careers in diverse settings. **Kristen Pierce** will join Spectrum Health in Grand Rapids, MI, where she will work in pediatric genetics. **Laura Harris** has accepted a position at Yale University where she will provide prenatal genetic counseling. **Amy Gaviglio** will work for the Newborn Screening Program of the Minnesota Department of Health's Public Health Laboratory. **Karen Knutson Wain** has accepted a genetic counseling position in the Cytogenetics Laboratory at Mayo. The "power couple" of **Laura Pfleger** and husband **Brian** are visiting academic institutions across the country, as Laura seeks a genetic counseling position and Brian seeks a faculty position in the same city. Similarly, **Amanda Openshaw** and her husband **Ryan** are exploring multiple opportunities across the country.

This spring our University of Michigan Genetic Counseling Program Director, **Beverly Yashar,** was awarded the Rackham Master's Mentoring Award. This award was established to honor and encourage the efforts and accomplishments of faculty who serve as distinguished mentors at Michigan, demonstrating a commitment to fostering the intellectual, creative, scholarly and professional growth of their master's degree students. As the first recipient of this award, Bev has provided her students with the support, encouragement and respect needed to take full advantage of their education while training at Michigan.

### Wayne State University

The Wayne State University Genetic Counseling Graduate Program would like to congratulate graduates of the Class of 2007: **Lori Felczak, Lindsay Weed, Stephanie Farner,** and soon-to-be graduate **Rupin Dhamankar.** We would like to also welcome the Class of 2009: **Tiara Johnson, Kelly Keener, Mary Nyhuis, Preethi Premkumar, Abbey Putnam** and **Kate Zellmer.**

## Upcoming Education Opportunities

### MAGC Fall Educational Conference and Membership Meeting

The Michigan Association of Genetic Counselors (MAGC) will hold their fall educational conference and membership meeting on Friday, September 14 in Lansing, MI. The conference, "Money Matters," will address issues of billing, reimbursement, insurance and grant funding as they relate to the genetic counseling profession. Elections for three Board of Director positions will also be conducted. For information, contact **Trudy McKanna,** trudy.mckanna@spectrum-health.org.

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

The 11th annual meeting of the Collaborative Group of the Americas on Inherited Colorectal Cancer (CGA-ICC) will be held October 21-22 in LaJolla, CA, directly before the ASHG meeting in San Diego. The CGA-ICC meeting focuses on clinical and research aspects of hereditary colorectal cancer. Category 1 CEUs will be available. Go to www.cgaicc.com for further information or contact **Anna Leininger,** 612.626.9898, leini018@umn.edu.

### Mayo Clinic Offering Genetic Counseling Rotations

Mayo Clinic in Rochester, MN, is offering a program for genetic counseling rotations through our clinical genetic testing laboratories. Internships are open to students currently enrolled in a genetic counseling program; a limited number of internships will be available at any given time. The program is administered through the Mayo School of Health Sciences.

Students will work directly with genetic counselors employed in a genetics laboratory and experience how genetic counseling skills are applied in this setting. The rotation is for 2-10 weeks. The duration and content will be structured according to the needs of the student and their genetic counseling graduate program. Travel and housing will be provided by Mayo Clinic. For information, contact **Teresa Kruisselbrink,** 507.538.2344, kruisselbrink.teresa@mayo.edu.

### General Courses at Mayo Clinic

Click on the following link for psych genomics, genetics and ethics courses being offered: mayoweb.mayo.edu/cme/genetics.html, or contact **Carrie A. Zabel,** 507.538.7229.

## Regional Practice News

### Licensure for Genetic Counselors in Illinois

An Act mandating licensure for genetic counselors in Illinois was passed several years ago. The Rules for the Act were approved December 18, 2006. The Act states that no one may practice as a genetic counselor in Illinois without a license one year after the Rules were finalized, so all genetic counselors who practice in Illinois must have a license by December 18, 2007.

We are currently writing the applications for temporary and permanent licensure, the final stage of implementation of licensure. When the application process is finalized, we will notify all NSGC members via a listserv message giving the Web site of the Illinois Department of Finance and Professional Regulation that has the applications for an Illinois genetic counselor license. All counselors who practice in Illinois must apply for a license. In addition, certified genetic counselors who practice in other states may apply for an Illinois license, allowing them to describe themselves as "licensed genetic counselors." The fee for a two-year license will be $150.

### Indiana Network of Genetic Counselors Pursuing Licensure

A bill was filed in December, but was never heard in committee, unfortunately. The Indiana State Medical Association (ISMA) had stated its support for the bill, which was a major accomplishment. The licensure committee is working on revising some of the language, will lobby ISMA for support again and will re-submit for the next legislative session. Activities of the INGC and its members can be found at our Web site, www.ingc.info.

## Member News

Kudos to the genetic counselors from Hubert H. Humphrey's Cancer Centers for their receipt of the following grants:

Optimizing Care for Breast Cancer Patients at Risk for Hereditary Cancers. (Supported by a grant from the Minnesota Affiliate of Susan G. Komen for the Cure.)

PI: **Thomas Amatruda, MD**
Investigators: **Barbara Kunz, Joy Larsen Haidle, Sarah Coombes** and **Kristin Baker Niendorf**

This is a renewal of a grant on refinement of a system of hereditary cancer risk triaging. As part of the previous grant, 500 breast cancers patients from the three clinics provided family history to create a pedigree, and hereditary cancer risk assessment was performed based on previously published criteria. A risk assessment letter and pedigree delineating the hereditary cancer risk as high, moderate or low was sent to the treating oncologist for use in referral for genetic counseling services. The current grant seeks to automate this system and simplify the process for ongoing clinical use and, possibly, other settings.

Hereditary Melanoma: Dermatologists' Knowledge and Practice. (Supported by a grant from the NSGC Cancer Special Interest Group Granting Committee.)

PI: **Kristin Niendorf**
Investigator: **Thomas Amatruda, MD**

This project includes developing a survey to assess dermatologists' understanding of genetics, melanoma genetics, opinions on genetic testing and knowledge of genetic counseling services.

**Lama Eldahdah** of Rochester, MN, recently had her thesis published. Great Job! Eldahdah LT, Ormond KE, Nassar AH, Khalil T, Zahed LF. Outcome of chromosomally abnormal pregnancies in Lebanon: obstetricians' roles during and after prenatal diagnosis. *Prenat Diagn* (In press). Published online in Wiley *InterScience* (www.interscience. wiley.com). DOI: 10.1002/pd.1721.

**Blaine Bendure** and **Shannon Barringer** from Arkansas presented at the American Telemedicine Association annual meetings held in Nashville, TN, on the "Evaluation of Telemedicine Use for Genetic Counseling Services in the Region."

**Lori Twenhafel** from Arkansas received a NSGC Prenatal SIG grant to further study national cooperation between prenatal and pediatric genetic counselors/services.

Arkansas Children's Hospital welcomes **Shobana Kubendran,** a graduate from the University of South Carolina School of Medicine.

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# Region V Update

**Region V Representative**
Karen Copeland, karenlcopeland@hotmail.com

**State Representatives**
Arizona - Zöe Powis, zoepowis@peds.arizona.edu
Colorado - Suzanne Davidson, sdavidson@myriad.com
Montana - Betsy Smith, smitelir@benefis.org
New Mexico - (vacant)
Texas - Colleen Buechner, Buechner@uthscsa.edu
Utah - Maureen Cantwell, maureen.cantwell@hsc.utah.edu
Wyoming - Rebecca Pollack pollackrebecca@yahoo.com
Canada (Alberta, Manitoba, Saskatchewan) - Paulien van Galen, paulien.vangalen@calgaryhealthregion.ca

## Genetic Counseling Programs

### University of Colorado

Congratulations to the Class of 2007 genetic counseling graduates from the University of Colorado! Commencement exercises were held May 25. The University of Colorado Graduate Program in Genetic Counseling will be moving to the new Anschutz Medical Campus of UCDHSC in September 2007. The students and faculty are looking forward to having modern classroom and laboratory facilities together on the same campus, including the new Children's Hospital at Fitzsimons and the new University of Colorado Hospital.

### University of Texas

Congratulations to the Class of 2007 genetic counseling graduates from the University of Texas Graduate School of Biomedical Sciences at Houston. Commencement exercises were held May 5.

The University of Texas (UT) Genetic Counseling Program was reaccredited in 2006 for the maximum period of eight years by the American Board of Genetic Counseling. To date the Program has graduated over 60 genetic counselors and currently has six students entering their second year of study and seven new students arriving in August.

The academic year of 2006-2007 brought several changes to the Program, including the arrival of new Program Director and Assistant Professor of Pediatrics, **Claire Singletary.** Previously, Claire was the Assistant Director at the University of South Carolina Genetic Counseling Program. Claire is an active member of NSGC, most recently sitting on the Board of Directors as Region III Representative from 2005-2006. Claire's arrival marks an exciting time at UT, as this Program's first allowance of a full-time director. This enables more focused teaching and advising by the Program leadership, which includes Assistant Program Director, **Sarah Jane Noblin.** Claire continues to see prenatal patients one day a week; she was not ready to give up her interactions with patients and feels it is important for the program faculty to maintain an active clinical practice in order to better facilitate class discussion and provide relevant case examples.

This summer also marks the first time UT students will be venturing off-site for their clinical rotations. The addition of Baylor as a permanent site in the UT system allows students to stay in the Houston area and still gain valuable insight of training under a new system. In subsequent years, there are intentions to add other permanent summer sites, such as at UTMD (University of Texas, Medical Branch) in Galveston.

The Program is also excited about year-round collaborations with the clinical and laboratory counselors at Baylor to provide supplementary experiences for the UT students. Other program innovations include the creation of an "Introduction to Genetic Counseling" class for the first semester of study and the incorporation of an ultrasound seminar, a professional issues series and ethical case studies in the course "Contemporary Issues in Genetic Counseling."

### University of Utah

The University of Utah Graduate Program in Genetic Counseling has graduated its first class this year. These six students will accept jobs in five different states in cancer genetics, reproductive genetics and genetic testing laboratories. Students attending the program have come from 11 different states overall. For more information, visit the program Web site at http://geneticcounseling.genetics.utah.edu.

## Upcoming Education Opportunities

### Mountain States Genetics Regional Collaborative Center

The Mountain States Genetics Regional Collaborative Center (GRCC), which includes genetics providers from Arizona, Colorado, Montana, New Mexico, Nevada, Texas, Utah and

Wyoming, will hold its annual meeting in Denver, July 12-14. CEUs will be offered. See www.mostgene.org for more information.

### Region V Virtual Meeting

Keep your eyes open for information regarding our upcoming virtual meeting. This is an exciting new direction and educational opportunity within NSGC, and Region V is leading the way. If you want to volunteer your time or have ideas, contact the Conference Co-Chairs: **Marisa Raymond** and **Jennifer Saucier.**

## Regional Practice News

### Canada

The Newborn Metabolic Screening Program in Alberta has expanded to include a total of 17 metabolic conditions in newborns, as well as cystic fibrosis. Alberta will be the first province in Canada screening all newborns for cystic fibrosis.

Edmonton is initiating first trimester combined prenatal screening. This will include a nuchal translucency scan and maternal blood test for PAPP-A and free Beta–hCG. Calgary has been offering first trimester combined screening since March 2006.

Manitoba is working towards making the nuchal translucency combined screening more widely available in the province in addition to the second trimester quad screen.

The Early Prenatal Risk Assessment Program Annual Scientific Meeting was held May 15 in Calgary and was available to other centers/cities via telehealth.