PERSPECTIVES
in genetic counseling

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nsgc

the leading voice, authority and advocate for the genetic counseling profession

www.nsgc.org

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Tax time is here. In reviewing our personal finances, many of us will ponder our expenditures to professional societies. What is your $175 to NSGC used for?

TOOLS WITHIN NSGC

NSGC impacts our professional lives daily through use of the listserve and online directory. However, annual dues support more than these tools. The majority of dues go to existing membership programs and services, including maintaining the listserve, the JobConnection service, the website, the *Journal of Genetic Counseling*, this newsletter and the Executive Office (staff and outsourced professionals like our PR team, web team, attorney, bookkeeper and accountant).

NEW INITIATIVES

Remaining dues (about 10%) go toward new initiatives and the work of committees and task forces. For example, NSGC has made inroads in billing and reimbursement. NSGC has funded research, developed a

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POINT-COUNTERPOINT

WHAT'S A BETTER TITLE?

GENETICS CONSULTANT

Donna Blumenthal, MS

The Encarta World English Dictionary defines counselor as "a person, usually a professional, who helps others with personal, social or psychological problems; a therapist." Consultant is defined as "an expert who charges a fee for providing advice or services in a particular field; an advisor." The two terms are synonymous in most other dictionaries – they all use the word "expert" to define a consultant, and all but Encarta define both counselor and consultant as advisors.

COUNSELOR SKILLS

Following a heated debate on the NSGC listserv, the name

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GENETIC COUNSELOR

Barbara Biesecker, MS

It is not surprising that some colleagues may find the title genetics consultant an attractive alternative to genetic counselor. Consulting is a function of many professions and is frequently a reimbursable service. In these days of limited health care dollars and inadequate reimbursement, consultant holds promise of financial reward. Yet there is no evidence that changing our title will promote reimbursement.

COUNSELOR AS ADVISOR

More to the point, genetics consultant inadequately portrays the role

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PRESIDENT'S BEAT

As time flies by, NSGC keeps busy on many fronts. I am pleased to give you the following updates.

BILLING AND REIMBURSEMENT

NSGC has taken action toward improving the outlook for billing and reimbursement (B&R). Members of the Billing and Reimbursement Committee and Task Force (**Aimee Tucker Williams, Leslie Cohen, Jennifer Farmer, Susan Manley, Dawn Allain, Barbara Pettersen, Kristen Shannon, Barbara Lerner** and **Bea Leopold**) are developing a three-armed approach.

1. Obtain CPT codes for genetic counseling services (headed by **Debra Lochner Doyle**).
2. Develop materials for third party payors documenting the value of reimbursement for genetic counseling services and recognition of genetic counselors as providers.
3. Work with organizations like the Secretary's Advisory Committee on Genetics Health and Society (SACGHS) and initiate outreach to governmental organizations that set payor standards for Medicare/Medicaid.

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The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Next issue ***June 15***
Submission deadline ***May 11***

Kelly Ormond, MS

Soon we expect results from last year's study on B&R. The recent SACGHS meeting addressed B&R for genetic counseling services. Several genetic counselors including myself, **Dan Riconda** (representing the NSGC Licensure Subcommittee) and **Andy Faucett** and **Anne Greb** (representing the American Board of Genetic Counseling) presented invited testimony and submitted a summary document.

HEALTH DISPARITIES

The NSGC has taken the first step in addressing health disparities as they relate to genetic counseling. We have provided funding to develop brochures aimed at increasing minority recruitment (spearheaded by **Nancy Warren**). We will begin discussions with individuals in underrepresented groups within our membership and groups that are underserved in their access to genetic counseling services. Our goal in 2005 is to develop a long-term plan to address these issues.

In an effort to evaluate issues on the horizon, a new *ad hoc* committee has been developed to address the impact of a professional doctorate degree. We are moving forward with the NSGC Foundation, and we continue to reassess our Code of Ethics and develop scope of practice and genetic service delivery models.

We also are developing a mechanism to keep members aware of the many tables where NSGC sits; we are a member organization in many larger coalitions and groups and send representatives to several meetings. Look for changes to our website to learn about NSGC's affiliate organizations and the strengths we gain from these partnerships.

SPEAK UP IN APRIL

More than anything, I must say how exciting it has been to attend meetings with key leaders in healthcare and to repeatedly hear the mantra "of course genetic counselors are important in the provision of genetic and genomic healthcare." NSGC and our profession has come far since I joined our organization and we have much to be proud of. But our hard work is not complete – I urge you all to get involved in ways to spread the word about genetic counseling, including becoming a mentor for DNA Day and giving talks in your community.

NSGC is working hard to advance our strategic plan. If you are interested in joining projects or have issues to discuss, please contact me or your Board of Directors. It continues to be my pleasure to represent you and our organization. ❖

Kelly E Ormond MS

Kelly Ormond, MS
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POINT-COUNTERPOINT, *from page 1*

Genetics Consultant...

genetic counselor held some merit over genetic consultant. We think of ourselves as empathic listeners trained to facilitate decision-making and the grieving process. We strive to use politically correct language, to be sensitive to other cultures, to be approachable and nonjudgmental and to help restore autonomy and control to distraught people. The term counselor best embodies these skills.

> ***"We need to define our goals in choosing a title in order for this title to help us reach these goals."***

SEEKING INFORMATION

On the other hand, while the patients who need counseling may be the most gratifying, most patients are seeking information. They want to know, "Why was my AFP low?" or "What is my chance of breast cancer?" By using the word counselor, we may be trying to sell warm-and-fuzzy to a clientele in the market for cold hard facts.

Also, consultant implies that the patient controls which issues get brought to the table. Someone coming in for amnio counseling regarding Down syndrome may not want to hear about CF testing. A patient once told me, "I'll cross that bridge when I come to it." While we may feel responsible to discuss all issues that are medically relevant, patients may presume that a counselor will introduce uncomfortable or unnecessary issues.

THE SALARY DEBATE

The term consultant commands respect, reimbursement for services and salary. It sounds more professional to the public and to our medical colleagues. Consultant also may appeal more to males entering the profession. Surveys show that male genetic counselors, and male-dominated professions in general, garner higher salaries. As genetic consultants we wouldn't change the way we practice, but unless we improve our reimbursement, we may stop attracting a high caliber of students, both male and female. Recall that the average genetic counselor leaves the field after five years, primarily due to limited earning potential. According to the 2004 Professional Status Survey, of the six activities genetic counselors pursue for additional income, "Consulting" came in second just after "Private Practice."

NAMING OUR GOALS

Genetic counselors serve many roles. Will a new title enhance referrals, improve our image, attract males to the field and increase fees and salaries? We need to define our goals in choosing a title in order for this title to help us reach these goals. ❖

Genetic Counselor...

of genetic counselors. Counselors advise. We explain genetics information to clients so they can integrate it in a meaningful way. We help clients find hope in their (genetics) situations. This process emerges from our objective to facilitate adaptation to a genetic risk or condition and is conveyed in our core proficiencies that serve as the basis for our accreditation and credentialing, our graduate education, our professional writings and how we portray ourselves to clients.

> ***"Much of genetic counseling is intimate, including the diagnosis of a child, difficult decision-making and loss. Intimacy is an appropriate expectation of our clients."***

CHALLENGING OUR PROFESSION

The debate between counselor and consultant suggests challenges to our profession, reflecting diversity and loss of a foundation. Our profession is sub-specializing and will face pressures to continue to evolve in response to new technologies. These challenges predict that we may lose focus of our expertise, making room for other professionals to assume our roles. While others are involved in delivering genetics services, this should not diminish the need for our expertise. If we are unclear and, by implication, uncertain of the fundamental nature of our profession, then we will be less likely to adapt to the pressures.

EXPECTING INTIMACY

The biggest drawback to the name genetics consultant is that any genetics professional can hold this title, it does not distinguish us. It has been argued that clients may equate us with therapists and worry about being asked intimate questions. Much of genetic counseling is intimate, including the diagnosis of a child, difficult decision-making and loss. Intimacy is an appropriate expectation of our clients. Emoting may not be necessary for all clients, but, if need be, we have the training as counselors to address their feelings. We are, above all else, compassionate counselors. ❖

Around the Globe

TRAVELS TO GUATEMALA – GENETICS AS A COMMON LANGUAGE

Susan Fernbach, BSN, RN

I am a pediatric genetic nurse and have worked in the Molecular and Human Genetics Department at Baylor College of Medicine for 20 years. I coordinate several congenital heart defect studies and the Cardiovascular Genetics Clinic at Texas Children's Hospital. Many of our patients and their families are immigrants from Central America, and I have long wished to visit that region.

FAITH IN PRACTICE

Five years ago, I learned of a medical mission group, Faith in Practice (FIP), which organizes medical and surgical teams to care for the indigent in Guatemala. The director of FIP encouraged me to apply and told me of a Guatemalan pediatrician, **Dr. Gabriel Silva,** who had studied with the country's only geneticist. The two physicians started a genetics clinic at the hospital in Antigua, Guatemala where the mission teams are based. The senior geneticist since retired, and Dr. Silva longed to contact other geneticists. Joining FIP seemed a unique opportunity, so I discussed it with the pediatric geneticist at my center, **Dr. John Belmont,** and he and his wife joined me on a medical mission trip in 2001.

Guatemala is a beautiful country recovering from 36 years of civil war. Approximately 75% of the people live in poverty, and many cannot access medical care. FIP organizes nine-day missions at the Hospital Obras Sociales Hermano Pedro. This hospital was built in the 1600's and has been rebuilt several times following earthquakes. There are active clinics, a surgical department and an orphanage for 500 people ranging from newborns to the elderly with special needs.

HELPING HANDS

During our mission, my medical team traveled daily to different villages. FIP notified village leaders of our visit in advance, attracting hundreds of children and adults with minor injuries and respiratory, ear, intestinal and skin infections. My role was to triage patients, and my first day facing a line of 300 seemed daunting. However, everyone was calm, and our team treated each person.


The Orphanage in Petzun

GENETICS IN PRACTICE

At the end of the week, Dr. Belmont and I visited the genetics clinic in the hospital. The clinic is run by Dr. Silva and his wife, Olga, a nurse with a keen interest in genetic counseling and education. The clinic started early and included families that had traveled for hours by bus. Some had more common conditions such as Down syndrome and muscular dystrophy, while others had rare conditions like Hypomelanosis of Ito. With each family, we discussed pedigree analysis, physical exams, test results, diagnosis and counseling and care plans. Dr. Silva's explanations were clear and families felt comfortable asking questions. Families with more education and resources had sought information via the Internet. For the majority of families, this visit provided their only discussion of genetic issues. Most families spoke Spanish, but a few spoke one of the 23 Amerindian languages, and verbal communication was limited if they did not bring an interpreter.

After clinic, the Silvas guided us through the immaculate hospital orphanage, and we saw individuals with probable chromosomal disorders, metabolic conditions and muscular dystrophies. Most did not have diagnostic testing. The next afternoon the Silvas took us high in the mountains to the small town of Patzun where they go monthly to care for children in another orphanage. This facility has a re-nutrition center for toddlers.

LIFELONG CONNECTIONS

Since my first visit to Guatemala I have remained in contact with the Silvas via email. On a return mission in 2002, Dr. Belmont and I gave introductory genetics talks to the appreciative medical/nursing staff at the hospital. In 2004, Dr. Silva traveled to Baylor College of Medicine where he studied cytogenetics with funding from FIP, SeqWright and other contributors. My travels with FIP have provided exhilarating, poignant and sometimes overwhelming moments. I cherish the connection and friendships that I have established with the Silvas and my FIP team members. ❖

☞ Faith in Practice,
www.faithinpractice.org

☞ Hospital Obras Sociales Hermano Pedro orphanage,
www.obrashermanopedro.org

NIHCD UPDATE:
ADVANCES IN PRENATAL SCREENING

Renee Chard, MS

I represented NSGC at the National Institute of Child Health and Human Development (NIHCD) workshop, "Prenatal Screening: Incorporating the First Trimester Studies," in Potomac MD on December 16 and 17, 2004, co-sponsored by the Society for Maternal-Fetal Medicine, the American College of Obstetrics and Gynecology and the March of Dimes. The meeting focused on studies evaluating first trimester screening and programs that combine first and second trimester markers including the FASTER, BUN and SURUSS trials.

INTEGRATED SCREENING

Until recently, second trimester screening for Down syndrome was the standard of care in the US. The advent of nuchal translucency measurement and PAPPA has allowed screening results when CVS is still available.

While first and second trimester markers can stand alone, integrated screening, which combines nuchal translucency and serum markers obtained in the first *and* second trimester, offers the highest detection. Disadvantages include delay of results until the second trimester and logistical problems, like patient compliance in returning for a second sampling and linking first and second trimester samples if a patient moves or changes doctors.

CONTINGENCY SCREENING

In contingency screening, first trimester markers are collected, interpreted and disclosed. Women who have a risk so high that second trimester markers probably will not bring the risk into the screen negative range are offered CVS or amniocentesis. Women with a risk too low for second trimester markers to bring the risk into the screen positive range are not recommended further testing. For women in between, second trimester markers should be analyzed before considering invasive testing.

Contingency screening has similar sensitivity, specificity and logistical problems to integrated protocols, but it omits withholding information after first trimester sampling. There also are economical advantages, since only a small proportion of women will have second trimester testing.

A meta-analysis would allow for comparison of all the different screening protocols. First trimester screening and/or the contingent approaches will never fully replace second trimester testing because not all women seek early prenatal care. However, the challenges of training and quality assurance needed for nuchal translucency may limit some patients' access to this technology, and thus, screening protocols should include the option of serum-based screening.

TAILORING PROTOCOLS

Growing opportunities to improve screening can maximize detection and minimize invasive testing and patient anxiety. In the end, there likely will be several screening protocols to choose from, providing women with more autonomy. Genetic counselors are integral in educating providers and patients so screening tests can be suited for each individual.

Note: *Seminars in Perinatology* will publish an issue on this workshop, and an executive summary will be published in an obstetrical journal. ❖

BUDGETING PROCESS, ***from page 1***

B&R primer (available on our website) and participated in national CPT code negotiations. Could any of us take $175 and achieve these accomplishments? NSGC members contribute their dues, time, energy and expertise to get the job done. This is the power of a professional society.

WHO AND WHY

Those of us overseeing NSGC's budget are careful and judicious.

- The finance committee drafts a proposed budget based on expected income and expenses with input from regional representatives, committee chairs, the President and the Executive Director.
- The Board of Directors establishes funding priorities under the guidance of our strategic plan. We are very careful to manage this money, as these initiatives most affect the growth of our organization.
- With a budget of over $1,000,000 per year, the Treasurer and Finance Committee carefully monitor our ongoing income and expenses compared to our approved budget.

MONEY WELL SPENT

When I stepped into the position of finance chair for NSGC I was surprised to see how intricately our membership dues are stewarded. NSGC is the leading voice, authority and advocate for the genetic counseling profession. When you combine dollars with volunteers working on our behalf, NSGC becomes a powerful force to advance our profession. Your contribution is important, and together we can make a difference! ❖

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STUDENT CORNER

LEARNING TO ASK THE HARD QUESTIONS

Lauren Lichten, BA and Carly Friedman Grant, BA

Recently at Brandeis University, social psychologist, **Adrienne Asch, PhD,** facilitated a discussion about the use and implications of prenatal diagnosis. For some of us, this was the first time we were pushed to think about how to provide the best care to our clients and how our personal biases may inadvertently affect a counseling session.


Carly Grant & Lauren Lichten

We are trained as genetic counselors to address both sides of a given situation, but is this really being accomplished? By definition, nondirectiveness means that a genetic counselor enters a session without a specific agenda. In reality, however, the topic is determined before each client enters the office, since a medical indication is necessary for each visit. In a prenatal setting, this is associated with the chance of a fetus having a given “disability” or “disease”. But what may be considered a “disability” or “disease” to some may not be to others.

ON BEING NON-DIRECTIVE

Just as Adrienne Asch challenged us to think about nondirectiveness, we must do more than simply provide information about prenatal testing and its optional nature. Wouldn’t we be missing the counseling part of genetic counseling if we didn’t encourage our clients to consider multiple scenarios associated with the possibility of having a child with a given condition? In doing this it is important to point out that each child, regardless of his or her genetic make-up, will have unique personality traits that are impossible to predict with prenatal diagnosis.

BEING NON-PRESCRIPTIVE

To help people make thoughtful decisions, it is necessary to be directive in the questions we are asking. Perhaps non-prescriptive, rather than non-directive, is a more appropriate term to describe the process of genetic counseling. In the end, however, what we do is far more important than how we describe our actions.

EXPOSURE LEADS TO EXPERIENCE

In order to feel comfortable asking the hard questions, exposure to “disability” outside of a medical clinic is essential. Without this, we may lose sight of the person and instead concentrate on the condition.

A STORY TO TELL

Part of our training at Brandeis involves spending time with children and adults outside of a medical setting. Whether it be going to the mall, helping out at school or eating a meal with a family, these activities have allowed us to recognize that every individual, “able” or “disabled,” has a unique personality and a story to tell. This is just the first step toward becoming well-rounded, wise and sensitive genetic counselors who are willing to go beyond the medical jargon and address the psychosocial needs of our clients. It is an honor to take part in this process, and it is one we certainly do not take for granted. ❖

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UNIVERSITY OF TEXAS PROGRAM RECEIVES GRANT

Catherine Wicklund, MS

The University of Texas Genetic Counseling Graduate Program was recently awarded a Smart Foundation grant titled, “Multicultural Training Program Development.” The main goal of the grant is to support development of cultural awareness in all areas of the program. The graduate program is fortunate to have two cultural and communication specialists, **Scott Sawyer, MA,** and **Carrie Cameron, PhD,** to help with the project.

Work on the grant has commenced via interviews with the genetic counseling faculty to develop several workshops focusing on culture and communication. In addition, the program is offering Spanish courses to the faculty and hopes to develop an optional bilingual Spanish track for genetic counseling students.

The program also is pleased to announce the promotion of **Catherine Wicklund, MS,** from Assistant Director to Co-Director and **Sarah Jane Noblin, MS,** to Assistant Director. ❖

LOS ANGELES – THE CITY OF ANGELS

WHEN: November 12 – 15, 2005

WHERE: The Westin Century Plaza
Hotel & Spa
www.westincenturyplaza.co

The 2005 Annual Education Conference (AEC) Committee is thrilled to host our annual NSGC meeting in Los Angeles, a spectacular city with something for everyone. Whether you prefer strolling the beach at sunset, shopping for haute couture or hiking in the mountains, LA has it all. With a population of close to ten million, greater LA caters to a varied population, both ethnically and culturally. Come early or stay after the AEC to take advantage of what LA has to offer.

SOME HISTORY

When the Spanish occupation of California began in 1769, an exploratory expedition camped by a river they named “El Rio de Nuestra Senora la Reyna de Los Angeles de Porciuncula,” or “The River of Our Lady the Queen of the Angels of Porciuncula.” Over time, the area around the river came to be known as the Ciudad de Los Angeles, “City of Angels,” and on April 4, 1850 became the City of Los Angeles. The discovery of oil, a real estate boom and the evolution of the film industry led LA to become the metropolis it is today.

WHAT TO SEE AND DO

LA temperatures in mid-November average 61 degrees. Bring an umbrella and a jacket just in case, but, if we’re lucky, it could be warm and sunny throughout the conference.

The Century City Plaza Hotel is located in the heart of LA, with easy access to attractions. Across the street is the Westfield Shopping Town Century City, a mall with a wide selection of shops, a food court and a movie theater. Highlights within cab distance include:

Santa Monica – Most notable is 3rd Street Promenade, a street mall with tons of restaurants, shops and street performers and a few minutes walk from Santa Monica Beach.

Venice Beach – For artsy types, eclectic shopping and people watching abound.

Beverly Hills – This is the place for high-end shopping (Rodeo Drive) and movie-star gazing.

Hollywood – Where the movie industry was born! Check out the Mann Chinese Theater, stroll the Walk of Fame or tour a movie studio. The Grove outdoor “mall” is nearby.

The Getty Museum – The Getty offers a museum and gardens.

Sights slightly farther include:

Griffith Park/Los Feliz – This outdoor area offers hiking, horseback riding and the LA Zoo. Nearby is a trendy shopping and eating venue.

Pasadena – Home of the Tournament of Roses Parade, Pasadena offers Old Town with great shopping and restaurants, the Norton Simon museum and the Huntington Library and Botanical Gardens.

Malibu – This city offers stunning views of the ocean and huge estates.

Amusement parks – Disneyland, Universal Studios, Six Flags Magic Mountain and Knott’s Berry Farm are all within an hour drive of the hotel.

GETTING AROUND

If you plan to sightsee, renting a car is useful, as public transportation is limited. However, the Century Plaza Hotel provides access to the Big Blue Bus which will bring you to Santa Monica, Westwood Village, Brentwood Village, Beverly Hills and downtown (www.bigbluebus.com). For other tours, check out www.alllosangelestours.com and www.sightseeingworld.com. ❖

☞ **Roxanne Ruzicka,**
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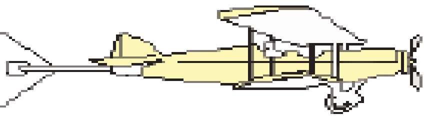
2004 NSGC SHORT COURSE UPDATE

Can genetic counselors improve their skills in communicating risks? Are the letters and brochures we write helping patients to understand their risk and make informed medical decisions? What does it mean to our patients to be “at risk?” The 2005 Short Course on Risk Communication will offer presentations on both theoretical and practical information that can be applied to all areas of genetic counseling. We have a diverse group of excellent speakers who are leaders in the fields of health psychology, communications and genetics. Whether you are explaining genetic test results, the chance of developing a disease complication or offering testing to family members, you are communicating risks. Look for more information about speakers and topics in the conference brochure later this spring! ❖

☞ **Julie Rutberg,** jrutberg@ohri.ca; **Suzanne O'Neill,** soneill@enh.org;
Short Course Co-Chairs

MEDIA WATCH



Angela Geist, MS and Roxanne Ruzicka, MS

November 8 – *Northern Nevada Business Weekly*, "Genetic Counselor Offers Time, Empathy, Expertise"

This article featured **Robbin Palmer** and her private practice. Robbin also was interviewed by the local KRNV evening news on November 24, with one of her patients who tested positive for a familial BRCA mutation, and by the radio talk show, "The Silver Lining," on January 25.

November 23 – *Wall Street Journal,* Health Mailbox column

In response to a question about a family history of lung cancer, genetic counseling was recommended for anyone with a strong family history of cancer, and the NSGC website was listed. Another article, "A screening test for high-risk mothers," discussed how preimplantation genetic diagnosis can test for single gene disorders and chromosome aneuploidy.

December '04 – *Cosmopolitan* magazine

Theresa Frezzo was quoted in a story about family history, and NSGC was listed as a resource.

January '05 – *E Pregnancy Magazine,* "I'm Not the Father"

In this article, **Karen Brewer** discussed the risks of paternity testing through amniocentesis. NSGC was listed as a resource.

January 14 – "Good Morning America," ABC-TV

A family from Minnesota whose child underwent prenatal treatment for neonatal hemochromotosis was interviewed. The mother noted that her genetic counselor helped her find a specialist in Chicago.

January/February '05 – *Health* magazine, "Make Your Family Work for You"

Robin Bennett was interviewed on the importance of family history and the benefits of knowing individual risk factors. The article included a sidebar, "What is Genetic Counseling," which mentioned the NSGC website.

February 15 – *Wall Street Journal,* Health page

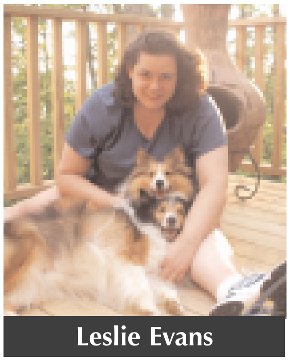
An article addressed what to do when your surgeon appropriately suggests BRCA testing, and the insurer refuses to cover. The answer: "The first step for you or anyone concerned about the genetic risk for cancer is to meet with a genetic counselor."

February/March, '05 – "Extreme Makeover: Home Edition" – ABC-TV

Three recent episodes highlighted genetic conditions. In one episode, the show's team made over the house of a family who has a seven year-old son with osteogenesis imperfecta. They described his brittle bones and how his parents were suspected of child abuse before the diagnosis was made. In another episode, a family with deaf parents and a child with autism and visual impairment had their home outfitted with the latest communications and safety devices. In a third episode, the home of a girl with Krabbe disease was improved, including mold removed because of the girl's allergies. ❖

A MEDIA SUCCESS STORY

Leslie Evans, MS



Leslie Evans

Our genetics center, like many others, struggles against the misconception that we are involved in controversial practices like human cloning and research on fetal parts. The NSGC E-blast announcing the first annual "Family History Awareness Day" provided a great opportunity for our center in North Carolina to present an important – and real – aspect of our service to the community.

I forwarded the E-blast to our marketing department and rewrote it for an article in our hospital newsletter detailing the importance of taking family histories. I wouldn't have been surprised if the news had stopped there. But we realized there was a chance to take it further. Knowing that newspaper, radio and television outlets are always looking for new ideas, especially around the holidays, we sent out a press release encouraging local families to take part in the first Family History Awareness Day on Thanksgiving.

A WARM RECEPTION

The story was very well received by our local media. By the time

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RESOURCES

MY SISTER'S KEEPER

By: **Jodi Picoult**
Publisher: Atria Books, New York,
423 pp.
Reviewed by: **Shelly Cummings, MS**

New York Times best selling author, **Jodi Picoult,** has written a provocative novel about medicine, family, relationships and the human application of genetics that will pull at the fiber of every reader. This page-turner tackles the complexity of morality and what it means to be a good person, a good parent and a good sibling. The timeliness of this book matches the current political and scientific battles over cloning and gene replacement therapy and makes readers think about what the future might hold and the potential situations that may arise.

BORN WITH A PURPOSE

The story begins with Anna, the 13 year-old daughter of Brian and Sara Fitzgerald, who "was born for a very specific purpose." Third child after her older brother Jesse and sister Kate, Anna was the result of preimplantation genetic diagnosis so she could be a donor match for Kate who has acute promyelocytic leukemia. Kate was diagnosed at age two and is alive at 16 – thanks to the multiple leukocytes, stem cells and bone marrow that Anna has donated over the years. Anna has never challenged her role until she decides to seek medical emancipation from her parents "for the rights to her own body."

OPPOSING SIDES

Sara Fitzgerald, mother, housewife and former lawyer, lives everyday waiting for Kate's next relapse. Now that Kate needs a new kidney to prolong her life, Sara is shocked and outraged that Anna has sought a lawyer, an action she believes will result in Kate's death and destroy the family.

Brian Fitzgerald, captain of the local fire department, knows how to extinguish a fire but can't control the "blazes" at home: Kate's unpredictable health, Jesse's dangerous and attention-seeking behavior and now Anna's legal move. Brian escapes by gazing at constellations millions of miles away but risks his marriage and his convictions in deciding whether to take Anna's side.

NOT SCIENCE FICTION

One of the novel's main themes is the challenge of relationships. Sara chooses to be the legal representative for her family, yet she tries continuously to convince Anna to donate her kidney. Anna's lawyer, Campbell Alexander, intervenes by having the court assign Anna a guardian *ad litem* – a woman who happens to be Campbell's first love 15 years ago. While the tracts that follow Anna, Campbell and the guardian are at times distracting, they keep the story grounded in reality and not in science fiction.

SIMILAR CHALLENGES

Genetic counselors especially may find this novel intriguing because it applies to the challenges we face daily with our patients. *My Sister's Keeper* explores the obligations of a family under duress and how people deal with the uncertainty of life. As genomic medicine becomes more prominent, questionable medical procedures will continue to create situations where there are no easy answers or solutions. ❖

MEDIA SUCCESS, *from page 8*

people sat down to Thanksgiving dinner, they had several opportunities to hear of the importance of family histories. Our ABC-TV affiliate broadcast an interview with me and a local family. Our public radio station conducted an hour-long interview and listener call-in show where **Dr. Bill Allen,** our clinical geneticist, and I answered questions about taking and using a family history. Our daily newspaper, the *Asheville Citizen-Times*, printed a feature story on Thanksgiving morning that likely prompted many valuable family conversations that day.

MEDIA TIPS

The NSGC provides tips that come in handy when media opportunities arise. For instance, as recommended in, "A Primer for Communicating Effectively through the Media" (under the Tools For Your Practice at www.nsgc.org), we provided each media outlet with statistics that demonstrated the importance of our story. We also planned ahead for a few key messages we wanted to incorporate in interviews.

A chance for good publicity can come up at any time. So get to know your marketing department and review those NSGC media tips to be ready!

***Leslie Evans** is the Genetics Education Specialist with the Fullerton Genetics Center at Mission Hospitals in Asheville, NC.* ❖

GENETIC COUNSELING LISTED AS NEW CAREER BY THE NIH

Terri Creeden, MS

The Education Committee is pleased to announce that the career of genetic counseling has been added to the NIH LifeWorks™ web site at www.science.education.nih.gov/LifeWorks.nsf.

A CAREER RESOURCE

LifeWorks™ is an interactive career exploration web site promoting awareness of occupations in health and medical sciences for middle and high school students. Users can review more than 100 medical science and health careers by title, education required, interest area or median salary. The "Career Finder" tool can generate a customized list of careers specially suited for a user's skills and interests. The site highlights true stories of successful professionals, including both carefully planned and unpredictable career pathways.

NSGC LEADS THE WAY

NSGC is the first organization to compile all of the necessary data to be listed as a new career on the LifeWorks™ web site. The NIH is very excited to add genetic counseling to their growing list of careers. A frontpage highlight of a genetic counselor currently is being planned.

Applying for a new career listing on the NIH web site was no easy task. The hard work can be credited to a small group of dedicated counselors: **Leigha Senter, Ellen Schlenker, Carol Christianson** and **Susan Manley.** Thank you for your great efforts! ❖

VOICES OF OUR COMMUNITY

Diversity Series, Issue Two

The Diversity Series highlights our profession through essays by a breadth of genetic counselors. This issue spotlights a GC with 30 years of experience. ***Myrna Ben-Yishay*** *reflects on her career milestones and the evolution of our profession. Myrna would like to honor* ***Dr. Harold M. Nitowsky*** *from Albert Einstein Medical Center in New York as a leader in medical genetics and a supporter of the genetic counseling profession.*

ON BEING A PIONEER

Myrna Ben-Yishay, MS

Thirty-one years ago, I was a science teacher and a mother to three young boys. Then one day an article in the *New York Times* described a new program in Human Genetics at Sarah Lawrence College. I was intrigued and went for an interview with **Melissa Richter,** a biologist and a founder of the program. Impressed and inspired, I applied and was accepted.

My class consisted of fewer than a dozen women, all with previous careers. We were excited about genetics and eager to become students again. The challenges were many: there was a paucity of articles about clinical genetics, there were few clinical sites for rotations, jobs had to be created and our future employers had to be convinced we could make a meaningful contribution to the field. We remained optimistic. After all, we were the pioneers of this new profession.

HIGHLIGHTS AND IMPRESSIONS

Several experiences in the past three decades have impressed upon me the impact of genetic medicine:

- the development of enzyme replacement for Gaucher disease and saving the first patient – a young woman who is now married with two children;
- the discovery by my team at Albert Einstein of the first cytogenetic prenatal diagnosis of Fragile X;
- the discovery of the genes for cystic fibrosis (CFTR) and hereditary breast ovarian cancer (BRCA1 and BRCA2).

To be sure, some things are surprising, even shocking, to my middle class sensibilities. I once found it incomprehensible how many young single women would have several children, each fathered by a different man. I have often been awestruck by the tolerant and accepting attitude of parents who have the burden of caring for severely disabled children. And no less inspiring is the calm resignation of women facing a hereditary susceptibility to breast and ovarian cancer.

REALISTIC EXPECTATIONS

I have no doubt that given the dynamic nature of the field of genetics, there will be many new opportunities for genetic counselors in the coming years. However, while my advice is positive to individuals soliciting my opinion about a career in our field, I remind them that the so-called "glass ceiling" exists. This is still a field dominated by MDs. Our salaries are not commensurate with our knowledge and responsibilities, and opportunities for career advancement remain limited.

Nevertheless, our success as a profession has far exceeded my expectations. If I had to do it again, I would not hesitate for a minute to choose this profession. ❖

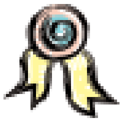
☞ Hunt.Katherine@mayo.edu,
Voices coordinator

SIG AND COMMITTEE UPDATES

CASIG GRANTS THIRD YEAR OF AWARDS

Cecelia Bellcross, MS
Co-Chair

The Cancer SIG is pleased to announce the recipients of the 2005 Cancer SIG Grant Awards.



1. *Assessing Patient Preferences for Genetic Counseling and Barriers to Cancer Genetic Services*

Alanna Kulchak Rahm, MS and **Judy Mouchawar, MD, MSPH,** Kaiser Permanente, Denver CO

Pre-test genetic counseling for hereditary cancer risk is standard practice as recommended by the American Society of Clinical Oncology (ASCO). In this age of Direct-to-Consumer advertising and the Internet, patients may prefer new ways of obtaining information. The aims of this study are to: 1) describe barriers to counseling uptake for patients referred to cancer genetic services; 2) describe preferences of patients for delivery of cancer genetic services; and 3) determine factors affecting barriers and preferences (such as education, race, age, knowledge family history, and actual or perceived risk) that may increase counseling uptake if patients are offered choice of service.

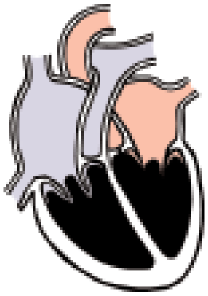
2. *Genetic Testing for New Cancer Syndromes: Current Practices Among Cancer Genetics Professionals and Means of Evaluating Clinical Relevance*

Kimberly Banks, MS, Kathy Blazer, MS and **Jeffrey Weitzel, MD,** City of Hope Medical Center, Duarte CA

Genetic testing for MYH and CDKN2A recently became available, but the clinical application of these tests by cancer genetics professionals remains unclear. This proposal aims to assess practices among genetic counselors, nurses and physicians regarding genetic testing for new cancer syndromes, with a focus on CDKN2A and MYH. This study will investigate how cancer genetics professionals determine when a genetic test is clinically relevant and evaluate the need for a governing committee to provide guidance/policy statements as to when a genetic test should be routinely offered. ❖

THE HEART OF THE MATTER: THE CARDIOVASCULAR GENETICS SIG

***Deborah A. McDermott, MS** and*
Amy C. Sturm, MS
Co-Chairs



Most genetic counselors have likely noted a family history involving cardiovascular disease. It is common to hear of a relative born with a "hole in the heart," having an "enlarged heart" or dying of a "heart attack." For decades, the cardiovascular information we could provide to individuals has been limited and largely epidemiological. This, however, is rapidly changing.

GROWTH OF A NEW SIG

As the genetics of cardiovascular disease has moved from investigation to clinical management, NSGC has responded. Recognizing this new area, a handful of NSGC members formed the Cardiovascular Genetics (CVG) SIG in 2004. Now there are nearly 50 members, working with a variety of conditions including congenital heart defects, arrhythmias, cardiomyopathies, aortic aneurysms and coronary artery disease.

AN ESTEEMED COLLECTION

Members of the SIG have presented at major cardiovascular meetings, such as the American Heart Association and the American College of Cardiology. Members and their colleagues have published in several peer-reviewed journals including *Circulation, Nature Genetics, The New England Journal of Medicine, PNAS, American Journal of Medical Genetics* and *Journal of Medical Genetics*.

LISTEN, LEARN, JOIN

The CVG SIG will sponsor an Educational Breakout Session at this year's Annual Education Conference to showcase advances and case reviews in cardiovascular genetics. Also this year, the SIG plans to unveil a web page for use by the general membership. The SIG welcomes all NSGC members seeking to discuss cases or enhance the cardiovascular genetics services at their institution. ❖

☞ **Deborah A. McDermott,**
dam2001@med.cornell.edu

☞ **Amy C. Sturm,**
sturm-1@medctr.osu.edu

SIG AND COMMITTEE UPDATES

NSGC 24TH AEC: CALL FOR ABSTRACTS

Abstracts of interest to genetic counseling and related professions soon will be reviewed for presentation at the 2005 AEC. Students, non-members and full members may apply. Read the Guidelines for Submissions of Abstracts carefully, as there are a few changes. For complete abstract submission guidelines, go to the NSGC web site (www.nsgc.org). ❖

GET INVOLVED IN THE PRENATAL SIG!

As the year begins, the Prenatal SIG says farewell and thanks to Co-chair, **Renee Chard,** and welcomes **Jennifer Hoskovec** to join **Sarah Noblin** as Co-chairs for 2005. The following activities are planned for the months ahead:

- co-sponsoring an Educational Breakout Session at the next AEC
- finalizing NSGC's Ancestry-Based Carrier Screening Guidelines for publication in *JGC*
- initiating a joint project with the Genetic Services Committee to evaluate preconception thyroid screening to detect children at risk for learning delay, and
- forming an online journal club to "chat" about interesting articles.

New members are welcome. Come get involved in the Prenatal SIG! ❖

☞ **Sarah Jane Noblin,**
Sarah.J.Noblin@uth.tmc.edu
☞ **Jennifer Hoskovec,**
Jennifer.E.Malone@uth.tmc.edu

VOLUNTEERS NEEDED!

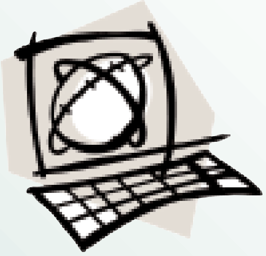
PUBLICATIONS SUBCOMMITTEE **Stephanie Cohen,** Chair, sacohen@st.vincent.org	Coordinate revision of existing publications; Write *PGC* article on publications review process
ONLINE-COMMUNICATIONS SUBCOMMITTEE **Debbie Keelean-Fuller,** keeleand@mail.ecu.edu	Help Committees/SIGs create web pages; Organize bookstore on website; Expand student webpage
EDUCATION COMMITTEE **Terri Creeden,** Chair, terricreeden@yahoo.com	Serve as reviewer for *JGC* CEU program
MEMBERSHIP COMMITTEE **Jolie Matheson,** Chair, jolie.matheson@bhs.org	Write brochure for minority recruitment
PROFESSIONAL ISSUES COMMITTEE **Susan Manley,** Chair, smanley@myriad.com	Write *PGC* articles on Professional Status Survey, billing successes, licensure
SOCIAL ISSUES COMMITTEE **Jill Fonda Allen,** Chair, JFonda@adventisthealthcare.com	Organize SIG web page; Serve as liaison to National Conference for State Legislators; Explore relationships with other advocacy coalitions; Monitor legislative activities; Develop legislative issues EBS; Write article summarizing discrimination literature
REGION I **Maria Del Vecchio,** mmihalek@charter.net	Join B&R subcommittee; Chair/organize '06 region meeting; Join Massachusetts GC Licensure Task Force; Establish CEU committee
REGION II **Ellen Schlenker,** ellen.schlenker@genzyme.com	Serve as State representative for West Virginia, upstate NY, Washington DC, Delaware; Serve as student representative from MCV, SLC, Howard University, NHGRI; Assist region newsletter and conference planning committee
REGION III **Lynn Holt,** lholt@genetics.uab.edu	Serve as State representative for Florida, Georgia
REGION IV **Karin Dent,** Karin.Dent@hsc.utah.edu	Assist conference planning committee
REGION V **Emily Burkett,** EBurkett@LHS.ORG	Assist conference planning committee; Serve as region newsletter editor

NSGC WEBSITE WATCH

INCREASING NSGC'S VISIBILITY THROUGH THE WEB SITE

Fourth in a Four Part Series

Debbie Keelean-Fuller, MS



PROVIDING A PUBLIC FACE

A picture is worth a thousand words, or so the saying goes. Counselor Spotlights on the NSGC web site provide snapshots about a varied group of NSGC members. Counselors' pictures and personal stories add a new dimension to our web site and allow us to highlight the diversity of our profession. This diversity lies in the background and personal characteristics of the counselors but also in the jobs and roles they fulfill. Since her posting, one genetic counselor that is featured on the web reports that she has experienced an increase in individuals contacting her about genetic counseling. As we expand our repertoire of highlighted counselors, we hope the public's desire for information increases by our provision of an identifiable personal contact.

MORE AND MORE HITS

With the addition of STAR/Rosen to our team, we have enhanced our visibility at the national level. In January of 2005, we had 983,970 hits on our web site, while in March 2004, we had 576,062 hits. That is a 58% increase in the number of hits! Of the top ten pages that were visited, the number one link is the resource page. Other links in the top ten that are publicly available include the training programs, the careers page and the family tree information. The "News Room" on the homepage of the NSGC web site includes a media kit, fact sheets on genetic counseling and contact information for several NSGC leaders. These features allow our profession to be more accessible to media organizations and other groups. Given the numbers, our visibility is growing, with increasing interest in locating a genetic counselor or making genetic counseling a career.

SPEAKER'S BUREAU COMING SOON

The Education Committee is creating a speaker's bureau – a publicly accessible database (through the NSGC web site) where genetic counselors will be listed to give presentations on their areas of expertise. This addition to our web site will hopefully advance our visibility and make it easier for the public to identify willing speakers. Look for the speaker's bureau soon, and sign up to share your expertise!

NSGC's Web Committee strives to make our web page easy to navigate and eye-catching. Development of the public side of the web page is integral to our future agenda. If you have suggestions or comments about the public side of our web page, please contact me at djfuller@med.unc.edu. ❖

NOMINATIONS FOR NSGC BOARD OF DIRECTORS

It is time to identify individuals to serve on the NSGC's Board of Directors (BOD). Nominate yourself or a colleague at the Member News section of the NSGC web site (www.nsgc.org). Open positions include: President-Elect, Treasurer and Representatives from Regions I, III and V. Full NSGC members are eligible. We appreciate your input in designating a high-quality slate of candidates!

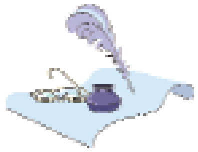
NSGC 2005 Nominating Committee: **Dawn Allain,** Chair, (Dawn.Allain@phci.org), **Lori Ann Correia, Karen Brown, Courtney Rowell, Shelly Cummings, Cynthia Frye** and **Sylvia Au.** ❖

NOMINATIONS FOR ABGC BOARD OF DIRECTORS

The American Board of Genetic Counseling (ABGC) is looking for genetic counselors board certified for five or more years to serve on its Board of Directors (BOD). Nominations are being accepted through April 1st from which a slate of four candidates will be chosen. Elections will take place August/September for two positions starting January 1, 2006.

The BOD meets three to four times a year in conjunction with the major genetics meetings. To make a nomination, contact **Sharon Robinson** (ABGC@genetics.faseb.org). Contact **Carol Walton** with questions about serving on the board (Walton.carol@tchden.org).

ABGC 2005 Nominating Committee: **Carol Walton**, Board Representative, **Diane Baker,** Chair, **Heather Hampel, Tressa Orthmeyer** and **Beverly Yasher** ❖



LETTERS TO THE EDITOR

IT TAKES THE ENTIRE GC PROFESSION...

Every year, when I review genetic counseling graduate program applications, I am struck by this thought: It takes all of us to promote and sustain our profession.

> *"I first heard about the profession when a Genetic Counselor came to give a lecture to my high school biology class. I was excited and intrigued... I knew genetic counseling was exactly the career I'd been looking for!"* – student applicant

THE EFFECT OF OUTREACH

Prospective graduate students learn the most about our career from you – through talks in high school and college classes, at career and health fairs and in other community settings. Applicants relate how they were positively influenced by the way you personalized the profession. Real people have real challenges living and coping with hereditary medical problems, but genetic counselors can help. Your job allows you to bring home a paycheck to perform rewarding and stimulating work.

HANDS-ON LEARNING

When you interest students in the field, you provide an even more critical opportunity. You invite students to your place of employment and allow them to watch and help you do your job. You ask them to write fact sheets, identify patient educational literature, compose lists of support groups. By now, the student is hooked.

MORE TO DO

Thank you for providing community outreach and touting our career. I, and my fellow Program Directors, appreciate how you prepare students to enter our programs. Your efforts create a strong and viable prospective student pool. Indeed, the ABGC recognizes your community education by granting continuing education units (see guidelines below).

Yet there is more to be done to attract students of color to study in our profession. I challenge every genetic counselor to give at least one talk this year to a minority student population. Don't underestimate the importance of your efforts. I will hear about these talks in graduate school applications – years later. ❖

Nancy Steinberg Warren, MS,
Director, Genetic Counseling Program,
University of Cincinnati and
Cincinnati Children's Hospital
Medical Center

NSGC SHOULD PRINT *JGC*

We are voicing our displeasure with the recent decision made by the NSGC to eliminate the print journal, despite considerable dissent from many members at the DC conference and on the listserv. A print journal lends visibility and credibility to a profession; a society that would choose to abolish such a benefit is certainly not a society whose aim is to promote its members. The NSGC's attempt at compromise by offering the "option" of a bound copy of the prior year's journals for an additional $75 unduly penalizes dues-paying members who simply want what was once a standard part of membership. Unfortunately, the list of legitimate journals to which we at Albert Einstein Medical Center will consider submitting articles for publication will no longer include the *Journal of Genetic Counseling*. ❖

Rosanne B. Keep, MS
Darnelle L. Dorsainville, MS

ABGC AWARDS PACS FOR COMMUNITY OUTREACH AND BOARD SERVICE

Beginning January 1, 2005, genetic counselors working towards recertification can earn Professional Activities Credits (PACs) for genetics-related presentations given to non-professional community groups. Examples of such groups include parent groups, religious organizations, advocacy agencies and K-12 classes.

PACs also can be earned for leadership activities including service on a Board of Directors or Medical/Professional Advisory Board for a genetics-related organization. PACs also will be given for service as the chair or leader of a committee, task force or work group for a genetics-related organization.

These activities join clinical supervision and publishing in a peer-reviewed journal as methods to earn PACs. One PAC is equal to one catetory one continuing education unit (CEU) and may be used for up to 20% of the total CEUs units required for recertification. For additional information go to the ABGC web site (www.abgc.net). ❖