PERSPECTIVES
in genetic counseling

Volume 26 Number 3 Fall 2004

national society
of genetic
counselors, inc.

nsgc

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

www.nsgc.org

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LOOKING OUTSIDE IN:

A SUMMARY OF NSGC'S EXTERNAL ENVIRONMENTAL SCAN

Angela Trepanier, MS

As part of the strategic planning process in 2003, NSGC commissioned the Melior Group to do an external scan, examining the perspectives of professionals with whom we work regarding the perceived utility of genetic counselors, barriers to our acceptance and steps to move the profession forward.

NSGC members identified individuals to participate in this project, which was qualitative in design and described previously in *PGC* (25(4):1, 2004). Eighteen interviews were conducted with professionals from allied health, medical academia, research, clinical medicine, industry and government. Results were tabulated and presented to the NSGC Board of Directors. Below is a summary of the findings.

UTILITY OF GENETIC COUNSELING

Value: There is significant value derived from genetic counseling. This value is determined by both the service provided and the extent to which genomic advances contribute to medical decision making and treatment.

Reimbursement: A physician referral for genetic counseling does not guarantee insurance reimbursement. Both NSGC members and the external interviewees see reimbursement as a barrier to services, yet members view it as a bigger problem.

Nondirectiveness: The nondirective stance of genetic counseling is of ambiguous value. While it serves reproductive genetics services well, its benefit in other settings is not clear.

BARRIERS TO ACCEPTANCE

Misinformation: Misconceptions and lack of information are barriers to acceptance. Educating providers about genetic counseling is not enough. Providers need to "buy in" to the value of incorporating genetic

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THE ROAD TO LICENSURE IN FLORIDA TAKES A DETOUR

Daniel Riconda, MS

On June 24th, the Governor of Florida unexpectedly vetoed Senate Bill 506 and House Bill 479, comprising The Genetic Counseling Practice Act. Although the bills passed unopposed in both the House and Senate, the Governor chose to ignore the legislatures' review process.

THE FINAL VOTE

Senate Bill 506 had passed five committees and the Full Senate unanimously. House Bill 479 passed the Health Standards Subcommittee and the full Healthcare Committee unanimously. Having counselors present at committee meetings proved to be crucial. The bill passed

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PRESIDENT’S BEAT

Recently a few colleagues asked if my views on the future of genetic counseling had changed now that my tenure as president is drawing to a close. The answer is easy – YES. Ironically, in discussions with my colleagues it became clear they expected me to be jaded, frustrated and exhausted after a year as president. They were surprised to hear the opposite is true. Don’t get me wrong, I am exhausted and have, at times, been frustrated! However, I am NOT jaded. Actually, I am more excited, passionate and hopeful than I was a year ago.

A Growing Respect

I am excited because NSGC was asked this year to provide presentations for the National Conference of Insurance Legislators and the Secretary’s Advisory Committee on Genetics, Health and Society. Our partnership was requested on a number of national grant applications, and we were asked to send official liaisons to over 20 professional and governmental meetings. NSGC has been approached to collaborate on genetic education programs for other health care providers, and we continue to hold successful educational conferences for our own members. Clearly our expertise is sought, our visibility is increasing and we are a respected player in the health care community. Yet we are not resting on our laurels. Our Visibility Taskforce is working to create a mechanism for NSGC to expand on these successes.

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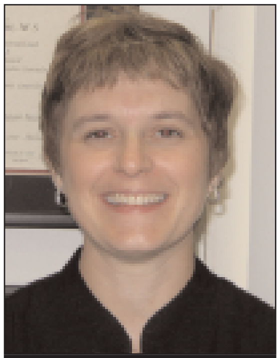
The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Next issue ***December 15***
Submission deadline ***November 11***



Dawn Allain, MS

Members’ Merits

I have interacted with many talented, well-educated and proactive NSGC members. These members have created new jobs, allowing others to follow in their footsteps. They have developed innovative collaborations with other professionals and organizations, benefiting our profession while simultaneously educating others about our unique skills. And many members selflessly dedicate their personal time to NSGC activities.

We Are the Experts

I am passionate because my interactions with other health care providers, policymakers and industry representatives have made me realize how much genetic counselors have to offer. We are the ones with the most comprehensive understanding of the implications and applications of genetic technologies. We are the experts, and our voices must be heard! We cannot let others decide our path in this era of genomic medicine. We must continue our efforts to define who we are, what we do and how we do it. We need to help others understand how our skills can enhance their efforts, whether in clinical care, research or in the business applications of genetic services.

Take Charge at the AEC

In October at our Annual Education Conference, we all can help move our profession forward by working on our strategic plan. Volunteer for committee work, attend the business meeting or speak out at the open mike session. You are the leaders of this organization; your Board of Directors and Executive Office work for you. Let your voices be heard. Let your energy and volunteer efforts move NSGC along the path to success!

Many Thanks

I thank you for believing in my leadership skills and providing me with the opportunity to help direct the future of our Society. Thank you for providing me with a rewarding, challenging and life-altering experience! I look forward to continuing to represent you on the BOD these next few years. ❖

Dawn C. Allain

Dawn Allain
2003-2004 President

EXTERNAL SCAN, *from page 1*

services into their practices. Buy in is tied to graduate and post-graduate education, professional standards and medical economics. Successful education requires developing relationships with allied health organizations whose referrals we seek.

Below are common barriers to genetic counseling health care services.

- Physicians and patients tend to seek directive interventions.
- Physicians tend to refer to other physicians they know or whose services insurance will cover.
- Physicians may not use a team approach in patient care. This trend is changing.
- Physicians may feel liability for the activities of genetic counselors who are not licensed professionals.

Other barriers include a deterministic view of genetics, the perceived association between genetic counseling, abortion and eugenics, and "turf protection" (physicians' concerns about reduced autonomy and monetary compensation due to the team approach).

POSITIONING OURSELVES

The following recommendations were made from the external scan results:

- Adopt a marketing strategy to improve physicians' and insurers' effectiveness in addressing genetic disorders. The physician and insurer are the consumers, not our patients, and are the ones to be targeted.
- Increase utilization and validation of genetic counselors. Currently, some view genetic counselors as "elitists" or "isolationists." Change this view by working more effectively with allied health professionals.
- Have an active presence in Washington DC.
- Increase members' preparation and capabilities in nontraditional areas.
- Develop materials that specify how genetic counselors can improve the physician/patient interaction.
- Seek opportunities in biotechnology.
- Reduce dependence on jobs in medical centers.
- Reconsider nondirectiveness.
- Seek licensure.

The external scan was a valuable addition to the strategic planning process as it provided some new perspectives to our Society. The scan highlights ways to approach "old" efforts (e.g., physician education), encourages us to re-evaluate how we practice genetic counseling (e.g., the role of nondirectiveness and service delivery models) and highlights the importance of building alliances with health care professionals.

Contact a Board member with suggestions or if you are interested in helping NSGC meet its strategic initiatives. The success of our strategic plan depends on the participation of all of us. ❖

☞www.nsgc.org/about/strategic_plan.asp

MEET YOUR BOARD OF DIRECTORS

We are pleased to announce the following elected, appointed and returning members who begin their 2004 – 2005 tenure as your Board of Directors on October 10th at NSGC's Business Meeting in Washington DC.

OFFICERS/EXECUTIVE COMMITTEE (ELECTED)

Kelly Ormond, MS (3)*	President
Nancy Callanan, MS (2)	President Elect
Angela Trepanier, MS (4)	Secretary
Jennifer Farmer, MS (4)	Treasurer
Dawn Allain, MS (4)	Past President I
Robin Bennett, MS (7)	Past President II

COMMITTEE CHAIRS (APPOINTED)

Aubrey Turner, MS (0)	Communications
Terri Creeden, MS, MPH (1)	Education
Peter Levonian, MS (1)	Finance
Elinor Langfelder Schwind, MS (0)	Genetic Services
Jolie Matheson, MS (1)	Membership
Susan Manley, MS (1)	Professional Issues
Jill Fonda Allen, MS (2)	Social Issues

REGIONAL REPRESENTATIVES (ELECTED)

Maria DelVecchio, MS (1)	Region I
Ellen Schlenker, MS (0)	Region II
Lynn Holt, MS (1)	Region III
Aimee Walter, MS (0)	Region IV
Karin Dent, MPH (1)	Region V
Emily Burkett, MS (0)	Region VI

*(n) represents previous years served on Board before this term

ACHIEVEMENTS

CHANGING THE FACE OF GENETIC COUNSELING: A NATIONAL AGENDA

Nancy Steinberg Warren, MS

The Midwest Consortium of Genetic Counseling Program Directors* was awarded a $25,000 grant to increase the level of racial and ethnic diversity in the genetic counseling profession. The grant, funded by the Community Outreach and Education Core, Center for Environmental Genetics at the University of Cincinnati, supports a three-year regional plan to promote collaborative minority recruitment and the publication of a consensus paper.

The project has two goals: (1) to address the unique barriers to minority recruitment, and (2) to increase the number of minority candidates interested in and prepared for admission to a genetic counseling program.

DOWN TO BUSINESS

On August 2-3 in Ohio, program directors from the region and minority recruiters and representatives of campus groups gathered to begin the project. **Karen Greendale, Judith Benkendorf** and **Bonnie LeRoy** presented the history of the profession and summarized data from national genetics workforce and genetic counseling program recruitment studies. **Michelle Boissiere** from Xavier University in Louisiana, **James Freeman** from the American Psychological Association and **Tawara Goode** from the National Center for Cultural Competence at Georgetown University discussed attracting and preparing minority students for careers in biomedical sciences, minority recruitment in psychology and setting cultural competency goals for genetic counseling programs. Brainstorming sessions focused on recruitment efforts, admissions criteria and cultural competence within our programs.

NEXT STEPS

Our next step is to implement minority recruitment activities in 2004-2005 and share these experiences with other programs. We plan to partner with the NSGC on its Strategic Plan Goal 2-1E, which addresses the need to increase the visibility of genetic counseling and focus on minority recruitment to obtain more diversity in our profession. ❖

***Nancy Steinberg Warren and Carol Christianson, University of Cincinnati; Betsy Gettig and Robin Grubs, University of Pittsburgh; Anne Greb and Angela Trepanier, Wayne State University; Bonnie LeRoy, University of Minnesota; Anne Matthews and Duane Culler, Case Western Reserve University; Kelly Ormond, Northwestern University; Casey Reiser, University of Wisconsin; Beverly Yashar, University of Michigan.**

GENETICS PROFESSION RECEIVES LANDMARK GRANT

Amber Roche, MPH

The Health Resources and Services Administration (HRSA) recently awarded a landmark grant to the Washington State Department of Health, Genetic Services Section (GSS) for two projects titled "Delivering Genetic Services" and "Translational Genetics Public Policy." The grant funds each project with $300,000 per year for three years, totaling $1.8 million.

Debra Lochner Doyle is the head of the GSS and the PI of the grant. Project partners include the University of Washington Health Policy Analysis Program and Institute for Public Health Genetics and the Fred Hutchinson Cancer Research Center.

PROJECT OBJECTIVES

The goals of the Services project are to 1) evaluate current models for genetic services delivery, focusing on the economic, legal, cultural and policy aspects; 2) evaluate potential alternative models for delivering services; and 3) assess options for public policies that promote cost effective, equitable delivery of services.

The goals of the Translational Genetics Public Policy project are to 1) develop an agenda to translate genetic research and information into practice; 2) develop consensus about the most effective methods to translate genetic services information and research; and 3) disseminate genetic services information and research findings to decision makers.

OUTCOMES AND GUIDANCE

Outcomes of these projects include a searchable database of genetics-related articles, case studies and presentations, service delivery recommendations, a projected timeline of service modalities, dissemination of policy briefings to target audiences and ongoing discussions among stakeholders.

An advisory committee and consultants will help guide both projects and assist in reviewing and disseminating materials. NSGC, which supported the grant's application, will provide a representative to the advisory committee. ❖

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GC PROGRAMS IN THE SPOTLIGHT

UNIVERSITY OF MARYLAND GC TRAINING GRANT

Lisa S. Steinberg, MS

The Health Resources and Services Administration (HRSA) awarded the University of Maryland School of Medicine (UMSOM) a three year grant entitled "Interdisciplinary Healthcare Training and Delivery," which helps expand or establish programs in allied health professions. Genetic counseling was specifically listed as a profession experiencing a workforce shortage. Projects focusing on genetic counselor training received priority funding.

PUTTING IT TOGETHER

Physical therapy and medical research and technology, the two other allied health graduate programs at UMSOM, collaborated with us to develop the program. One of our projects is to implement an online health care course for our graduate students covering interdisciplinary teaming, regulatory updates, health promotion and disease prevention, geriatrics, long term care, home health and hospice care, ethics, multiculturalism, disaster preparedness and bioterrorism. This course will be adapted as a continuing education activity.

NEW GC OPPORTUNITIES

A weekly consultative service within a family medicine practice will be established and a family history tool administered. Those patients with a moderate or high risk will be referred for genetic counseling.

The course and clinical experiences will be integrated into our program's curriculum. The consultative service will serve as a training site for students and help us expand the program. ❖

☞ www.bhpr.hrsa.gov/interdisciplinary/allhlth.html

SARAH LAWRENCE COLLEGE ACHIEVEMENTS

Caroline Lieber, MS

NEW GRANT SUPPORTS TRENDS IN GENETICS

The Graduate Studies Division at Sarah Lawrence College (SLC) was recently awarded a Council for Graduate Studies/Ford Foundation planning grant entitled, "Meeting the Challenge of the New Genetics." This grant supports assessment and program planning activities designed to investigate new social needs and employment opportunities in the field of human genetics. The goal is to determine ways to incorporate new professional components in SLC's Human Genetics Program, in collaboration with its Health Advocacy Program, including research ethics, public health issues and recruitment.

PROFESSIONAL DEVELOPMENT

The Human Genetics Program held a work-shop in June for genetic counselors in the field for five or fewer years. The workshop,"Clinical Supervision: Setting Students up for Success," included 25 participants in both didactic and small group activities. Topics included, "Why does supervision matter?" and "Teachers and Learners: Who are you as a Learner?"

NEURO-DEVELOPMENT TRAINING FOR STUDENTS

This fall, in collaboration with New York Medical College and the Westchester Institute for Human Development, three SLC second year students will participate in a new, year-long training program entitled, "Leadership Education in Neuro-developmental and Related Disabilities," funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources Service Administration (HRSA). Participants will appreciate the impact that having a child with a disability has on the family and work with other health care professionals to directly service families' needs.

CELEBRATING 75 YEARS

This year is the 75th anniversary of Sarah Lawrence College. As part of reunion activities, alums of the Human Genetics Program, **Debra Collins, Jessica Mandell, Lori Correia** and **Karlla Welch Brigatti** participated in the panel, "SLC Culture in the Genomic Age." Each discussed the influence of SLC on their development as innovators in the field, highlighting their accomplishments in private practice, public policy, research, grantsmanship, board certification/accreditation, pharmacogenetics and the use of the Internet. The discussion included current trends in genetics that affect the general population. Just weeks after the college's reunion, the Human Genetics Program hosted a luncheon honoring the Class of 1979 during their 25th year celebration. ❖

SLC Class of 1979 at a luncheon held on campus in their honor.

STUDENT CORNER

UNIQUE INTERNSHIP BRIDGES ROLES IN GENETIC COUNSELING

Jamie Jones, BS

As a second year Sarah Lawrence College graduate student, I had the unique experience of participating in the first joint internship between the Huntsman Cancer Institute and Myriad Genetic Laboratories, Inc. in Salt Lake City UT this summer. Through this collaboration, I not only collected logbook cases and enhanced my counseling skills but gained exposure to the roles of clinical and non-clinical genetic counselors.

A VIEW FROM INSIDE AND OUTSIDE OF THE CLINIC

At Myriad, I learned how genetic counselors who work in sales and marketing educate health care providers about hereditary cancer syndromes and genetic testing. With the marketing and medical services departments, I created an educational flyer for APC mutation positive individuals and participated in the telephone counseling process. Through both institutions, I witnessed the interaction between clinical and non-clinical genetic counselors in providing risk assessments, determining testing strategies and serving as resources for patients and health care providers.

WORKING TOGETHER

This experience has prompted me to examine the future of genetics and evaluate where we, as a profession, are headed. In addition to providing genetic counseling services, I see a growing role of genetic counselors as educators for other health care professionals. It is clear that the skills learned in a genetic counseling program are applicable to many arenas in genetics. It is also clear that, working together, clinical and non-clinical genetic counselors will reach more patients who can benefit from genetic services. ❖

INTERNSHIP ABROAD: A UK EXPERIENCE

Alice Hawkins, BS

I am a genetic counseling graduate student, born and raised in Scotland and now studying at Sarah Lawrence College. After a year in the U.S., I was curious how genetic counseling in Britain differed from America, so I decided to find a summer placement in London. Via NSGC's website, I contacted two genetic counselors and arranged to spend five weeks in prenatal counseling at Queen Charlotte's Hospital and five weeks in cancer counseling at Great Ormond Street Hospital.

PRACTICAL DIFFERENCES

At both centers, I noticed a variety of differences from the U.S. The UK has more relaxed abortion laws, diminishing the pressure to make prenatal decisions in a certain time frame. Also, the concept of AMA does not really exist. Invasive testing (CVS or amnio) is only offered after some screening, such as MSS, nuchal translucency or integrated testing (the combined test). Integrated testing theoretically will be offered nation-wide starting in 2007. Regarding cancer, the UK has a nation wide mammography program, offered every three years to all women over 50, but does not have an equivalent colorectal or pancreatic cancer screening program.

The UK system was at times frustrating. The National Health System only tests about 60% of the BRCA1 and BRCA2 mutations, as opposed to Myriad's 95%, though I am told this will change in the next year. Among the Ashkenazi Jewish population, only Tay Sachs screening is offered routinely while other genetic diseases, such as cystic fibrosis, require a family history. On the flip side, however, there are no concerns about medical insurance or billing. Also, while there are fewer genetic counselors in the UK, many other health professionals fill the role, such as hemoglobinopathy counselors, midwives and cancer genetic nurses.

SIMILAR AT HEART

It was not a surprise to witness cultural, demographic, economic and ethnic differences between the two countries. However, this summer taught me that aside from the variables, there is one major similarity – the global nature of genetic counseling. Genetic counselors face similar issues wherever they practice, and these do not alter the fundamentals of our profession: to educate, advocate and support. ❖

AEC 2004 – GETTIN' READY FOR DC

Barbara Harrison, MS

The Logistics Committee has been busy organizing information and activities for your free time during the upcoming Annual Education Conference in Washington DC.

COLLEGE OUTREACH NIGHT

Campus career centers, biology and psychology departments and associated academic clubs from local colleges and universities were asked to invite students to our "College Outreach Night" to introduce them to the genetic counseling profession. This 2-hour event, held Sunday at 5pm in the Congressional C/D/E conference room, will feature Q&A sessions with genetic counselors practicing in diverse settings and genetic counseling students. All are welcome to join this exciting event! RSVP by September 17.

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TOURS OF WASHINGTON DC

Take advantage of the following tours, which leave from the Old Town Trolley booth at Union Station. Cost per tour is $28.00.

1. **Old Town Trolley Tour:** A 2-1/2 hour tour covering the Lincoln Memorial, Washington National Cathedral and the White House. Tours depart on the hour (9am-5pm). Reservations are not required.
2. **DC Ducks:** This 90-minute tour begins with the monuments on the mall and ends with a cruise along the Potomac River. Tours depart on the hour (9am-5pm). Reservations are not accepted – this tour often sells out by noon.
3. **Monuments by Moonlight:** This 2-1/2 hour nighttime tour covers over 100 points of interest with stops at several memorials. Tours depart daily at 6:30 pm.

For a different adventure, there are kayak tours, bike tours, canal boat rides, anecdotal history tours, best addresses tours, Eleanor Roosevelt's Washington, Arlington National Cemetery, the Lincoln Assassination, the most haunted houses and a moveable feast sampling area restaurants.

To arrange for an NSGC group tour, use the RSVP form found in your conference materials.

☞Emily Kuchinsky,
emilybittner@hotmail.com

CULTURAL AND CITYWIDE EVENTS

Take advantage of these cultural events during your stay:

- The Kennedy Center for Performing Arts is offering Shear Madness, On Golden Pond, Absolute Frida and the NSO pops.
- The Smithsonian Museums have new exhibits such as, "Vote! The Machinery of Democracy," the lives of Sikh people and the Art of Mughal India.
- Local attractions include the Capitol, U.S. Supreme Court, Holocaust Memorial Museum, World War II Memorial, National Zoo, National Arboretum, Ford's Theater, National Gallery of Art and the National Aquarium.
- DC neighborhoods offer a vibrant nightlife. Capitol Hill is famous for happy hours while Adams Morgan caters to dancing and ethnic restaurants. Dupont Circle has a lively club scene. Foggy Bottom is low key with bars and dining.

☞Michele Choe, mchoe@lumc.edu

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NEW AT THE AEC!

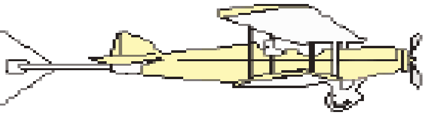
NSGC is rolling out a new program at our AEC this year. We will host a breakfast event on Friday, October 8th for human resource directors from national and international corporations, trade associations and local DC based firms. All attendees are members of the DC area chapters of the Society for Human Resource Management, the professional membership association of more than 180,000 human resource professionals internationally.

The program will include a keynote address entitled "The Future of Benefits," by **Harriet Hankin,** an internationally renowned human resource strategist. Ms. Hankin is President of CGI, a consulting firm in the Greater Philadelphia area, specializing in Employee Benefits Consulting and Administration. Her book, *The New Workforce: Five Sweeping Trends That Will Shape Your Company's Future,* is due out this fall.

Following the talk, genetic counselors will hold small group Q&A break out sessions with attendees, targeting pre-selected interests about genetic services expressed by the human resource professionals. Attendees will be invited to view our Poster Session with a genetic counselor as a guide. ❖

☞ www.shrm.org;
www.cgiconsulting.com

MEDIA WATCH



Angela Geist, MS and Roxanne Ruzicka, MS

May '04 – Nevada Newsmakers

Robbin Palmer, PhD was interviewed for this local TV show about the purpose of genetic counseling. She discussed first cousin marriages. Previously she appeared on another show and discussed genetic counseling, testing and discrimination.

May 12 – *South Jersey Courier Post,* "Combination test available for Down syndrome"

This article explained that a new combination blood test plus ultrasound in the first trimester of pregnancy tells women "within an hour after its completion whether their baby has Down syndrome." This misleading article failed to state that the screening test is not diagnostic.

June 3 – Discovery Channel, "Unmasked: Treacher Collins syndrome"

Individuals with Treacher Collins were interviewed, including a mother and daughter who had been counseled by **Janet Ulm.** This patient described the genetic code being like the writing inside a book, but didn't mention that she learned this through genetic counseling.

June 3 – CNN, "Larry King Live"

Ex-newscaster, **Brea Walker,** who has ectrodactyly, was interviewed. She did not mention genetic counseling but did express a negative view about how she was informed that her pregnancy was affected and was given the option of pregnancy termination.

June 15 – ABC, "Law and Order: SVU"

A laywer tries to get his client acquitted for charges of racism and murder by claiming that "racism was in his genes." In the end it was concluded his hatred was learned.

June 17 – *The Wall Street Journal*

A front-page article about newborn screening featured two children with glutaric acidemia born last year in California. One was diagnosed immediately by tandem mass spec and the other was missed because the expanded screening was not performed.

June 20 – *The New York Times,* "In New Tests for Fetal Defects, Agonizing Choices"

This front-page article reviewed prenatal diagnosis and the tough choices facing patients. It was well-written but did not portray genetic counseling services in the best light: "genetic counselors flood patients with scientific data, leaving them alone for the hard conversations about the ethics." The article seemed to focus on the controversial topic of abortion while failing to mention how genetic counselors help facilitate patients' decision making. Several counselors were interviewed, but only physicians and patients were quoted.

June 23 – NPR, "The Diane Rehm Show"

Lisa Freese answered questions from the host and listeners about prenatal screening, testing and the role of genetic counselors. She sat on a panel that included **Dr. Art Beaudet** and a bioinformation specialist.

June 29-July 2 – NBC, "The Today Show"

A four-part series on newborn screening included interviews with **Dawn Allain** and **Dr. Jennifer Howse** from the March of Dimes. They discussed the discrepancies in newborn screening between states, why there are no standards for screening and parental consent issues. They pushed for all states to offer the minimum nine screening tests recommended by the March of Dimes.

July 12 – major newspapers

A news wire article highlighted Baylor College of Medicine's new test to identify more than 40 genetic conditions by the Chromosomal Microarray Method. **Dr. Art Beaudet,** principal investigator, stated, "We can detect a huge amount of problems that we don't test for. I think it is time for somebody to get out there and say we ought to offer this kind of testing to all pregnant couples." The article discussed the associated ethical issues facing doctors and pregnant couples.

July 21 – *The New York Times,* "As Gene Test Menu Grows, Who Gets to Choose?"

This article analyzed the growing number of genetic tests available and the lack of guidelines about which tests health care practitioners should offer. It discussed the conflicting issues of the cost of the tests and the incidence of diseases, parents' right to know about the availability of tests and physicians' fear of legal consequences if they are not knowledgeable of the tests that can or should be offered.

August 5 – ABC, "20/20"

John Stoessel interviewed **Robin Bennett** in his story of cousins who marry. Robin reviewed the potential biological risks to children and the role of genetic counseling for consanguineous couples. The NSGC was mentioned. ❖

RESEARCH NETWORK

✓ ALZHEIMER'S DISEASE: SEEKING LATE ONSET FAMILIES

The Alzheimer's Disease Genetics Study, sponsored by the National Institute on Aging and supported by the Alzheimer's Association, is looking for genes linked with late-onset Alzheimer's disease (AD). Eighteen U.S. centers are participating.

AD families are asked to provide clinical and demographic information and donate blood samples. Participants can be of any racial and ethnic background and live anywhere in the U.S. Preferred families include:

- two siblings who developed symptoms of AD after age 60 and
- another family member over age 50 with memory loss OR over age 60 without memory loss.

Information is anonymized and forwarded to the National Cell Repository for Alzheimer's Disease in Indiana. DNA and data will be available to researchers investigating the genetics of AD, aging and related conditions. ❖

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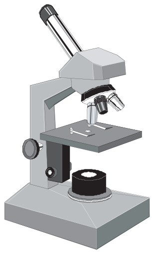
✓ STUDIES AT EMORY UNIVERSITY

COLOBOMA STUDY

Dr. Christa Lese Martin is seeking volunteers with uni/bilateral coloboma, plus other abnormal features including birth defects, developmental delay or dysmorphic features, to look for subtle duplications in the 22q11 region. Clinically significant results will be reported back to the family.



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MARKER CHROMOSOME STUDY

Dr. David Ledbetter is examining the euchromatic content of marker chromosomes, excluding those derived from chromosome 15, to establish genotype/phenotype correlations. They are collecting pre- and postnatal samples with a marker chromosome. ❖

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✓ SPINA BIFIDA RESEARCH

The Spina Bifida Research Resource (SBRR), funded by the NIH, is studying the genetics of spina bifida. Individuals with spina bifida (myelomeningocele, meningocele) and their families are eligible to participate. Women who have terminated an affected pregnancy also may be eligible. Participation includes a phone interview to obtain family and medical histories and collection of either cheek cells or blood samples. Travel is not required. All information is kept confidential. Study related materials are available in English and Spanish, and interviews can be conducted in either language. A study newsletter provides participants with results and information on spina bifida research. Genetic counselors and families are invited to call for more information. ❖

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AEC, *from page 7*

DINING IN DC

You can find just about anything to eat and drink in DC. Local Union Station has seven restaurants, a handful of cafes and more than 30 on-the-go choices. A 15% discount coupon is available on the Union Station website; www.unionstationdc.com.

Below are other recommendations within walking distance or a short cab ride from the Hyatt:

Andale (Mexican)
www.andaledc.com

Bistro Bis (French)
www.vidaliadc.com

B. Smith's (Creole, Southern)
www.bsmith.com/dine/bsmiths_dc

Capitol City Brewing Company
www.capcitybrew.com

Charlie Palmer Steak
www.charliepalmer.com/steak_dc

Dubliner Restaurant & Pub
www.dublinerdc.com

Il Raddichio (Italian)
www.robertodonna.com

Kanlaya Thai Cuisine
www.kanlayathaicuisine.com

Look for more information about "Dining in DC" and hosted dinners in your registration packet.

WELLNESS ACTIVITIES

Wellness activities will include yoga, massages, walking/running groups and meditation. RSVP via the card in your conference materials. ❖

☞Becki Hulinsky,
rebecca.hulinsky@hci.utah.edu

RESOURCES

MIDDLESEX

Author: **Jeffrey Eugenides**
Publisher: Picador, 2003; 544 pages
Reviewer: **Shelly Cummings, MS**

A double entendre lurks in the title of this Pulitzer-prize winning novel. The book's narrator, Cal Stephanides, is a hermaphrodite, raised as a girl but living as a man. Middlesex is the name of the leafy street in Michigan where Cal's family of Greek immigrants lives in the 1970s. This novel also tells how sexual and cultural conditions in a family led to Cal's birth and his own history as both and neither a man and a woman.

FROM HIGH ON MT. OLYMPUS…

Cal was born a girl named Calliope but revealed as a teenager to be a boy. The story begins in Greece in 1922, when Calliope's grandparents, siblings Lefty and Desdemona, fall secretly in love. The Turks invade Asia Minor, forcing Lefty and Desdemona to flee to America, where they hide their secret even when their son, Milton, marries his cousin, Tessie. As Cal explains, this union creates a genealogical tangle, producing a child with 5-alpha-reductase deficiency syndrome.

NATURE VS. NUTURE

Calliope realizes her sexual differences when she sees a doctor for lack of menstruation and is told she should remove her undescended testicles and "crocus," take hormones and reclaim the nature that nurture has dictated, "making an honest woman of him." Calliope – or Cal, as he now becomes – instead sets out for California and decides he will live between the genders and be "middlesex."

Middlesex is a well-researched, hilarious book filled with history, family and assimilation. The most powerful point of this book seems to be that everyone, not just Cal/Calliope, is the culmination of an infinitely unlikely journey through genetic and social history, the result of fate, passion, destiny and, most of all, what we choose to do with it. ❖

DOWN SYNDROME: THE FIRST 18 MONTHS

Video: VHS or DVD, Color/108 mins
Creator: **Will Schermerhorn**
Publisher: Woodbine House, 2003
Reviewer: **Karen Brookhyser, MS**

Created by the father of a son with Down syndrome (DS), this video offers accurate, useful information in an uplifting manner and emphasizes treating each child as an individual with needs and potential.

A BREADTH OF INFORMATION

The video opens with photographs of babies and toddlers and an overview of the chromosome diagnosis. The video has four parts: The Newborn, Health Concerns, Therapies and New Expectations. Each features interviews with experts in pediatrics, physical and speech therapy, pediatric otolaryngology and nutrition.

PRACTICAL ADVICE

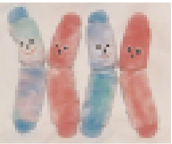
The video's information includes tips on feeding, tooth brushing, early intervention, sign language and posture assistance. Pediatricians give specific advice on screening for heart defects, cataracts, thyroid function, hearing loss and GI abnormalities. Advice for assessing breathing problems, ear infections and cervical spine instability is given. The therapies section illustrates common home activities such as reading, play and bath time to optimize development of language, social and physical skills.

Dr. William Cohen of the DS Center of Western Pennsylvania states that the family has two tasks: to make a place for the disability and to put the disability in its place. It is acknowledged that these tasks may not be easy, and the video ends on a philosophic note.

PARENT VIEWS

This video was well-received by families from a local Down syndrome support group. Some parents wished they had received this video when their child was born. Others thought the suggestions might be overwhelming for parents of newborns. The video seems an excellent resource for families and professionals, for information and discussion. ❖

CHROMI THE CHROMOSOME™ NOW AVAILABLE!



Attention all genetics educators: A new visual teaching aid is available for your genetic toolbox. Created by **Alicia Salkowski,** Chromi the Chromosome™ is a cute stuffed model of a chromosome for teaching basic genetic concepts. Alicia first made this teaching chromosome by hand to help patients understand genetics. Now, made by a plush toy manufacturer, they are available to genetic counselors and educators.

A future model, Translocation-Ring Chromi, is currently being designed. Alicia has plans to publish a children's book featuring Chromi the Chromosome™ so parents and children can read and have fun while learning about genetics. ❖
☞www.chromi.com

NSGC WEBSITE WATCH

FIND ME A GENETIC COUNSELOR

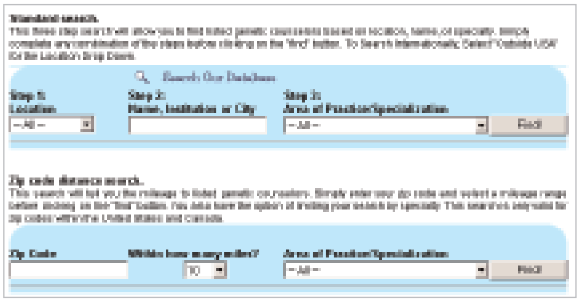
Second in a Four Part Series

Aubrey R. Turner, MS

When you visit a website, you're usually looking for some information or service, right? With this in mind, we have been looking at how visitors use the NSGC website. We want to know what types of information people seek on www.nsgc.org. As it turns out, the answer is most often YOU!

THE "FIND A COUNSELOR" PAGE

The most visited page on the website is the "Find a Counselor" page at www.nsgc.org/resourcelink.asp, with more than 4,000 visits per week. This page receives more traffic than our homepage, due to the large number of other websites that link here directly. This web traffic also has increased since last year when we added the ability to search by zip code for the nearest counselor.



The "Find a Counselor" page on NSGC's website.

We know that virtually every visitor to "Find a Counselor" conducts at least one search, and the majority actually try several different searches. There may be any number of motivations for these searches. An appointment to discuss family history. Interest in a genetic counseling career. A need for a local genetics expert to speak to a class or civic group. A reporter looking for a story. The list of good reasons goes on and on! However, this feature of our website is only as good as the information it contains. Therefore, the value of this information depends on YOU. "Find a Counselor" is a freestanding information service, and you must opt-in to participate.

UPDATING YOURSELF

The electronic records kept by the Executive Office and the information displayed publicly by the website are completely independent of one another, even though you can make changes to either via the website. This separation helps protect your personal information and allows you to control how (and if) you are listed publicly on our website. With this in mind, let's review how to keep your contact information up to date. All changes should first be submitted to the Executive Office at www.nsgc.org/members/membersprofile_forEO.asp, to make sure official NSGC mailings reach you. Then be sure to update your online "Find a Counselor" profile at www.nsgc.org/members/membersprofile.asp. More details and additional update options are described under the heading "corrections" on page 3 of your printed NSGC membership directory.

Next month: An update on the MEMBERS section of the website! We'll highlight some of your favorite resources, describe how new pages are added and let you know about new features on the horizon. ❖

Voices of Our Community

CELEBRATING THE RICHNESS OF GENETIC COUNSELING

Katherine Hunt, MS

Our profession is rich with diversity. Even though we all train to become expert health care providers, we bring to this career our own beliefs, values and cultural understandings. These personal systems shape how we present information, provide support and interact with our colleagues.

The next several installments of this column will display the texture and substance of our profession. *PGC* will run a year long series in which we feature personal perspectives about being a genetic counselor from the various faces among us. Upcoming editions will feature reflections from a seasoned veteran, a male genetic counselor, a minority genetic counselor and a new graduate. Stayed tuned! ❖

If you like to write and would be interested in sharing your own perspective on this topic, please contact:

☞Katherine Hunt,
hunt.katherine@mayo.edu

PROFESSIONAL STATUS SURVEY TRENDS 1980-2002

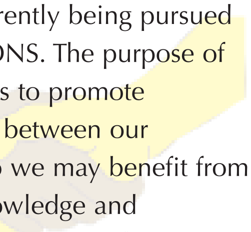
Check out this new report that is available on the NSGC website:

www.nsgc.org/careers/pss_index.asp

CAG SIG AND ONS UNITE

Cecelia Bellcross, MS

The Familial Cancer Risk Counseling SIG is announcing the development of an "informal" liaison with the Cancer Genetics SIG (CAG SIG) of the Oncology Nurses Society (ONS). This "informal" liaison between the SIGs is part of a formal relationship currently being pursued by NSGC and ONS. The purpose of the SIG liaison is to promote communication between our organizations so we may benefit from each other's knowledge and experience. GCs can join the ONS as associate members and become part of their CAG SIG.



THE POWER OF CONNECTION

Benefits of joining the ONS CAG SIG include: access to their listserv and website; opportunity to provide a perspective on cancer genetic issues; ability to attend the ONS Congress' abstract presentation; and the chance to collaborate on projects.

A joint workshop, "Power of Partnerships," is scheduled for the ONS Congress next spring with plans to repeat it at our Annual Education Conference in 2005. Ideas also are being developed for collaborative projects and publications.

Many ONS members already are associate members of NSGC and value our expertise in genetics and counseling. Similarly, they have much to offer us with their expertise in the diagnosis, treatment and management of cancer. We are excited about this new relationship and the opportunities it will provide for our profession. ❖

☞www.ons.org

FLORIDA LICENSURE, *from page 1*

the full House unanimously as the last of the legislative session and was sent to the Governor with the expectation that he would sign it.

The following represents a direct quote from the Governor as justification for the veto: "1) The potential for substantial harm resulting from lack of regulation is vague and speculative; 2) the current system of national certification constitutes an adequate alternative form of regulation; and 3) the cost effectiveness and economic impact of the regulation is not necessarily favorable to consumers, who may experience increases in insurance premiums if genetic counselors succeed in obtaining reimbursement from health plans." Although each of these issues was addressed extensively through testimony provided to the legislature (the bill even provides a disclaimer that licensing would not require reimbursement from third party payers), it seems apparent that much of the testimony was not reviewed by the Governor's office.

SEEKING REASSESSMENT

After meeting with key legislators and advocacy groups like the Florida Chapter of the March of Dimes, we are prepared to return to the legislature if we can obtain a compromise or reassessment from the Governor's office. We are attempting to arrange a meeting with the Governor's acting Policy Coordinator for Health and Human Services and are planning to meet with the Secretary of the Department of Health.

OUTSIDE ACTION

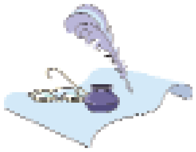
The House Committee on Healthcare (possibly in response to the Governor's veto) is creating an interim working group on licensure entitled "Background Information on Health Profession Licensure Issues." The charge of the committee staff is to "prepare a white paper for legislators to use in responding to legislative proposals to change licensure requirements for specific health care professions in order to accommodate changes in technology and professional specialization, protect a profession from competition and establish licensure of a new profession."

As a result of the veto, STAR/Rosen Public Relations, our PR firm of record, released a media advisory on licensure. I urge all genetic counselors to join efforts with their colleagues working on licensure efforts in their states. ❖

ETHICS SUBCOMMITTEE WELCOMES NEW MEMBERS!

The Ethics Subcommittee is happy to welcome two new members! After receiving a record number of applications, **Bonnie LeRoy** and **Kate Walsh Vockley** have been selected to serve a three-year term. We look forward to working with them and encourage everyone to continue submitting ethical dilemmas to us for input.

We are sponsoring an Educational Breakout Session at our upcoming Annual Education Conference, "Emerging Ethical Issues in Genetic Research," to be presented on Sunday, October 10th. We will be discussing ethical dilemmas affecting genetic counselors who work in research settings or who have patients involved in research studies. Based on debates at our EBS last year, we expect another great discussion! ❖



Letters to the Editor

Conflict of Interest: A Call for Broader Disclosures

Recently, increasing attention and contention has arisen related to the disclosure and implications of conflict of interest in scientific research, clinical contexts and scholarly publications. A conflict of interest (COI) is "a set of conditions in which professional judgment concerning a primary interest (such as a patient's welfare or the validity of research) tends to be unduly influenced by a secondary interest (such as financial gain)."[1] A straightforward example is disclosure of industry sponsorship of clinical trials. A potential conflict is the publication of genetic counseling and/or testing practice guidelines by an NSGC SIG with contributing authors who are employed by commercial testing labs.

Many journals have COI policies, some which require very specific disclosures for authors, editors and peer reviewers. Some journals (e.g., *JAMA*) publish a tag line at the end of each article where COI disclosures by each author are indicated. If none exist, this fact is stated.

NSGC Policies

Within NSGC, speakers at national and regional meetings must complete a COI disclosure form. The listing is published in conference manuals. Members of NSGC's Board of Directors are required to complete a COI document annually.[2] However, for elected NSGC positions, COI disclosures have not been disseminated to the membership prior to voting (i.e., such statements have not been included with candidate statements and voting ballots). This information also has not been made public after an elected or appointed official takes office. Existing guidelines also stipulate that "NSGC officers and agents shall clearly differentiate between public statements made as an NSGC representative and those statements made as an individual..."[2] The Board enforces this policy through an internal mechanism of discussion. In addition, neither *Perspectives* nor the *Journal of Genetic Counseling* have formal COI policies, but the editorial board of the *JGC* plans to address this at an upcoming editorial meeting.

Suggested Changes

It would be interesting for the membership to learn more about NSGC's process and how decisions about the existence of COIs are made. It would also be valuable to request broader, more specific requests for disclosures of possible COI including relevant stock holdings, honoraria, consulting fees, grant funding, organizational memberships, royalties, employment, etc. It also might be worthwhile to add statements to the NSGC bylaws, administrative manual and/or Code of Ethics about what may constitute a COI and what the appropriate disclosure process is.

I hope the membership and the Board of Directors will consider these points as our involvement and visibility in the public arena continue to expand. ❖

Beth N. Peshkin, MS

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[1] Thompson DF. Understanding financial conflicts of interest. *NEJM* 1993;329:573-576.

[2] NSGC Conflict of Interest Policy and Disclosure Form for Officers and Agents. September, 1996.

Response to Traditional vs. NonTraditional roles

As a member of the NSGC Scope of Practice Task Force, I have been struggling with how to reconcile the roles of clinical vs. non-clinical counselors. Thus I was pleased to read **Mary Freivogel** and **Dawn St. Armand's** insightful Letter to the Editor (*PGC* 26(2):12, 2004) on traditional vs. nontraditional roles.

Serving The Customer

This letter reminded me of a well-established business concept: if you're not serving the customer, you should be serving someone who is. Applied to genetic counselors: if you're not providing direct clinical service to patients, you should be providing services to those who are. As the authors point out, counselors who coordinate research studies, market genetic tests, write about genetics for lay or professional audiences, and direct public health efforts are part of the support infrastructure essential to the provision of clinical care.

Not Selling Out

Old enough to remember when genetic counselors opting to work for corporate labs were accused of "selling out," I hope that we finally recognize that "nontraditional" means neither non-critical nor second-rate. Although we may not have been trained for nontraditional roles, it is our genetic counseling training (and experience) that makes us so valuable in these positions. ❖

Edward M. Kloza, MS