PERSPECTIVES
in genetic counseling

Volume 25 Number 3 Fall 2003

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of genetic
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nsgc

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

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NSGC acknowledges
Women's Health Care Services of Wichita KS, for a sponsor's educational grant to support this newsletter.

BUZZ AND BUZZ WORDS ABOUT STRATEGIC PLANNING

Bea Leopold, MA

WHAT'S AN ENVIRONMENTAL SCAN?

Environmental Scans are often predecessors to Strategic Plans. While they don't have anything to do with the "environment," e.g., assessing our planet or saving trees, they do assess the world around a given group or entity to determine how to move forward.[1]

Environmental Scans take a global look at the realities of how businesses, associations or other entities are perceived. Environmental Scans are not a requirement of strategic planning, but responsible groups periodically will look at the factors they encompass.

BACKGROUND AND PRECEDENT

NSGC last conducted a formal Environmental Scan in 1992, in advance of our first Strategic Plan. As a result of that Scan, we learned valuable information about our Society, as identified by individuals inside and outside of our membership.

Issues at that time included:

- how will impending health care reform affect the profession?
- how can we address the growing need for GCs resulting from the introduction of the Human Genome Project?
- how can we effectively communicate with the public and third party payors?
- how can we maintain strong ties with the medical genetics

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PERSPECTIVES NEW EDITOR

Jessica Mandell, MS

With great pride and excitement, I accept the position as the next editor of Perspectives. From my days as a biology undergraduate to my job in biotechnology and health care PR to my genetic counseling training at Sarah Lawrence, I have sought to incorporate science writing and journalism in my career. Editing developed as my forté, and when I first learned of Perspectives as a student, I quickly joined the staff.

I was fortunate to meet **Janice Berliner** as the supervisor of one of my clinical rotations in New York, where I learned nuances of genetic counseling, editorial skills in writing patient letters (I will always remember her circles around my split infinitives) and a zest for volunteerism through her involvement with NSGC. When Janice became the editor of Perspectives, I appreciated my mentorship under both Janice and **Bea Leopold** as I grew into a professional counselor and an active NSGC member.

For the past two years, I have served as Chair of the Publications Subcommittee of the Communications Committee. I have enjoyed overseeing the drafting of new publications that enhance our society, as well as the updating of old publications to match advancements in science and the expanding needs of our

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President's Beat

The Word is Out

What a great year for NSGC! We've been at the right tables and set the menu. **Anne Madeo** is our first NSGC liaison to the National Center on Birth Defects and Developmental Disabilities (NCBDD). In June, I participated in the American College of Medical Genetics (ACMG) strategic planning meeting in the Bay area. ACMG applauded our successes in marketing and the dissemination of our practice guidelines. The message is clear that ACMG and NSGC have many common goals, and we have a strong, shared voice. Genetic counseling and NSGC also are highlighted in two feature articles in the November *Journal of Clinical Investigation* that I was solicited to write as President of NSGC. Co-authors are **Heather Hampel**, **Leslie Ciarleglio**, **Jennifer Williamson**, **Jessica Mandell** and **Joan Marks**.

Global Effort

Our human genome celebration continued into the summer at the International Congress of Genetics (ICG) and Australasian Society of Genetic Counselors (ASGC) meetings in Melbourne, Australia. An international exchange of genetic counseling ideas occurred with **Allyn McConkie-Rosell** and me as keynote speakers at the ASGC meeting, and **Diane Baker**, **Joe McInerney**, **Janice Edwards**, **Beth Balkite** and Allyn making up over half the speakers at the day-long clinical symposium at the ICG meeting. Janice, Diane and I met with representatives from Australia's four genetic counseling programs. NSGC was front-and-center at the meetings with a display table directly across from the ICG registration booth and a poster of the NSGC practice guideline process prepared by **Barbara Pettersen** and the Genetics Services Committee. Even the media took note with my picture and quote featured next to the coverage of **Francis Collins's** keynote address. The NSGC presence at international meetings validates genetic counseling as a branch of allied health. An added bonus to the meeting is the addition of **Clara Gaff** to the editorial board of the Journal of Genetic Counseling.

"My presidency of NSGC fulfilled a career dream for me that far exceeded my expectations."

Membership Feedback

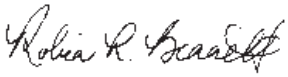
Thanks to all of the NSGC members who provided their comments for our Internal Scan. Your participation is essential to move the NSGC forward as we develop our strategic plan for the next few years. Your responses to the proposed changes in the Code of Ethics have been supportive and thoughtful. They all will be considered as the Ethics Subcommittee, our attorney and Board of Directors work to develop the final document.

A Fond Farewell

While I've completed my work as your president, my representation of NSGC continues as I am invited back to the Secretary's Advisory Committee on Genetic Health and Society (SACGHS) in October to provide a statement on the potential for expansion of genetic counseling training programs and the genetic counseling workforce. President **Dawn Allain** will also provide testimony on behalf of NSGC.

My presidency of NSGC fulfilled a career dream for me that far exceeded my expectations. I am energized by my interactions with our membership and our affiliates. To serve such a talented group of individuals is an honor. I welcome Dawn and our new Board members who will continue the forward momentum of NSGC.

Finally, my "retirement" book from the NSGC Amazon.com bookstore? The Long Journey Home, by **Michael Byers,** a novel based on a medical geneticist who studies connective tissue disorders, modeled after Michael's father, and my boss, **Dr. Peter Byers,** president-elect of the American Society of Human Genetics. ❖



Robin L. Bennett
2002-2003 President

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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***

Licensure Subcommittee Status Report

Sara Goldman, MS, Cheryl Harper, MS, Chris Miller, MS, Daniel Riconda, MS & Christine Seward, MS

As genetic testing requests increase, so will the demand for genetic counseling and the need for genetic counselor licensure. Licensure protects the public from harm by identifying individuals qualified to provide genetic counseling. It increases access to genetic counseling services by providing professional recognition and allowing for autonomous billing.

Licensure Online

The NSGC, through a Special Projects Fund award, now has a page on our website to guide members through the process of licensure. It begins with how to assemble a team, define the state's need, identify stakeholders and legislative sponsors and explore the licensing process and how a bill becomes law. Other sections include key issues to consider when developing licensure acts and rules, the use of a lobbyist, administration of the licensing program and billing and reimbursement issues. The website provides a state-specific grid delineating progress in licensure as well as contact information for the person(s) leading the process. It also provides links to other web resources.

An NSGC ad hoc committee also has established recommendations for licensure language to assist genetic counselors in the development of licensing bills and regulations, thus increasing the likelihood of interstate reciprocity. These recommendations have been approved by the NSGC Board and should be on the website soon. These recomendations include definitions (scope of practice), qualifications for licensure and temporary licensure (educational and certification) and continuing education and supervision requirements. Additional recommendations describe the ordering of genetic tests, exemptions from genetic counseling licensure, creation of a genetic counseling licensing board and grounds for license revocation.

One-By-One

Many states are now actively engaged in the licensing process, including: **Arizona, Kentucky, Massachusetts, Minnesota, New Mexico, Oregon, Vermont, Virginia** and **Wisconsin.**

These states have begun discussing the need for licensure amongst their counselors and developing core-working groups. **Washington** has completed a Sunrise Application being reviewed by the state's genetic counselors. **Colorado, Michigan** and **Texas** have identified either a lobbyist to support, or a legislator to sponsor, their bills. **Florida, Illinois** and **New York** have submitted prior bills and are revising and developing new strategies for the next legislative session. **California** passed a bill in the year 2000 but is awaiting the Department of Health Services to approve the Rules/Regulations to implement the licensing program. **Utah** is the only state that has both successfully passed a bill and implemented a licensure program.

The Licensure Subcommittee is composed of individuals who have been directly involved in the licensure process in their own states. The committee welcomes questions on licensure-related issues from genetic counselors. ❖

☞ www.nsgc.org/members/licensure/

Meet Your Board of Directors

We are pleased to announce the following elected, appointed and returning members who began their 2003 - 2004 tenure as your Board of Directors on September 15 at NSGC's Business Meeting in Charlotte NC.

Officers/Executive Committee *(elected)*

Dawn Allain, MS (3)* . . . . . President
Kelly Ormond, MS (2) . . . . . President-elect
Catherine Wicklund, MS (3) . . . . . Secretary
Jennifer Farmer, MS (3) . . . . . Treasurer
Robin Bennett, MS (6) . . . . . Past President I
Katherine Schneider, MPH (7) . . . . . Past President II

Committee Chairs *(appointed)*

Angela Trepanier, MS (3) . . . . . Communications
Terri Creeden, MS, MPH (0) . . . . . Education
Peter Levonian, MS (0). . . . . Finance
Barbara Pettersen, MS (3) . . . . . Genetic Services
Stephanie Kieffer, MS (1) . . . . . Membership
Susan Manley, MS (0). . . . . Professional Issues
Cheryl Scacheri, MS (1) . . . . . Social Issues

Regional Representatives *(elected)*

Maria DelVecchio, MS (0) . . . . . Region I
Melissa Kershner Lenihan, MS (1) . . . . . Region II
Lynn Holt, MS (0) . . . . . Region III
Heather Hampel, MS (0) . . . . . Region IV
Karin Dent, MPH (0) . . . . . Region V
Elizabeth Kearney, MS (1) . . . . . Region VI

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

Protecting Patients While Managing Lab Errors...

Jennie Feiger, MS

Recently, I posted the following query to the NSGC listserv. I received a diverse response and was encouraged to share the case.

A middle-aged man was diagnosed with an autosomal dominant, highly penetrant, severe adult-onset neurological condition. His neurologist ordered genetic testing through Lab A, which identified a pathogenic mutation. The neurologist referred the family to our Adult Medical Genetics clinic for counseling and presymptomatic genetic testing.

Three first-degree relatives, Sarah, Phillip and Mary, scheduled appointments. None were symptomatic, and all desired to undergo testing. They all traveled to our clinic and chose to pay out-of-pocket, so I decided to use a less expensive laboratory (Lab B). Lab B offered custom site-specific mutation testing based on the result report provided by Lab A. A positive control from the proband was not requested.

Sarah and Phillip tested first, and both received negative results. Mary tested six weeks later. However, before she received results, Lab B informed us they had made an error; they sequenced the wrong region of the gene due to different nomenclature used by Lab A. They needed to retract Sarah and Phillip's results, delay results for Mary and re-run the three specimens. Lab B declined our request to confirm the results in Lab A, at their expense, and pay for patients' additional genetic counseling.

The Questions

At this point, I had several concerns…

- Should I have questioned Lab B's ability to perform the test accurately? In trusting the lab, I didn't think to offer a positive control, though it was easily obtainable.
- `When should I inform Sarah and Phillip of the retraction — before or after re-testing?
- Is it less harmful to reintroduce the uncertainty of their genetic status or respect their autonomy and re-consent them?
- Should I require that Sarah and Phillip come in person to discuss their new results? A follow-up visit could cost several hundred dollars, plus travel and lost time from work.

The Process

I discussed the situation with our medical geneticist who recommended I inform Sarah and Phillip the test was being repeated. He did not suggest re-consent, as only six weeks had passed. A genetic counselor colleague felt that Sarah and Phillip needed to be re-consented because their perspective over the weeks may have changed. From the NSGC listserv, several counselors recommended waiting to inform until the reports were reissued, while slightly more recommended informing the patients up front. My institution's bioethics department recommended that I err on the side of full disclosure, informing and re-consenting the patients and asking if they would like to receive results by phone or in person.

I also consulted the head of the Genetic Testing Section of the Clinical Laboratory Evaluation Program in New York, the only state that regulates genetic testing laboratories. She said it would be difficult to require Lab B to pay for additional testing or counseling. Such a customized test would be permitted with proper quality control. Any laboratory doing customized testing should test the proband to assure that they have the right gene/

The Ethics Subcommittee Response

Peter Levonian, MS, Chair & Subcommittee Members

The Ethics Subcommittee reviewed this case to elucidate the main ethical dilemmas and demonstrate how the Code of Ethics can be helpful in a difficult situation. The main issues for the counselor were:

1. whether to inform the patients about the retraction of the results prior to or after the samples had been re-tested and
2. whether to trust a lab, without a positive control, after an initial testing error.

Assistance with the first point can be found in section II.3 of the Code, "Enable clients to make informed independent decisions...by providing or illuminating the necessary facts…." As evidenced by the varied responses on NSGC's listserv, the Code may be interpreted in different ways. The counselor's decision to fully disclose all information to the patients at the time she received them is supported by section II.3. Of course, the challenge to disclose this information in a way that minimizes additional anxiety and doubt, unfortunately, is not directly addressed by the Code.

Guidance for whether or not future results from Lab B should be considered reliable can be found in section I of the Code. Both section I.1, "Seek out and acquire all relevant information required..." and section I.4 "Recognize the limits of their own knowledge..." are relevant to the counselor's responsibilities for knowing or learning whether a positive control sample is necessary and for determining a testing laboratory's qualifications to perform the requested test. The genetic counselor addressed section I.4 in her debriefing of the case. It would help to ensure that samples are sent to laboratories that comply with guidelines created for quality assurance. ❖

... A Case of Ethics in Practice

region. A database and literature search would indicate the proper region to test, particularly with this variant.

The Outcome

I called all three relatives, informed them of the situation and obtained consent for re-testing. Sarah and Phillip wanted their new results by phone, with their spouses, the medical geneticist and me present. Both also said they would probably come to our clinic to discuss the results if they were positive. Mary rescheduled her appointment, but her husband could not attend, so Sarah came as her support.

Sarah's results were unchanged. After the disclosure, Sarah wished we had simply called with the new results because waiting the second time was too stressful. Since her initial disclosure, she had spent time with the proband who was dying and felt her chances of being positive seemed greater. She said that re-consenting for the test was a "no-brainer."

Phillip's results were unchanged. Phillip felt the situation was handled appropriately and said he would not have trusted the retracted test and new results without prior notification. However, the second waiting period was stressful and caused the "knot in [his] stomach" to reappear.

Mary's results were positive. Lab B felt this served as a positive control for Sarah and Phillip. Lab B also confirmed the mutation through restriction enzyme digestion. Mary was upset, and it was difficult without her husband present.

This experience reminded me of the uncertainty in genetic testing. I have always relished cases with "true negative" results and recognize the value of a positive control. While trying to save my patients some money, I seemingly relaxed my criteria. If the situation arose again, I would consider using a different lab for custom mutation analysis, first checking to see if it meets the NY State regulatory criteria. I also may change how I counsel about laboratory errors. Usually I rely on a lab's consent form, but I am now more cautious. I am sure mistakes have occurred in the past, and I can only hope for the best in the future and never assume a test is perfect. ❖

New Editor Appointed, *from p. 1*

profession. I turn the Chair over to one of my dedicated committee members, S**tephanie Cohen.**

I expect the editorship of *Perspectives* to bring challenges, lessons and accomplishment. I am humbled at the thought of serving the voice of our community but also thrilled at the task of keeping an eye on the forefront of information. Some goals for the next few years include: tracking the creativity and variety of genetic counseling across the globe, exploring interesting case studies matched with commentary from related NSGC Committees and SIGS, presenting point-counterpoint discussions between genetic counselors and other professionals who impact genetics and patient issues, trailing political changes and activities within NSGC and the health care/genetics community at large, seeking new and interesting conferences and helping bring *PGC* online.

Thank you all for the opportunity to take on this NSGC position. Please contact my committee or me with ideas, suggestions and constructive criticism as we progress through the next few years. Thank you, also, to Janice and Bea for your continued help and support. *Perspectives* is an NSGC tradition that I will seek to uphold. ❖

Birth Defects Prevention Network

Call for Manuscripts

The National Birth Defects Prevention Network (NBDPN) will publish its 6th national report on birth defects surveillance and prevention in 2004. The NBDPN is issuing a call for manuscripts for potential inclusion in the next report. They are interested in manuscripts that utilize or evaluate birth defects surveillance data, use these data in analytical epidemiological investigations or apply these data to prevention or intervention programs. The report will be published in Birth Defects Research, Part A.

Of special interest are manuscripts focusing on:

- registry data used to facilitate or plan services for children and families or evaluate health promotion/birth defects prevention activities
- cluster investigations
- birth defects rates and trends with graphical presentation of data or new statistical insights or observations
- roles of advisory committees, model legislation, methods for planning and evaluation and prenatal surveillance in public health programs.

Manuscripts are due by Monday, November 3. Ideas outside of the areas above are welcome. ❖

☞ **Russell Kirby, PhD**. . . . . 205-934-2985, rkirby@uab.edu

☞ www.nbdpn.org/NBDPN/callforman04.html

THE BUZZ ABOUT ENVIRONMENTAL SCAN, *from page 1*

community, in light of the impending split of the American Board of Medical Genetics and the formation of the American Board of Genetic Counseling?

Now, a decade later, the human genome has been mapped, an accomplishment that has already begun to revolutionize medicine. Health care has been revamped, but not in the way we expected, and we continue to grapple with third party payor issues. We have risen above the ABMG split, and the ABGC, our certifying body, has emerged strong.

LET'S GET PERSONAL

Factors in an External Scan can include economic, social, political and technological systems. The research in our current scan has included a five-pronged approach and includes:

- interviews and discussion with the Board of Directors at the interim Board meeting last April
- a literature search, a study of genetic counseling and several permutations of the topic
- interviews with non-members representing genetics and non-genetics medical specialties and government, industry, legislative, public health and bioethics professionals
- participation for all members in a survey designed to examine concepts that will drive the profession and NSGC into the future
- individual discussions with **Maitlon Russell,** Executive VP of The Melior Group, for members at our recent Annual Education Conference. Although that session was cancelled due to illness, interviews will take place by telephone before the scan is completed.

All of this information will be analyzed by The Melior Group, and we will use it as a base for our 4th Strategic Plan. A special Board meeting will be held in January to discuss and approve the plan, which will guide NSGC's activities over the next two to three years. The Plan will be released to the membership upon completion. ❖

☞ www.asaenet.org/environmental_scan

[1] Type in "Environmental Scan" on your favorite search engine, e.g., google.com or yahoo.com to view samples.

ANNOUNCING NSGC COMMUNITY CONNECTIONS

Nicole Teed, MS

Have you ever wished you could tap into NSGC resources for professional and personal reasons?

Do you want to initiate collaborations with genetic counseling colleagues?

When visiting a new city, would you like restaurant or hotel recommendations from a local?

Do you want to share your experience as a working parent, a Yankees fan or a marathon runner?

NSGC is happy to announce a new web-based resource that will facilitate sharing these interests — and more! — within our community.

Community Connections was developed in collaboration with project director **Seth Horwitz** at CommuniShare, a project of Nonprofit Technology Resources. The site is based on a process called community self-indexing. This tool is designed to enhance the natural interaction among community members in sharing voluntary information in a convenient, impartial and mutually respectful manner. This is especially valuable for a geographically vast community like ours, which gathers face-to-face only a few times per year.

NSGC's Community Connections can be used to discuss professional issues and personal interests. For example, while the listserv remains extremely helpful for case feedback, it is not appropriate for posting a request for a dinner recipe. With Community Connections, however, topics are virtually unlimited. Members can identify others who share their professional interests, make recommendations for books, plan social events at upcoming gatherings and express thoughts on the latest journal articles, hot topics in genetics or popular movies. Simply put, this site will be driven by the interests and participation of its members.

Come share your interests and ideas with your peers! Participation is voluntary, but the more members that enroll, the more useful the site becomes. The site is open to all NSGC members. The privacy policy is posted for your review. After a short registration process (different from your regular NSGC member ID), you will be on your way to utilizing and becoming an even more valuable resource within the NSGC community. ❖

Community Connections Committee:

- ☞ **Nicole Teed**, nteed@dmc.org
- ☞ **Dana Farengo-Clark,** dfarengo@mail.magee.edu
- ☞ **Melissa Hill,** mvhill118@yahoo.com
- ☞ nsgc.communishare.org *(do not key in www)*

AEC Heads for DC in '04

Julie Rutberg, MS & Liz Melvin, MS

When: October 7 - 11, 2004

Where: Hyatt Regency, Capitol Hill, Washington DC

Prelude: Two short courses, one on neurogenetics and the other on research roles for genetic counselors, are being offered October 6-7 (see the Summer 2003 issue of *Perspectives* for more details).

Deadlines: Although we are investigating many ideas, we are still looking for additional speakers and topics and more committee members. The deadline for submitting your ideas to the planning committee is November 1.

New Features: There are a few changes to expect in 2004:

- Our conference — and all future conferences — no longer will have a theme. We strive to present a well-rounded conference with wide appeal to all genetic counselors. No theme means no conference title, thus the next AEC meeting will simply be called the "23rd Annual Education Conference."
- Two short courses instead of one will provide variety and meet the needs of a greater audience.
- We are experimenting with the conference schedule, possibly beginning on the day of registration or having an evening session.
- We will add a "track system" to our successful Educational Breakout Sessions, successfully launched at our AEC in Charlotte.

The New Track System

Genetic counselors don't have a reputation for living by the philosophy "leave well enough alone!" This holds true not only for patient care and our professional interactions but also for our attempts to optimize our continuing education. So we are incorporating a new track system for AEC breakouts.

The track system reformats Educational Breakout Sessions (EBS), retiring the old Workshops, Practice-Based Symposia and Mini-courses. The goal of EBSs is to provide a flexible format for in-depth exploration of a variety of topics appealing to our increasing professional diversity.

How the New Structure Works

Individuals or groups (i.e. SIGs or committees) from within or outside of the NSGC are invited to submit a proposal for an EBS. Each two-hour EBS may include a panel discussion, hands-on activities, didactic lectures or a combination of formats. There will be four time slots with multiple sessions occurring at one time.

The addition of the track system is modeled after other professional organizations' conferences. EBS submissions will be divided broadly into four or five general tracks, possibly following the format of our concurrent papers:

- preconception/prenatal
- pediatric/adult
- expanded/professional roles
- cancer and
- counseling and psychosocial issues.

The exact track categories will depend upon the submitted EBS proposals. Registrants may choose to attend all prenatal or cancer talks, for example, during each EBS time slot, or those interested in more than one area can vary their choices.

Stay a While

Washington DC is a top travel destination with great museums and interesting neighborhoods and restaurants. As usual, we will have a busy schedule during the conference to provide the necessary CEUs. However, we encourage you to plan to come early or stay late and enjoy the sights! Our conference has been scheduled three weeks prior to the national Presidential election. It will be an exciting time to be in DC! ❖

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Media WATCH

Angela Geist, MS & Roxanne Ruzicka, MS

Thank you to everyone who forwarded us information on these news stories. We had many great media tidbits to write up! Please keep them coming for future issues!

March '03 — NBC affiliate, Tucson AZ

Katherine Hunt was interviewed about the genetic counseling profession. She discussed the genetic counseling process, the training of genetic counselors and insurance protection through local legislation. A woman pursuing genetic counseling for BRCA testing also was interviewed.

May '03 — *Reuters Health*, "Sperm Chromosome Defects Tied to Repeat Miscarriage"

A study in the June issue of *Obstetrics and Gynecology* showed that the rate of chromosomal defects in a man's sperm appears increased in couples with multiple miscarriages. Overall, these men had an increased level of aneuploidy in their sperm, about twice the rate in men without a history of miscarriages. The study's lead author, **Dr. Douglas T. Carrell** of the University of Utah School of Medicine, told Reuters Health that couples with failed pregnancies should see "a competent expert in this area."

May/June '03 — *Experience Life*, "Emerging from the Gene Pool"

This article discusses how insight gleaned from the Human Genome Project will affect medical care and predictive genetic testing for adult-onset conditions and how it will help us understand individuality through DNA polymorphisms. **Bonnie LeRoy, Katherine Schnieder, Bea Leopold** and **Cate Walsh-Vockley** were interviewed. They stated that despite advances in genetics, understanding how genes interact with each other and the environment is complicated, and individualized health care based on genetic profiling is still a ways off. The article suggests consulting a genetic counselor to determine what genetic testing, if any, is appropriate for a person. The NSGC and GeneTests websites are listed, as well as other genetics resources.

May/June '03 — *Quest* (MDA Publication), "The Pros and Cons of Genetic Testing"

Questions to consider when deciding whether to pursue genetic testing are discussed. The article explains the advantages of receiving an accurate diagnosis, such as family planning, enabling participation in clinical research trials and anticipating symptoms. It acknowledges that receiving a diagnosis can be emotionally difficult. **Karen Krajewski** and **Cheryl Scacheri** are quoted. Given the complexities surrounding genetic testing, the value of genetic counseling is highlighted, and a link to NSGC is provided.

June 10 — Bloodlines, "Technology Hits Home"

This TV show reveals how new life technologies are raising ethical, legal and social dilemmas as cutting-edge science intersects with the law. Cases presented include a baby created with artificial reproductive technology that has five "parents" with none recognized by law, a patent application for a creature that would be genetically part human and part chimpanzee and a corporation secretly doing genetic tests on its workers. The show discusses how these scenarios challenge our most fundamental beliefs and establish legal precedents that govern our future.

June 17 — The Guardian, "Sacrifice"

The lawyers and social services are challenged with finding a home for a teenage girl and her baby after the girl's father is accused of killing the girl's invalid mother who has Huntington disease (HD). After social services learns about her family history, they decide that she needs to get tested before they can finalize the adoption for the baby, stating that the adoptive parents have the right to know if the baby has a chance of developing the disease. The girl tests positive, and there is no involvement of a genetic counselor or geneticist.

July '03 — *Washingtonian*, "Is our baby okay?"

Jill Fonda Allen gives an in-depth interview about her job as a genetic counselor. Topics include how a genetic counselor relays bad news to patients, decision-making after abnormal prenatal diagnosis results and sources of comfort for patients potentially learning bad results. The interview highlights the benefits of genetic counseling for patients and the fact that giving bad news is the exception rather than the rule with most patients getting good results.

July '03 — *Glamour*, "The amazing life of Laura"

This emotional article portrays a 22-year-old woman dying with CF. The symptoms and course of CF and the epidemiological aspects of the condition are presented correctly, but autosomal recessive inheritance is not mentioned. The article captures social difficulties faced by people with a chronic illness, the ways a person with a fatal illness prepares for death and the urgent need of this woman to make her mark on the world.

July '03 — *Rhode Island Monthly*, "Leap of Faith"

A family from Rhode Island tells their story about very bad luck ("horrible cosmic dice") regarding odds for DMD. Seven males in the family have had DMD. **Jessica Blasko** was interviewed. The course of DMD, the emotional aspects of chronic disease and the guilt associated with passing on an inherited condition are presented.

...to next column

....Media WATCH, from p. 8

Contacts for more information about DMD, including the NSGC website, are included.

July 8 — *Wall Street Journal*

A front-page article discusses a couple whose 8-month-old daughter was diagnosed with Hurler syndrome. The article follows them through meetings at two centers offering different treatments (bone marrow vs. umbilical cord stem cell transplant) and gives insight into how they made their choice of treatment. The word genetic appears only once ("rare genetic disorder called Hurler syndrome"), and there is no mention of any contact with a genetic counselor.

***August '03 — Discover Magazine,* "Kiss your cousin, in fact marry her if you want to"**

This article accurately discusses the study by **Robin Bennett** et. al. about consanguineous couples. Both the NSGC and the Journal of Genetic Counseling are mentioned.

September '03 — *Women's Health and Fitness*

Robin Bennett was asked to write a section called "Genetic Counselors: An Essential Resource for Women Concerned about Inherited Ovarian Cancer." This section accompanied an article on ovarian cancer and genetic testing for BRCA1 and BRCA2 and an ad placed by Myriad Genetics. The section included information on genetic counseling and contacts for NSGC.

Sept/Oct '03 — *Vive*, "Genetics & Breast Cancer"

Lines between the personal and the professional merge in this moving article by **Melanie Bone, MD,** who was diagnosed with breast cancer and tested positive for BRCA2. **Kathy Schneider** was quoted in a sidebar article, "Fighting Cancer with Innovative Techniques," which outlines breakthroughs in detection and treatments. ❖

Genetic Alliance

THE POWER OF PARTNERSHIPS

Wendy R. Uhlmann, MS & Diane L. Baker, MS

The Genetic Alliance conference, "Securing Our Future: Bank on Us," held in early August, brought together approximately 200 lay advocacy leaders, industry representatives, researchers, clinicians, policy makers and genetic counselors. NSGC sponsored a coffee break and **Dawn Allain,** then NSGC's President-elect, was selected to provide opening comments.

The key message of the meeting was the power of partnerships. It was informative and inspiring to hear lay advocacy leaders describe partnering with researchers, pharmaceutical companies and other organizations to reach goals of finding disease genes, developing diagnostic testing and therapeutics and improving health care for affected family members. Many of these lay advocacy leaders have successfully interested researchers in their genetic conditions, and some are directly involved in the laboratory research. **Scott Berns** and **Leslie Gordon** of the Progeria Research Foundation, along with **Dr. Francis Collins,** shared the story of how their partnering led to the recent identification of the gene for Hutchinson-Gilford Progeria.

ACTION TEAMS

The Genetic Alliance has formed Action Teams on seven core genetics issues:

- Public Health and Newborn Screening
- Disparities and Diversity
- Nondiscrimination and Privacy
- Access to Affordable Quality Genetics Services
- Youth Coalition
- Genetic Research and Translation
- Public and Health Professional Education.

Diane Baker, Beth Balkite, Joan Scott, Vivian Ota Wang and **Wendy Uhlmann** co-facilitated different Action Team meetings. Genetic counselors are encouraged to join these teams, which meet and conduct their work "virtually" via listservs. There is no membership fee to join.

CONFERENCE ACTIVITIES

The Genetic Alliance announced the launch of BioBank – a bio-respository enabling lay advocacy groups and disenfranchised communities to accelerate research and treatments by banking blood and tissue.

Geneticist **Eric Lander** gave the keynote address, "Bringing Home the Genome," which focused on the implications of the Human Genome Project. Former fashion photographer **Rick Guidotti** shared his moving exhibit, "Positive Exposure," vibrant photographs of individuals with genetic conditions put together "to celebrate diversity, to challenge stigma, to illustrate strengths and to share experiences."

Workshops were conducted on dispelling myths about genetic disorders, securing basic science partners, giving effective presentations, planning conferences and managing fundraising activities.

This conference was the kick-off for the "Human Helix on the Mall," an event scheduled in Washington DC in 2005 emphasizing the universality of genetic conditions and the importance of genetics in research and healthcare.❖

☞ www.geneticalliance.org

☞ www.positiveexposure.org

Resources

Wonderwise - Women in Science Learning Center

Produced by: University of Nebraska Museum, Lincoln NE, in partnership with Nebraska Cooperative Extension 4-H, 2002
Funded by: Informal Science Program of the National Science Foundation
Reviewed by: Shelly A. Cummings, MS

The integration of genetics into the vocabulary of health care professionals and the public is a focus of many organizations including the NSGC, ASCO and the U.S. Dept of Energy. Early education is vital for the public to become more knowledgeable about genetics and the advances and implications of the Human Genome Project. The Wonderwise learning series is an educational tool that explores the role of women in science. Each kit is a comprehensive instructional package including a video, CD-ROM and activity book. These materials help teachers and students explore the world of women scientists and the fun of learning about science.

This learning tool is an excellent resource, introducing genetics in elementary school. One of its strengths is the in-depth description of the practice and diversity of genetic counseling. **Cathy Burson** is the featured genetic counselor and a content consultant for the program. The viewer sees actual patients and families with various conditions and observes the counselor and patient interaction. CD-ROM graphics are exceptional and provide clear explanations of basic genetic concepts. The CD-ROM also includes a link to download a 44-page activity book, genetic resources, a section on women and minority scientists, a detailed glossary of terms and a video guide. The "DNA Up Close" and "Meet Your Cells" sections allow the user to view different cell types via compound and a transmission electron microscopes.

The learning series features five hands-on activities designed for 8 to 12-year-olds. Each activity includes a 30 to 45 minute project with extensions. Examples of the interactive component of this tool include identifying features of the body or behaviors that come from genes, watching a video tape on the role of genetic counselors and sorting chromosomes from karyotypes. These learning tools can be used in any order and include assessment questions, ideas for presentations, exhibits and topics for further investigation.

Each module and associated activity focuses on a learning objective or outcome. In Module 1: Meet Cathy, students use simple tools to gather scientific data and develop an understanding of genetic counseling by watching a video and then exploring their own genetic features (hair type, dimples, cleft in chin, etc.). The complexity of each activity increases through the work book. In Module 5: Inside DNA, students build a model gene using gumdrops and licorice and learn aspects of DNA structure and replication. Learning outcomes for each activity are based on national science education standards identified by the Mid-Continent Research for Education and Learning, the Nebraska Educational Standards and the National Science Education Standards developed under the direction of the National Research Council. The activity book incorporates concepts of inquiry-based learning and the 4-H Youth Development experiential learning model.

I highly recommend this National Education Association Award Winning Series for genetic counselors lecturing at elementary schools or who help educators in their communities. Genetics is the future, and our professional society can act as ambassadors of this technology to those who shape young minds. It is nice to know that this valuable resource exists so children can learn how genetic counselors can assist in health care services. ❖

Research Network

Klinefelter Syndrome and Madelung Disorder

Dr. Judith Ross at Thomas Jefferson University in Philadelphia PA is seeking participants for two research studies. One study investigates the physical features and cognitive learning styles associated with Klinefelter syndrome in males aged one day to 70 years. Participation includes a one to two day visit, history and physical examination, cognitive learning evaluation and a blood sample. Subjects will be paid $50 as well as $10 for parking and travel expenses.

Dr. Ross is also seeking children and adults who have a wrist abnormality called Madelung disorder to determine if these individuals are missing the SHOX gene, whether or not they have short stature and how they learn. The study includes a history, physical examination, a learning evaluation and a blood sample. Subjects will be paid $100. Detailed summaries of the evaluations will be made available to study participants and referring physicians upon request. ❖

☞ Dr. Judith Ross, 215-955-1648; judith.ross@mail.tju.edu

Letter to the Editor

Salaries v. Patient Volume: An Issue of Equity

Michael Begleiter, MS

Since shortly after its inception, the NSGC has been conducting periodic professional status surveys (PSS) of its membership to assess employment experience, work environment, professional status, salaries and benefits, professional activities and job satisfaction. The PSSs have become an industry standard, and many genetic counselors have been able to use the data collected to successfully negotiate changes in their work environments (salaries, responsibilities, faculty appointments, etc.).

The most recent PSS included responses to questions in all of the aforementioned areas. In reading the 2002 PSS, I was struck by a question which none of the previous surveys had addressed, i.e. have genetic counselor salaries increased in real dollars?

Revealing Data

Data from all of the previous surveys were collected (Table), and the average salary was adjusted for inflation using a website which makes such calculations based on the Consumer Price Index. When all salaries are converted to 2002 dollars, the average genetic counselor earns approximately 25% more today than in 1981. Until recently, the average number of patients seen per year has remained relatively constant. But, the data show that there was a dramatic increase in the average number of patients seen from the 2000 PSS to the 2002 PSS. From 2000 to 2002, the average patient volume increased from 345 to 572; an increase of 65.8%. During the same time period, salaries increased from $48,311 to $50,130 (in 2002 dollars); an increase of 3.8%. From 2000 to 2002, the average genetic counselor compensation per patient (annual salary/number of patients seen each year) decreased from $140.03 in 2000 to $87.64 in 2002; a 37.4% decrease.

Genetic Counselor Salaries —Dollars v. Patients

Year	N	Average Salary	Average Salary in 2002 Dollars	Average # of Pts. Seen	Salary per Patient in 2002 Dollars	Reference from *PGC*
1981	143	$18,621	$39,033			3(4):1-2.1981
1984	177	$23,000	$39,838			6(3):2-4.1984
1986	141	$26,102	$41,888	377	$111.11	8(2):1-2.1986
1992	477	$38,116	$48,358	448	$107.94	14(2):7-10.1992
1994	605	$38,047	$45,499	389	$116.84	16Suppl:1-12.1994
1996	684	$42,545	$48,379	385	$125.66	18Suppl:1-8.1996
1998	779	$43,703	$47,442	351	$135.16	20(3):S1-S8.1998
2000	956	$46,436	$48,311	345	$140.03	22(4):S1-S12.2000
2002	838	$50,130	$50,130	572	$87.64	NSGC website

Equity

This brief analysis does not take into account the areas of specialization in which counselors are working, the distribution of years of experience among counselors or any other demographic data which might explain these changes. Nevertheless, it appears that salaries have continued to increase. Unfortunately, those increases have not kept pace with patient care responsibilities. If the average number of patients seen in 2000 was 345 and the average number of patients seen in 2002 was 572, an increase of 65.8%, then one might expect to see a comparable increase in salary to acknowledge the increase in work expectations. This would translate into an increase from $48,311 in average salary in 2000 (in 2002 dollars) to an average salary of $80,100 in 2002; an increase of 65.8%. Perhaps genetic counselors should consider negotiating with employers about salary changes not just on the basis of the salaries published in the PSS but also based on the patient volumes they serve. ❖

☞ www.westegg.com/inflation

Correction

Ann Forsythe, from the Office of Communication, American Society of Human Genetics, wrote the article, "CDC DES Update: What Genetic Counselors Need to Know," (PGC 25:2, p. 8). The article was mistakenly attributed to **Alexis Poss** as the author. ❖

Membership Committee & Diversity SIG Activities

Kathryn Spitzer Kim, MS

Winning Ideas

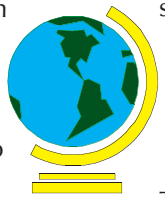
For several years, the Membership Committee and the Diversity SIG have awarded scholarships to two genetic counseling students, based on answers to counseling-related essay questions. This year, the questions focused on attracting a diverse student body into the field of genetic counseling and addressing the issues of minority groups during genetic counseling sessions. Many students participated, and congratulations go to the students with the highest scoring essays: **Lih Yeen Tan** from University of British Columbia, Canada, and **Diana Moglia** from Mount Sinai School of Medicine NY. Both are current NSGC student members. Their essays are highlighted here:

Attracting Students High School & Beyond

Many of us think about speaking to college groups on genetic counseling. But high school students are already considering careers and may not make choices appropriate for a career in genetic counseling unless they know about the rich opportunities in the field. High school biology classes are an obvious target. Health, psychology, general science and family and consumer classes also may reach students interested in science.

We think about educating science teachers about genetic counseling, but we also should reach out to guidance counselors, since they may have more influence on a student's class selection and career considerations.

Perhaps your school district needs a speaker for an in-service day. High schools with high minority enrollment would be good choices for speaking engagements. The speaker could be a genetic counselor who is a member of a minority group represented in the school or anyone with enthusiasm and an engaging presentation. The Diversity SIG has a Speakers Bureau that provides materials to help in giving talks to students. Please contact **Tressie Dalaya** or visit the NSGC website for more information.



Talks to college students can begin to address more of the specifics of becoming a genetic counselor. One way to find high achieving students in biology and psychology is to arrange to speak to an honor society such as the National Honor Society in Psychology (Psi Chi) or the National Biological Honor Society (Beta Beta Beta). Arranging to speak at an historically African-American college or other campus with a diverse population could achieve the goal of reaching a multicultural audience. Again, we must remember that career counseling offices and student advisors are important contacts. Perhaps a talk at a professional meeting or continuing educational conference for guidance and career counselors, or other advisory personnel, would advance our cause.

Advancing Across Cultures

For several years, genetic counselors have been aware of the need for better cross-cultural counseling skills. Sessions at our regional meetings and AECs address some of these issues. As much as our training should include a cross-cultural perspective, it is impossible to include everything required to achieve a global appreciation of ethnicity, religion and philosophy. Perhaps counseling programs should have prerequisites (or at least recommendations) for undergraduate courses in language, religion, philosophy, sociology and/or other social sciences that broaden and expand knowledge of world views. Recruiting efforts could be aimed at students with majors in these disciplines rather than in traditional sciences.

Making a Difference

The Membership Committee hopes that you will be inspired to take action and make some of these ideas for diversifying and bettering our profession a reality. Perhaps if each of us sets a goal to act on just one of the suggestions made here this year, we can take a critical step in the right direction.

Thanks to the rest of the committee, chaired by **Barbara Harrison,** who reviewed the essays: **Catherine Downs**, **Cecilia Fairley**, **Chieko Chijiwa**, **Jennifer Eichmeyer**, **Naghmeh Dorrani**, **Nisha Isaac**, **Sheetal Parmar** and **Teresa Blake**. ❖

Membership Committee & Diversity SIG Unite

Last Spring, the Diversity SIG membership approached the Membership Committee with a request to become an official Standing Subcommittee. That action has been approved by the Board of Directors.

Members will no longer find the Diversity SIG as an option on their annual dues; rather, persons interested in working toward a more diverse membership are invited to join the Membership Committee.

☞ **Stephanie Kieffer,** Chair, skieffer@cw.bc.ca ❖

Cancer SIG Grants Fund

Rob Pilarski, MS, Chair, Susan Manley, MS & Karen Huelsman, MS 2003 Cancer SIG Grant Award Committee

We are pleased to announce the recipients of this year's Cancer SIG Grant Award (CSGA). This award was designed to maximize the use of Cancer SIG funds by allowing SIG members to compete for any surplus money. Recipients must present the results of their studies at either NSGC's AEC or the SIG meeting. This year, three out of eight applications were awarded funding totaling $3000.

This Years' Recipients

1."Investigation of Follow-Up Letters in Familial Cancer Risk Counseling," **Eric Rosenthal, PhD, ScM,** UCSD Cancer Center, La Jolla CA

This project is a retrospective, anonymous patient survey to objectively document which patients find follow-up letters useful, which aspects of letters are valuable, whether letters improve understanding of complex medical information and which letter formats are most effective.

2."Determining Families' Preferences for Contact and Recruitment to Cancer Genetics Studies," **Sara Michelson, MS,** *et. al.,* MD Anderson Cancer Center, Houston TX

This study will evaluate families' needs and preferences for contacting relatives for recruitment to cancer genetics studies. Interviews will be conducted to assess the understanding, benefits, limitations and risks of several family recruitment methods.

3."Determining Eligibility for Genetic Susceptibility Testing for Unaffected Individuals at Increased Risk for Carrying a BRCA Mutation," **Janice L. Berliner, MS,** *et. al.,* Cancer Institute of New Jersey, Summit NJ

Cancer SIG members will be surveyed to determine how they evaluate a client's likelihood of carrying a BRCA1 or BRCA2 mutation, what level of risk (if any) is used in deciding eligibility for genetic susceptibility testing, who decides whether testing is offered and how clinical judgment is factored into the decision process.

Progress From 2002

We are also happy to report on the progress made by the two projects that received the CSGA last year, with a total of $2456 in funding.

1."Current Practice Issues in Hereditary Cancer Counseling," **Karen Huelsman, MS** and **Elizabeth Barry, MS,** Cincinnati Children's Hospital Medical Center, Cincinnati OH

Karen and Elizabeth, along with **Karen Copeland**, **Joy Larsen Haidle**, **Wendy Kohlman**, **Kristen Shannon**, **Jessica Everett** and **Jennifer Gamm**, developed a web-based survey inquiring about cancer counselors' roles and responsibilities before, during and after appointments; time commitment to clinic and other tasks; interaction with members of a multidisciplinary team; and billing practices.

Respondents reported seeing 3.4 new patients and 2.0 follow-up patients per week, while balancing other non-clinical duties. On average, respondents spent 4.4 hours for new visits and 1.9 hours for positive results sessions. On average, 48% of respondents reported having a billing clinician present during each session. Patient insurance was billed for 66% of consultations, while 16% of respondents did not bill for services.

These results indicate that counseling for hereditary cancer syndromes is a time consuming process primarily performed by genetic counselors balancing a variety of professional roles. Complete results were presented at the NSGC AEC in Charlotte. The work has also been submitted for publication.

2."A Pilot Study to Evaluate Family Communication of Prostate Cancer Risk Among Men with Prostate Cancer (PC) and their Families," **Mónica Alvarado, MS**, **Jina Faurot, MS** and **Derek Raghavan, MD,** USC/Norris Comprehensive Cancer Center, Los Angeles CA

This study surveyed over 100 men diagnosed with prostate cancer (PC) to look at personal and family history of cancer; perception of heritability of PC and risk to male relatives; number of sons and brothers; frequency of communication with relatives about prostate cancer; and potential obstacles to communication. Of the men who have living sons, 42% reported that they have spoken to their sons a "few times" and 38% "many times" about PC screening since their diagnosis. Preliminary analysis suggests that factors correlating (75% or more) with frequent PC communication with sons/brothers are believing that a high proportion of PC is heritable, perception that PC risk is increased for sons/brothers and having a positive family history of cancer. Of those who said they "never" speak to their sons/brothers about PC, most indicated they believed their relatives already had enough information. Only 11% of respondents said that a physician had ever spoken to them about PC screening for their sons/brothers. The data from this study are still being collected, with plans to submit for publication to the Journal of Genetic Counseling. ❖

☞ www.nsgc.org/members/sig/sig_familial_crc.asp.

Cancer SIG Elects Co-chair

Cecelia Bellcross joins **Kristin Baker Niendorf** as Familial Cancer Risk SIG Co-Chair. Thanks to **Jeff Shaw,** who served as co-chair from 2001- 2003.

CLASSIFIED

LOS ANGELES CA
Immediate opening for BC/BE Regional Medical Specialist w/ excellent public speaking skills. Travel w/in defined geographic region & i'pendent work style req. Exp in hereditary cancer risk assmt strongly desired. Join Div of Med Svcs as Regl Med Specialist. Prim respon: educ health care profess re hereditary cancer risk assmt, genetic tstg & result interp through didactic lectures, on-site case reviews & trngs. Travel area: S. CA, AZ & S. NV.
☞Ingrid Ziebarth, MS, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108; ✆800-469-7423 x3447; iziebart@myriad.com. EOE/AA

MADERA CA
Immediate opening for Genetic Counselor. Must have interest in pediatric genetics & metabolism. Join 3 BC geneticists, 1 BC GC & 3 nurses in exciting fast-paced peds clin genetics unit: dysmorphology, general genetics, metabolism and NB scrng fol-up. Sole peds hosp-based prac in region; provide metab svcs to the entire central valley. Tertiary care hosp w/ full range svcs from neonatal intensive care to most outpt svcs.
☞Judy Phaliin-Roque, Valley Childrens Hospital, 9300 Valley Children's Place, Madera CA 93638; ✆559-353-6409; jphalinr@valleychildrens.org; www.childrenscentralcal.org. EOE/AA

WASHINGTON DC
Immediate opening for PT BC/BE Genetic Counselor. PN GC exp req. Must be energetic & able to work independently. Join PN genetics prog incl 1 GC, 2 PhD cytogeneticist & 5 MFM specialists. Provide GC for breadth of women's health issues in interesting & diverse pt pop. Train health prof: residents, fellows & GC stud.
☞CV & 3 ltrs of rec: Jeanne Meck, PhD, Georgetown University Hospital, 3PHC, 3800 Reservoir Rd, Washington DC 20007; ✆202-444-8810; Fx: 202-444-1757; meckj@gunet.georgetown.edu. EOE

S. FL- FT. LAUDERDALE/BOCA RATON FL
Immediate opening for BC/BE Genetic Counselor. Previous GC & computer exp pref. Knowledge of Human Genetics; principles utilized in crisis i'vention & i'viewing tech. Spanish as 2nd lang & i'pendent work style pref. Fluency in English at the business level, personal transportation & valid driver's license req. Relocation expense allowance avail. Provide GC svcs in state-approved PNDx ctrs. Usual referrals, incl AMA, MSM scrng, fam hx, terat & U/S abn.
☞CV, brief cover ltr & 2 ltrs of rec: Human Resources, Alfigen, Inc., The Genetics Institute, 11 West Del Mar Blvd, Pasadena CA 91105; Fx: 626-568-9643; HR@alfigen.com. EOE/AA

JACKSONVILLE FL
Immediate opening for BC/BE Genetic Counselor. Flex & good org skills req. Independent, flexible, excellent i'personal skills req. Work in busy tertiary care ped setting: focus on dx, GC & mngmt of ped pts. No satellite clins or routine PN respon.
☞Pamela Arn, MD, Chief, Div Genetics or Heather Hansen, MS, Genetic Counselor, Nemours Children's Clinic - Jacksonville, 807 Children's Way, Jacksonville FL 32207; ✆904-390-3586;
Fx: 904-390-3565; parn@nemours.org; www.nemours.org. EOE/AA

ATLANTA GA
Immediate openings for BC/BE Cancer Genetic Counselor. 1 yr exp or completion of an internship in GC. Successful BC req w/in 3 yrs of hire date to maintain employment. 3-5 yrs exp in cancer GC pref; strong initiative, excellent commun skills & abil to work w/ different depts req. Org, flex & abil to handle variety of respon incl cancer risk assmt, commun educ, clin rsrch, grant writing & tchg req. Oppty to design & build new cancer genetics prog to meet rapidly growing demand. Join team of 11 GCs in stimulating acad env to implement a reg'l cancer GC svc in Atlanta w/ reg'l Emory affiliates & priv ONC grps.
☞Online: //emory.hremory.edu/careers.nsf or Employment Svcs, Denese Jester, Emory University, 1762 Clifton Rd, Atlanta GA 30322; ✆404-727-7209; Fx: 404-727-7108; djester@emory.edu; www.emory.edu. EOE/AA

ATLANTA GA
Nov 1 opening for BC/BE Centers for Disease Control (CDC) Fellow. 1-yr w/potential for continuation. Span fluency pref. Oppty to learn about public health activities related to genetics while working on NB scrng, Duchenne MD & hearing loss projects.
☞Aileen Kenneson, PhD, MS, CDC/NCBDDD/DHDD, 1600 Clifton Rd, N.E., Mailstop E-88, Atlanta GA 30333; ✆404-498-3039; akenneson@cdc.gov. EOE/AA

ATLANTA GA
Immediate opening for BC/BE Genetic Counselor. Join perinatal clins. Org, flex & able to handle variety of respons, incl c'hensive pt fol-up & back-up for GC colleagues. Spanish, PN GC & lab exp desired. Join team of 12 GCs in acad env: provide PN GC in Atlanta to reg'l/ outreach affiliates and priv perinatology groups.
☞Resume & ltr of interest: Catherine Tesla, MS, Emory Genetics Laboratory, 2711 Irvin Way, Ste 111, Decatur GA 30030; ✆404-297-1521; Fx: 404-297-1517; ctesla@genetics.emory.edu. EOE/AA

ATLANTA GA
Immediate opening BC/BE Genetic Counselor. Org, flex & abil to handle variety of respon incl utilizing commun resources & providing med, educ & psychosocial supt to individuals/families all req. Join team of 12 GCs in acad env: coord & explain genetic lab & other dx tests (cyto-, biochem- & molec) to physicians & pts primarily via phone. May fill in as needed for pt fol-up & back-up in perinatal & ped clins. Possible opptys for collab w/ CDC on projects as needed.
☞Resume & ltr of interest: Catherine Tesla, MS, Emory Genetics Laboratory, 2711 Irvin Way, Ste 111, Decatur GA 30030; ✆404-297-1521; Fx: 404-297-1517; ctesla@genetics.emory.edu. EOE/AA

HONOLULU HI
Immediate opening for BC/BE Genetic Counselor. Exp pref. Highly motiv, flex, team player to work in multicult env. Join dynamic team of 4 MFMSs, 1 MFM/BC Geneticist, 2 BC GCs/1 BE GC. Serve State of HI & Pacific Basin in all aspects of PN w/ oppty for cancer GC.
☞Online: www.hawaiipacifichealth.org and click on Careers *or* Tammy Stumbaugh, MS, ✆866-244-8133 x2; tammys@kapiolani.org *or* Kristine Tao, Kapi'olani Medical Center for Women and Children, 55 Merchant 23rd Fl, Honolulu HI 96813; ✆808-535-7227; Fx: 808-535-7550; kristinet@kapiolani.org. EOE/AA

BALTIMORE MD
Immediate opening for BC Genetic Counselor/Medical Genetics Education Coordinator w/ ≥2 yrs exp req. Exp w/ educ progs highly desirable. Prim respon: s'vise Med Genetics Trng Prog (Med Genetics & combined Peds/Med Genetics residency & Clin Lab Trng Progs in biochem, cyto- & molec genetics); monitor educ activ of residents & post-doc trainees, med students, GC students & residents in other disciplines. Opptys to coord med genetics educ activ for other depts, org & partic in CME progs.
☞Garry Cutting, MD, Johns Hopkins Hospital, 600 N. Wolfe St, CMSC 1004, Baltimore MD 21287; ✆410-955-1773; Fx: 410-614-0213. EOE/AA

ROCKVILLE MD

…next column

CLASSIFIED, *from previous page*

Immediate opening for Biomedical Specialist Bilingual (Span) Biomedical Specialist. Exp in identifying health resources, internet search skills needed. BS in science or relevant exp req; genetics trng/exp pref. Excellent oral, written & listening skills. Respon: rsrch, devel & commun info for consumers, health professionals & public; respond to phone/em req for info re rare/genetic diseases for fed-funded project.
☞ Cover ltr, writing sample & resume: Aspen Systems Corporation, ATTN: EJ-GARD, 2277 Research Blvd., Rockville MD 20850; Fx: 301-519-5445; resume6@aspensys.com. No phone calls. EOE, M/F/D/V

BOSTON MA
Immediate opening for BC/BE Genetic Counselor. 3 yrs exp pref. Work w/ 4 BC med geneticists in acad env. Direct pt care & triage. Based in peds clin; 1/2 patients adults w/ repro genetic issues or cancer GC and testing. Coord new & expanding preimplant genetic dx prog.
☞Helen E. Evans, Floating Hospital, Tufts-NEMC, 750 Washington St, Box 394, Boston MA 02111; ✆617-636-3026; Fx: 617-636-1469; hevans@tufts-nemc.org. EOE/AA

DETROIT MI
Immediate opening foor BC/BE Genetic Counselor. Join busy PN prac w/ 5 MFMs & 2GCs: amnio, CVS, dx & 3D U/S w/ample oppty for GC & tchg.
☞CV & cover ltr: Adel D. Gilbert, MS, Clin Coordinator/Counselor, Hutzel Hospital, Div Reproductive Genetics, 4707 St. Antoine Blvd, Detroit MI 48201; ✆313-745-7068; Fx: 313-993-0153; gilbert@med.wayne.edu. EOE/AA

ROCHESTER MN
Immediate opening for BE/BC Genetic Counselor. Provide genrl pre- & post-tstg supt for genetic tstg. Serve as consultant for physicians, GCs & geneticists; serve as liaison betw lab & clin staff.
☞Ref job #03-2542.NSGC in all forms of application & commun: Barbara S. Thomley, Mayo Clinic, 200 First Street SW, OE-4, Rochester MN 55905; ✆800-562-7984; careers@mayo.edu. EOE/AA

COLUMBIA MO
'04 flexible opening for BC/BE Genetic Counselor. Join vigorous, full-svc, acad Div Med Genetics w/3 GCs & 3 MD geneticists. Coord & GC in peds/adult genetics, Down Syndrome clins, PN & spec clins & in-pt consults. Oppty for prof growth, rsrch & prog devel in energetic, friendly college town.
☞Judith Miles, MD, PhD, Univ of MO-Columbia, Div Medical Genetics - H.S.C. NW507, One Hospital Drive, DC058.00, Columbia MO 65212; ✆573-882-6992; Fx: 573-884-3543 or Diane Kiry, ✆884-7594 for questions. EOE/AA

ST. LOUIS MO
Immediate opening for BC/BE Genetic Counselor. Join team of 4 med geneticists, 3 GCs & 2 dietitians in acad medical ctr. Clin partic: peds, adult, spec, outreach & cancer genetics clins. Opptys for partic in profess educ & clin rsrch.
☞Rachel Slaugh, MS or Linda Piersall, MS, Washington University School of Medicine and St. Louis Children's Hospital, 1 Children's Place, Div Medical Genetics, Box 8116, St. Louis MO 63110; ✆314-454-6093; Fx: 314-454-2075; slaugh@kids.wustl.edu; piersall_l@kids.wustl.edu. EOE/AA

NEW BRUNSWICK NJ
Opening for BC/BE Genetic Counselor. 1 yr PN exp pref. Span a plus. Join large mutidisc team w/ 2 MD geneticsts, 4 GCs, 3 nurses & 1 metab nutritionist at tertiary care private hosp. Interesting, varied PN cases, incl U/S abn; some spec clins.
☞Michele Horner, MS or Rosemarie Peschek, Saint Peter's University Hospital, 254 Easton Ave, New Brunswick NJ 08903; ✆732-745-6659; Fx: 732-249-2687. EOE/AA

BRONX NY
Immediate opening for BC/BE Genetic Counselor. Spanish flency pref; abil to work w/ team req. Join The Faculty Practice of leading tchg hosp. Diverse oppty in genrl genetic svc: PN, peds & adult clinics. Unique oppty to provide GC for cult-diverse pop.
☞ Dr. Ernest Leiber, Lincoln Hospital, Dept Pediatrics, Div Genetics, 234 E 149 St. Ste 4-20, Bronx NY 10451; Fx: 718-579-4640. EOE/AA

BUFFALO NY
Immediate opening for BC/BE Genetic Counselor. Cancer & genrl genetics exp pref. Join clin genetics svc, wk w/ multidisc teams in various oncology clinics & w/ clin/scientific rsrchrs. Partic in & provide clin, educ & rsrch activ & svcs at Comprehensive Cancer Ctr.
☞ Carolyn D. Farrell, MS, CNP or Mollie K. Lyman, MS, Roswell Park Cancer Institute, Clin Genetics Svcs, Elm & Carlton Sts, Buffalo NY 14263; ✆716-845-8400; Fx: 716-845-5720; Carolyn.Farrell@RoswellPark.org; Mollie.Lyman@RoswellPark.org. EOE/AA

NEW YORK NY
Immediate opening for BC/BE Genetic Counselor. Rsch exp a plus. Motivated, abil to work i'pendently, excellent org & people skills, computer competency req. Coord rsrch & clin GC in lg acad med ctr. Dynamic, high growth env; rsch focus on genetics of LSD's & complex trait disorders. Respon: at-risk GC, study coord & rcrtmt, work closely w/clinicians & lab, s'vise GC students.
☞ Dana O. Doheny, MS, Research Coordinator, Mount Sinai School of Medicine, Dept Human Genetics, 1425 Madison, Rm#14-75A - Box 1498, New York NY 10029; ✆212-659-6779; Fx: 212-659-6780; dana.doheny@mssm.edu. EOE/AA

DURHAM NC
Dec '03 opening for BC/BE Genetic Counselor w/ 2+ years exp. Enthusiastic, motiv, i'pendent prof w/good comm & org skills. Span a plus. Join expanding MFM & GC prac: PN & Preconcept GC to pts for PNDx, terat, ART. Oppty for diverse GC activ, rsrch & tchg.
☞ Kristin Paulyson Nunez, MS, Coordinator, Prenatal Diagnosis, Duke University Medical Center, DUMC Box 3390, Durham NC 27710; ✆919-684-3604; pauly001@mc.duke.edu. EOE

WINSTON-SALEM NC
Immediate opening for BC/BE Reg'l Public Health Genetic Counselor. Strong knowledge of med genetics, GC & commun org req. GC exp & knowledge of public health svc system pref. Provide regl GC svcs & org satellite genetics clins for fams covering 15-county area. Provide consult, educ & trng to health care providers & commun groups. Affil w/ Wake Forest Univ Baptist Medical Ctr; directly s'vised by NC Div Public Health, Genetics & Newborn Scrng Unit.
☞ Ref #4431-0000-0021-704: Fax resume & fol-up w/ hard copy *or* apply online: www.ncgov.com *or* DeAnn Rudd, DHHS-Public Health-Recruitment Office #23073, 1930 Mail Service Center, Raleigh NC 27699-1930; ✆919-715-3661; Fx: 919-715-7949; deann.rudd@ncmail.net. No email CVs. EOE

CINCINNATI OH
Immediate opening for PT (avg 16 hrs/wk) BC/BE Genetic Counselor. Extensive computer skills needed, perinatal exp pref. TriHealth is a community partnership of Bethesda & Good Samaritan Hospitals.
☞ Melissa Jansing, TriHealth Human Resources, 375 Dixmyth Ave, Cincinnati OH 45220; ✆513-872-3671; Fx: 513-872-3672; melissa_jansing@trihealth.com. EOE/AA

DALLAS TX

…next page

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for the genetic counseling profession*

233 Canterbury Dr Wallingford PA 19086

PLEASE NOTE THIS IMPORTANT EXECUTIVE OFFICE CHANGE

NSGC email accounts have transitioned away from aol.com. Please note the following contact information in your e-dress books:

Bea Leopold . . . . . FYI@nsgc.org
Audrey Lombard . . . . . nsgcassist@nsgc.org
JobConnection • Dues and Conference Payment Inquiries and Receipts • labels
Lisa Brodeur . . . . . nsgclistQ@nsgc.org
General & Cancer listservs • Credit card payment inquiries (exc. JobConnection) • Publication Orders • Database Changes

CLASSIFIED,

from previous page

Immediate opening for BC Genetic Counselor w/5 yrs progressively respon exp in GC incl cyto, cystic fibrosis, PN, molec or other genetic tstg. Faculty Associate position. Devel lab progs to meet svc demands/trends. Bring new tests on board. Provide GC & result rept. Serve as liaison w/ drs-clients & pts. Tchg respons.
☞ CV & ltrs of rec: Frederick Elder, PhD, UT Southwestern Medical Center, Dept Pathology, 5323 Harry Hines Blvd, Dallas TX 75390-8840; ✆214-645-7000; frederick.elder@utsouthwestern.edu. EOE/AA

DALLAS TX
Immediate opening for Genetic Counselor. Genetics is at the forefront of applying genetic knowledge for disease prevention, outcome improvement & med cost reduction. Excellent compensation & benefits pkg incl 3 wks pd vaca, 401(k) plan w/ co match, extens insur benefits & Emp Stock Purchase Plan. Oppty to work i'pendently to mng and maintain top qual genetic svcs in perinatal offices w/ support from team of geneticists & GC colleagues.
☞ Amy Foster, Corporate Recruiter, Genzyme Genetics, 3400 Computer Dr, Westborough MA 01581; ✆508-389-6623; Fx: 508-389-5558; amy.foster@genzyme.com. EOE/AA

FT HOOD TX
Immediate opening for BC/BE Genetic Counselor. Sign on & relocation bonus, great salary & benefits package available.
☞ Fax resume including salary req: Darnall Hospital, Ft Hood TX; Fx: 254-526-2717; HeflinLD@yahoo.com. EOE/AA

HOUSTON TX
Immediate opening for BC/BE Genetic Counselor. Join Cancer Genetics team, staffing Cancer Genetic Clins at TX Childrens & Methodist Hospitals. Serve diverse pop of child & adults w/ variety of cancer predisp synd. Partic in ongoing rsrch studies as part of the NCI-funded Cancer Genetics Network integral to position.
☞ Resumes & 2 ref: Sharon Plon, MD, PhD, FACMG, Baylor College of Medicine, 6621 Fannin St, MC 3-3320, Houston TX 77030; ✆832-824-4539; Fx: 832-825-4276; splon@bcm.tmc.edu. EOE/AA

CHARLOTTESVILLE VA
Immediate opening for BC/BE Genetic Counselor. Respon: 60% MSM prog (coord, epidem monitoring, QA, provider liaison, profess educ) & 40% clin activ & pt GC (Peds, Adult, PNDx clins). Stats/computer exp desired. Travel to satellite clinics req. Join 2 GCs & 3 MDs at acad med ctr.
☞ Resume & 3 ltrs of rec: W.G. Wilson, MD, Div Medical Genetics, University of Virginia Health System, PO Box 800386, Charlottesville VA 22908-0386; ✆434-924-2665; Fx: 434-982-3850; wgw@virginia.edu. EOE/AA

ROANOKE VA
Immediate opening for BC/BE Genetic Counselor. Exp pref. Enthusiastic, motiv, i'pendent prof w/ commun & org skills. Join 1 GC & 2 perinatologists in busy PN dx ctr. Commun, resident & med stud tchg.
☞ Ann Jewel, MS, Prenatal Diagnostic Center, Carilion Roanoke Community Hospital, 102 Highland Ave, Suite 455, Roanoke VA 24013; ✆540-985-9985; Fx: 540-985-9817; afj4n@virginia.edu. EOE/AA

IN CANADA

KINGSTON ON
Immediate opening for CAGC BC/BE Genetic Counsellor. Join med genetic svcs team: partic in genrl genetic clins, coord and provide PN GC. 2 yrs exp req.
☞ Human Resources Consultant, Human Resources Svcs, Kingston General Hospital, 76 Stuart St, Kingston ON K7L 2V7; Fx: 613-548-1334; kghhr@kgh.kar.net. ❖