PERSPECTIVES in genetic counseling

Volume 17 Number 3 Fall 1995

Encouraging Diversity Among Genetic Counselors

by Ilana Mittman, MS, Sinai Hospital; Stephanie Smith, MS, Univ of Mississippi Med Center; Colleen Dougherty, MS, Howard University

Ethnic minorities represent an increasing segment of the US and are expected to compose one-third of the nation's population by the year 2040.[1] Yet multiple barriers to genetic counseling services exist for members of minority groups, including low minority representation in the genetic counseling profession.[2]

NSGC's 1992 and 1994 Professional Status Surveys show that the vast majority of genetic counselors in this nation are white (94%) and female (94%). The number of minorities in genetic counseling declined between 1992 and 1994, from 6.5% to 5.8%.[3,4] From 1982-1992, 62 of the 730 students accepted to training programs were from minority groups (8.5%); 56 (90%) completed their training.[5]

Recruiting and training minority genetic counselors "is an essential, parallel component of providing appropriate genetic counseling services to these (minority) groups. Individuals who share similar upbringing, culture and language have a unique ability to meet the needs of members of their respective cultures. Furthermore, they will greatly enrich the education, training and cultural sensitivity of their student and professional peers."[6]

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Resolution on Prenatal and Childhood Testing Submitted for Member Vote

The Genetic Research Issues Subcommittee has completed a resolution on a controversial topic—predictive testing for adult-onset disorders in children and pregnancies at risk. NSGC resolutions reflect timely issues that impact the ethical, legal and social climate of our profession—they help clarify and communicate our views on these complex subjects.

The resolution represents the culmination of nearly two years of work by the Subcommittee, chaired by Dorene Markel. Members of the working group were Stephanie Cohen, Marisa Ladoulis, Dorene Markel, Katherine Schneider and Chantelle Wolpert.

This resolution is now submitted for approval by full NSGC members. To be adopted, it must be approved by a majority of those returning ballots. The resolution is printed on page 5; ballots are included in this issue. ***Please exercise your right to vote!***

Resolutions—one way NSGC represents and addresses members' needs—are adopted according to formal guidelines. To learn more about how this process works, see page 4.

national society of genetic counselors, inc.

nsgc

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

ON THE INSIDE

NSGC acknowledges our following corporate friend for a grant to support this newsletter.

INTEGRATED GENETICS

Integrated Genetics, committed to providing quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

Parting Thoughts...

Building Bridges, Reinforcing Relationships

The Annual Education Conference is soon upon us and my term as your president is nearing completion. I thought this would be a good time for me to reflect on the past year, as well as package up all the paperwork and ship it off to Vickie!!!

OUTSIDE TIES

For NSGC, this year has been one of new and renewed alliances. In some areas we have built new bridges and in others, the old ones were reinforced. NSGC members formally represent our society with the following organizations: CORN, ASHG, ACMG, COMGO, Healthy Mothers Healthy Babies and ISONG.

We are also visible and active in groups under the NCHGR: the ELSI working group, National Advisory Council, Breast Cancer working group and Task Force on Genetic Testing.

LINKING MEMBERS

Besides developing external associations, we are strengthening our internal working relationships. As we grow, our interests are becoming more specialized—NSGC is moving to meet our members' needs. The Board of Directors has introduced sections, or special interest groups, within NSGC.

The initiation of Practice-Based Symposia at our Annual Education Conference this year is the first attempt to help organize interested colleagues working in specialized areas so they can share expertise.

Our committees are developing practice guidelines, pursuing CPT codes, progressing toward an effective continuing education program and much more. Our Society has been actively working so that we indeed are *the leading voice, authority and advocate for the genetic counseling profession.*

I am very proud to have had the opportunity to serve NSGC.

Bonnie S. LeRoy, MS
President

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Send articles, reviews, correspondence to the Editor-in-Chief; address changes, subscription inquiries, advertisements and classifieds to the Executive Director. Contact any Editorial Board member with ideas or suggestions.

Publication date, next issue: December 15
Deadline for submissions: November 10

Election Results

1995-1996 Board of Directors

OFFICERS/EXECUTIVE COMMITTEE

President	Vickie Venne	801-585-7364
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Social Issues	Lori Williamson-Kruse	417-256-8126
Journal Editor	Deborah Eunpu	215-572-2875
Newsletter Editor	Liz Stierman	213-380-5362

REGIONAL REPRESENTATIVES

Region I	Kathy Schneider•	617-632-3480
Region II	Sue Moyer	215-955-1116
Region III	Lisa Amacker North•	704-355-3159
Region IV	Rich Dineen	309-655-7436
Region V	Christine Barth•	303-861-3128
Region VI	Karen Wcislo	408-972-3306

• newly elected or appointed

Thanks to the 1995 Nominating Committee: Karen Greendale, Chair, Marisa Ladoulis (Region I), Sharon Suntag (Region II), Cam Knutson Brasington (Region III), Amy Lemke (Region IV), Juli Horwitz (Region V) and Linda Ramsdell (Region VI).

Spotlight on...

The Membership Committee: Projects Previewed

The Membership Committee strives to increase the number of NSGC members and encourage their active participation.

RECRUITMENT

Our goal is to increase NSGC's total membership by retaining current members and adding new ones, particularly minorities and students. Current projects to help meet this goal include:

- Creating and distributing a recruitment poster for college career offices, directing interested students to contact NSGC for further information.
- Identifying college career guidebooks including those targeted for minorities; pursuing listings for genetic counseling as a career option as well as training programs.
- Interviewing members leaving NSGC and applying their feedback. (This is a joint project with the Professional Issues Committee.)

PUBLICITY

Another goal is enhancing the visibility of the genetic counseling profession in the medical community, among students and in the general public. We have one current project in this area:

- Creating and distributing NSGC rolodex cards for media at the local and national levels. (This is a joint project with the Genetic Services Committee.)

MENTORING

We plan to develop mentorship programs for student and new members of NSGC by:

- Organizing a student Recruitment Fair at the Annual Education Conference, encouraging students to become active in NSGC.
- Creating links between student members and professional genetic counselors.

PUBLICATIONS

Our standing subcommittee, the Publications and Communications Review, chaired by Janice Berliner, examines any printed materials published by NSGC (brochures, fact sheets) for content, accuracy and audience appropriateness.

The subcommittee also writes responses to lay articles about genetic counseling (*see box below*) and can act as a sounding board for members wishing to send an article or letter to lay publications.

☛ To share ideas or work on any of these projects, contact Nancy Steinberg Warren, 513-559-4475.

Nancy Steinberg Warren, MS
Chair

Advocacy in Action

Earlier this year, the Publications Subcommittee responded to an error-filled article appearing in *McCall's* magazine. The letter, drafted by Mary Martin with input from the entire committee, corrected misinformation and emphasized one of genetic counseling's guiding principles: "We encourage our clients to make informed decisions that reflect their own personal beliefs and values."

NSGC received this reply from *McCall's* Health Editor Ann Ranard:

> "Thank you for sending your letter regarding the January article in *McCall's* entitled 'Is the baby okay?' We regret the error about the capabilities of ultrasound exams and the fact that we didn't fully explain the meaning of amniocentesis results.
>
> "Your points are well taken. We would like to keep our readers informed about genetic testing, so we would appreciate it if you would keep us up-to-date about the latest news and information in the field."

Ethics Subcommittee Announces Changes

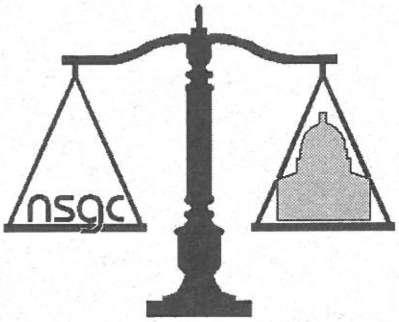
■ Barbara Bernhardt and Robin Gold have accepted positions on the subcommittee. Their terms begin October 31 and last three years. We thank Vivian Wang and Anne Matthews for their fine past work.

■ In response to requests, the business portion of the subcommittee's meeting in Minneapolis will open. Once this section is completed, the meeting will be closed for confidential discussion of consults.

■ To request an ethics consult, contact a subcommittee member:

Karen Supovitz Eanet, Chair	410-706-3815
Beth Balkite	800-848-4436
Barbara Bernhardt	410-955-7894
Kevin Fitzgerald	202-687-6425
Robin Gold	313-493-6060
Linda Nicholson	302-651-4234
Sandra Peacock	713-781-1680
June Peters	301-594-2951

GOVERNMENT 101: How an Idea Becomes Law



Ever wonder what's behind our resolutions and position statements? The Social Issues Committee outlines the process, from proposal to formal policy, for NSGC and the US government.

IN THE NSGC...

- Members, the Social Issues Committee or Board of Directors propose ideas. **Resolutions** state new policy and reflect issues impacting the ethical, legal or social climate of genetic counseling. **Position statements** are extensions of our accepted mission or a concrete application of our Code of Ethics.
- Discussion within a Social Issues subcommittee culminates in a first draft, which includes a statement of purpose.
- The statement of purpose is sent to Social Issues Committees of ASHG, ACMG and ISONG to alert them to works-in-progress and to foster joint efforts.
- The proposal is published in *Perspectives* for review and comment by NSGC members.
- Review by the Ethics Subcommittee and an attorney identifies potential conflicts with our Code of Ethics or legal liability issues. They have 2 weeks to respond.
- The Board of Directors reviews the revised draft 6-8 weeks before their next meeting. They return written comments within 3 weeks.
- The authoring subcommittee presents the revised proposal at the Board of Directors meeting. Significant changes will need to be reviewed again by the attorney or Ethics Subcommittee.
- The Board of Directors votes on the proposal at one of its two annual meetings. A FAX vote is acceptable but must be unanimous (according to NY State regulations for not-for-profit organizations).
- A **position statement** is adopted after Board approval.
- A **resolution** is voted on by full NSGC members. It is adopted if approved by a majority of respondents.

NSGC RESOLUTIONS

Reproductive Freedom (1987)
Prenatal Substance Abuse (1992)
Fetal Tissue Research (1992)
National Health Care Reform (1994)

POSITION STATEMENTS

Access to Care (1991)
Nondiscrimination (1991)
Confidentiality of Test Results (1991)
Disclosure & Informed Consent (1991)
Cystic Fibrosis Screening (1993)
Genetic Screening (1994)

HOW LONG DOES IT TAKE?

NSGC's National Health Care Reform Resolution:

First draft	Oct 1992
Board approval	April 1994
Membership vote and adoption	Nov 1994

Americans with Disabilities Act:

Committee hearings	June 1987
S2345 introduced	1988
S933/HR2273 introduced	1989
Revised bills passed	1990
President signed	July 1990
Law effective	July 1992

IN THE UNITED STATES...

- Any member of congress may introduce (or "drop") a bill on the House or Senate floor. The bill is referred to the appropriate committee or subcommittee for consideration and review.
- The bill is placed on the committee's calendar for debate. By law, these sessions are open hearings.
- The committee votes. The bill may leave committee with or without recommendation for passage. If not voted out, it dies.
- The bill is placed on the legislative calendar for open debate on the full House or Senate floor. When debate has ended (its length is set by the Rules Committee), the bill is voted on by voice vote or roll call. It need pass only by a simple majority.
- All bills must be considered in *both* the House and Senate. If not voted on before a legislative session ends (2 years), a bill dies.
- If the House and Senate pass similar bills with dissimilar language (a result of the separate committee and debate processes), a joint committee redrafts the language.
- The bill goes to the President, who can either sign the bill, making it law, or veto it.
- Congress can override a Presidential veto and make the bill into law, but this takes a two-thirds majority in both House and Senate—*not* easily accomplished.
- Committee and subcommittee chairs wield a lot of power, as they set the calendar determining what will be considered. Given all the places where things can get stalled, it's a wonder any legislation makes it through!

RESOLUTION FOR MEMBER VOTE

Prenatal and Childhood Testing for Adult-Onset Disorders

Adult-onset genetic disorders are defined as disorders which are usually phenotypically asymptomatic until the third decade of life or later. For those disorders for which the identification of gene carriers does not provide an avenue for therapeutic or preventive treatment in the prenatal or childhood periods, genetic testing must be carefully considered. In response to the unique nature of these disorders, the NSGC supports the following recommendations:

1. Clients considering a pregnancy or who have a fetus or child at-risk for an adult-onset genetic disorder should be made aware of clinically available testing technologies for that disorder.

2. Testing during pregnancy or childhood allows the parent, rather than the individual (fetus or child) being tested, to provide informed consent to proceed. Given that many at-risk adults may elect not to be tested, testing in pregnancy or during childhood should be undertaken cautiously. Parents should consider whether the decision to test should be reserved for the child to make upon reaching adulthood.

3. Prenatal and childhood testing for adult-onset genetic conditions should always include genetic education and counseling. Genetic counseling for clients considering such testing should include exploration of the psychological/social risks and benefits of early genetic identification from both the parents' and child's perspectives. When possible the child should be involved in the decision about whether or not to be tested. Other issues discussed should include the possibility of discrimination in insurance, education and employment for the child or family in both the immediate and more distant future.

4. Prenatal testing for adult-onset genetic conditions should be offered regardless of whether or not an affected fetus would be terminated. Prior to prenatal testing, genetic counselors should discuss the possible results as well as advantages and disadvantages of learning this information. It may also be helpful to ascertain and discuss the parent's motivations for testing. It is the role of the genetic counselor to educate and counsel clients about testing, but the decision about whether to proceed must be the parents' to make.

5. Individuals who have declined predictive testing for themselves can consider testing for their child or fetus, or utilizing non-disclosing prenatal testing. However, prior to performing such testing, they must be made cognizant to the fact that (with the exception of non-disclosing prenatal testing) a positive result may also disclose their status. Discussion of the possible ramifications of this information should be included in the genetic counseling provided prior to testing. If prenatal or childhood testing could result in the disclosure of the carrier status of family members who are not part of the testing decision process, attempts should be made to contact, counsel and obtain their permission for testing. If a conflict should arise between parents and other at-risk family members, consultation with an ethics committee or similar body is strongly recommended.

6. Caution should be exercised in the communication and documentation of test results. The child's parents should be made aware of the sensitive nature of the test results and the implications of sharing them with other professionals for whom the information is non-essential.

7. Genetic counselors are encouraged to consider both patient autonomy issues as well as the principle of nonmaleficence when requests are made for this type of testing. As with any type of genetic testing and counseling situation, genetic counselors should not be expected to offer a service that they feel uncomfortable providing and should be allowed to remove themselves from such a case, or refer the case to another genetics professional.

8. Pilot studies are needed to assess the medical and psychosocial risks and benefits of testing for adult-onset genetic conditions in children or fetuses carried to term when no direct medical benefit is known. Until more data is gathered on the impact of this type of testing, extreme caution should be taken regarding the use of such tests.

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☑ **Vote!**

- Only full NSGC members are eligible to vote.
- Deadline **October 23, 1995.**
- Vote "I approve" or "I do not approve." Do not write conditions or changes on the ballot—this will disqualify your vote.

Grant Supports Outreach and Minority Recruitment

The Genetic Services Branch of the Maternal and Child Health Bureau has awarded Ilana Mittman of Baltimore's Sinai Hospital a three year grant. With collaborators at Howard University, the grant—entitled "Genetic-LINC; Liaisons Into Cultures"—aims to increase access to genetic counseling services among African-Americans and Russian immigrants in the Baltimore/ Washington area.

Recognizing that these populations are underrepresented among providers, the project devotes significant efforts to enhancing minority recruitment into the genetic counseling field. Two full time genetic counselors were hired. Colleen Dougherty coordinates the Howard University Genetic Counseling Training Program and Sidra Shapiro provides outreach to underserved Baltimore populations.

The project's staff has promoted minority recruitment into genetic counseling by:

- Identifying 114 predominantly minority institutions of higher education nationwide. Career packets will be sent to these schools.
- Presenting inservices to students and faculty at minority colleges on career days, in genetics classes and at preprofessional society meetings.
- Featuring career booths at health fairs in communities as well as in local middle and high schools.
- Educating public health nurses with local Maternal and Child Nursing programs.
- Welcoming interested minority college students to visit genetic counseling clinics.
- Helping strengthen the country's only predominantly minority counselor training program, Howard University, by securing accessible field placement sites.

As a result of this outreach, several African-American health care providers became interested in genetic counseling. One applied and was accepted to a genetic counseling training program. A local minority college student plans to apply next year.

The project's counselors hope to develop training methods that encourage professional satisfaction and success for minority students.

☛ To share your experiences and suggestions with them, contact

Ilana Mittman, 410-578-5853, EM: imittman@welchlink.welch.jhu.edu

Colleen Dougherty, 202-806-6329, EM: pgzx92a@prodigy.com

Stephanie Smith, 601-984-1900, EM: stephani@fiona.umsmed.edu

Overcoming Barriers: A Minority Genetic Counselor's Story

I came to the US from Israel in September 1980. I had just married and followed my American husband to settle in his country. It was my first time out of my homeland—I left a whole lifetime and a part of my soul behind.

Although I was bilingual, having taken extensive English instruction since fourth grade, adjusting to my new country was quite overwhelming. Many of the things I had learned about life no longer applied; I had to relearn how to manipulate my environment.

Within a few years of my arrival, I began genetic counseling training. I worked diligently to meet the program's didactic and clinical requirements while I was still trying to acculturate and assimilate to my new environment. My training was superb; the academic staff and my classmates were caring and supportive.

In spite of this, I was self-conscious about my differences, and in every aspect tried to become just like my American-born classmates. I struggled with how I came across—my straightforward style wasn't always appropriate in this society. I was particularly sensitive to the "language handicap" cited in my student evaluations. I needed positive reinforcement and constructive help on how to communicate better.

FINDING MY PROFESSIONAL NICHE

My job search was long, difficult and disheartening. My linguistic difficulties and lack of job searching skills made it hard for me to compete; I did not seem to fit in at the places where I applied. I began to doubt my decision to become a genetic counselor.

I accepted the first position offered me; in time, I worked my way to a situation more closely matching my interests. I learned how to write grants and obtained grant funding for my position.

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Encouraging Diversity Among Genetic Counselors

TRAINING OBSTACLES

Multiple barriers limit minorities from entering the genetic counseling field: two frequently cited are the lack of available information about the profession in undergraduate institutions and tuition costs.[5]

Minorities attending predominantly white schools may have difficulty adjusting to the academic environment. Minority nursing students on white campuses experienced psychosocial and academic problems which, if not addressed, could decrease self-concept, academic performance and even cause them to leave the program.[6]

Some minority students or counselors feel like outsiders. As one genetic counselor recalls, "While in school, no particular measures were taken to help me adjust and cope given the barriers I was experiencing. Few people were interested in learning who I was, and what it meant to be [from my culture]. Instead, I was urged to be more like my Anglo-American classmates."[8]

ENRICHING OUR FIELD

By increasing diversity in our profession, genetic counseling will better reflect our client base and the population at large. How can you help accomplish this?

- **Be sensitive** to students and colleagues with differences—in background, culture, lifestyle or physical abilities. Learn about their experiences; respect their unique identities.

- **Serve as a contact person** for educational institutions in your area, particularly those with ethnically diverse student populations. Provide information about the genetic counseling field and training opportunities.

- **Become a mentor** for local students who share your cultural background.

- **Include racial/ethnic data** when completing surveys, particularly NSGC's Professional Status Survey. This helps us better understand our collective identity, document needs and monitor our progress.

- **Volunteer** for one of NSGC's subcommittees or projects dealing with ethnic diversity.

NSGC & Minority Recruitment

Here are some of the ways NSGC is working towards increasing minority representation in genetic counseling:

- In June 1992, the **Education Committee** sponsored a 3-day conference for training program directors exploring ethnocultural issues in genetic counseling recruitment and education. Many specific resources and recommendations resulted.

- The *Journal of Genetic Counseling* devoted most of the September 1993 issue (Vol 2, No 3) to the challenges of ethnocultural diversity and training, including a report on minority recruitment and suggestions for developing a cross-cultural curriculum.

- Spearheaded by Jon Weil of the UC Berkeley training program, the **Membership Committee** coordinated a Winter 1993 mailing to 1000 college academic counseling offices, biology and psychology departments. Accompanying the packet of materials about a genetic counseling career was a cover letter encouraging applications from qualified individuals of all ethnocultural groups.

- The **Diversity Among Counselors Subcommittee** of the Genetic Services Committee encourages more heterogeneity within our profession, targeting groups currently underrepresented: racial, ethnic and cultural minorities, men and those with disabilities. The subcommittee is assessing the current status of minority recruitment and enrollment in training programs, and plans to review the career packet in light of the needs of diverse populations.

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CYBERGENES

More About E-Mail

As those of you with e-mail already know, it is not only simple to use but can help make communication faster and easier. For those of you who are scared off by computer stuff it is never too late to get started. E-mail is an easy, safe way to use the Internet.

NSGC WILL HELP YOU GET STARTED

The Education Committee is sponsoring a workshop at the Annual Education Conference in Minneapolis to help you access resources on the Internet. Even those with no experience can attend and see first-hand how to sign on and send e-mail.

One of the Education Committee's goals is to use computers and Internet access to benefit our entire membership. We are currently working on our own "home page" on the World Wide Web—a kind of bulletin board of information—enabling NSGC members to exchange ideas, concerns and even files (I don't mean patient files).

MORE AND MORE COUNSELORS ON-LINE

Last year at this time only a very few genetic counselors had e-mail addresses; today there are approximately 200. Ultimately we hope the entire membership will have e-mail access.

E-mail is a simple way to reach many people at the same time. We are able to send a message simultaneously to all 200 counselors on the current e-mail list. (Just imagine if we could send it to 1200!) What better way to ask if any colleague has a patient with a rare condition? Or to survey NSGC members on an issue at virtually no cost?

NETIQUETTE

Since e-mail is not a face-to-face meeting, you cannot emphasize your point with a gesture or a look. That's why a new language was created. (I suppose it might also be done to confuse novices.) This language of abbreviations and symbols represent emotions and are called *emoticons*. To see the following examples turn you head to the left.

:-) happy **:-(** sad **;-)** a wink **:-o** a look of shock

Some common abbreviations include:

btw - by the way
imho - in my humble opinion
lol - laughing out loud
otf - on the floor
<g> grin.

And since it is easy for someone to misunderstand your intent—sarcasm may not travel well on the net—you may want to add: **ymmv** - your mileage may vary. Finally, a personal favorite of many: **rtfm** - read the #%&*$ manual.

FREE-NETS

If you are still looking for a cheap way to get connected, here's an option. Free-Nets provide free Internet access to local communities—there might be one near you. This list is always growing and there are sites in most states, provinces and many countries. Contact me or call the National Public Telecomputing Network at 216-247-5800.

Steven Keiles, MS
pokeilss@scpmg.com

Legislative Update

■ Medicaid reform is the biggest health related legislative issue slated for Fall. Currently there are efforts to reduce Medicaid costs by 30% in the next seven years. The amount of health coverage (such as prenatal care) and the way Medicaid funds are distributed (block grants) will be considered.

■ HR 1010 (Birth Defects Prevention Act) still needs full committee consideration before floor action and voting can occur. No date has been set at this time.

Lee Fallon, MS
Chair, Legislative Issue Subcmte

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A Minority Counselor's Story

HARNESSING MY UNIQUENESS

Over the years, I realized my language skills were not as bad as I once thought. I learned to take pride in my cultural heritage, and view what makes me unique—and yes, different—as a source of strength rather than weakness. My experiences empowered me to become an advocate for others. I wonder about counselors who were less fortunate and eventually gave up—peers who could have enriched our profession so.

I hear similar stories from colleagues who look, sound or behave differently than "the norm." By being sensitive and tolerant, I hope we can welcome those from diverse backgrounds, helping them overcome barriers to a genetic counseling career.

Ilana Mittman, MS
Baltimore MD

E-mail/FAX Poll

Do you use CGC?

■ I do not use the letters CGC after my name because I am not sure that it would mean anything to people other than genetic counselors. I do use MS because I feel it is more recognizable.

Darcy L. Thull, MS
Pittsburgh PA

■ Whenever possible I try to write out "Certified Genetic Counselor" instead of using the initials, which many people find confusing. My business cards and other printed material read "Anne Spencer, MS Certified Genetic Counselor." Only if there is a space constriction will I use "CGC." Our secretary came up with this solution and we have been very happy with it.

Anne Spencer, MS
Boise ID

■ I do use CGC after my name. I am now on the Board of Directors of ABGC and from this perspective, it strikes me that certification will take on (even) more importance in the future. We are using it to evaluate who teaches in GC training programs—I think the message is coming across loud and clear that programs need to have certified counselors teaching. That is really the only logical standard to use.

Bonnie Baty, MS
Salt Lake City UT

■ I have recently begun to use CGC on my reports. The State Genetic Disease Branch makes distinctions between certified counselors and those who are not, so I figured, why hide it? No one has asked what it means, but some patients do ask what my training/credentials are. I always say both Masters degree plus certification. My badge at work says "MS, CGC."

Debbie Thibodeau, MS
San Jose CA

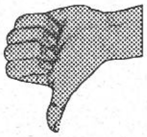
■ I use CGC after my name if it is something official or I'm signing something with others who show that they are boarded. Although it is somewhat pretentious, using CGC after one's name does beg the question "What do the letters stand for?" giving an opportunity to talk about genetic counseling as a profession.

Nathalie McIntosh, MSc
Stratford CT

YES

In the last issue, we asked for your thoughts and experiences about using the letters CGC (Certified Genetic Counselor) after your name. Here's what you had to say.

NO



■ I only use the words "Certified Genetic Counselor." I doubt that I would begin to use the initials by my name unless everyone started to use them. People who want/need to know if I'm certified can ask me or look it up in the ASHG directory. Most of the referring OBs I work with probably do not even realize we have a certification process. I guess I am turned off when health professionals insist on putting lots of initials after their names.

Katie Leonard, MS
Houston TX

■ I have used CGC after my MS since it became available. I have worked hard to earn my certification and want recognition. (It did not do very much else for me either by salary or job status!) It also causes people to ask "What does that stand for?" especially among other health professionals. Nurses have been doing it for years. Why not us? We need to feel comfortable tooting our own horns!! Those counselors who have not passed the exam or are not eligible to sit for the exam are not diminished by those who have. It makes me remember how far I have come.

Robin Gold, MS
Detroit MI

■ I am proud of my Board-certified status. It distinguishes me from others at our institution who also do "genetic counseling." We are initiating a pay differential between board-certified and non-certified counselors—CGC reinforces the distinction. If it does give those of us who are certified elevated status, that is incentive for appropriately prepared genetic counselors to take the boards. Nurses, social workers, PTs and OTs all have a string of initials after their names! If we as a profession do not value our own certification, why should anyone else (employers, insurance companies, etc.)?

Judith Benkendorf, MS
Washington DC

■ I do not use CGC because no one outside of the NSGC would know what it means. I prefer to sign off with MS and "Board Certified Genetic Counselor" under my name.

Joy B. Redman, MS
Houston TX

Bulletin Board

JEMF GRANTSMANSHIP SEMINAR

Since the ability to secure funding to support research, education and professional opportunities has become more critical, the advisory board of the Jane Engelberg Memorial Fellowship will sponsor an interactive seminar to enhance grantsmanship skills February 8-9, 1996 in Colorado Springs CO. The JEMF is supported by an annual grant from the Engelberg Foundation to the NSGC.

Attendance is limited to 20 full NSGC members who are either board certified or board eligible, and will be based on a competitive application process. There is no registration fee; JEMF will reimburse participants for hotel, travel and meals. Participant selection will be based on a short application in which applicants outline a project they wish to develop into a proposal. Seminar participants are not obligated to submit a proposal to JEMF.

☛ Information and application materials were mailed to full NSGC members in September. Application deadline is **November 15, 1995.**

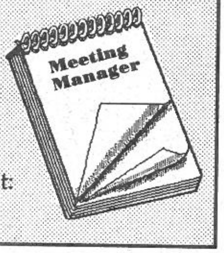
NEWSLETTER FILING SYSTEM

Can you find your back issues of *Perspectives* when you need them? NSGC has a limited supply of loose leaf binders, divider tabs and indices to help keep your archives organized. The cost is $20. Back issues also available.

☛ To request an order form, leave your name and fax when you call: 610-872-7608, Mailbox 8.

Upcoming Meetings

October 21-24	3rd International Meeting of the Society for Neonatal Screening, Boston MA. Contact: 617-647-5530.
October 24-28	The American Society of Human Genetics 45th Annual Meeting, Minneapolis MN. Contact: 301-571-1825.
October 29-November 1	NSGC's 14th Annual Education Conference: "Conditions that Affect Adults: Implications for Genetic Counseling, Testing and Public Policy," Minneapolis MN. Contact: 610-872-7608, Mailbox 6.
February 23-25, 1996	Southeastern Regional Genetics Group Meeting, Atlanta GA.
March 11-14	Joint Clinical Genetics Meeting of the American College of Medical Genetics and March of Dimes, San Antonio TX. Contact: 301-530-3998.
March 27-30	Region VI Education Conference, Asilomar CA. Contact: Karen Wcislo, 408-972-3306.
March 28-30	Great Lakes Regional Genetics Group Annual Meeting, Kansas City MO. Contact: 608-265-2907
June 23-28	International Clinical Genetics Seminar: "Genetic Counseling as We Enter the 21st Century" and "Therapy of Genetic Disorders," Aegean Sea, Greece. Contact: Christos Bartsocas, MD, 30-1-7709316.



ACMG ROUND-TABLE

The 1996 American College of Medical Genetics/March of Dimes meeting will include a round-table discussion on genetic counseling, co-moderated by Judith Benkendorf and Nataline Kardon, MD. The round-table will re-examine the 1975 definition of genetic counseling and explore what the past 20 years might tell us about the future. We are looking for genetic counselors and medical geneticists whose ideas, writing and/or research might elucidate new perspectives, challenge our colleagues and stimulate discussion to participate on this invited panel.

☛ Interested genetic counselors contact Judith Benkendorf, 202-687-8810, by **November 1.** Medical geneticists should contact Nataline Kardon, 800-955-4363, ext 210.

FRAGILE X VIDEO

"Understanding Fragile X Syndrome" is a 25-minute educational videotape produced by the UMDNJ-Newark Fragile X Diagnostic and Treatment Center in cooperation with the Fragile X Association of New Jersey. The video is suitable for individuals and families with a high school education or more. Emphasis is on adjusting to the diagnosis and dealing with the implications for other family members.

☛ Cost is $30. To order, send a check or money order payable to:

Center for Human and Molecular Genetics
c/o Tillie Young, MS - UMDNJ
Doctors Office Center, Suite 5400
90 Bergen Street
Newark NJ 07103-2499
Phone: 201-982-3313.

At the Annual Education Conference

■ There will be three theme-based **ABSTRACT SESSIONS:**

- Issues in Prenatal Diagnosis
- Cancer Genetic Counseling
- Genetic Conditions in Adults/ Genetic Counseling & Public Policy

■ Interested in seeing Garrison Keilor's **PRAIRIE HOME COMPANION?** Obtain tickets to the October 28, 4:45 pm performance at the Fitzgerald Theater in St. Paul MN through Ticketmaster, 612-989-5151.

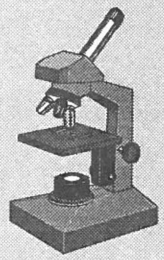
■ The practice-based **SYMPOSIUM ON PSYCHOTHERAPY & GENETIC COUNSELING** will be in two sections: a didactic workshop and an experiential group. Limited to those already using counseling theory in their practices, the experiential group will be in a group supervision format, where clinician Annette Kennedy, PsyD, will guide case review and reflection of counselor/patient dynamics. To participate or learn more about this group, contact Luba Djurdjinovic at 607-724-4308, e-mail: luba.djurdjinovic@oho.com before **October 15.**

■ **GENETIC COUNSELING PROGRAM DIRECTORS** Meetings Sunday, October 29, 10:30-11:45 am, and Monday, October 30, 7:30-8:30 pm.

■ Planning for the **1996 EDUCATION CONFERENCE**—addressing the broad diversity of the genetic counseling profession—is already underway. There will be a planning meeting Monday, October 30 at 12 noon. Want to help but can't attend? Contact Conference Co-Chairs Lisa Amacker North, 704-355-3159, or Robert Resta, 206-386-2101, e-mail bc928@scr.org.

Research Network

NEURAL TUBE DEFECTS



The Center for the Study of Inherited and Neurological Disorders at Duke University Medical Center is looking for families with more than one living affected member for a study of the inheritance of neural tube defects. Participating patients and family members must provide blood samples and allow access to medical records documenting the level and extent of the lesion.

CSIND will arrange for phlebotomy and obtaining records and pay all associated costs. For more information, contact Chantelle Wolpert, 919-684-6515, e-mail chantell@weinberg.mc.duke.edu.

FRAGILE X SYNDROME

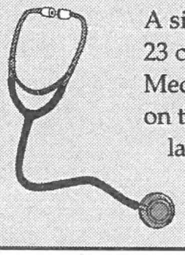
Beth Pletcher, MD, at the Center for Human Molecular Genetics in New Jersey, is studying elastin defects to learn more about the basis of the Fragile X syndrome's connective tissue symptoms, such as loose, elastic skin, lax joints and mitral valve prolapse.

Affected males over age 18 are eligible. Any male with Fragile X having elective surgery can participate by providing a small skin sample at the time of surgery. For more information, call Dr. Pletcher at 201-982-3300.

RUSSELL-SILVER SYNDROME

Researchers at the Hospital for Sick Children in Toronto are screening for uniparental disomy, following up on a recent report of maternal uniparental disomy of chromosome 7 in some children with Russell-Silver syndrome or primordial growth failure.

The study requires blood samples from the patient (5-20 cc) and parents (20 cc) in yellow top ACD or lavender top EDTA tubes. There is also a clinical checklist to help correlate genotype-phenotype results. Contact Cheryl Shuman, 416-813-7550, or e-mail cshuman@sickkids.on.ca.



A similar study screening for uniparental disomy of all 23 chromosomes is being done at Columbia Presbyterian Medical Center in New York. They request blood samples on the affected child and both parents (at least 5 ml in lavender top EDTA tubes). Contact Janine Lewis, 212-305-6731, Dr. Steven Brown, 212-305-7317, or e-mail lewiska@cpmail-am.cis.columbia.edu.

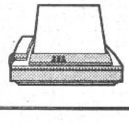
E-mail/FAX Poll

Who was your mentor?

Thanksgiving is coming—is there someone who helped or inspired you professionally that you would like to thank? Someone who taught you the ropes, helped you through a tight spot, was there with encouragement or words of wisdom when you needed them most?

Let us know your experiences. The next issue of *Perspectives* will explore what it means to have or be a mentor.

☛ Contact Liz Stierman
FAX 213-380-7344
e-mail LStierman@aol.com



Resources

■ Book ■

Signs of Life: The Language and Meanings of DNA

By Robert Pollack.
Boston: Houghton Mifflin Co.
(1994). 198 pages, $19.95.

Signs of Life is an interesting, well written and current book intended for the general public. Pollack, a molecular biologist, writes about molecular genetics and its clinical implications.

Parallel Trains

Pollack uses analogies to illustrate complex topics; for example, he compares DNA structure to northbound and southbound trains on parallel tracks linked by the passengers leaning out the windows to hold hands. His less useful analogies draw comparisons that may not be familiar to most people; for instance, he likens transfer RNA to a Chinese chop block.

The most useful analogy likens the task of the Human Genome project to a molecular word processor, using cut, copy, move and paste commands. Pollack demonstrates the limitations of this imaginary word processor: knowing the molecular words and phrases does not automatically confer understanding of their molecular meaning.

One of the book's strengths is its focus on ethical issues, although Pollack becomes moralistic in the final chapter. Besides genetic discrimination by insurance companies, he raises lesser known ethical issues—NIH's interest in patenting DNA probes, the lack of government/scientific regulation of DNA recombination for food products and gene therapy curing one malady but causing another (as has occurred in mice studies).

An "Aha" Experience

Pollack's style and analogies enabled me to integrate a couple of previously disparate ideas. I had an "Aha" experience, where the pieces seemed to fall into place.

Genetic counselors should find understandable, valuable information in this fascinating book. I will use some of the ideas and analogies when lecturing to medical students and nurses.

Although described as "understandable to non-scientists" by Secretary of Health and Human Services Donna Shalala, I don't think this book is for the general public—it deals with molecular genetics at a level most patients would not understand, appreciate or, quite frankly, care to know.

Deborah R. Rada, MS, MBA
Fontana CA

■ Support Groups ■

Electronic Support Groups: Information & Comfort Online

I recently ventured into the emerging arena of e-mail support groups and found an excellent resource for genetic counselors and the families with whom we work. As part of a student project, I subscribed to online support groups for spina bifida and muscular dystrophy for 7 weeks.

These groups have greater breadth of participants than traditional groups, extending across the US and the world. Postings came from Canada, Chile, Ireland and Australia.

Access beyond their immediate geographic area allows participants to make connections they might not otherwise make. One parent planning to adopt a child with Duchenne muscular dystrophy found another parent with that experience. Likewise, the parent of a child with autism and spina bifida found support from another family with similar circumstances.

Accessibility

Users can participate from home, a plus for parents as well as people with disabilities. For those who rely on ventilators and/or have limited mobility, this contact may be the sole means for support.

These support groups "meet" 24 hours a day, 7 days a week. People usually respond to questions and postings within a few days. A rich array of topics surfaced in a short time: practical concerns such as medical research, treatment, adaptive living devices and insurance problems as well as emotional and personal concerns.

No Hugs

The disadvantages of an electronic support group are obvious. There is no physical presence: no handshakes, no eye contact, no hugs. However, some people may be more inclined to participate in a support group if they can retain some anonymity.

E-mail support groups are growing. I found references to groups for Down syndrome, deafness, developmental delay and many others through a Psychology and Support Groups Pointer, available through grohol.@alpha.acast.nova.edu.

Jason Coryell
Cincinnati OH

Letters to the Editor

CHALLENGES FOR COUNSELORS IN RESEARCH ROLES

The Summer 1995 issue of *Perspectives*, with its focus on the role of genetic counselors in facilitating and evaluating research studies, could not have been more timely for me. For the first time in my career, I have moved beyond serving as the gate-keeper between patients and research studies to actually performing patient education and genetic counseling as part of the interventions being examined in a randomized, clinical trial. While involvement in research examining the genetic counseling process is a new and exciting role, this experience has come with a new set of challenges.

In this study we are comparing alternative pre-test education and counseling models for BRCA-1 testing in women at increased risk for breast and/or ovarian cancer. Because they are being seen in the context of a research program, it is imperative that women in each arm of the study receive the intervention to which they have been assigned. To assure consistency, the counselor must adhere to a protocol and not alter the content or format of the sessions.

As a clinician first, I am constantly grappling with the tension between adhering to the protocols or best serving the participants' counseling needs. Although I am confident that all study participants are given clear, complete information, difficulties have arisen for me as a counselor when the women raise tough, and often acute, emotional issues concerning their cancer worries and experiences. Simply put, I am conflicted between making a paradigmatic shift from my well-honed role as patient advocate to becoming an advocate for maintaining the integrity of the study design. While neither of the two interventions we are piloting have the inherent flexibility of a traditional genetic counseling session, there is no opportunity to attend to these highly charged issues in the standard education intervention. Furthermore, doing so would either force us to eliminate the participant from the study, or confound the data we are collecting.

As more counselors become involved in research projects examining the genetic counseling process, there will be a growing need to reconcile the tension between leaving the client-centered model in which we were trained to let the session evolve as a result of the client's agenda, versus allowing the counselor's agenda to control the session. It has only been after discussion with colleagues—including the nurse educators also seeing study participants—that I have begun coming to terms with these issues. Our research team has responded by assembling a folder of educational materials, given to all participants, including a list of support groups and referrals for various types of individual counseling.
I hope sharing these new experiences and challenges with the genetic counseling community will open a dialogue that will continue in the genetic counseling training programs, through continuing education activities and both formally and informally with colleagues and researchers from ours, and related, disciplines.

Judith L. Benkendorf, MS
Washington DC

WITH APPRECIATION

I want to thank all of the NSGC members who have actively taken the time to mentor undergraduate students for the genetic counseling profession. The University of Pittsburgh received 120 applications for the 12 positions available in the genetic counseling program. It was delightful to see the number of counselors who wrote letters of recommendation but more importantly, who had taken students into their offices and their clinical settings for interviews and hands-on experience. These events decidedly enhanced the students' applications and made selection very difficult. We had many qualified and eager candidates who we could not accommodate. Thank you for your efforts in bringing forth the next generation of genetic counseling professionals.

On a separate note I would like to thank all members of the Society for the opportunity to serve on your Board of Directors of the past six years. My term expires in Minneapolis—I have enjoyed my Board experiences immensely. I look forward to being an active committee member and continuing to support NSGC projects.

Lastly, thanks to all of you who sent me MAYOR congratulations. I served as acting mayor of the Borough of Forest Hills (a suburb of Pittsburgh) from June 1-12. I am seeking re-election on November's ballot for my Borough Council seat (four year term) and will keep you posted!

Thanks for all the kind words and for the experience of serving as an elected official for the NSGC.

Betsy Gettig, MS
Pittsburgh PA

Student Page

Letters to the Editor: Graduates Finding Jobs

The last issue of *Perspectives* carried comments about the job market for new genetic counseling graduates. Having received quite a bit of feedback on the subject, I gathered some recent statistics. I asked training program directors how many students graduating by August 1 had secured genetic counseling jobs. Ninety students graduated from the 14 programs responding; 60 (67%) had jobs. As we do not have data for that date last year, we cannot draw any conclusions regarding a trend.

What did program directors say about the job market? Many felt the market is responding to changes in the health care industry and is truly tighter than it has been for a few years. Before, we saw a fairly unreal situation—employers begging us for graduates.

Most directors have been around long enough to know it hasn't always been easy to get jobs. Many stated that graduates now must network more than ever and be a little creative. Graduates who are confined to specific cities definitely have more difficulty than those who are mobile.

Bonnie LeRoy, MS
Minneapolis MN

Here's what two new graduates say:

Whether the issue is health care reform, hospital economy or job saturation, there definitely appears to be a decline in desirable genetic counseling positions—full time positions that are in a chosen city or region offering a reasonable salary and work environment.

As one of the fortunate few in my graduating class to find a position, I feel training programs have an obligation to inform their interview candidates of this trend. Genetic counselors are dictated by the idea of informed consent; I believe eager candidates deserve the same service as our patients.

Genetic counseling has often been described in the media as a growing and innovative field. The entering students I know assume graduating from a master's program guarantees them their ideal position. To maintain the reputation of a client-driven field, training programs should correct these false assumptions.

Charli Loebl, MS
Chicago IL

I have had first hand experience in this job shortage dilemma. Two years ago while researching the genetic counseling field, I would never have imagined being in the scenario I find myself in today. We were told that for every counselor who graduates there would be three jobs waiting. That may have been true two years ago, but it is certainly not true today.

I applied for jobs in five states but did not obtain any of them. This was quite frustrating since I knew that despite the few jobs available, more genetic counselors are needed in the medical field. I focused on creating a new position and obtained a part-time job developing a prenatal genetics program at a community hospital.

My new job met with significant resistance within my department due to a lack of awareness about the role and responsibilities of a genetic counselor. I'm happy to report that mood seems to be changing as more people learn about me and my position. As a genetic counseling advocate, my frustration at surviving on two days a week salary will be forgotten if I can make a difference.

I write to let others know of this hopefully temporary job situation so we can inform future genetic counseling students. The answer is not the limit the number of new students to our training programs. Some health care professionals simply do not know or appreciate the value of genetic counselors—this perception limits necessary funding for our jobs. I hope we can open the eyes of the world to our worth. If not, we could some day be a dying breed of genetic specialists.

Katherine Hunt, MS
St Louis MO

Student Research Projects

Students from the University of California, Irvine share their thesis projects. Contact them directly for more information.

Kelly Chen: "Segregation analysis of primary congenital glaucoma." 415-637-1046.

Sheri McKeague: "Development, implementation and evaluation of a genetics teaching model for presentations to high schools." 714-997-0827.

Deborah Phillips: "Identifying the underlying dimensions of the quality of genetic counseling services." 213-669-2178.

Shari Riskin: "Assessment of understanding of the California Expanded Alpha-fetoprotein Screening Program in primary care settings." 310-985-1400.

Joyce Seldon: "Segregation analysis of kindreds of probands with childhood absence epilepsy." 310-410-4611.

■ EMPLOYMENT OPPORTUNITIES ■

■ *These classified listings represent the most recent additions to the NSGC JobConnection service. Members and students interested in complete or regional information may receive a computerized printout, at no charge, by calling 610-872-7608 Mailbox #2. Printouts are mailed on the first and third Monday of each month. This service is strictly confidential.*

Scottsdale AZ: Immediate openings for BC/BE Genetic Counselors. Full-time, part-time or per-case basis considered. Exp pref.
Responsibilities: Case mngmt & PN svcs positions in **CA, NY, PA & AZ.**
Contact: Janet Atkinson, Director of Clinical Services, Genetrix, Inc., 6401 E. Thomas Rd, Scottsdale AZ 85251; 800-333-4363x120. EOE/AA.

Tucson/Phoenix AZ: Upcoming openings for 2 Genetic Counselors. BC/BE; exp pref but not req; fluency in Spanish req for Tucson position. App review begins November 1.
Responsibilities: Phoenix: Coord ped genetic & metabolic clinical activ; partic in med educ. Tucson: Devel & coord genetic educ program & clinical care for Hispanic populations in So. AZ.
Contact: H. Eugene Hoyme, MD, Chief, Section Medical & Molecular Genetics, Univ Arizona College of Medicine, Dept Pediatrics, Tucson AZ 85724; 520-626-5175. EOE/AA/ADA. Women & minorities encouraged to apply.

Irvine CA: Immediate opening for BC Genetic Counselor. MS & 3 yrs min related exp; familiarity w/ cancer genetics. Must submit complete application—No resumes!
Responsibilities: Work w/ cancer risk pt population in cancer genetics study conducted by UCI Epidem Div: Cancer risk assessmt w/ emphasis on pt educ.
Contact: Human Resources Dept, Attn: Job #CU257, UC Irvine Campus, Irvine CA 92717-4600; 714-824-4117. EOE/AA.

Los Angeles CA: See SBCL, **Phila PA**

Atlanta GA: Immediate opening for BC/BE Genetic Counselor. Exp pref.
Responsibilities: Join busy private perinatal prac; all aspects of PNDx: amnio, CVS, abn U/S, terat, AFP, DNA tstg. Oppty to partic in resident & med student educ.
Contact: Phillip L. Potter, MD, Maternal Fetal Diagnostic Center of Atlanta, 340 Boulevard NE, STE 103, Atlanta GA 30312; 404-265-4824.

Atlanta GA: See SBCL, Phila PA

St Louis MO: See SBCL, Phila PA

Greenville NC: Immediate opening for BC/BE Genetic Counselor w/ Faculty Position.
Responsibilities: Wide range of GC oppty: peds, PN & specialty genetics clinics; partic w/ satellite clinics.
Contact: O.J. Hood, MD, East Carolina University School of Medicine, Brody Medical Sciences Bldg, Room 3E140, Greenville NC 27858-4354; 919-816-2525. EOE/AA/ADA. Applicants must comply w/ Immigration Reform & Control Act.

Cleveland OH: Immediate opening for Genetic Counselor. Exp pref; familiarity w/ cancer genetics & molec diagnosis req.
Responsibilities: All aspects of GC: PN, peds, adult & cancer genetics in joint clinical program at MetroHealth Med Ctr & Cleveland Clinic Fdt Program: provide comp coun svcs to diverse pt populations.
Contact: Brian A. Clark, PhD, MD, MetroHealth Medical Center, Dept Obstetrics & Gynecology, 2500 MetroHealth Dr, Cleveland OH 44109-1998; 216-778-5896. EOE/AA.

Portland OR: Immediate opening for BC/BE Genetic Counselor. Joint apptmt in dept molec & med genetics/ child dev & rehab ctr.
Responsibilities: Team member in genr'l genetics diagnostic clinic w/ wide variety of ped & adult clients, PN clinic, consults; partic in educ.
Contact: Karen Kovak, MS, Oregon Health Sciences Univ, PO Box 574, Portland OR 97207; 503-494-5606. EOE/AA.

Abington PA: Immediate opening for Part-time [3-4 days/wk] BC/BE Genetic Counselor.
Responsibilities: Comp PN coun: amnio, CVS, triple screen, PUBS, abnorm U/S. Join 2 GCs at busy ctr w/ high degree of independence.
Contact: Ann Isaacs, MS, Abington Hospital, 1235 Old York Rd, Abington PA 19001; 215-576-2566. EOE/AA.

Philadelphia PA: SmithKline Beecham Clin Labs (SBCL). Immediate openings for BC/BE GCs in Atlanta, St. Louis, Los Angeles, Phila.
Responsibilities: StL, Atl, Phila: Coord reg'l genetic tstg; LA: Coord genetic tstg in west plus add'l Genetic Testing Ctr respon. All req close collab w/ med genetics in StL & LA and GCs in Atl & Phila. Primary respon: Clin consult w/ physician/ clients; convey results; assist w/ interp & approp clin action; assist w/ devel of genetic tstg (single gene/oncol); coord ongoing preg outcome follow-up prog; reg'l sales supt; prof & staff educ.
Contact: Nancy Shapiro, SBCL, 121 S, Collegeville Rd , #CV1010, Collegeville PA 19426; 800-877-7478x4101.

Philadelphia PA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Work in univ-hosp setting w/ multidisc team: ped & adult GC & case mngmt; oppty to partic in rsrch studies & multidisc spec clins.
Contact: Elaine H. Zackai, MD, Director, Clinical Genetics Ctr, Childrens Hospital, 34th & Civic Center Blvd, Philadelphia PA 19104; 215-590-2920. EOE/AA.

Houston TX: Immediate opening for BC/BE Genetic Counselor; fluency in Spanish a plus but not req.
Responsibilities: Partic & coord genetics outpt clins; s'vise GC grad students; med mngmt of in-hosp consults; spec clins & commun educ re: genetic issues.
Contact: Jacqueline Hecht, PhD or Dr. Northrup, Univ Texas Medical School Dept Pediatrics, PO Box 20708, Houston TX 77225; JH: 713-792-5330x3022; Dr N: 713-792-5330x3074

Houston TX: Immediate opening for Senior Genetic Counselor w/ MS + 3 yrs exp as GC incl 1 yr mngmt + BC; Exp must include risk assessment for adult onset diseases.
Responsibilities: Design, implement, provide GC svcs for all assigned pt & at-risk individuals.
Contact: Dara Biegert, HR Dept, Univ Texas M.D. Anderson Cancer Ctr, 1515 Holcombe, Box 205, Houston TX 77030; 1-800-25-UTMDA, #5.

Richmond VA: Upcoming opening for BC Genetic Counseling Program Director/Instructor. Masters or PhD in GC or genetics. Admin, coun, tchg, rsrch grant collab, achievement in provision of clin gen svc, superior mngmt skills *ALL* req. App Deadline: November 30.
Responsibilities: Interact w/ dept faculty & staff in clin placements, resource dev, commun outrch; Send CV + 3 ltrs rec
Contact: Joann Bodurtha, MD, MPH, GC Program Director Search Cmte, Medical College of Virginia/VCU, PO Box 980033, Richmond VA 23298-0033. EOE/AA/ADA. Women, minorities encouraged to apply.

nsgc
National Society of Genetic Counselors
233 Canterbury Drive
Wallingford PA 19086-6617

Virginia CORSON MS
Johns Hopkins Hospital
CMSC 1001
Baltimore MD 21287-3914

Human Genome Project Update

■ NEW GENE MAPPING APPROACH COMES OF AGE

A new approach, positional candidate strategy, lets researchers combine information about a gene's chromosomal location with increasingly detailed genetic and physical maps. This approach should streamline the process of identifying disease genes within the next few years.

Positional candidate studies have already led to the identification of over 50 disease genes. It relies on a three step process that saves time and effort:

- localizing the gene to a chromosome subregion, generally using traditional linkage analysis;
- searching databases for an attractive candidate gene within that subregion; and
- testing the candidate gene for disease causing mutations.

NIH Human Genome Research Center Director Francis Collins predicts that using this approach, "more than half the human transcripts will be placed on the human genome map in the next 18 months."

■ GENETIC PRIVACY ACT

The Genetic Privacy Act, the first legislative product of the US Human Genome Project's Ethical, Legal and Social Issues component, is proposed legislation governing collection, analysis, storage and use of DNA samples and the genetic information obtained from them. Drafted as a federal statute to provide uniformity, the act has been introduced in six state legislatures.

The Act's main premise is that no stranger should have or control identifiable DNA samples or genetic information unless the individual providing the sample specifically:

- authorizes use of the DNA sample for analysis and creation of genetic information, and
- retains access to and control over its dissemination.

■ GENES THAT MAKE NEWS, NEWS THAT MAKES GENES

Partly funded by the DOE, this meeting, held December 1994 in Boston, was the fourth in a series on science and journalism. Attending scientists, reporters and teachers discussed concerns over falsely raising public expectations about predictive genetic screening and the importance of emphasizing gene-environment interaction. They generally agreed that both scientists and journalists must assume greater responsibility for promoting accurate reporting.

JoAnn Inserra, MS
Norwalk CT