PERSPECTIVES
in genetic counseling

Volume 18 Number 2 Summer 1996

Medical Staff Membership: Fostering Professional Identity and Influence

by Chantelle Wolpert, MBA, PA-C, Genetic Counselor/Physician Assistant, Duke University, Durham NC

When one genetic counselor applied for her first position, she was asked by an administrator at the Texas hospital for her Master's degree in Social Work. When she also offered her genetic counseling credentials, she was politely told "that paperwork was not needed."

Unfortunately, this true scenario illustrates the often ambiguous professional identity of genetic counselors within hospitals. Most do not routinely have their professional credentials reviewed when applying for a position at a hospital or medical center. Yet this formal review—credentialing—is one step toward medical staff membership.

Medical staff affiliation clarifies professional status but can also expand a genetic counselor's influence. Although genetic counselors do not diagnose or admit patients, they contribute significantly to patient care, teaching and research. Their expertise is applicable to many medical staff committees; serving on these committees brings opportunities to improve clinical practice and help formulate policies at the medical center. For these reasons, hospital-based genetic counselors should strive to become more integrated into medical staff functions.

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Support Groups: Helping Parents Who Terminate Pregnancies

by Molly A. Minnick, ACSW, Memorial Healthcare Ctr, St. Johns MI; Kathleen J. Delp, ACSW, Butterworth Hosp, Grand Rapids MI

Prenatal testing has become increasingly available in the last decade. At least 1-2% of women tested will learn their unborn children have serious or lethal anomalies, yet few programs exist to help these parents. This may be due to a number of factors.

■ **Lack of resources.** There are few resources or training programs available to those wishing to initiate and facilitate support programs.

■ **A difficult topic.** Health professionals often shy away from the challenging task of working with bereaved parents;[1] support group facilitators must be willing and able to deal with the intense feelings which are sure to surface.

■ **Teamwork needed.** "This may be too big a job for any one professional. The professional caregivers themselves experience conflict and loss. An interdisciplinary team may be the best approach to helping families facilitate the grieving process."[2]

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national society of genetic counselors, inc.

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

On the Inside

NSGC acknowledges Women's Health Care Services, Wichita KS, providers of late abortion care for fetal anomalies, George R. Tiller, MD, Medical Director, for a grant to support this newsletter.

Presidential Remarks

Puzzles Without Borders: Expanding our Domain

A fun aspect of using the puzzle metaphor to frame activities during my presidency is its flexibility: this quarter's puzzle is entitled "World Without Borders." It has been an amazing time of outreach—to our genetic colleagues, the medical community and the public at large.

In the Genetics World

Those attending the American College of Medical Genetics meetings in March enjoyed good weather, networking and educational programs—such as one about billing/reimbursement that offered new insight to documenting genetic counseling visits. We were invited to increase our involvement in the College's educational activities and proposed offering our Neurogenetics Short Course a second time in conjunction with their meeting next spring. As we go to press, we are awaiting a response.

In April, the ASHG executive committee flew to Chicago to meet with NSGC's executive committee, discussing common concerns related to education. We look forward to working with both ASHG and ACMG to maximize educational opportunities for NSGC members at national conferences.

Another puzzle piece expanding our borders was the Medical Genetics/Genetic Counseling Review Course we co-sponsored with the University of Pittsburgh. 167 attended the three day program; about 40% of participants were not genetic counselors. In addition to being a financial success, the course earned overwhelmingly positive reviews.

Planning our future

Why is marketing important? As health care economics change, so might the job market. NSGC is strategically preparing for a future that *will* include genetic counselors. *(See opposite page.)*

The Future is Now

Cancer genetics is like a rapidly moving train—we can sit on the track or hop on board. We are doing the latter! Genetic counselors are solidifying our position as the professionals with content expertise in this exciting new niche—by giving media interviews, writing grants and being instrumental in developing cancer assessment programs and guidelines. A special issue of our *Journal* will focus on cancer genetics.

Get a Piece of the Puzzle

As the year progresses, hundreds of puzzle pieces are being given to deserving members. Although you won't receive a physical puzzle piece, here are two opportunities for full members to "earn" one:

■ Professional Status Survey—if it's still sitting on your desk, take 25 minutes to complete it soon.

■ NSGC Election—exercise your citizenship by voting for an

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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.

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Celebrate Ourselves!

■ **Jamie McDonald** traveled to Edinburgh, Scotland in May for an invited scientific session on hereditary hemorrhagic telangiectasia. The sole non-MD/PhD attending, she presented her quest for the HHT gene in a seven generation Utah family with over 3,000 at-risk descendants.

■ **Nancy Steinberg Warren** received her fourth grant in preconception health—a $2500 award from the Great Lakes Regional Genetics Group to bring a health education curriculum to junior and senior high schools.

■ Fifteen minutes of fame have eluded **Charlene Schulz**, **Katherine Schneider** and **Jill Stopfer** for now—they were interviewed for a recent "60 Minutes" segment on genetic discrimination, but ended up on the cutting room floor.

■ A profile of **Andy Faucett**—illustrating genetic counseling as a science career option—appears in a new college biology textbook from Saunders Publishing.

■ LGS/NSGC Speakers' Travel Fund Award winner **Diane Baker** will address the National Association for Biology Teachers in Charlotte NC this fall. Her topic: "The Human Genome Project & Genetic Counseling."

Marketing Our Profession: One Voice, One Message

Since my last update in *Perspectives,* NSGC has selected the Center for Applied Research to guide our marketing efforts. Florina Gogarnoiu, assigned to be our consultant, attended our April Board of Directors meeting to:

■ Introduce herself.

■ Stress the importance of research in the marketing process.

■ Learn our leadership's perceptions about marketing.

■ Better understand NSGC's culture—the way we operate.

Florina guided the Board's creative thinking in a productive, enlightening five hour session. By afternoon's end, we realized we have much ground to cover before we initiate any type of marketing campaign. Below are some of the comments made as two themes emerged:

■ **Relationship Marketing**
"Today's managed care environment alters the manner in which patients are referred to us. To date, few limits have been imposed on that referral process." Relationship marketing is based on developing relationships, in this case, with decision makers and influencers in the managed care system. Genetic counselors have excellent one-on-one relationship building skills—our challenge will be to refocus those skills on this new market, ultimately enabling patients who need genetic counseling services to obtain them.

■ **Defining Ourselves**
"Misinformation is our strongest competition." The key to sound marketing is the concept of "One Voice, One Message"—a clear core message defining the genetic counseling profession. This message is consistent with our vision or mission statement. The challenge will be to succinctly state what genetic counseling services are and why genetic counselors are *the best qualified professionals* to provide them.

To appropriately market ourselves, we must first build a solid foundation of credible quantitative data, supported by facts, clinical outcomes and patient satisfaction. As we have become painfully aware, data documenting the value of our services simply does not exist.

Redefining our Targets

In the course of the session, we challenged our initial assumptions about who we are trying to reach. Originally, we planned to focus on specialists (obstetricians, oncologists, neurologists) likely to refer to genetic counselors. Since primary care physicians are becoming the clinical decision makers who control referrals, educating them about the value of genetic counseling will be paramount to effective marketing.

The Next Step: Research

Florina underscored the importance of laying a solid ground of research, identifying the facts that will ultimately make the difference in developing our "One Voice, One Message." This research will focus on understanding our target audiences, ourselves and our competition.

To that end, Vickie Venne appointed the following members to serve on an *ad hoc* marketing task force: Nancy Adams, Beth Balkite, Andy Faucett, Ed Kloza and Shane Palmer, with Vickie, Ann Boldt and myself as *ex officio* members. This team is charged with collecting the marketing research and providing support as the marketing plan is developed. The first phase includes interviewing appropriate resources internally and externally to answer the following questions:

■ Does data about the value of genetic counseling services exist? If so, how can we best tap into it?

■ Who or what competes with or substitutes for genetic counseling services?

■ What unique niche does the genetic counselor fill that other professionals cannot?

Member Involvement

Many of you have expressed interest in participating in the marketing process. Although the *ad hoc* task force will provide oversight, others will be involved as we progress into subsequent phases. But first things first! Members can begin by:

■ Identifying decision makers and influencers in your own institutions.

■ Compiling state or regional studies to provide insight into the economic value of genetic counseling services.

■ Providing the task force with data and experiences in which genetic counseling has enhanced health care.

Therein lies the foundation of our marketing plan. Once the research is complete, we will be one step closer to controlling genetic counseling's future.

Bea Leopold, MA
Executive Director

☛*Members with data, supportive documentation, strategic contacts or insights are encouraged to contact one of the task force members. Your involvement will help move our efforts forward.*

NSGC Notes

Committee Activities

■ The **Genetic Research Issues** Subcommittee of the Social Issues Committee has compiled a bibliography on genetic research issues. To get a copy or suggest a reference, contact the Executive Office, 610-872-7608, #8.

■ The **Membership Committee** is looking for volunteers for several projects: developing an exhibit display, conducting exit interviews, exploring career guide entries and researching scholarship sources. For more information, contact Chair Nancy Steinberg Warren, 513-559-4475, EM: warrn0@chmcc.org.

Liaison Reports

■ The Task Force on Genetic Testing has issued a working document on the Principles of Genetic Testing. To receive a copy or offer comments, contact our Task Force representative, Katherine Schneider, 617-632-3480, EM: Katherine_Schneider@DFCI.harvard.edu. The Interim Principles are also available on the World Wide Web: http://infonet.welch.jhu.edu/policy/genetics.

■ Rosalie Goldberg reports on the May 20 meeting of the **National Advisory Council for Human Genome Research:** After an intensive two year search, Eric Meslin, PhD, Assistant Director of the Center for Bioethics at the University of Toronto, has been appointed Chief of the ELSI branch of the NCHGR. He replaces Elizabeth Thomson, RN, who has been serving as acting Chief.

From the Executive Office

■ Over 200 NSGC members—17% of the total—belong to one or more Special Interest Groups. The Cancer SIG is the largest, with 111 participants.

New Amendment Process

The Prenatal & Childhood Testing Resolution Revisited

The debate surrounding the recently passed Prenatal and Childhood Testing Resolution highlighted the need for a system to amend or rescind NSGC Resolutions and Policy Statements—such a process was approved by the Board of Directors in April.

In the future, proposed amendments must by submitted before April 1 as part of a yearly approval cycle. Recognizing the need for closure on the Prenatal and Childhood Testing for Adult-Onset Disorders Resolution, the Board will consider proposals on this issue if submitted before **August 1.**

Policy Statement Amendment Process

Purpose: As the law, society and technology change, NSGC policy statements which were written within a particular legal, societal and technological framework may become outdated. The following process establishes a mechanism that will allow NSGC to amend or rescind existing policy statements to reflect current times.

Process:

1. Proposed amendment(s) or proposal(s) to rescind will be submitted in writing to the Executive Office. A petition with 10% of full NSGC members names showing support of the proposal must accompany each proposed amendment/recision. Only full members can submit such a proposal. The deadline for submission is April 1.
2. The Executive Director will verify full membership of the individuals signing the petition and notify the Social Issues Chair of the submitted proposal.
3. The Social Issues Chair will send the proposal to the Ethics Subcommittee and NSGC attorney for comment. Their comments will be limited to potential conflicts with the NSGC Code of Ethics or issues regarding legal liability. The Ethics Subcommittee and attorney will send their written comments to the Social Issues Chair within two weeks of receipt of the draft proposal.
4. The proposal will be published in the Fall issue of *Perspectives* for membership notification. In addition, the comments from the attorney and Ethics Subcommittee as well as a balanced discussion presenting the pros and cons will accompany the proposed amendment(s)/recision.
5. At the Annual Education Conference (AEC), time will be allotted for discussion about the proposed amendment. The AEC Planning Committee will work with the Social Issues Chair regarding the forum for discussion.
6. Between the end of the AEC and December 31 of the current year, ballots will be mailed to all full NSGC members as a distinct mailing. The existing version of the policy statement and the proposed version will be represented on the ballot. Ballots should be postmarked within 30 days of when the ballots were mailed. (A postmark deadline will be printed on the ballot).
7. The amendment/recision passes with a 2/3 majority of respondents.

Professional Issues Committee Update

CPT Code for Our Services? Not Yet...

Current Procedural Terminology (CPT) codes are used by nearly all fee-for-service payers to describe services rendered. They are also indirectly used by insurers to set reimbursement rates.

Last winter, I reported on the proposal submitted to the American Medical Association's CPT Editorial Panel for numerous CPT code changes, including the addition of a genetic counseling code.

The proposal came from the American College of Medical Genetics Committee on Economics, on which Barbara Bernhardt and I serve. I was one of the four members of the ACMG committee selected to defend the proposal at the annual AMA CPT Editorial Panel meeting in San Antonio this February.

Entering the AMA meeting, we knew there were three possible outcomes—the codes would be accepted, rejected or tabled pending further clarification—a "win, lose or draw" scenario. We also knew the genetic counseling code was a definite underdog.

Advisors Unclear on Services Provided

The CPT Editorial Panel distributed the proposal to 63 advisors, members of other professional organizations represented within the AMA. Twelve recommended approval as written, 15 did not recommend approval and 29 advisors offered no comments.

From examples of concerns shared with us, it was clear these practitioners did not understand or appreciate the differences between genetic counseling and the general consultation occurring with any good clinical assessment. For example, the advisor for the American Academy of Neurology wrote, "If genetic counseling requires an E & M (evaluation and management) series, then what about all the other types of counseling physicians do in patient care?"

The laboratory codes appeared to be much less controversial. Based on advisors' comments, we expected the molecular and cytogenetic codes to be accepted and thought only the biochemical codes might be tabled.

Codes Denied

In April, we learned that the genetic counseling codes were denied and that all laboratory codes were tabled pending discussions between the ACMG and the CPT committees of the College of American Pathologists and the American Society of Clinical Pathologists. The CPT office later indicated they were favorably impressed with the proposed lab codes but wanted to ensure uniform agreement.

Resubmission Planned

ACMG's Committee on Economics of Genetic Services met in early March. Anticipating the denial, we began to strategize our next proposal to the CPT Editorial Panel. The Committee remains very committed to pursuing a genetic counseling code.

The seed has been planted and we have no intention of allowing it to wither and die. So, while we may not see a genetic counseling code in the 1997 edition of the CPT manual, don't give up hope. To borrow a line from the great Yogi Berra, "It ain't over till it's over!"

Debra Lochner Doyle, MS
Chair, Professional Issues Cmte

Legislative Update

Major activity occurred in both the House and Senate in April regarding Health Insurance Reform legislation. HR 3160 and S 1028 passed in both houses, and now await consideration in joint committee to rectify differences. Both bills contain language to prevent insurance companies from denying coverage to persons based on their genetic information. While not the main purpose of the bills, the fact that non-discrimination language was included is a tremendous accomplishment. No date has been set for joint-committee action at this time. Call the Legislative Issues voice mail for updates (610-872-7608, #5).

Late Abortion Bill Vetoed

Also in April, President Clinton vetoed legislation outlawing certain types of late-term abortion procedures. No move has been made to attempt to override this veto, and it appears unlikely any further action will occur this legislative session.

Where Do They Stand?

The summer will see major platform issues set for the presidential candidates as well as other upcoming elections. Listen as both an educated professional and constituent and *get involved*!

Lee Fallon, MS
Chair, Legislative Issues Subcmte

Vote!

NSGC election ballots are due by **August 1, 1996.**

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Support Groups: Helping Bereaved Parents

■ **No institutional support.** With intense competition for health care dollars, institutions may be reluctant to back endeavors that do not generate funds.

Addressing Obstacles

In 1994, we were awarded a grant from NSGC's Special Project Funds to develop a manual for conducting support programs for parents who had interrupted pregnancies with fetal anomalies, specifically addressing the factors which may impede these support programs.

We had facilitated an ongoing support group for many years at Michigan State University. To gather information about others' experiences we developed two surveys—one for support group facilitators and one for the parents who attended. Here are some of the things we learned.

Types of Support Groups

■ **Open groups** are ongoing but tend to meet less frequently than other groups. Members may join or leave the group at any time; they attend whenever support is needed. The newly bereaved can learn from the healing witnessed in other parents. For facilitators, attendance that ebbs and flows may be a disadvantage.

■ **Closed group**s are more structured, meeting for a predetermined number of sessions. A set number of participants generally contract to attend all meetings. Closed groups usually meet more often than open groups. Parents may have to wait some time until the next session begins, and they may need support beyond that found in a limited number of sessions. Predictable attendance is an advantage—participants are more likely to form attachments to one another and facilitators can better plan each session.

■ **Single session groups** meet once for an all day presentation; they provide information as well as time for sharing in small groups. Single session groups are often held in sparsely populated areas where parents must travel great distances to attend; participants may have to wait many months to a year for the next meeting.

Starting a Group

These are some of the ways to help ensure a successful group:

■ **Perform a needs assessment** by surveying parents—results may help you decide which group format to use.

■ **Have more than one facilitator** including representatives from several disciplines to add their expertise and experiences.

■ **Plan the first meeting carefully**, including attention to refreshments, handouts and resources.

Care for the Caregivers

Just as professionals work hard to meet the emotional needs of bereaved parents, we must also see that our own needs are met. Taking time to share and process after each meeting is an important way to deal with some of the powerful emotions which arise.

Watch for use of defense mechanisms; while important to self-preservation, they may hinder our ability to meet the needs of bereaved parents. Finally, consider seeking professional supervision—to better understand interactions in the group as well as your own feelings and reactions.

References

1 Lewis E, Page A (1978). Failure to mourn a stillbirth. *British Journal of Medical Psychology*, 51: 237-241.

2 Stack J (1982). Reproductive causalities: Effects on families and professional caregivers. *Seminars in Family Medicine*, 3(2): 98-104.

Special Project Fund

Manual Now Available

Support Group Manual—A Training Manual for Conducting Support Programs for Parents Who Have Interrupted Pregnancies Secondary to Fetal Anomalies was written by Kathleen Delp and Molly Minnick with support from a grant from the NSGC Special Projects Fund. The 60 page manual comes complete with sample handouts, resource materials and information needed to facilitate a support group. Published by Pineapple Press, 10% of the manual's proceeds will be returned to NSGC.

To order, send $14.95 plus $3.50 shipping and handling to:

Pineapple Press
PO Box 312
St. Johns MI 48879
Phone: 517-224-1884

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Medical Staff Privileges: Professional Identity & Influence

What is a Medical Staff?

A hospital medical staff is a group of health care providers, usually physicians, who have been granted the authority by a governing body, typically the Board of Trustees, to provide medical care and other duties as specified in the hospital bylaws. Medical staff membership entitles the health care provider to vote on issues affecting medical staff, serve on medical staff committees and run for medical staff office.[1,3,7]

Medical Staff Committees Influence Policy

An important benefit of medical staff membership is the right to serve on the committees that set and monitor many hospital policies. Medical staff committees may address standards for patient care and quality assurance; review ethical conduct and professional practices; allocate resources; and create training opportunities, possibly even training programs for genetic counselors.[1,2]

Genetic Counselors & Staff Membership

A health care provider must apply for clinical privileges before practicing in a hospital—this may or may not include medical staff membership. Eligibility for staff membership is determined by state law and hospital bylaws. In some states, membership is restricted to physicians and osteopaths; in others, a broader definition of "practitioner" allows institutions to extend membership to nonphysician providers.

When medical staff membership is not available, genetic counselors may still be eligible to join a professional affiliate staff or an allied health staff. Members receive clinical privileges, but generally cannot vote, hold office or serve on medical staff committees.

Nonphysicians Struggle for Staff Membership

Genetic counselors are not the only health care providers with limited access to medical staff membership—other nonphysician providers have lobbied for privileges for years.[4,5,7] Some state laws now require hospitals to offer staff membership to certain health care providers, like psychologists or chiropractors, especially if they are independent practitioners who need medical staff membership to practice their specialty.[4]

In 1984 the Joint Commission on Accreditation of Healthcare Organization (JCAHO) relaxed its definition of types of health care providers eligible for medical staff membership. Despite changes in state laws and JCAHO standards, nonphysician representation on medical staffs remains limited. A 1984 survey found that fewer than 40% of medical staffs extend voting privileges to nonphysician practitioners, with similar restrictions on committee membership.[6]

Pursuing Medical Staff Privileges

Hospital-based genetic counselors should inquire about the possibility of becoming medical staff members to take advantage of the opportunities membership offers. To do so:

■ **Obtain a copy of the medical staff bylaws.** Bylaws specifically define medical staff functions and delineate whether nonphysician providers are considered members of the medical staff. If ineligible for medical staff affiliation, the bylaws usually address provisions for nonphysician providers to join an allied health or professional staff.

■ **Speak with a representative from the medical staff office.** Learn if genetic counselors or other nonphysicians are eligible for medical staff membership. Psychologists are an analogous professional prototype to use as a guide to eligibility.

■ **Challenge existing restrictions.** Become knowledgeable about state laws and hospital bylaws pertaining to the rights and privileges of nonphysicians. In some cases, statutes or regulations must be amended before genetic counselors are eligible for medical staff membership.

■ **Explore other openings.** Even if not eligible for staff membership, genetic counselors may be able to attend medical staff meetings or serve on staff committees by special appointment.

References

1 1994 Accreditation Manual for Hospitals, Joint Commission of Accreditation of Hospitals, Medical Staff. Vol 1 MS.1-MS.6.2 65-84.

2 Litwin WJ, Boswell DL, Kraft WA (1991). Medical staff membership and clinical privileges: A survey of hospital-affiliated psychologists. *Professional Psychology Research & Practice.* 22: 322-327.

3 McDonald, MG, et al (1991). "The Medical Staff." in *Health Care Law: A Practical Guide*, 6th edition. New York, NY: Mathew Bender; S15.01-S15.05.

4 Middleton M (1984). Now, antitrust meets medicine; hospitals and doctors face more suits. *National Law Journal*: 1-6.

5 Morris, C (1993). Medical staff membership: An elusive privilege for physician assistants. *Physician Assistant,* 17(1): 99-106.

6 Morrisey MA, Brooks DC (1985). The expanding medical staff: Nonphysician practitioners. *Hospitals*, 59: 58-59.

7 Smith JW (1991). "Hospital Organization Structure." in *Hospital Liability, 11th release.* New York NY: Law Journal Seminars Press; S1.02-S1.04.

Get excited about 1996; start planning for 1997!

DNA: The New Frontier 1997 Annual Education Conference

Planning is underway for an exciting and stimulating conference in Baltimore, October 25-28, 1997. Our focus will be the practical applications of DNA/molecular genetics in today's dynamic and changing environment.

Please join us in shaping the conference: contact the chair of the committee that interests you. If you can, attend the 1997 Annual Education Conference Planning Meeting during this year's conference in San Francisco. Not quite sure where you fit in? Contact one of us—we will be happy to help channel your energy where it's needed! Call a committee chair soon; they are already gathering ideas and would like to include yours!

Program Committee selects and makes arrangements for plenary speakers who fit the theme of the conference.
CHAIR: Linda Robinson, MS, 510-883-6027

Symposia Committee identifies expert speakers to give in-depth presentations on a theme-related topic.
CO-CHAIRS: Lavanya Misra, MS, 212-523-3112 &
Dawn Allain, MS, 312-633-7768

Workshop Committee arranges interactive discussions on practical applications, led by NSGC members.
CHAIR: Vivian Weinblatt, MS, 215-955-4295

Abstract Committee reviews and selects abstracts submitted for presentation or poster.
CHAIR: Laura Thomson, MS, 315-464-7610

Communications Committee develops conference publications, particularly the registration brochure and program book.
CHAIR: Ellen Eisenbraun, MS, 617-667-7110

Media Center Committee gathers and displays materials in various formats—written, slides, videos, etc.—from relevant organizations.
CHAIR: Rhonda Schonberg, MS, 202-806-6329

Logistics Committee makes arrangements for the conference special/social event and serves as a local resource for transportation, weather and sites of interest.
CO-CHAIRS: Cathleen Escallon, MS, 410-955-3091 &
Julie Rutberg, MS, 410-955-3071

We look forward to hearing from you!

Cindy Soliday, MS, 510-795-9478
Barbara Pettersen, MS, 408-972-3311
Conference Co-Chairs

Job Status Update

Graduates Are Finding Jobs

I recently surveyed genetic counseling graduate programs—21 in the US and 1 in Canada—to better understand the current job market and how it compares to 1994. Here's what I discovered:

- 20/22 programs responded to the survey. Four programs are new and have yet to graduate students into the work force.
- In 1994, there were 107 graduates from 18 programs; 97 of them—91%—secured jobs in the field within 6 months of graduation.
- In 1995, 80 of 100 graduates from 17 programs—80%—found jobs within 6 months. (Michigan was excluded from this sample because they do not graduate in Spring or Summer.)
- 140 students have been accepted into 20 programs to begin their education Fall 1996.

I asked program directors if they felt there is a real job shortage: 10 said "no," 5 said "yes," 3 were unsure. Many qualified their answers, stating there may be fewer jobs than we are used to but not a true *shortage.* There is general consensus that job market changes dictate new job seeking strategies—students must be flexible, creative and should network more.

Can NSGC help? Many directors agreed NSGC should take an active role in marketing our profession and re-evaluating our skills to take advantage of new opportunities.

A number of years ago, Beverly Rollnick said, "The future holds much promise." As a program director, I believe this remains true.

Bonnie LeRoy, MS
Minneapolis MN

Board Prepares for Exam and Program Accreditation

The Credentials Committee reviewed 369 applications for this year's certification exam. Results of the June 26 test will be available to examinees in October.

Modifications to the 1999 logbook form will be developed during the summer and should be available at the NSGC Annual Education Conference in the fall.

Recertification Options to be Considered

Most specialty boards have developed some mechanism of recertification to ensure the continued competence of their members. As 1996 will be the first time-limited exam for genetic counselors, the Board will be exploring options for recertification in more detail over the next year.

Review of Training Programs Continues

Major activities of the Accreditation Committee during the past six months have included the review of training program annual reports, development of the full accreditation self-study document and processing of *ad hoc* site applications.

Recent Grads Taking Exam

The Credentials Committee is interested in any opinions from the 1996 graduates regarding the benefits/drawbacks of being able to sit for this year's exam. Send comments to the Administrative Office, address below.

Virginia Corson, MS
President, ABGC

☛American Board of Genetic Counseling
9650 Rockville Pike
Bethesda MD 20814-3998
FAX: 301-571-1895
EM: srobinson@abgc.faseb.org

Recertification Concerns Voiced

■ *n April, 73 genetic counselors wrote to NSGC Education Committee Chair, Jill Fischer, expressing concerns about the upcoming decision by the American Board of Genetic Counseling on recertification requirements. Noting the far-reaching consequences for our profession, they proposed that NSGC develop a position statement on this issue. Excerpts from the letter follow:*

...We have learned that the ABGC is considering a policy which would require counselors who sit for the boards during and after the 1996 cycle to retake this examination every ten years. We also understand that those who passed the boards before 1996 may be grandfathered out of this policy. We strongly disagree with this proposed policy for several reasons. First, the board examinations are extremely expensive, time consuming and are only offered every three years in four locations in the United States. As indicated in the NSGC 1994 Professional Status Survey, only 30% of counselors are being completely reimbursed for these significant expenses. For many, the board exams represent a considerable hardship of both money and time, for which we are not being reimbursed. This situation will only escalate if we have to sit for the boards every ten years. It is unlikely that in this age of health care reform our institutions will be willing to absorb these major expenses, or that we will receive raises each time we repass the boards.

We foresee that not all will agree to retake these exams every ten years. This is especially true for those counselors in established positions who may derive little or no benefit from retaking the exam and for the increasing number of counselors who have specialized in one area. This could cause splintering in our profession between those who are certified for life, those who were once certified but have chosen not to recertify, those who do recertify and those who have never been certified....

We understand that some system of checks and balances is necessary to maintain high standards within our field. We believe continuing education units for our entire society...would be a more effective, feasible and fair method of maintaining these standards....

■ *Portions of Jill Fischer's response—written after discussion with NSGC's Board of Directors and the ABGC—are published below. ABGC President Virginia Corson will address the concerns in the next issue of* ***Perspectives.***

...Thank you for the letter....We encourage and welcome input from our colleagues. As NSGC members, it is appropriate to contact our Board of Directors with concerns; however NSGC does not make the decisions regarding recertification. These decisions are made by the ABGC..... Currently, the main focal points of the ABGC are accreditation of training programs and the board exams. Recertification will be a focus of the ABGC after the Fall of 1996. Reexamination appears to be an option, but continuing education units, as are being defined by the NSGC, are another option....

Bulletin Board

Call for Papers

The Center for Biomedical Ethics at the University of Minnesota seeks papers for a conference November 1-2 in Minneapolis to assist clinicians, policymakers and health industry leaders in improving end-of-life care in managed health care systems. The authors of selected papers receive honoraria and may have travel expenses paid.

☛Submit papers by **August 1** to: Candace Holmbo, Center for Biomedical Ethics, Suite 110, 2221 University Ave SE, Minneapolis MN 55414. EM: holmb006@maroon.tc.umn.edu

It's Time to Revise the NSGC Directory

If you've been assigned a new area code or have other changes that should appear in the next NSGC membership directory, please fill out the form at the back of the current directory (page 78) and fax it to the Executive Office.

Genetic Disease Web Site

Check out a new home page devoted to rare genetic diseases in children. Highlights include a comprehensive resource directory and linkage to other disease specific web sites: http://mcrcr4.med.nyu.edu/~murph01/homenew.htm

Ethics Subcommittee Seeks Cases, Consults, New Members

■ Have you had predicaments with labs, Children's Protective Services referrals, or philosophical differences with other health professionals? The Ethics Subcommittee seeks cases fitting the theme "Dealing with Other Disciplines" for the Difficult Dilemmas Workshop at the Annual Education Conference. You do not have to attend to submit a case.

■ The Subcommittee has openings for two new members to serve a three year term starting fall 1996. Candidates must be full NSGC members, able to attend the next three Annual Education Conferences and should have pertinent interest/experience. Submit a letter of intent and current CV.

■ Contact any Ethics Subcommittee member for confidential consultations on ethical issues confronting you or your institution. Consults can clarify the counselor's role as outlined by the Code of Ethics. This committee does not serve as a regulatory or punitive board.

☛For more information, contact Ethics Subcommittee Chair, Karen Eanet, MS, Division of Human Genetics, 22 South Greene Street, N6E10, Baltimore MD 21201, 410-328-3335, FAX 410-328-3379, EM: KARENE@genetics.ab.umd.edu

At October's Annual Education Conference

■ The Neurogenetics Short Course is filling up fast. Register soon to ensure your space!

■ Do you need to schedule a room for an ancillary meeting at the

Upcoming Meetings

July 14-19	"Midwest Intensive Bioethics Course,"from the Center for Biomedical Ethics, Minneapolis MN. Contact: 612-626-9756
July 23-25	"Williams Syndrome: Biology, Medicine and Behavior," 7th Annual Professional Conference on Williams Syndrome, King of Prussia PA. Contact: 215-590-5CME
Aug 6-11	1996 Fragile X Conference, Portland OR. Contact: The National Fragile X Foundation, 800-688-8765
Aug 18-23	9th International Congress of Human Genetics, Rio de Janeiro, Brazil. Contact: Congress Secretariat 011-55-21-286-3536
Sept 26-28	Tuskegee Univ Conference on the Human Genome Project, Tuskegee AL. Contact: 334-727-8028 or EM: edsmith@Acd.Tusk.edu
Oct 21-24	3rd International Meeting of the Society for Neonatal Screening, Boston MA. Contact: Travel Vision International, 617-647-5530
Oct 26-28	NSGC 15th Annual Education Conference, San Francisco CA. Contact: 610-872-7608, #6, or NSGC@aol.com
Oct 28	International Society of Psychiatric Genetics Symposium, San Francisco CA. Contact: Lynn DeLisi, Dept Psychiatry, SUNY, Stony Brook NY 11794-8101
Oct 28-29	"Genetic Testing for Huntington's Disease Workshop," from the Foundation for the Care and Cure of Huntington's Disease, San Francisco CA. Contact: Liz Mueller, 908-739-5621, EM: emueller@monmouth.com
Nov 7-10	"Perinatal Care: Recent Advances and Future Challenges," National Perinatal Association Annual Clinical Conference, Nashville TN. Contact: 813-971-1008 or EM: npaonline@aol.com

Bulletin Board

San Francisco Conference? Contact the NSGC Executive Office, 610- 872-7608, #8, by **August 1.**

Alliance of Genetic Support Groups Gala

The 10th Anniversary Benefit Gala honoring Joan Weiss, MSW, founder and Executive Director of the Alliance, will be held October 12 in Washington DC. Dr. Victor McKusick and Judy Woodruff of CNN are chairing the awards gala. Tickets are $125 each. A Membership Meeting and Computer Workshop will be held the afternoon of October 12.

☛Contact: The Alliance of Genetic Support Groups, 800-336-GENE, EM: alliance@capaccess.org

Get MMWR by E-mail

CDC's Morbidity and Mortality Weekly Report is now available electronically. It provides information about epidemics, environmental hazards and public health issues—including several recent articles on birth defects and prenatal diagnosis. To receive the weekly table of contents and get instructions for downloading articles, send an e-mail message to lists@list.cdc.gov. In the body of the message type subscribe mmwr-toc.

Materials Available

■ The National Center for Human Genome Research has concise fact sheets on NCHGR, ELSI, genetic mapping and other topics. Contact the NCHGR Communications Office, 9000 Rockville Pike, Bldg 31, Room 4B09, Bethesda MD 20892, 301-402-0911 or http://www.nchgr.nih.gov.

■ "Understanding Genetic Testing," a new booklet from the National Cancer Institute, contains simple color illustrations and covers the relationship between genes and cancer, predictive testing and

Research Network

Tuberous Sclerosis Complex

A research team at the Genetic Research in Inherited Disorders (GRID) Program at the Massachusetts General Hospital is conducting research on Tuberous Sclerosis Complex—performing linkage and mutation analysis of the TSC2 gene (chromosome 16) and working to locate the TSC1 gene (chromosome 9). The lab needs blood samples from families in which one or more members has been diagnosed with TSC (both familial and sporadic cases).

☛For more information, contact Pamela Cohen, MS, GRID Program, Molecular Neurogenetics Unit, 6th floor, Massachusetts General Hospital Bldg, 149 13th St, Charlestown MA 02129; 617-724-2365, FAX 617-726-6982, EM: cohen@helix.mgh.harvard.edu

New Registry for Anticonvulsants

The Antiepileptic Drug (AED) Pregnancy Registry is the first North American registry for pregnant women taking anticonvulsants—old drugs or new, monotherapy or polytherapy. Women or their care providers can call for free educational materials. Follow-up information on infants born to women enrolled in the registry will be analyzed to assess fetal risks. The Registry is in the Genetics and Teratology Unit at Massachusetts General Hospital; staff include specialists in public education, genetics, epilepsy and epidemiology.

☛For more information, contact Kelly Huntington, 617-726-1742, FAX 617-724-1911. Toll free AED Registry line: 1-888-233-2334

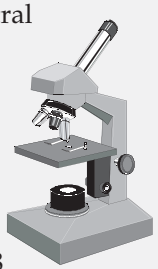
Beckwith-Wiedemann & Overgrowth Syndromes

Dr. Rosanna Weksberg has a longstanding interest in Beckwith-Wiedemann, Simpson-Golabi-Behmel and other overgrowth syndromes. Current studies in her lab include molecular analysis of chromosome 11 for BWS and mutational analysis of X for SGB.

☛For more information, contact Cheryl Shuman, 416-813-7550, EM: cshuman@sickkids.on.ca, or Dr. Weksberg, 416-813-6386, Hospital for Sick Children, Dept of Genetics, 555 University Ave, Toronto Ontario Canada M5G 1X8

Disorders on Chromosome 7

Dr. Steve Scherer is interested in samples from patients with disorders mapped to chromosome 7, such as EEC syndrome, split hand/split foot, Smith-Lemli-Opitz syndrome, sacral agenesis, holoprosencephaly, Russell-Silver syndrome and Pendred syndrome. He has markers spanning the entire chromosome.



☛ For more information, contact Dr. Scherer at 416-813-8140, FAX 416-813-4931, EM: steve@genet.sickkids.on.ca, Dept of Genetics, R 9102, Hospital for Sick Children, 555 University Ave, Toronto Ontario Canada M5G 1X8

E-mail/FAX Poll

BRCA1: Are You Ready for Clinical Testing?

THE QUESTION:
A commercial lab recently offered BRCA1 testing as a clinical service, targeting patients at high risk because of family history and/or ethnic background. Should testing be available to all women or limited to research protocols?

■ Kaiser Permanente is currently developing a clinical practice guideline for BRCA1 testing. We are evaluating testing's impact on health outcomes, including reduced chances of getting or dying of cancer and the effect of medical/surgical interventions. The guideline will emphasize the need for appropriate genetic counseling including an in-depth presentation of ethical, legal and social implications of testing. A confidential patient registry is being set up to ensure long term follow-up of high risk women.

Kermit Anderson, MS
Pasadena CA

■ I counsel women with a family history of breast cancer as part of two ELSI-funded grants. I think genetic testing for breast cancer should be kept within the realm of research protocols because:

• BRCA1 test sensitivity and specificity are not adequate; BRCA2 testing has not been developed.

• Social and psychological effects of testing are not yet known; insurance issues must be resolved.

• The predictive value of a positive test is not clear.

• The efficacy of screening and prophylactic surgery is not known.

• By confining testing to research studies, families are more likely to be given adequate counseling, Yet there should be more opportunities for families to participate in research.

Julie Bars, MS
Seattle WA

■ BRCA1 testing should be done in high risk families within research protocols. Counselors should encourage team members who are considering offering testing to do so within a study that includes behavioral counseling research. We all stand to gain valuable information about BRCA1 test results and their impact that will shape the future of cancer genetic counseling.

Barbara Biesecker, MS
Bethesda MD

■ The debate surrounding cancer predisposition screening really is about who gets to make the decision regarding testing. If access to testing is denied, whether by outright refusal to offer testing or by arbitrarily defining parameters limiting when it is or is not valid to offer testing, then the right of patients to make informed, autonomous decisions has been revoked.

Genetic testing should be performed with appropriate pre- and post-test counseling and informed consent. To deny appropriately counseled patients access to information about themselves is paternalistic and hypocritical. As a patient, Joy Simha, wrote in the *New York Times*, "Who are they to tell me that knowing the results could do me more harm than good?"

Lee A. Fallon, MS
Shirley L. Jones, RN, MS
Emilie A. Cummings, MS
Cindy Becchi, MS
Suzanne Holowinsky, MS
Fairfax VA

■ I think testing should be offered to all interested women, on the condition that appropriate counseling is done. I disagree with selling tests by mail, but I think if Jewish women want testing and we can explain the limits of the test, it should be available, just like other genetic screening tests.

Jamilyn Daniels, MS
Seattle WA

■ Genzyme Genetics currently does not offer BRCA1 testing. Our clinical trials laboratory is working with academic collaborators to help establish responsible clinical testing protocols.

Judith King
Framingham MA

■ I don't think testing should routinely be offered to all women; we should emphasize that testing is most useful at this time in women with a family history or unusually early cancer onset. Affecteds need to be tested first to confirm a mutation in the family.

The reality is that these tests are now available, like it or not. It 's best that genetic counselors are involved to make sure tests are used appropriately, patients give informed consent and results are interpreted accurately.

Ellen Matloff, MS
New Haven CT

...Clinical Research Trials versus Access to Testing

■ Testing should not be offered to all Ashkenazi Jews regardless of meeting high risk criteria. We are uncertain about specificity and sensitivity and how to provide appropriate follow-up. The Consortium for Breast Cancer Testing *has not* published their findings yet. I believe BRCA1 testing should be offered under experimental guidelines (IRB protocols).

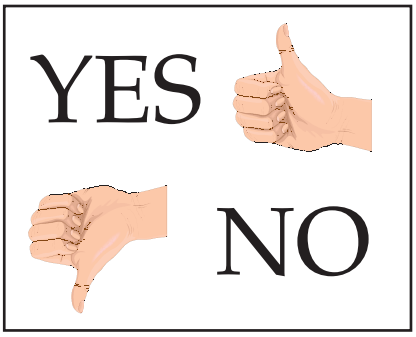
Ilana Mittman, MS
Baltimore MD

■ Why is there such a rush to test when so little data exist but when the promise of more data is so shortly forthcoming? Since we are doing clinical trials of the sensitivity, efficacy and safety of BRCA1 testing, it is appropriate to wait for findings. This data can be used to develop community standards of practice and educate physicians about how and when to offer testing. The medical community is used to the idea of clinical trials—for new drugs, for example. I don't think BRCA1 testing should be regarded differently.

To test for only one mutation in a Jewish woman with no cancer history herself is not state of the art when three common mutations are known in the Jewish population. It is not sufficient to tell her "a negative test is uninformative and a positive test is likely to be informative." It would be better to quote actual probabilities based on her family history and test results. Even with a strongly suggestive family history, I am still swayed to wait by the 50% chance that she will test negative.

Until we have full data, I believe testing should be provided only if it is comprehensive and only in the context of genetic counseling. Offering incomplete testing to a worried, unaffected woman is to avoid managing her anxiety. Instead, I suggest saying, "The test is investigational right now and is in clinical trials; it will be available to you once we can better interpret these tests and understand how individuals use and cope with this information."

Beth N. Peshkin, MS
Washington DC



■ I think BRCA1 testing should be limited to research or IRB protocols until we have more information on the impact of testing and on potential genotype/phenotype correlations. It is extremely difficult to counsel patients about the ramifications of a particular mutation without good outcome data on a large group of individuals with the same mutation.

Barbara Pettersen, MS
San Jose CA

■ At this point, I feel that offering BRCA1 testing as a clinical service is a bit premature. Testing should continue to be offered within research protocols so some very critical issues can be considered—for example, the cancer risk for an individual carrying a BRCA1 mutation in the absence of a family history. There are currently no standard recommendations for screening or preventing cancer in a woman with a known mutation. The social and psychological ramifications are still unknown. The capability to test also generates an ever increasing demand to educate physicians about the use and implications of genetic testing for hereditary cancer. Furthermore, legislation should be put forth to protect individuals who have testing from both insurance and employment discrimination.

Jeri Reutenauer, MS
Washington DC

■ Testing should be limited to protocols that include thorough pre-and post-test counseling, often not available through commercial testing centers. Until we know more and the public is better informed, caution must be exercised in offering testing to all women. I'm afraid we're opening Pandora's box.

Kathryn Spitzer Kim, MS
Waltham MA

■ I think we should really have resources in place before any of these new DNA tests start to be commercially available.

Janice Stryker, MS
Boston MA

■ I believe clinical testing for BRCA1 can be performed in a clinical setting with appropriate counseling so the limitations of the technology can be explained to the consultand. My approach is to use three counseling sessions spanning an average of six months. The first is general cancer genetics, pedigree documentation and request for pathology. The second is refined risk assessment, further testing discussion and blood drawing. The third is post-test counseling with continued follow-up by phone or correspondence.

Gail Vance, MD
Indianapolis IN

Survival Skills for Genetic Counselors

The Jane Engelberg Memorial Grantwriting Seminar

The Jane Engelberg Memorial Fellowship sponsored a grantsmanship seminar this February 7-9, funded by a grant from the Engelberg Foundation to NSGC and hosted by the Biological Sciences Curriculum Study in Colorado Springs. Twenty-two genetic counselors successfully competed for the opportunity to attend the skills-based seminar, facilitated by Judith Benkendorf.

Selected for their expertise and respect for genetic counselors, the faculty were given clear objectives for conducting both didactic and small group sessions delving into these topics: identification and development of a research question (Beth Fine, MS), qualitative methods and evaluation (Diane R. Beeson, MA, PhD), quantitative methods & evaluation (Karen Glantz, MPH, PhD), informed consent, institutional review boards and other ethical issues in research (Mary Ann Cutter, MA, PhD) and skills for effective grant writing (Pamela Van Scotter, MS).

Sharing Research Pearls

Complementing formal presentations were personal accounts of the trials, tribulations and successes inevitably experienced in the process of becoming recognized researchers. Here are some of these research "pearls":

■ **Learn to work "smart."** When setting up any new clinical or educational program, identify applicable research questions and design the program to collect research data.

■ **Look to your daily activities for potential research projects**. Clinical cases may generate unanswered questions; journal articles may inspire opportunities for further investigation.

■ **Translate clinical skills into research skills.** Research protocols can be developed to test counseling hypotheses arising from clinical observations and psychosocial data.

■ **Publish clinical observations and descriptions of innovative programs.** Articles in professional journals help you carve out a niche, establish your expertise, demonstrate longstanding interest in a particular area and provide citations for grant proposals.

■ **Network, network, network!** Visit your institution's sponsored programs office to learn about funding sources and technical support for grant preparation. Contact ethicists, behavioral scientists and science writers. Multidisciplinary collaborations enhance a grant's scope and appeal. As a hot research area, genetics should be of interest to colleagues in related fields.

■ **Select advisors, collaborators and consultants carefully.** Don't include every possible expert in your proposal lest none are left to serve on the study section reviewing your grant! Allow time to seek outside input and critical review of your proposal.

■ **Think of your grant as a dream you wish to market.** Write it clearly, succinctly and with conviction.

■ **Remember, first grants do not have to be huge, they only have to be funded.**

The seminar provided one-on-one consultation with faculty and networking among participants. Evaluations were extremely positive—attendees left with enthusiasm, motivation and momentum for conducting funded genetic counseling research. We recommend conducting similar seminars in the future and thank Alfred B. Engelberg for his continued generosity and commitment to the advancement of our profession in memory of his wife, Jane.

Judith L. Benkendorf, MS
Founding JEMF Advisory Board

Audrey Heimler, MS
Chair, JEMF Advisory Board

CORRECTION: Joseph McInerney, MS, was inadvertently omitted from the list of JEMF Advisory Board members in the last issue.

Letter to the Editor

Professional Support at Grantsmanship Seminar

Participating in February's JEMF Grantsmanship Seminar provided us with new sources of energy. The faculty had tremendous respect for the work of genetic counselors and was incredibly supportive; it was invigorating to spend a concentrated period of time learning from other counselors with similar goals and interests.

As members of the committee responsible for developing the NSGC Code of Ethics, we can think of few professional experiences that better exemplify the spirit of mentoring and peer support set forth in Section III (especially III.1) of the Code. In that same spirit, we encourage all who attended to share this new knowledge and enthusiasm, and to foster collaborations formed at the seminar. We are grateful to Alfred B. Engelberg and the JEMF Advisory Board for providing this opportunity.

Judith L. Benkendorf, MS
Washington DC

Susan Schmerler, MS, JD
Paterson NJ

ADS

national society
of genetic
counselors, inc.

nsgc

233 Canterbury Drive • Wallingford PA 19086-6617

Student Corner

Student Thesis Projects

Congratulations to the 1996 graduates! Here is a sampling of research interests in this year's graduating class.

California State University, Northridge

For more information about these projects, contact the authors through the CSUN Genetic Counseling Program Office, 818-885-3355.

Melody Naghmeh Kohan: "21-hydroxylase deficiency: A form of congenital adrenal hyperplasia"

Danielle LaGrave: "Homocystinuria occurring with pneumothorax: A case report"

Tressa Padellford: "Misconceptions about multiple-marker screening among prenatal health care providers"

Angela Grace: "Fragile-X testing at a clinical genetics center"

Cheryl Ikeda: "Identification of mutations in two individuals with Emery-Dreifuss muscular dystrophy"

University of California, Irvine

For more information, contact the UC Irvine Genetic Counseling Program, 714-456-6873.

Jennifer Ann Cato: "Amniocentesis: Are the risks of the procedure related to the indication?"

Kristin A. Kalla: "Hard of hearing and deaf: Knowledge and interest in genetic counseling"

Amy B. Keglovits: "Dermatoglyphics and cleft lip: An evaluation of the Chinese population"

Selvi Palaniappan: "Segregation distortion in humans"

Resources

Support Groups

Androgen Insensitivity Syndrome (AIS) Support Group USA

c/o Sherri Groveman
4203 Genesee Ave #103-436
San Diego CA 92117
619-569-5254
EM: aissg@aol.com

Peer support for adults with partial or complete feminization resulting from defective androgen receptors; the group also serves parents of affected children. With 100+ members worldwide, they publish three newsletters annually, offer reprints of articles of interest and hold regular meetings.

Stickler Involved People

c/o Bill & Pat Houchin
53 Angelina
Augusta KS 67010
316-775-2993
EM: houch@southwind.net

A network to educate and give support to those affected by Stickler syndrome.