nsgc

PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 14, No. 2 **Summer 1992**

NEW CF PUBLICATION FOR PATIENTS AVAILABLE

The NSGC is pleased to announce the publication of "Genetic Testing for Cystic Fibrosis: A Handbook for Families," a companion to "Genetic Testing for Cystic Fibrosis: A Handbook for Professionals." Members interested in previewing or ordering copies are invited to use the postcard enclosed with this newsletter.

The NSGC expresses gratitude to the committee for their outstanding efforts on the two projects: Becky Anderson, Karen Albiez Brooks, Amy Lemke, Wendy Uhlmann and Kathy Valverde.

in this issue...

The NSGC acknowledges Integrated Genetics' support of this issue of *Perspectives*

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INFORMATION TO IMPACT YOUR CAREER

DELIBERATION, DECISION AND DATA

REVIEW AND UPDATE ON ABMG STATUS

by the Restructuring Committee

A formal proposal to restructure the American Board of Medical Genetics (ABMG) will be presented to ABMG diplomates later this year. The proposal will call for the revision of the ABMG bylaws to reflect the fact that the board will no longer certify Master's level genetic counselors. At the same time, counseling diplomates will be asked to ratify bylaws for an autonomous board (American Board of Genetic Counseling, or ABGC) that will certify *only* genetic counselors.

REVIEW OF INITIAL ACTIVITIES

As explained in *PGC* 14:1, p.7, and in a recent letter to diplomates by ABMG President Anne Spence, PhD, this proposed change is necessary for recognition of the ABMG by the American Board of Medical Specialties (ABMS) which stipulates

continued on page 2, col 1

NSGC IS NOT GOING TO NEW ORLEANS

by Bea Leopold, Executive Director

The Board of Directors of the NSGC voted on May 2 to relocate the 12th Annual Education Conference from New Orleans, Louisiana to an alternate site. This decision was based on Louisiana's legislation which severely restricts reproductive freedoms in that state.

The NSGC joins a growing number of other professional health organizations refusing to convene in Louisiana, among them, the Society for Neuroscience, American College of Obstetricians and Gynecologists, American Public Health Association and Endocrine Society.

In their deliberations, the Board considered both the NSGC's 1987 Resolution in support of reproductive freedom, including the right to prenatal diagnosis and access to safe and legal abortion, as well as

continued on page 6, col 1

REPORT TO MEMBERSHIP: 1992 PROFESSIONAL STATUS SURVEY

Every two years, genetic counselors take time out to evaluate our professional roles. The results of past Professional Status Surveys have been used to negotiate salaries, faculty status and other benefits. While this survey is sometimes perceived as the "salary survey," the results are also important for tracking our changing responsibilities and professional growth. As the genetic counseling profession continues to grow, the task of developing a survey that accurately reflects our roles becomes more difficult. Interpreting the survey information is also a challenge because several factors may influence a particular result. Salaries, ABMG benefits, faculty status, publications, professional activities and job satisfaction will be the focus in this issue of *PGC*. Other results from the survey will be presented at the 1992 Annual Education Conference in San Francisco and will be submitted to the *Journal of Genetic Counseling*. If more specific information from the survey is needed, contact the Professional Issues Committee.

— **Wendy R. Uhlmann, M.S., Chair, Professional Issues Committee**

Your Vote on ABMG Restructuring...

from p. 1

that the ABMG *cannot* certify non-doctoral level genetic professionals.

Convinced that ABMS recognition of medical genetics as a specialty would result in important opportunities for everyone involved in the field, an ABMG ad hoc Restructuring Committee designed a plan that would advance the interests of all members of the ABMG. Members serving on the committee are listed at end of this article.

After an initial meeting in Philadelphia in March, the group proposed that the ABMG separate into two distinct new boards; one for genetic counselors and one for doctoral-level geneticists. These two boards were to be connected by a liaison committee, and neither was to retain the ABMG name. However, when this idea (dubbed the Philadelphia Plan) was introduced to the ABMS by the ABMG's attorney, the concept was rejected. The ABMS would allow neither a formal liaison between the two boards nor the proposed name change for the doctoral-level board.

Contingency Plan Developed

Disappointed by this rejection, the counselors on the Restructuring Committee met again in June at Asilomar to prepare Articles of Incorporation and bylaws for a proposed American Board of Genetic Counseling. Policies and regulations governing the accreditation of genetic counseling training programs, credentialing ABGC candidates and the examination process were deliniated. They also examined ABMG's finances to ensure that the assets would be divided in such a way that the fiscal health of both boards would be assured.

These restructuring steps were taken with the assumptions that

- no alternative arrangement would be acceptable to the ABMS, and
- if the ABMG membership voted to exclude genetic counselors, an alternative structure would need to be in place to preserve counselors' status.

The committee approached it's duties knowing that, to satisfy the timetable dictated by ABMS, a vote was imminent.

A Primer of Practical Concerns for Genetic Counselors

- ***What will happen to current ABMG certification?***
  It will remain in effect. It was rightfully earned and *cannot* be rescinded.
- ***What impact will this have on the 1993 exams?***
  Candidates who apply for the genetic counseling section of the ABMG exams in 1993 will have their application transferred to ABGC for determination of eligibility. The transition will be nearly imperceptible. If restructuring does *not* occur, status quo will be maintained for the exam.
- ***How would the exams be given?***
  There will be essentially no change in how the exams are administered. The general exams would be given at the same time, and at the same site, to all candidates of both boards, as it always has been. The specialty exam for genetic counseling would be written by genetic counselors and administered by the National Board of Medical Examiners. Each board would issue certificates to its own diplomates.
- ***How would entry to the ABGC be gained?***
  Current ABMG members holding certificates in genetic counseling would automatically become charter members. In the future, genetic counselors passing the ABGC certification exam would also become diplomates.
- ***Who will direct the proposed ABGC?***
  Plans call for the counselors on the restructuring committee, plus the counselor elected the ABMG Board of Directors this year, to form the initial ABGC Board of Directors. The bylaws will establish staggered terms of office that will provide for orderly replacement by elected officers.
- ***Who will establish accreditation criteria for training programs?***
  The ABGC.
- ***Would genetic counselors still be members of the ABMG?***
  No, new ABMG bylaws would exclude non-doctoral level members.

Directors Address Practical and Procedural Concerns

As the committee concluded its scheduled meeting, the participants of the NSGC-sponsored program directors' meeting was convening at Asilomar. Ann Walker, Chair of the Restructuring Committee and Director of the UC Irvine Genetic Counseling Program, took the opportunity to update the participants on the progress of the committee. The ensuing discussion was, as expected, lively, thoughtful and provocative. Answers were already available for several of the practical concerns. *(See sidebar, A Primer of Practical Concerns for Genetic Counselors.)*

Others questions dealt with

- the process the ABMG followed to gain ABMS recognition
- the degree to which the ABMS was pressed to allow the admission of Master's level counselors and
- the concessions proposed by the Philadelphia Plan.

Because of these concerns, Dr. Charles Epstein was asked to meet with the Asilomar attendees that Saturday. He emphasized the delicacy with which inquiries to the ABMS had to be made and verified that the ABMS was reluctant to provide written responses to questions. The ABMS also had cautioned the ABMG that approval was tenuous and a brief time frame to satisfy the requirements was allotted.

After the meetings, both Drs. Epstein and Spence investigated the possibility that an ABMS appeal process might allow recognition of counselors. Dr. Epstein learned that while a mechanism to petition for such an exceptional case exists, the process is a lengthy one. Furthermore, it was implied that it was

…An Informed Decision is the Best Decision

unlikely the ABMS would recognize counselors in the foreseeable future and the mere act of petitioning at this time could further damage the ABMG's newly won recognition.

Hopeful Chord Struck

However, on a more hopeful note, two significant actions have occurred since the Asilomar meeting.

- Council Initiated: ASHG proposed the formation of a Council of Medical Genetics Societies, initially composed of one representative from ASHG, ABMG, NSGC and the American College of Medical Genetics. The purpose of the Council would be to provide a forum for discussion and coordination among the major U.S. genetic groups. This council would be similar to, but more broadly constituted than, the liaison committee between the doctoral board and counseling boards proposed by the Philadelphia Plan, which had been vetoed by the ABMS. The presidents of the four organizations will meet in September to define the Council's mission.
- Postponement of Vote Requested: ABMG is considering postponing the restructuring vote until *after* the San Francisco meetings. This would give ABMG diplomates an opportunity to discuss these issues in an open forum, rather than be asked to vote on an issue of such paramount importance to this profession based on correspondence, telephone conversations and heresay. One roadblock is that postponing the vote causes a problem with the timeline for printing the 1993 exams although it is unlikely to delay the examination, itself. More importantly, delaying the vote would not satisfy the ABMS timeline.

Where Do We Go From Here?

The Restructuring Committee plans to meet in July to review legal counsels' comments on the proposed bylaws and Articles of Incorporation as well as the results of fiscal projections. Another meeting is scheduled in August to finalize information that will be submitted for action by the ABMG diplomates.

Dr. Spence has invited ABMG diplomates to contact her, ABMG Board members or Restructuring Committee members with questions or concerns. Now is the time to communicate. Writing or FAXing would provide a permanent record, but, for those who prefer, phone calls are an acceptable means of communicating.

Restructuring Committee Members and Fax Numbers

Member	FAX#
Ann Walker, Chair	714-456-5330
Diane Baker	313-763-3784
Debra Collins	913-588-3995
Charles Epstein	415-476-9976
Betsy Gettig	412-578-1587
Edward Kloza	207-883-1527
Joan Scott	916-733-1752
Ann C.M. Smith	703-758-0233
Anne Spence	714-725-2513

Commentary from the President

The actions of the ABMG have thrust genetic counseling diplomates into a complex situation:

Support restructuring and change the peer relationship we have enjoyed with our doctoral-level colleagues as members of the same certifying organization, or

Oppose restructuring and deny medical genetics the specialty status it deserves.

Either way, the relationship we share with our doctoral level colleagues will be forever changed.

The ABMG deserves credit for moving the field of medical genetics to its next logical step. Drs. Epstein and Spence, who orchestrated the application and are navigating this process through rocky waters, deserve recognition for their efforts on behalf of the ABMG.

The question is: *What is best for us as genetic counselors?*

ABMG diplomates who are NSGC members now have a vision of the future. Adopted by the Board of Directors in May and awaiting endorsement by our membership, it is: "The NSGC will be the leading voice, authority and advocate for the genetic counseling profession." Simply put, which course of action is most likely to bring us closer to this vision?

The establishment of an American Board of Genetic Counseling will provide a measure of autonomy that has only been discussed in the past. *Genetic counselors* will assume responsibility for certifying genetic counselors, accrediting training programs and writing the counseling exams.

Asking ABMG diplomates to decide on restructuring is like asking a couple to decide on a high-risk procedure. One partner may be more willing to take a risk than the other. I encourage ABMG diplomates to be deliberative in their decision making process: to take time to understand the risks as well as benefits, to talk with trusted friends and advisors, to search their value systems for guidance, to decide which alternative is consistent with *their* vision of our future.

As the doctoral-level ABMG diplomates sit poised on the threshold of new opportunity, Master's level diplomates are also being pushed toward the edge. Diane Baker, Past President of NSGC, referred to this concept in her presidential address in 1987. She quoted French poet Apollinaire:

> "Come to the edge," he said. / "We can't, we're afraid." / "Come to the edge," he said. / "We can't, we might fall." / "Come to the edge," he said. / And they did. / And he pushed them. / And they flew.

Is this the Edge for the Genetic Counseling profession? And if so, do we fly?

– Edward M. Kloza, NSGC President
June 22, 1992

CASE REPORT

When the Patient Doesn't Want to Know

Genetic counselors often deal with issues surrounding a patient's right to be given information. Equally important is the issue of a patient's right not to receive information (See companion article, p. 5)

It is common practice to withhold information about fetal gender upon patient request. However, it is not as clear how to handle other requests for partial amniocentesis results.

THE PROBLEM

Four days after her amniocentesis, VB called to say she was anxious about her results. She asked if we could limit the information we gave her about them. She requested knowing only those results that would indicate a severe abnormality or early death. We discussed the variability of certain chromosomal abnormalities and the possibility of ambiguous results. She stated that she had discussed the issue with her husband who also agreed not to be informed of ambiguous or non-serious chromosome abnormalities.

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Send case reports, resources, materials and books for review to appropriate editors; address changes, subscription inquiries and advertisements to Executive Director; all other correspondence to Editor-in-Chief.
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Our genetic team discussed VB's request for partial results and agreed that her request was reasonable. We felt that ethically she had the right not to know certain things about her fetus. Legally, we knew about our liability if the baby were born with or developed problems that could have been realized from those results. We drafted a consent form stating the conditions about which VB and her husband did and did not want to be informed.

THE ANSWERS

Specifically, VB requested to be informed in the case of trisomy 13, 18 and 21, true mosaicism for these trisomies or any chromosome abnormality that would result in neonatal or early childhood death, mental retardation, or major structural abnormalities. She declined to be informed of a fetal sex chromosome abnormality, an apparently balanced translocation, pseudomosaicism or any chromosome finding that would have unclear implications for the fetal outcome. She also declined to be informed if the AFP was elevated unless the acetylcholinesterase was positive. The consent form was approved for use by legal counsel and was signed by VB and her husband.

THE RESULTS

Five days later, VB was informed that the fetal chromosome analysis revealed a normal male karyotype and the AFP was within normal limits. She was informed that with greater than 99% accuracy, the fetus did not have Down syndrome or any other chromosome abnormalities that would result in neonatal or early childhood death, mental retardation or major structural abnormalities.

This case has set a precedent for how UCI Medical Center will handle future requests for partial amniocentesis results. I am interested in knowing how others have handled similar requests.

Denise M. Greene Simonsen, M.S.
UC Irvine Medical Center
Orange, California

STATEMENT OF INFORMED CONSENT FOR PARTIAL AMNIOCENTESIS RESULTS

We have discussed the range of chromosome abnormalities detectable by amniocentesis with ....*(name of Genetic Counselor)*.... and have requested to be informed only of certain fetal chromosome abnormalities. We wish to be informed in the case of trisomy 13, 18 or 21, true mosaicism for these trisomies, or any chromosome abnormality that would result in neonatal or early childhood death, mental retardation, or major structural abnormalities. We do not wish to be informed of a fetal sex chromosome abnormality, an apparently balanced translocation, pseudomosaicism, or any chromosome finding which has unclear implications for the fetal outcome. We do not wish to be informed if the amniotic fluid alphafetoprotein is elevated unless the acetylcholinesterase is positive. We wish for ....*(name of OB)*.... to be informed of the complete amniocentesis results. We understand that if we change our minds and wish to be informed of the complete results that we may do so.

We have read the above information and we understand it. Our questions have all been answered.

Patient's signature ....

Spouse's signature ....

Witnessed by .... Date ....

A SUCCESSFUL BLENDING OF GENETIC COUNSELING AND PSYCHOTHERAPY

The issue of how psychotherapy fits into genetic counseling is an ongoing challenge. We learned a great deal from the following case and felt that others might benefit from our experience. (Refer to Case Report, p. 3)

VB was a 36 year old G4P3 woman who initially declined amniocentesis in favor of MSAFP screening. She had a positive low MSAFP and elected to proceed with amniocentesis. VB requested partial results, wanting only to be informed of certain chromosome abnormalities. VB had additional anxieties which she stressed during her initial genetic counseling session and follow-up telephone conversations which provided ample clues that a psychotherapy referral might benefit her.

INDICATIONS FOR REFERRAL

VB was extremely distressed about her abnormal MSAFP results. In addition, she had marked ambivalence regarding acceptance of the pregnancy. It appeared as if her personally unacceptable feelings about the pregnancy were transformed into a fear of pregnancy loss. She alluded to the fact that she and her husband disagreed about whether having a Down syndrome child was acceptable. Social support was minimal. VB's anxiety continually shifted focus, beginning with her abnormal MSAFP result and then switching to fears of pregnancy loss and ambiguous or abnormal amniocentesis results. It seemed unusual that no direct contact was made with VB's husband, despite multiple invitations. Beginning four days after amniocentesis, VB called her obstetrician and genetic counselor repeatedly to complain of fluid leakage. Pelvic exams, repeat ultrasound and nitroside paper tests were negative.

REFERRAL PROCESS

Preparation: The benefits of therapy and the limitations of the genetic counseling role and setting were discussed. The therapy referral was normalized and actively facilitated by providing background information about the therapist, who, in this case, is also an experienced genetic counselor.

Confidentiality: Client confidentiality was respected by discussing with VB which information would and would not be shared with the therapist at the time of referral. The therapist was informed of the genetic counseling scenario as well as the counselor's concerns for the client's stability. Client/therapist confidentiality and its exceptions were also explained.

VB's privacy was honored by limiting the content of exchanges between genetic counselor and therapist.

> ***"We speculate that clients may selectively reveal themselves to genetic counselor and therapist."***

Coordination: The genetic counselor and therapist discussed and delineated their separate roles and set boundaries for areas of discussion, which were subsequently discussed with VB. VB's obstetrician's nurse was informed that this referral had been made and accepted.

PSYCHOTHERAPY

VB's psychological assessment confirmed her strong need for therapy. She was in crisis, at moderate suicidal risk and suffering from multiple symptoms of anxiety, depression and somatization. Additional long-standing problems included unresolved grief and guilt from a prior pregnancy termination, chronic depression, an unsuccessful job history and multiple dysfunctional primary relationships.

OUTCOME

Genetic: Chromosome analysis and AFAFP were normal, and the pregnancy continued to term.

Psychological: Suicidal risk decreased with structured social support, ventilation of angry feelings, grief counseling and use of a relational model of crisis intervention. As anxiety and depression decreased, self-esteem and assertiveness increased. VB ceased having the sensation of fluid leakage shortly after entering therapy. Her sleeping and eating habits improved and she returned to work within a few days.

CONCLUSIONS

The genetic counselor's recognition of the need for referral, the availability of a therapist familiar with genetic counseling issues and a carefully coordinated treatment plan provided successful resolution in this case. Psychotherapy can be of benefit when there are clinical signs of anxiety, depression, suicidal ideation or attempts, somatic complaints, a psychotic break with reality or impaired function at home, job or in relationships.

A striking feature of this case is the different perspectives on VB's personality and issues from genetic counseling and psychological evaluations. One example is the suicidal fantasy VB expressed to the therapist in response to questions about hypothetical ending of an affected pregnancy. This depth of feeling was not conveyed to the genetic counselor despite her being very supportive. We speculate that clients may selectively reveal themselves to genetic counselor and therapist.

For some patients, an appropriate psychotherapy referral may enhance the genetic counseling process by allowing confrontation and resolution of matters that interfere with the ability to focus on genetic counseling issues and decision-making.

Denise M. Greene Simonsen, MS
UCI Medical Center, Orange, CA
and June Peters, MS, MFCC
Long Beach Memorial Medical Center and Private Practice
Long Beach, CA

NSGC NIXES NEW ORLEANS

from p. 1

the results of a recent membership poll in which over half the respondents opposed New Orleans as a meeting site.

A task force is currently exploring alternate sites.

ACTION PLAN UNDERWAY

Among the issues discussed at the Board meeting was a desire that the action taken by our organization make a difference. Essential to the success of the boycott was a plan to communicate our action to appropriate institutions and organizations. Therefore, the Executive Office has mailed press releases announcing our action. The releases, along with the Green brochure describing the genetic counseling profession, have been mailed to nearly four dozen groups who may help publicize or choose to emulate our decision. The list includes, but is not limited to, the following:

- Tourist and Convention Bureaus in key Louisiana, Texas, Pennsylvania, Utah and Mississippi cities
- Governors in key states (see above)
- Pro-Choice groups: Catholics for Free Choice, NARAL, RCAR, NOW, Fund for a Feminist Majority
- Professional membership organizations: ASHG, ISONG, AMA, American Medical Womens Association, American Fertility Society
- Publications: American Medical News
- Public Policy Institutions: Center for Reproductive Law and Policy, Alan Guttenmacher Institute, The 80% Majority Report.

PERSONAL ACTION ENCOURAGED

The Board recognizes that many NSGC members may attend the 1993 ASHG conference in New Orleans and strongly encourages members wishing to take a proactive stand to participate in the planning or the program of those ASHG-sponsored public activities while in New Orleans.

For more information, contact Dr. Peter Rowley, Chair, Task Force on Louisiana, 716-275-3461.

MEMBERS FAVOR NSGC-SPONSORED SHORT COURSES

The last issue of *PGC* included a survey to solicit potential interest in NSGC-sponsored short courses. Here are the results:

Total Newsletters Mailed	1044
Total Ballots Returned *[Full, 259; Associate, 7; Student, 15]*	281
Total % Returned	27%

DEMOGRAPHICS OF RESPONDENTS

The years of experience and work settings broke down as follows:

1 - 2 years experience	60
3 - 4 years experience	48
5 - 7 years experience	54
≥8 years experience	108
Prenatal	153
Prenatal and Pediatrics	45
Pediatric	48

RESPONSES NOTED

1. *Should the NSGC establish a program of "short courses"?*

Yes/260 No/5

2. *When should they be offered?*

Spring/86 Summer/59
Fall/19 Winter/31
with Annual Educ Conf/69
with Regional Meetings/109

3. *I would pay...*

Amt time	# Responses	Cost
1 day	208	<$99
	51	$100 - $200
	3	>$200
2 days	118	$150 - $200
	158	$200 - $250
	3	>$250
3 days	147	$250 - $300
	57	$300 - $400
	8	>$400

4. *Would you be willing to travel to another part of the country to attend a short course?*

Yes/183 No/66

5. *What topic(s) would be of interest to you?*

DNA	218
Prenatal	174
Cancer	120
Scientific writing	116
Teaching/curriculum devel	111
Write In Suggestions:	
Board review	87
Administrative/management	68

The committee will keep you informed as we continue our study of this new opportunity.

— **Carol Strom, M.S.**

IN MEMORY OF KURT FENOLIO
1954 - 1992

It is with great sadness that we announce the death of our friend and colleague, Kurt Fenolio, on May 31 of AIDS-related complications. A graduate of Sarah Lawrence College in 1980, he worked as a genetic counselor in Houston and San Francisco. In 1985, he and his wife, Deborah, undertook a two year health education project in Burkin Faso, Africa. All who worked with Kurt benefitted from his knowledge, warmth and deep sense of commitment to others. He will truly be missed.

IN MEMORY OF MURIEL M. GLUCKSON
1924 - 1992

Muriel Gluckson received her master's degree in classical genetics before the number of human chromosomes was known. Her love of science encouraged her to become a member of the first graduating class of the Sarah Lawrence Genetic Counseling Program and then one of the first speciality counselors hired by a CF center. She was a role model for many, and the strides she made in her professional life have made it easier for all of us who followed in her footsteps. Muriel was a kind, compassionate and caring woman. She died April 9.

MEMORIAL DONATIONS ACCEPTED BY NSGC

In recognition of Kurt Fenolio's interest in cultural diversity and his desire to learn about and from other cultures, donations made to the NSGC in his memory will be designated to support cross-cultural genetic counseling projects and underrepresented populations.

Donations made in memory of Muriel Gluckson will be directed to the Special Projects Fund.

Send donations to the NSGC c/o Linda Lustig, 2223 McGee Ave, Berkeley, CA 94703. Please designate your donation and include your name and address for acknowledgement.

PERSPECTIVES

IN GENETIC COUNSELING

PROFESSIONAL STATUS SURVEY RESULTS

Supplement to Vol. 14, No. 2 Summer 1992

by Wendy R. Uhlmann, MS, Chair, Professional Issues Committee

THE 1992 PROFESSIONAL STATUS SURVEY was mailed to 769 Full members of the National Society of Genetic Counselors in February 1992. The number of surveys returned was 537 (69.8%); 45 (8.4%) returns were excluded (late returns, blank forms, not working) from the analysis. The total number of respondents for each question differs since some respondents did not answer all questions in the survey. For questions where respondents could circle more than one option, the summation of the percent column will total more than 100%. Since the results generally were normally distributed, the mean was approximately equal to the median, and therefore *mean* values were reported. The results for approximately two-thirds of respondents fall within one standard deviation (SD) of the mean value.

DEMOGRAPHICS

Four hundred sixty-one (94.9%) respondents were female and 25 (5.1%) were male. The mean age was 34.6 years (SD=8.4) and 97.6% hold a Master's Degree. The mean number of years employed as a genetic counselor as of 1/1/92 was 6.3 (SD=5.0).

The regional distribution of genetic counselors was:

Region I	7.8%
Region II	32.0%
Region III	10.9%
Region IV	19.2%
Region V	8.0%
Region VI	21.7%
outside US	0.4%

This regional distribution of respondents is almost identical to the national distribution of NSGC Full members.

The employment status of respondents was:

Full-time	80.3%
Full-time as a combination of part-time positions	2.1%
Part-time	17.6%

Forty-eight (58.5%) of those working part-time worked more than 20 hours/week. For 68.2% of respondents, part-time status was preferred long term for personal reasons while 18.2% indicated that their part-time status was temporary. Some respondents worked part-time because no full time position was available (9.1%), and 4.5% cited other reasons.

Primary work settings, primary focus of genetic counseling, primary role and institutional job classification are listed in Tables 1,2,3 and 4 respectively. The mean estimate of number of patients counseled independently or with a team in 1991 was 448 (SD=311). This number may not be an accurate reflection since some respondents appeared to answer this question for the number of patients seen by the entire team.

CERTIFICATION

The American Board of Medical Genetics certification status of respondents was as follows: Certified (67.9%), Eligible (30.7%) and Not Eligible (1.4%). For the 149 respondents who were board eligible, 82 (55%) were recent graduates. Other respondents indicated that they had not taken boards yet because of timing (7.4%), not re-

1: PRIMARY WORK SETTING

	N	%
Federal/State/County Office	19	4.0
Health Maintenance Organization	26	5.5
University Medical Center	242	50.7
Private Hospital/Medical Facility	131	27.5
Diagnostic Laboratory	23	4.8
Outreach/Satellite/Field Clinic	6	1.3
Private Practice	17	3.6
Other	13	2.7
	Total=477	

2: PRIMARY FOCUS OF GENETIC COUNSELING

	N	%
Prenatal	226	47.0
Pediatric	47	9.8
Adult	1	0.2
Specialty Disease Counseling	14	2.9
Prenatal and Pediatric	122	25.4
Pediatric and Specialty Disease	16	3.3
Adult and Specialty Disease	4	0.8
Molecular/Cytogenetic/Biochem	8	1.7
Public Health/Newborn Screening	8	1.7
Screening	9	1.9
Other	26	5.4
	Total=481	

3: PRIMARY ROLE

	N	%
Clinical	275	56.8
Coordination/Administration	27	5.6
Clinical and Coordination/Admin	118	24.4
Teaching/Educational	5	1.0
Clinical and Teaching	27	5.6
Research	12	2.5
Customer Liaison/Business/Marketing	7	1.4
Other	13	2.7
	Total=484	

quired for job (5.4%), cost (4.7%), no perceived benefit (3.3%) and other reasons (3.4%). Thirty-one (20.8%) respondents had taken the ABMG boards previously and had not passed. The proportion of employers who completely or partially covered costs for the ABMG exam was 36.3% (complete-27.6%; partial-8.7%). The benefits received as a result of certification are described in Table 5.

FACULTY STATUS

One hundred eighteen (25.5%) respondents indicated that they hold a faculty position: 93 (20.1%) non-tenure track; 5 (1.1%) tenure track and 20 (4.3%) had faculty appointments at another institution. An additional 111 (24%) respondents indicated that it may be possible to obtain faculty status at their institution. The majority of faculty appointments were automatic at the time of hire (37.3%) or self-requested (36.4%). Faculty status was also achieved after a certain service period (12.7%), after a precedent was set by a colleague (5.1%) and by other means (8.5%). The majority (76.3%) of faculty appointments were in medical schools in the departments of Pediatrics (42.4%), OB/GYN (25.4%) and Genetics (8.5%). This distribution of faculty appointments was an interesting finding, given that the majority of respondents worked primarily in prenatal genetics. Eighty-six (74%) respondents with faculty status were ABMG certified. Faculty status resulted in increased salary for 19.2%.

PUBLICATIONS, TEACHING AND PROFESSIONAL ACTIVITIES

Publications, teaching and professional activities are described in Tables 6, 7 and 8 respectively. There was strong involvement of genetic counselors in these areas: 324 (66%) respondents have published at least once; 456 (93%) were involved in teaching/clinical rotations/guest lectures and 420 (85%) have been involved in professional activities (i.e. served on committees, developed programs, quoted in the media).

4: JOB CLASSIFICATION

	N	%
Director/Administrator	30	6.2
Genetic Counselor Coordinator	59	12.2
Clinical Coordinator	11	2.3
Genetic Counselor/Genetic Associate	308	63.9
Genetic Nurse Counselor/ Nurse Geneticist	9	1.9
Research Assistant/Associate	10	2.1
Other	55	11.4
	Total=482	

SALARIES AND "PERKS"

Salaries

The mean yearly gross salary of the 449 respondents who reported their salaries was $38,116 with a standard deviation of $7,972. The distribution of salaries by years of experience is in Tables 9 and 10. There were statistical differences between regions (Table 11). When California, New York and New Jersey were excluded, there was no significant difference in salaries among the regions (p>0.45); therefore, salaries are listed by years of experience and

5: CERTIFICATION BENEFITS

	— — Year member became certified — —			
	1981 (N=70)	1984 (N=64)	1987 (N=99)	1990 (N=92)
Raise in salary	11%	12%	16%	23%
Promotion	3%	5%	5%	9%
Faculty Status	4%	0%	3%	2%

6: PUBLICATIONS SINCE JANUARY 1990

	N	%
Abstracts or articles on case reports	141	28.8
Abstracts or articles on original research	120	24.5
Platform presentations, etc.	144	29.4
Brochures/Pamphlets/Videos	132	27.0
Chapters in books	38	7.8
Books	10	2.0
Other	40	10.0
No publications	166	33.9

7: EDUCATIONAL ACTIVITIES

	Teaching/ Clinical Rotations		Guest Lectures	
	N (Yes)	%	N (Yes)	%
Genetic counseling students	210	42.9	73	14.9
Medical students/physicians	317	64.8	221	45.2
Nursing students/nurses	150	30.7	210	42.9
Social workers/students	38	7.8	78	16.0
Other health professionals	45	9.2	117	23.9
Graduate students	53	10.8	69	14.1
Undergraduate students	47	9.6	104	21.3
Community college students	15	3.1	73	14.9
Kindergarten-12th grade	24	4.9	177	36.2
Other	11	2.2	73	14.9

8: PROFESSIONAL ACTIVITIES *(Since January, 1990)*

	N	%
Served on committee or board of NSGC, ASHG, ABMG, CORN	128	26.2
Served on committee(s) (local/state/national) dealing with delivery of health/genetics services	150	30.7
Developed/coordinated/served on advisory board/been a resource for support group(s)/voluntary organizations	186	38.0
Developed/been a resource for local screening program	89	18.2
Developed outreach program(s)	83	17.0
Developed/organized conference/workshop/ symposium for patients/health professionals	158	32.3
Spoken to lay/community groups	310	63.4
Written grant proposal(s) which were funded	87	17.8
Written grant proposal(s) which were not funded	49	10.0
Developed genetics curriculum for students/teachers	71	14.5
Quoted/appeared on television, radio, newspaper	158	32.3
Other	30	6.1

9: SALARY BY YEARS OF EXPERIENCE
(TOTAL SAMPLE)

Yr exp	N	Avg Sal	SD
1	50	$32,001	$4,349
2	42	$32,998	$4,106
3	34	$34,557	$5,524
4	40	$35,288	$4,331
5	31	$37,609	$6,511
6	37	$38,451	$5,940
7	25	$39,269	$5,447
8	22	$37,787	$7,627
9	30	$40,214	$7,846
10	15	$39,795	$5,924
11-12	35	$42,922	$10,333
13-14	24	$43,612	$7,487
15-16	19	$45,484	$8,675
17-18	12	$42,999	$9,983
19-20	9	$45,634	$9,523

(Salaries are grouped by two years of experience after 10 years to preserve anonymity)

10: SALARY BY YEARS OF EXPERIENCE
(CA, NY, and NJ only)

Yr Exp	N	Avg Sal	SD
1	12	$35,459	$3,539
2	16	$35,991	$2,148
3	14	$38,140	$4,583
4	12	$37,252	$3,820
5	15	$41,180	$6,568
6	12	$40,845	$3,442
7	9	$43,552	$5,848
8	6	$39,066	$4,718
9	7	$48,079	$12,680
10	6	$44,797	$2,649
11-12	13	$46,384	$7,355
13-14	7	$47,898	$9,844
15-16	11	$48,984	$8,951
17-18	6	$45,776	$12,885
19-20	5	$49,040	$9,611

(Salaries are grouped by two years of experience after 10 years to preserve anonymity)

11: SALARY BY REGION

	N	Mean	SD
Region 1 CT, ME, MA, NH, RI, VT	36	$36,796	$4,504
Region 2* DE, DC, MD, NJ, NY, PA, VA, WV	144	$39,522	$9,735
Region 3 AL, FL, GA, KY, LA, MS, NC, SC, TN	48	$34,598	$6,520
Region 4 IL, IN, IA, KS, MI, MN, MO, NE, OH, WI	86	$35,602	$6,033
Region 5 AR, AZ, CO, MT, NM, ND, OK, SD, TX, UT, WY	38	$35,388	$5,610
Region 6** AK, CA, HI, ID, NV, OR, WA	98	$41,536	$7,276

* *When NJ and NY were excluded from Region 2, the mean salary was $37,036.*

** *When CA was excluded from Region 6, the mean salary was $35,078.*

12: COMPARISON OF MEAN SALARIES BETWEEN CA, NY AND NJ RESPONDENTS AND RESPONDENTS FROM ALL OTHER STATES

	N	Mean	SD
CA, NY, and NJ members	160	$42,247	$8,299
All other states	289	$35,829	$6,789

13: ADDITIONAL GENETICS RELATED INCOME

	N	Mean	Minimum	Maximum
Teaching	20	$1,223	$60	$5,000
Lecturing	69	$392	$50	$3,000
Consulting	34	$5,237	$200	$18,000
Private Practice	12	$7,708	$2,000	$15,000
Other	14	$2,846	$50	$20,000

Respondents were excluded who claimed more than $20,000 in a category when that appeared to be their primary source of income.

not by region. There was a highly significant difference (p<0.0001) in salaries between respondents from California, New York and New Jersey and respondents from all other states (Table 12). There was no significant difference in average salaries between California and New York/New Jersey.

Regression analysis indicated that the average salary for a genetic counselor with no experience was $32,154 and with each year of experience, there was a $895 increase in salary. For California, New York and New Jersey, the average salary was $35,193 with a $950 increase per year of experience. The majority (88.3%) of respondents were salaried. Approximately one-third indicated that their salaries were either partially or completely dependent on grant money and two-thirds felt that their employer would cover their salaries if grant support were discontinued.

Raises

The mean percent raise received in 1991 by 365 respondents was 5.9% (SD=3.8%). One hundred sixty-three (44.3%) indicated that their raise was above average (27.7%) or maximum (16.6%). The percentage of respondents receiving other types of raises was: minimum (3.3%), average (11.4%), automatic (32.6%) and unknown (8.4%). Raises were defined as cost of living only (17.1%), merit/performance only (20.5%), cost of living and merit (33.9%), unknown (24.6%) and other (3.9%).

Additional Income; Reimbursement

One hundred eighty-five (38.7%) respondents indicated that they either receive compensatory time or additional pay for overtime. Table 13 lists the additional income received by 128 (27.1%) respondents from other professional activities. Employer reimbursement for professional meetings is described in Table 14. The proportion of employers who completely or partially covered job-related expenses was as follows: Interview, 44.1%; Moving, 29.6%; Professional Memberships, 42.9%.

The method of billing for genetic counseling services is described in Table 15.

JOB SATISFACTION

Four hundred eight (83.4%) respondents were either very satisfied or satisfied with their current job. Two-thirds or more of the respondents were either very satisfied or satisfied with their variety and number of patients/cases, autonomy, director's support and interactions with other genetic counselors on staff. Over one-half of the respondents were either very satisfied or satisfied with their institutional support, salary, administrative responsibilities, teaching opportunities and opportunity for continuing education. More than half of the respondents were dissatisfied with their research opportunities and opportunity for advancement. Two hundred nine (42.9%) respondents indicated that they have never changed genetic counseling positions. There was a very high correlation ($p<0.001$) between years in the field and years at current job, suggesting that respondents generally stay in a particular job. The two main reasons for job changes were relocations and desire for different job content.

PROFESSIONAL SATISFACTION

Similar questions were asked regarding the *field* of genetic counseling. Over 80% of respondents were either very satisfied or satisfied with patient contact/counseling, scientific content, learning opportunity and personal growth. Over one-half of respondents were either very satisfied or satisfied with opportunities for professional growth, opportunities to develop/ administer programs and respect from the medical community.

Approximately 75% of respondents were dissatisfied with their opportunities for advancement and earning potential. Two-thirds of the respondents are *not* planning to leave the field of genetic counseling. For those respondents who are considering leaving the field of genetic counseling, the four main reasons were: limited opportunities for professional advancement, limited earning potential, change in professional interests and limited job responsibilities. The main career options cited by these respondents were obtaining another advance degree and joining a business.

PARTING THOUGHTS...

It is evident from these survey results that genetic counselors are working in diverse settings, performing a variety of tasks and contributing in both educational and professional arenas. Given this diversity, there is no simple description that can be given to employers to define what genetic counselors actually do. It is hoped that this survey summary will be a useful tool in providing a general overview of the genetic counseling profession. While the increase in average yearly gross salary is encouraging to see, it is becoming more evident that the salaries of less experienced counselors are outpacing those who are more experienced. Concerns about the issues of salary compression, limited earning potential and limited opportunities for advancement are not unique to the genetic counseling profession. It is, however, important that we continue to explore ways to address these issues on a national level. It is a testimony to our profession that the majority of respondents indicated that they are satisfied with their jobs, their profession, and they are not planning to leave the field of genetic counseling.

14: EMPLOYER REIMBURSEMENT FOR PROFESSIONAL MEETINGS

	N	Mean	SD	Min	Max
SPECIFIC AMOUNT OF TRAVEL FUNDS/YEAR*	154	$1,164	$758	$250	$5,000

**Note:* most frequent value was $1,000 (N=43, 27.9%)

SPECIFIC NUMBER OF MEETINGS ALLOWED/YEAR	N	%
1	124	65.3
2	52	27.4
3 or more	14	7.3
	Total=190	

	N	%
Meetings funded by employer and other source	68	14.2
Meetings funded solely by other source	16	3.3
All relevant meetings covered	76	15.9
Reimbursement only if presenting	27	5.6
Other	44	9.2
No reimbursement	37	7.7

15: BILLING FOR GENETIC COUNSELING

	N	%
Bill in my name	23	5.9
Bill in my name and supervising MD	73	18.6
Bill in supervising MD's name	202	51.4
Bill included in comprehensive fee	57	14.5
Other	38	9.7
	Total=393	

ACKNOWLEDGEMENTS

I would like to acknowledge the comprehensive statistical analysis that was performed by Diana DeVries, MA and Sharon Reilly, PhD. I would also like to acknowledge the work of the Professional Issues Committee in preparing the survey: Beth Balkite, Robin Bennett, Janice Berliner, Kathy Boland, Ann Boldt, Barbara Briscoe, Diana Chambers, Leslie Ciarleglio, Debra Doyle, Janice Edwards, Mary-Frances Garber, Robin Gold, Cheryl Harper, Priscilla Harris, Jacqueline Hecht, Valerie Jansen, Kathy Keenan, Lucinda Malin, Diana Punales-Morejon, Robin Schwartz, Elaine Sugarman and student members Stephanie Brown, Lisa Carpenter and Golnaz Kavianian.
Diane Baker, Barbara Bowles Biesecker, Debra Collins, Beth Fine, Betsy Gettig, Ed Kloza, Bea Leopold, Linda Lustig, Linda Nicholson, Joan Scott and Vickie Venne reviewed the survey and provided helpful comments.

The Inside Line on the NSGC

It seems that one or two myths or misconceptions must plague every organization. NSGC's is that the leadership belongs to a select few. Here's why I believe this is simply not true...

Let me begin by exploring the power the *membership* holds in determining the direction of our Society. If you have believed the myth of the powerful few, I hope you will reconsider your misperception.

The members *elect* the President-Elect, Secretary, Treasurer and Regional Representatives. The President-Elect commits to a four year term on the Board of Directors, the longest term of *any* elected Board member. The President-Elect is responsible for communicating with Regional Reps, a great opportunity to learn about the issues of the members. After serving as President Elect, the Presidential Year is followed by one year each as Past Presidents I and II.

Members may not be nominated for this leadership position until they have served on the Board in at least one appointed or elected position. This valuable learning experience, I believe, may erroneously contribute to the misconception that the "same people" are holding onto the leadership of the NSGC.

The Treasurer and Secretary both serve two year terms and are elected in alternate years. Regional Representatives are our closest parallel to the United States Congress...though these days, that might not be a favorable comparison! These Reps are often asked to check the pulse of the membership. They also greet new members to their regions, coordinate regional educational meetings and write newsletters. These elected positions rotate in each election cycle by odd and even numbered regions, to maintain continuity and constancy on the Board. Therefore, the membership has direct representation not just through the officers ('executive branch'), but also directly through the Regional Reps, each of whom serve two year terms.

Standing committees of the NSGC are Education, Social Issues, Professional Issues, Membership and Finance, with each chair sitting for two years. Activities of the Education Committee are highlighted below. Other committee activities will be featured in future issues.

A total of 20 individuals compose the board - another 250+ participate *actively* on various committees. Clearly, the *work* of the NSGC occurs in the committees. And becoming involved on the committees is the easiest way to become active in leadership.

All it took for me was the decision to volunteer my ideas, energy and some time! You can become a part of NSGC's leadership. Join this *non*-exclusive club. Call a committee chair. Seek to hold office. This is an open invitation from your President Elect. The NSGC does not belong to me; it belongs to us. The time to become involved is now.

— Betsy Gettig, MS
President-Elect

PROFILE ON...The Education Committee

AMPLE OPPORTUNITIES FOR INVOLVEMENT EXIST ON EDUCATION COMMITTEE

Currently, there are several subcommittees coordinating exciting projects that await your creativity and input. The opportunities are many; the options are yours to take... Every NSGC member is invited to become involved in the planning process.

- **ANNUAL EDUCATION CONFERENCE** — The Education Committee's responsibilities have changed over the years, but the Annual Education Conference (AEC) has remained a constant and vital charter responsibility. The conference theme and co-chairs are selected two years prior to each meeting. Subcommittees include: logistics, program, abstracts, workshops, communications and the media resource center. Have a creative idea to enhance an upcoming AEC? Stephanie Smith and Ron Cadle will be co-chairs of the 1993 AEC and now is the perfect time to let them know of your interest.
- **SPEAKER'S BUREAU** — About 100 NSGC members responded to the request for participation in the speaker's bureau two years ago. Those individuals may not be utilized as efficiently as possible at this time, but future opportunities are growing as we integrate this service with "Connecting Links."
- **PATIENT LITERATURE** — We are hoping to join forces with the CORN Education Committee and representatives from the Alliance of Genetic Support Groups to establish a patient literature database and review mechanism. Dr. Virginia Proud, the GPGSN representative to the CORN Education Committee, has the responsibility of writing a grant, and Barbara Pettersen and Jannell Sloan, co-chairs of the NSGC patient literature subcommittee, will keep us posted on its progress.
- **ASILOMAR CONFERENCE** — A subcommittee, spearheaded by Barbara Bowles Biesecker, organized a three day conference in early June for training program directors and invited consultants. Funded by a $30,000 NIH ELSI grant, this conference fostered discussion regarding current curricula specific to ethnocultural issues and the recruitment of minority students. They also discussed the impact that the Human Genome Initiative will have on genetic counseling and explored innovative strategies to address the human resource shortage in the field.
- **SHORT COURSES** — Maureen Smith-Deichmann is exploring the initiation of short courses, possibly beginning as early as October '93.
- **STUDENT RECRUITMENT** — Bonnie LeRoy and members of her subcommittee are exploring student recruitment. They are evaluating methods of encouraging students to pursue careers in genetic counseling.

The Education Committee provides an enjoyable, energizing and enlightening way to make a difference in your professional organization. Comments, ideas and you are welcome at all times.

— Carol Strom, MS
Chair, Education Committee

GENE BYTES

TERATOGEN DATABASES: A REVIEW OF REPROTOX

by Karen Wcislo, MS and Robert Resta, MS

Teratogen phone calls: from the patient's standpoint, a valuable and reassuring service. From the genetic counselor's perspective, well ... not the high point of your day. And the things you get asked: from medications and street drugs to envelope glue, dental floss (waxed vs. unwaxed), and the ever popular bug spray. However absurd the question may seem, the concern is real to the patient, and a pregnancy may hinge on your response.

Keeping current with teratology literature is difficult, as it is scattered across journals not common in genetics departments, such as the *Journal of Occupational Medicine*. Summary books are useful but dated before they are published. Computerized databases are an ideal medium for storage, retrieval, and frequent updates of teratogen information.

REPROTOX, run by the Reproductive Toxicology Center in Washington, D.C. since 1986, is an excellent example of an on-line teratogen database. The service is accessible via modem (1200 or 2500 baud) from all computers - IBM, Macintosh, Mainframes. The cost is modest - $150/year for private primary care clinicians, $350 for specialty groups such as genetics departments, or $750 for an institution. The phone number is toll free, and there is no charge for connect time. Learning to access the system is simple, especially if your communications software can be used to automate dialing.

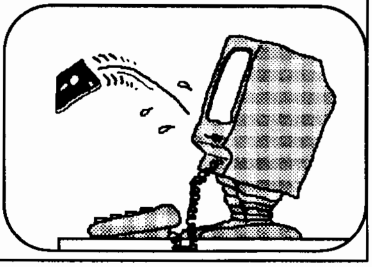
More than 4,000 agents are currently listed, accessible by generic name, CAS number or REPROTOX number. A concise, critical summary of human and animal studies of each agent is provided along with a bibliography. The summaries contain information on teratogenic potential, impact on fertility, breast feeding and male-mediated effects. In our experience, the length of time it takes to dial REPROTOX, find the agent, print a summary and disconnect has been about five minutes.

The REPROTOX staff monitors about a dozen journals, and new studies are regularly incorporated into the summary and bibliography. The date of the most recent update is provided, and thorough literature searches are done approximately every two years. If an agent is not listed, a literature search can be requested on line with a summary available in about a week. If specific clinical information about a patient's exposure is provided, REPROTOX will mail a letter summarizing the potential risks to that patient's physician.

Generally, we have found their summaries to be accurate and up-to-date, and have almost always agreed with their critical evaluations. A printed copy is easily obtained to keep in your files or for the patient chart.

Comments, questions and inquiries can be made on-line, and REPROTOX has been responsive to suggestions. Significant technical improvements have been made in the last few years, resulting in better accessibility and decreased search time.

Using REPROTOX can dramatically decrease the amount of time spent to research a teratogen exposure. Although most of us have a working knowledge of teratogens, REPROTOX will help assure you that you are not missing any important studies and help you sleep easier at night.



An earlier version of this review appeared in Genetics Northwest [Vol IV (4), 1989].

LETTERS...

GUIDING PRINCIPLES BECOME POSITION STATEMENTS

To the Editor:

Concern arose in our committee regarding the articulation and representation of some of the principles found in the article, "Guiding Principles, Resolutions Clarify Stance (*PGC*, 14:1, Spring 92). Ms. Palmer states that the Code of Ethics "is a document for internal use." This statement appears to contradict the Preamble of our Code and the definition of the function of such a document: "With the establishment of this code of ethics, the NSGC affirms the ethical responsibilities of its members and provides them with guidance in their relationships with self, clients, colleagues, and society." This guidance need not remain exclusively within the NSGC.

A code of ethics also "announces to society the ethics that the profession stands for."[1] *POSITION STATEMENTS* reflect concrete applications of a code of ethics; they are natural outgrowths of that code. New *GUIDING PRINCIPLES* are *not* such an outgrowth. They require their own justification and development, especially when claiming to be "universal beliefs."

These statements represent the kind of concrete application of the Code of Ethics we believe the NSGC desires, and we fully support their *content*. However, we propose that such statements, both now and in the future, be called *POSITION STATEMENTS* rather than guiding principles.

The Ethics Subcommittee
Judith L. Benkendorf, Chair,
Nancy P. Callanan, Rose Grobstein, Susan Schmerler, Kevin FitzGerald

[1] Reiser, Stanley J. 1984. Codes of Medical Ethics. *Health Matrix* 2(2):43.

Response

The Social Issues Committee would like to thank the Ethics Subcommittee for the above letter. We appreciate the correction in terminology, and we support the recommendation to change the name GUIDING PRINCIPLES *to* POSITION STATEMENTS. *The Board unanimously approved the change.*

...TO THE EDITOR

Therefore, Access to Care, Non-discrimination, Confidentiality of Test Results and Disclosure and Informed Consent are now POSITION STATEMENTS.

The Social Issues Committee urges Full members to vote on the two proposed resolutions, Prenatal Substance Abuse and Fetal Tissue Research. Please refer to the updated information in the Legislative Briefs column and to the enclosed ballot.

– Shane Palmer, Chair,
Social Issues Committee

A DIFFERENT VIEWPOINT

To the Editor:

I am troubled by Elsa Reich's *Viewpoint* about "Advanced Paternal Age: Risk and Reason" *(PGC* 14:1, Spring 92). Two issues appear paramount in this case: first, the ethical and legal responsibility to disclose information and secondly, the interpersonal dynamics inherent in any counseling session.

Although the amount of anxiety that a couple experiences during prenatal counseling may increase with the amount of additional information provided, this anxiety can be acknowledged, discussed and hopefully diffused given adequate time. Even if the anxiety *cannot* be diffused, we can all accept that anxiety is normal and common, especially during pregnancy.

Withholding pertinent information from a counseling session or providing this information to one couple but not to another appears to run counter to the concept of full disclosure. Therefore, I wonder whether the tone of Ms. Reich's counseling might be considered condescending, co-dependant or discriminatory.

Genetic counselors must strive to provide *all* the information available to a couple...even when that information is difficult or incomplete. I would remind Ms. Reich that even when we deliver *good* prenatal news, it is always with the disclaimer that we cannot *guarantee* a normal pregnancy outcome. Life is not perfect and there is no need to make our counseling sessions any different.

Gary S. Frohlich, MS
N.L.A.C.R.C., Sepulveda, CA

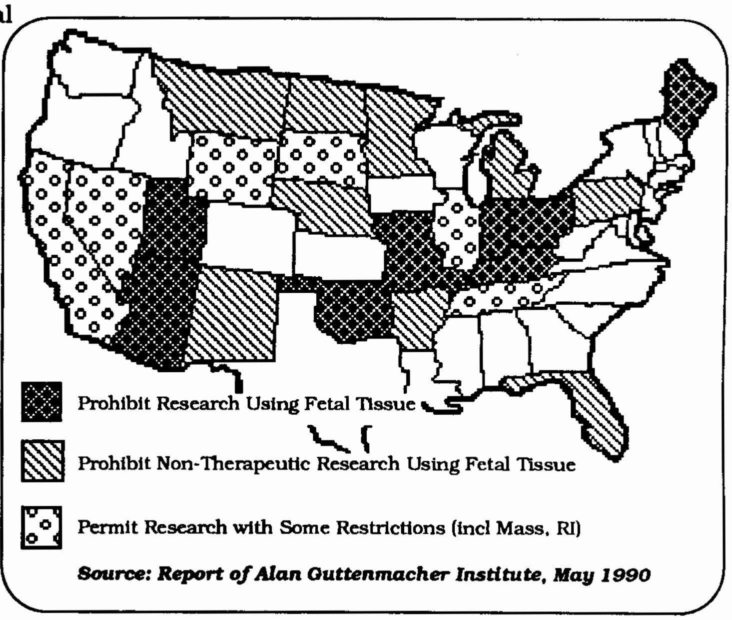
LEGISLATIVE BRIEFS

FETAL TISSUE RESEARCH CAUSES PRESIDENT TO DIG IN HEELS

In recent weeks, Congress tried several times to lift the ban on Federal funding for fetal tissue research. Both the House and Senate have passed bills that would overturn the ban and have tied the lifting of the ban to the passage of the NIH budget. However, the President is vehemently opposed to lifting the ban. Congress has thus far yielded to President Bush's election year plea not to override his veto on this issue.

At the center of this argument is the administration's view that fetal tissue research is an inducement for women to have abortions. While it is true that many types of fetal tissue research rely on abortus material, NIH guidelines ensure that women are not induced to have abortions solely to contribute tissue for research purposes.

Several misunderstandings relating to fetal tissue research remain. According to the May 1992 issue of NIH Research, "new researchers, confused about what the Federal funding ban covers and discouraged by the controversy, turn to other areas of research."



Source: Report of Alan Guttenmacher Institute, May 1990

In fact, the federal ban pertains *only* to funding research for the *transplantation* of fetal tissue; it does *not* affect the funding of basic research using fetal tissue. But, in addition to the federal funding ban, researchers must obey state laws on fetal tissue research. Currently, 25 states (see map) have laws prohibiting or restricting fetal tissue research. These laws vary widely from state to state. If and when the Federal ban is overturned, state laws would continue to pose a substantial limitation on this research. Genetic counselors wishing to become involved in this issue are urged to educate themselves and their state legislatures about the implications of their own state laws.

LEGISLATIVE LIAISON POSITION AVAILABLE

After four gratifying years as NSGC's Legislative Liaison, I feel that it is important to "pass the baton" and give another member the opportunity to serve the society in this capacity. Duties include serving on the Social Issues Committee, writing this column, representing the NSGC at coalition meetings and other Washington events, signing on to amicus briefs, and making policy recommendations to the Social Issues Committee. The legislative liaison works closely with the Social Issues Chair, the Editor of *PGC* and the NSGC president to ensure that activities are in keeping with NSGC policy. Washington area residency is a big plus for this position, but not an absolute necessity.

Contact Trish Magyari at 301-588-5484 x 356 for a more complete job description. Appointment is subject to approval by the Board of Directors.

Trish Magyari, MS
Legislative Liaison

BULLETIN BOARD

RESOURCE CENTER TO ADDRESS NEEDS OF VIETNAMESE; CAMBODIANS

The Genetics Unit of The Brooklyn Hospital Center is forming a Resource Center to provide information about genetic conditions affecting Vietnamese and Cambodians and the use of health services by these populations. As part of a new federal grant to improve access to genetic services by these groups, the staff is assembling resource articles as well as all available patient education materials in the Vietnamese and Cambodian languages. This material will be made available free of charge to interested health care professionals. For more information, or to share your resources, please call The Brooklyn Hospital Center Genetics Unit at 718-403-8032.

BROCHURE ON PRENATAL, PEDIATRIC SERVICES TO BE DEVELOPED

The Medical University of South Carolina Prenatal/Pediatric Genetics unit plans to create a brochure to describe and clarify its services.

If your genetics unit has a patient or professional guide to services (in any format) that you would be willing to share, contact: Lyn Hammond, M.S., Medical University of South Carolina, Genetics, Vince Moseley Center, 41 Bee St, Charleston, SC 29403; FAX# 803-792-6799.

CANCER RESEARCH PROJECT

Beth Peshkin, a graduate student in the Genetic Counseling Program in Madison, needs help compiling a reference manual on cancer for genetic counselors. Information will be collected on certain types of cancers, molecular diagnoses, as well as psychosocial and other pertinent issues.

If you have suggestions, names of contacts, articles or pamphlets you have found helpful, or if you would like to see an expanded outline, please contact Beth c/o Genetic Counseling Program, University of Wisconsin-Madison, Waisman Center, 3rd Floor, 1500 Highland Avenue, Madison WI, 53705-2280; 608-262-0592 or 263-2066.

FRAGILE X CONFERENCE SLATED

The First Canadian Fragile X Conference will convene August 13-17 at Queen's University, Kingston, Ontario. Scientific sessions are scheduled for August 15 - 17. Fax your requests for information to Queen's University Events Management, 613-531-0626.

REGION III TO MEET IN FLORIDA

The annual Region III NSGC meeting will be held July 7-8 at Sandestin, Florida, just prior to the 14th Southern Genetics Group meeting. Members planning or considering attending are invited to contact Andy Faucett, Region III Representative, c/o Savannah Perinatology, 912-350-5970

STUDY GUIDE AVAILABLE

Janice Berliner has written a study guide for the 1993 ABMG examination. For information and a price guide, please write to her c/o 34 Webster Drive, Berkeley Heights, NJ 07922; 908-771-5582.

ETHICS SUBCOMMITTEE TO EXPAND

Full members interested in joining the Ethics Subcommittee may submit a CV and a letter outlining your experience in bioethics to Judith Benkendorf, Dept OB/GYN, GUMC, 3800 Reservoir Rd NW, Washington, DC 20007-2197 by August 31. Questions can be addressed to Rose Grobstein, 503 Weatherstone Dr, Paoli, PA 19301; 215-889-7418.

11TH ANNUAL EDUCATION CONFERENCE: NOVEMBER 6 - 8

THE HUMAN GENOME PROJECT: IMPACT, IMPLICATIONS AND ISSUES

(OR WHEN WE'VE SOLVED THE MYSTERIES, WHAT WILL WE DO WITH THE CLUES?)

Announcement and Registration brochures for the NSGC's 11th Annual Education Conference were mailed to the membership in early May. If you have not received your copy or would like another, please contact the Executive Office. Confirmation letters and a reading list will be sent to all registrants in early fall.

OF OTHER CONFERENCE INTEREST

- The Media Resource Center has been reactivated this year, thanks to efforts spearheaded by the UC Berkeley student members. Videotapes, slide sets and other innovative educational materials will be available for your review. Students from any program who would like to participate in staffing the Center or reviewing materials are invited to contact Conference Co-Chair, Lynn Hauck, 602-795-5675.
- This year, members can help students reduce the cost of the meeting by sharing hotel rooms. If you are budgeted for a single room and want company, why not invite a student to join you? Coordinating the Roommate Match/Student Share is Beth Buehler (305-547-6006)
- Special requests for meeting space during the conference other than those designated on the conference announcement brochure must be received in writing by September 1 at the Executive Office. Please include the name and size of your group. Assignments will be made on a space available basis.

CORPORATE AND ORGANIZATIONAL CONFERENCE SUPPORT ACKNOWLEDGED

The NSGC is pleased to welcome, (and welcomes back,) our friends who have offered support and/or will be exhibiting at our conference:

Alfigen – The Genetics Institute
Alliance of Genetic Support Groups
Analytical Genetic Testing Center
Collaborative Diagnostics
Genentech
Genica Pharmaceuticals
Genzyme
GeneScreen
Integrated Genetics
JHU/Welsh Medical Library
March of Dimes
Nichols Institute
ONCOR
Palo Verde Laboratory
Roche Biomedical
SmithKline Beecham
TERIS
Vivigen

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Davis, CA: Immediate opening for BC/BE Genetic Counselor. Salary: $2600-3900/mo.
Responsibilities: Join team in UC-based general genetics program serving diverse, multicultural population.
Contact: UC Davis Employment Office, TB122, Davis, CA 95616 (ref #VL2-0178) or Dr. Art Grix, 916-734-2391. EOE/AA.

La Jolla, CA: Immediate opening for BC/BE Genetic Associate.
Responsibilities: Rapidly-growing academic center w/ wide range of clinical & lab services & GC oppty: general & repro genetics, amnio, CVS, teratology, MSAFP screening.
Contact: Terri Richards, RN, University of California San Diego, Medical Genetics #0639, 9500 Gilman D, La Jolla, CA 92093-0639; 619-597-2600. EOE/AA.

Pasadena, CA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: All aspects of PN coun & case mgmt: CVS, amnio, U/S, teratology & MSAFP. Involvement in ped/gen, teaching & development of new clinical programs possible. Guaranteed mtg/yr.
Contact: Sharon Langshur, MS, Alfigen-The Genetics Institute, 11 W. Del Mar, Pasadena, CA 91105; 818-666-3300. EOE/AA

Sacramento, CA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Highly motivated GC for expanding So. Calif activities to work in Prenatal Diagnosis Centers where BC clinical geneticists will provide direct supervision.
Contact: Martin Marks, Vivigen California, Inc., 77 Cadillac Drive, Ste 200, Sacramento, CA 95825; 714-794-3559. EOE/AA.

San Francisco, CA: Summer 1992 opening for BC/BE Genetic Counselor.
Responsibilities: Comp care for 25% of No. Calif residents: PNDx & coun, AFP, terat coun, heterozygote scrng, clinical & metab genetics, dysmorph, newborn scrng.
Contact: Bruce Blumberg, MD or Nancy Hanson, MS, Kaiser-Permanente Medical Group, 2200 O'Farrell St, San Francisco CA 94115; 415-202-2998. EOE/AA

San Francisco, CA: Immediate opening for BC/BE Genetic Counselor. 3-4 yrs exp pref.
Responsibilities: Join 2 GCs in dynamic growing hospital-based practice. Counsel & follow-up for amnio, CVS, MSAFP, PUBS, terat, U/S, hi-risk pregnancy, family history concerns. Certified Calif PDC & AFP center.
Contact: Karen Copeland, MS, California Pacific Medical Center, 2100 Webster, Suite 300, San Francisco, CA 94115; 415-923-3046. EOE/AA

San Francisco, CA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Full range of coun in repro genetics: amnio, CVS, MSAFP, fetal treatment program.
Contact: Mitchell S. Golbus, MD, University of California, San Francisco, Room U-262, San Francisco, CA 94143-0720; 415-476-4157. EOE/AA.

Denver, CO: July 1992 opening for BC/BE Genetic Counselor (Entry Level).
Responsibilities: Primary respon for coord of NF Clinic: organize, assess, counsel, clin rsrch & educ activ; Genl Genetics Clin/consult
Contact: Eva Sujansky, MD, Co-Director, or Anne L. Matthews, RN, PhD, Asst Clinical Director, Div Genetic Services, Childrens Hospital, 1056 E 19th Ave, B-300, Denver, CO 80218; 303-861-6395. EOE/AA.

Bridgeport, CT: Immediate opening for part-time BC/BE Genetic Counselor.
Responsibilities: Diverse respon in community-based tertiary care ctr. PN coun: amnio, CVS, anomalies, other referrals; Monthly ped clin; resident trng, prof educ, other proj
Contact: Sharon Suntag, MS, Bridgeport Hospital, 267 Grant St, Bridgeport, CT 06610; 203-384-3049. EOE/AA.

New Haven, CT: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Varied PN coun & consult w/ pts & physicians in tertiary care facility.
Contact: Miriam S. DiMaio, MSW, Yale University School of Medicine, Dept Genetics, P.O. Box 3333, New Haven, CT 06510; 203-785-2661. EOE/AA.

Chicago, IL: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join 4 GCs in busy PN & genrl genetics ctr; s'vise GC students; oppty for clin rsrch.
Contact: Beth Fine, MS, Northwestern Univ Medical School, Dept Pediatrics, Sec. Repro Genetics, 333 E. Superior, Ste 1564, Chicago, IL 60611; 312-908-7441. EOE/AA.

Brighton, MA: July opening for BC/BE Genetic Counselor.
Responsibilities: Working with Ped/Gen staff of the National Birth Defects Ctr. PN coun, parent groups, assist w/ teratogen hotline.
Contact: Caroline Hobbs, Natl Birth Defects Center, 30 Warren St, Brighton, MA 02135; 617-787-5958. EOE/AA.

St. Louis, MO: July 1, 1992 opening for BC/BE for Genetic Associate.
Responsibilities: Broad range of general ped & adult GC in high-volume, multidisciplinary setting; research investigations in endocrinology, cardiac and craniofacial genetics. Position does not involve significant PN coun.
Contact: S. Bruce Downton, MD, Washington Univ School Medicine, St. Louis Children's Hospital, Pediatrics/Medical Genetics, 400 S. Kingshighway St. Louis, MO 63110; 314-454-6093. EOE/AA

Winston-Salem, NC: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Primary responsibility for MSAFP coord; option of rotating with 3 other GCs through MSAFP, PNDx & general genetics, incl craniofacial & Marfan clinics.
Contact: Peggy Berry, Bowman Gray School of Medicine, Medical Center Blvd, Winston-Salem, NC 27157; 919-748-2213. EOE/AA

Paterson, NJ: Immediate opening for BC/BE Genetic Counselor. Experience preferred; Spanish helpful.
Responsibilities: Join active, expanding full-service medical genetics ctr in multiethnic urban hospital; oppty in PN & ped coun; develop new projects; teach GC, med students & residents; educ programs for parents & professional groups.
Contact: Victor K. Vena, Sr. Recruiter, St. Josephs Hospital & Medical Center, 703 Main St, Paterson, NJ 07503; 201-997-2429. EOE/AA.

Long Island, NY: Immediate opening for BC/BE Genetic Counselor; Exp preferred; Spanish helpful.
Responsibilities: PN & general GC: in-

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**NATIONAL SOCIETY OF
GENETIC COUNSELORS, INC.
EXECUTIVE OFFICE
233 CANTERBURY DRIVE
WALLINGFORD, PA 19086**

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house/outrch to clinics in Nassau & Suffolk Counties & local community hospitals; educational presentations to schools, community agencies, health professionals. Affiliated with New York Hospital-Cornell University Medical College. CONTACT: Barbara Miller, MS, St. Charles Hospital and Rehabilitation Ctr, 200 Belle Terre Road, Dept. Genetics, Port Jefferson, NY 11777; 516-474-6374. EOE/AA.

NEW YORK, NY: July 1 opening for BC/BE Genetic Counselor. Bilingual, Spanish pref. RESPONSIBILITIES: Oppty for independence in i'disc setting; comphnsv PN, ped prog svcs. CONTACT: Lisa Stevens, MS, Dept. OB/GYN, St. Lukes/Roosevelt Hosp, 425 W. 59th St, 6B, New York, NY 10019; 212-523-3454. EOE/AA

VALHALLA, NY: Immediate opening for BC/BE Genetic Counselor. RESPONSIBILITIES: Wide range of respon at tertiary care center with full range of clinical and laboratory svcs: all aspects of coun/case mgmt for broad range of genetic conditions: birth defects, MR, chrom disorders, PNDx (CVS, PUBS, terat exposures, MSAFP). Specialty clins: craniofacial, NTD, NF, CF + 7 county outreach program. CONTACT: Linda Higgs, MS, Supervisor, Medical Genetics Unit, Westchester County Medical Center, Valhalla, NY 10595; 914-347-3010. EOE/AA.

WHITE PLAINS, NY: Immediate opening for Associate Director, Professional Education. 5-7 yrs exp devel & implem professional contin ed programs; broad understanding of local, state, fed maternal/infant health care delivery systems. Some travel req. RESPONSIBILITIES: Plan, develop & evaluate Fdt's educ programs geared to technical & clinical skills of health professionals. CONTACT: Human Resources Director, March of Dimes Birth Defects Fdt, 1275 Mamaroneck Ave, White Plains, NY 10605; 914-997-4467. EOE/AA.

TOLEDO, OH: Immediate opening for BC/BE Genetic Counselor. RESPONSIBILITIES: Coordinate MSAFP program for professionals & pts: test, counsel, follow-up; follow-up data collection; potential for research. Program to expand to incl HCG & estriol screening. CONTACT: Thaddeus Kurczynski, MD, PhD, Medical College of Ohio, Dept. Pediatrics, PO Box 10008, Toledo, OH 43699-0008; 419-381-4435. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Counselor. RESPONSIBILITIES: PN & general coun for amnio, CVS, MSAFP; opportunity exists for molecular genetic workups. CONTACT: Rose Giardine, MS, Hospital of University of Pennsylvania, 3400 Spruce St, Dept OB/GYN, Philadelphia, PA 19104; 215-662-3232. EOE/AA

PHILADELPHIA, PA: July 1 opening for BC/BE Genetics Associate. RESPONSIBILITIES: Coord & counsel for 3 new multidisc clinics: Williams synd, Connective tissues directed by Paige Kaplan, MD, (50%); and neuro-cancer genetics clinic directed by Jaclyn Biegel, PhD, (50% effort to establish pediatric Cancer risk clinic in neuro-oncology. Interact w/ basic scientists, clinicians in multidisc rsrch program. CONTACT: Paige Kaplan, MD, Div. Metabolism, or Jaclyn Biegel, PhD, Section of Genome Analysis, Childrens Hospital of Philadelphia, 34th & Civic Center Blvd, Philadelphia, PA 19104; 215-590-3376 (PK) or 215-590-3856 (JB). EOE/AA.

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor. RESPONSIBILITIES: Join growing PNDx svc: establish multiple marker screening; CVS; amnio, PUBS, level II U/S; teratogen & dysmorphology counseling; follow-up & support groups; clinical research. CONTACT: Krista Sauvageau, Employment Manager, Women & Infants Hospital, 101 Dudley St, Providence, RI 02905; 401-274-1100. EOE/AA

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor. Exp. pref. RESPONSIBILITIES: Ped & adult genrl GC in academic setting w/ tchg & rsrch oppty. CONTACT: Dianne Abuelo, MD, Genetic Counseling Center, Rhode Island Hospital, 593 Eddy St, Providence, RI 02902; 401-444-8361. EOE/AA

SAN ANTONIO, TX: July opening for BC Genetic Counselor w/ 3 yrs related exp. RESPONSIBILITIES: Intake, follow-up, referral, mgmt of genetic data for analysis, reports, scientific publcn in fetal diag unit (OB/GYN) CONTACT: Office of Human Resources, University of Texas Health Science Center, San Antonio, TX 78284-7972. EOE/AA.

RICHMOND, VA: Immediate opening for non-tenure track BC/BE Lecturer in GC Trng Prog. Teaching experience & organizational skills pref; travel required to referring hospitals & satellite clinics. RESPONSIBILITIES: Teach grad, medical, dental & nursing students; assist in direction of GC instructional track; counsel variety of genetic disorders; develop educational materials & programs for students, professionals & patients. CONTACT: Joann Bodurtha, MD, MCV/VA Commonwealth University, Dept Human Genetics, Box 33, MCV Station, Richmond, VA 23298-0033. 804-786-9632. Send 3 ltrs of reference & CV. EOE/AA.

SEATTLE, WA: Immediate opening for BC/BE Genetic Counselor. Non-smoking required; independent personality pref. RESPONSIBILITIES: Join 3 GCs in large, diverse, multidisc team: pt consultations for amnio, CVS, PUBS, AFP/HCG/Estriol scrng, abnormal U/S, teratogens. Oppty for developing computer skills, teaching, publishing & conducting clin-oriented research. CONTACT: Robert Resta, MS, Director, Genetic Counseling Service, Swedish Hospital Medical Center, 747 Summit Ave, Seattle, WA 98104; 206-386-2101. EOE/AA.

MONTREAL, QU: Immediate opening for BC/BE Genetic Counsellor. Oral and written skills in French an advantage. RESPONSIBILITIES: Counsel for broad range of clinical & PNDx; involvement in org various clinics; s'visory role in McGill GC Program; ample oppty for teaching & research. CONTACT: Vazken M. DerKaloustian, MD, Montreal Children's Hospital, 2300 Tupper St, Room A-724, Montreal, Quebec, H3H 1P3, CANADA; 514-934-4336/4427. *In accordance with Canadian Immigration requirements, priority will be given to Canadian citizens or permanent residents of Canada, although others are also invited to apply.*