PERSPECTIVES
in genetic counseling

Volume 15:2 Summer 1993

Interim Board Meeting Focuses on Strategic Plan; Society Issues

Betsy Gettig, MS, President

■ *On May 8-9, the NSGC Board of Directors met in Chicago for our bi-annual business meeting. Our energies were first applied to strategic planning, followed by a session devoted to current issues facing the Society. This article underscores my commitment as your President to keep you informed about your Board's activities and actions. I welcome your comments and involvement.*

Strategic planning requires several steps. Following the adoption of our vision and mission, we needed to objectively assess our strengths and weaknesses. To accomplish this goal, Unger Consulting Services in Philadelphia was selected to facilitate NSGC through this process. (See *PGC* 15:1,11 for background.)

In January, you received a survey from Janet Unger exploring your perceptions of key issues facing our Society. A 40% response was received. "This number alone signals a high interest of your membership in your Society and the issues you face," reported Ms.

continued on p. 6

Teamwork Benefits Patients

Lori Williamson-Kruse, MS and Kimberly Harris, LCSW, ACSW, University of Arkansas for Medical Sciences, Arkansas Children's Hospital, Little Rock, AR

■ *As our caseloads increase, many genetic counselors are identifying creative ways to better service our patients. Some counselors are merely tapping resources that may have always been available, but ineffectively used. Below is an interview with Genetic Counselor Lori Williamson-Kruse and Social Worker Kimberly Harris demonstrating the power of one union between a social worker and a genetic counselor in a pediatric setting.*

What prompted formation of the team?

LW-K: My goal was to have more counseling time with patients because I was viewed primarily as an educator. Time was rarely allotted for psychosocial counseling. Meanwhile, a social worker had been requested and assigned to the genetic team.

What expectations did you have about the social worker's role within the genetic team?

LW-K: My preconception of a social worker's role was that she would care for the psychosocial needs of patients. This role threatened me because I viewed the counseling as initially my role; the social worker could then provide additional resources or counseling if necessary.

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

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NSGC gratefully acknowledges Integrated Genetics for a grant in support of this newsletter.

Issues of Quality Assurance Explored…

■ *A first step in developing standards of clinical practice is the documentation of variation in current service delivery models. Very few such studies have been conducted to date, and the prevailing impression of significant variation is based primarily on anecdotal evidence. Individual members of the* ad hoc *Quality Assurance Committee, now in the process of being subsumed under the new Genetic Services Committee (see page 7) have begun several studies relating to diversity in service delivery and quality assurance. They will report on these small-scale projects in a series of articles. Two future articles will focus on patient caseload and incorporation of cross-cultural principles into practice. The subcommittee members are open to suggestions for additional topics.*

It is important to note two caveats. First, the point of these studies is to explore different modes of service delivery, not to assign positive or negative values to them. It is hoped that such exploration will enable all of us to consider alternatives and eventually to formulate recommendations. Second, these small studies should be considered pilot projects. It is not possible to draw universal conclusions from limited surveys. Rather we hope that the data herein will stimulate discussions which may lead to the adoption of improved protocols by interested practitioners.

Karen Greendale, Chair
ad hoc *QA Committee*

As our profession begins to develop quality assurance guidelines, several members of the *ad hoc* QA committee agreed to look at specifics of how genetic counselors deliver services. As expected, there is considerable variation.

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc.
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Publication Date: September 15
Deadline for Submissions: August 10

The first area addressed was the telephone. All counselors use the telephone, but for what, and how?

In April 1993, a questionnaire regarding genetic counselors' use of the telephone was sent to the 45 full members of NSGC in New Jersey, Delaware and West Virginia. New Jersey was chosen because, as my home state, I thought I could count on colleagues I knew to respond and because of its diverse population and urban/rural variety. In contrast, in Delaware and West Virginia, only a few counselors serve a large geographic area.

The three states are also part of the MARHGN region, which is evaluating QA. Therefore, the data could be used for several purposes.

A copy of the complete questionnaire and raw data are available from the author.

Response and Results

Of the 45 questionnaires sent, 26 were returned, a 58% response rate. All 26 respondents are board certified (2/3) or eligible (1/3). Their years experience in genetic counseling range from two to 20, with an average of nine years. Almost 90% are employed by a hospital or medical center; the others are self-employed or work within a commercial laboratory setting.

Replies were anonymous. Some did not answer all the questions, so answers were tabulated as a *percentage of the total received for each question.*

Table I summarizes information about specific indications for which counselors use the telephone. Most counselors provide *some* information over the phone, but more than 75% meet with every client. Telephone counseling is regularly conducted by 4 to 5% for routine screening tests, but rarely for more complex cases.

Table II outlines phone use for teratogen information. It demonstrates the negative correlation between degree of risk and willingness to provide counseling by phone. The 4% (n=2) who noted that they *always* use the phone for teratogen counseling with a known increased risk indicated that they conducted a brief phone conversation followed by a visit.

Table III demonstrates that the nature of the test results

…Is Telephone Counseling An Oxymoron?

appears to influence how counselors relay information.

Documentation

Documentation varies widely, with 72% of counselors logging phone sessions and 50% maintaining a written chart of each session. No counselors reported taping phone sessions, and over 80% do not include phone cases in their state data entries.

Follow-up letters are not always sent to the clients after a phone contact only; those that are usually are *not* co-signed by a clinical geneticist. However, in two-thirds of the instances in which letters are sent, a copy is also sent to the referral source.

Billing; Time Factor in Phone Consultations

The inability to collect a fee was one reason cited for not conducting phone counseling. Only one fourth ever bill clients following a telephone consultation, and third-party billing is rare.

Over 90% reported spending less than 10% of their counseling time on phone sessions, while 78% reported the volume of their phone consults to be one tenth or less of their total caseload. However, calls are not brief, with about one third lasting 10 to 15 minutes each.

The average respondent handles 463 cases per year, with a workload range of 100 to 1000 cases per counselor per year. An average of 35 phone consults per year was reported, or 8% of the total caseload.

Table 1: Percentage who use phone for certain tasks

Tasks	Always	Sometimes	Never
Give general information	08	73	19
Arrange appointments	76	16	08
Preamnio counseling	00	45	55
PreCVS counseling	00	33	67
MSAFP/Triple Screen	04	48	48
Hemoglobin carrier testing	00	30	70
Tay-Sachs carrier testing	05	43	52
Newborn screen follow-up	00	36	64
Fragile X testing	00	15	85
DNA testing	00	10	90
Paternity testing	00	15	*85
Other	00	36	64

** 24% of these respondents commented that they refer these calls elsewhere*

Table II: Use of Phone for Teratogen Counseling (%)

Teratogen Risk	Always	Sometimes	Never
No known increase	21	67	12
Possible increase	00	38	62
Known increase	04	09	87

Table III: Use of Phone to Provide Results (%)

Results	Always	Sometimes	Never
Normal	73	27	00
Inconclusive	00	40	60
Abnormal	00	22	88

Pros and Cons of Phone Counseling

Those who counsel by phone are motivated primarily by the patient's convenience. The counselor's convenience was cited as secondary. Reduced cost and paperwork and the ability to handle a larger caseload were less important.

The lack of interpersonal contact was the main concern of counselors who do not conduct phone sessions. Concern for potential legal liability was next in importance.

Conclusions

Neither the length of their experience nor the type of work setting appears to effect counselors' willingness to counsel by telephone. Several commented that phone conversations would not be considered counseling, and one suggested that "phone counseling may be an oxymoron."

Clearly the concept of the personal encounter is deeply rooted in our practice. Variability was found, and the telephone adds a measure of convenience for both client and counselor, but the majority of counselors polled continue to rely upon face-to-face genetic counseling sessions. ■

Tillie Young, MS
University of Medicine and Dentistry of New Jersey, Newark, NJ

When the sum is greater than …

from page 1

KH: My expectation of my role in the genetic team was much like that of any other team in our hospital. The two teams I had experience with worked much the same: the physician dealt with the diagnosis and treatment of patients; the nurse practitioner carried out the physician's orders and instructed patients on self care and treatment; and the social worker took care of the emotional and concrete needs of the family. I envisioned the genetic team operating the same way with the genetic counselor acting in the role of nurse practitioner.

KH: Meanwhile, patients and families were not getting the emotional counseling and support they needed… .

What turf issues did you recognize?
KH: I was really clueless about turf issues. However, I was becoming frustrated because the team had difficulty knowing how or when to use social work services. They appeared to limit my responsibilities to assisting with resources and dealing with crises.

Meanwhile, patients and families were not getting the emotional counseling and support they needed to help them deal with the effects of their genetic conditions.

LW-K: My view of genetic counseling includes both education and supportive, nondirective counseling. Therefore, I expected to provide both services. When the social worker was introduced, I became resentful and disappointed because I thought she would be counseling, which I felt competent in doing and enjoyed.

What was the turning point?
LW-K: For me, the turning point was when I realized that I was letting my resentments prevent me from creating new ways to meet the needs of our patients and that Kimberly was not usurping my counseling role.

KH: One day after clinic, Lori and I began to discuss our frustrations regarding meeting the emotional needs of patients and families. We had different educational backgrounds, but a similar vision. We were both working toward the same goal of supporting patients and families, but not succeeding. So we discussed a strategy to use our respective strengths and weaknesses to compliment each other.

LW-K: That discussion helped me realize that Kimberly wanted to continue being a social worker working with the psychosocial needs of the genetic patients, not a genetic counselor. That made her less threatening to me.

What was your strategy to meet the goal?
KH: I wanted and needed a better understanding of genetic conditions, long-term effects and prognosis to counsel patients more effectively. I also needed more time to build a relationship with patients and families and wanted them to use their clinic time to share, obtain and retain information more effectively.

LW-K: Our strategy was to define appropriate cases and provide both the genetic education and psychosocial counseling as a team. If the genetic counselor and social worker are in the room together, more time is allowed for both the educational and psychosocial needs of the family to be met.

KH: Working directly with the genetic counselor enables the family to tell their history, concerns and medical information only once. I can hear the information first hand and assess the family's understanding and coping skills throughout the entire process.

How does your strategy work?
KH: Lori first reviews patient charts to select patients she thinks might benefit from social work services. During pre-clinic conference, I identify others who might be appropriate.

We prioritize the list, and Lori educates me regarding the recurrence risk and natural history of the genetic conditions. We discuss the format of the session, diagnosis and prognosis, expectations, personal biases and the level of expected intervention.

LW-K: During clinic, we enter the room together and sit such that we are perceived as a team.

KH: Lori begins by outlining the session. When patients know what to expect from their visit, they are able to pace themselves. We then solicit concerns or questions, and Lori obtains a family history.

The physician enters to examine the patient and answer questions. Next, Lori reiterates the diagnosis and provides information about inheritance and recurrence risks.

…the component parts

We then discuss the psychosocial implications of the genetic condition and/or past experiences or losses. Finally, we review the session and make recommendations for further follow-up or define other resources.

LW-K: As the session progresses, we both identify issues; we co-counsel. Afterwards, Kimberly and I de-brief.

What was the team's response?
LW-K: Overall, positive. They are becoming more aware of the psychosocial issues facing patients and are using social work services more often and in a more appropriate way. They are also realizing that genetic counselors are both educators and counselors.

KH: Initially, I think everyone wondered what we were doing and why it took so long! As I worked with other counselors, they better understood the complete process.

How has this teamwork been of benefit to your patients?
LW-K: Many genetic professionals claim to offer both education and counseling as component parts of their service. However, varied training methods and lack of time often limit the services offered. Our team approach allows us to come closer to offering the "real product" of genetic counseling.

KH: Patients and families come with fears and anxiety. They need time to talk about their experiences, gain understanding and receive help. With two professionals from differing backgrounds listening to the complete history, more "red flags" are identified.

Subsequent exploration of the issues and responses allows both of us to better assess the family's coping skills so more appropriate intervention can be offered in a manner more appropriate *and* more acceptable to the families.

What professional benefits have been realized?
LW-K: This approach allows me to fulfill my professional obligation as a genetic counselor. Therefore, I am more satisfied with myself and my career. My counseling skills are improving because I am learning from Kimberly. I am gaining a better understanding of the impact genetic conditions have on families because we have time to ask and listen to families.

Since Kimberly is present throughout the session, I have someone with whom I can debrief, which involves more than a critique of our skills. We also discuss how the family's issues affected us, providing emotional support for each other. Therefore, some of the work related stress is reduced.

KH: I get first hand information from patients and hear what they are told regarding diagnosis and education the same way they hear this information. I also have the opportunity to learn more about genetic conditions, which I can sometimes apply to other families.

The debriefing sessions help me develop stronger counseling skills. It provides time to discuss the session's effects, process with a professional who has experienced the situation and allows for personal growth.

Do you see any disadvantages to this approach?
LW-K: It takes more preparation time, and the actual time with the family is increased.

KH: The time is limited. We can't see everyone who comes to clinic and are often pulled in several directions. Since I work with two other teams in our hospital, I am often stretched and have to prioritize when emergency situations interrupt during genetic clinic hours.

What suggestions could you offer other colleagues?
LW-K: First, identify the social work services in your facility. Then seek social workers who are *interested* in genetics. Obtaining the input of the entire team is important as you develop a plan for incorporating the social worker into the clinic. Be honest about your views regarding each other's roles. Finally, being open to change makes the integration easier and fosters teamwork.
KH: I would stress the importance of having someone familiar with the counseling process to build a trusting relationship. Be willing to try co-counseling. It offers much more insight into families, their coping, under-standing and

LW-K: Our team approach allows us to come closer to offering the 'real product' of genetic counseling..

Strategic Planning; Societal Issues Addressed…

Unger to the Board. The inquiry process also included telephone interviews and two site visits to the Executive Office.

STRENGTHS, WEAKNESSES, OPPORTUNITIES, THREATS

Unger compiled a report that studied services, representation and communication in NSGC. The report identified and analyzed the *internal* strengths and weaknesses and *external* opportunities of and threats to our organization.

Defined *external* factors affecting NSGC were:

- nation health care reform,
- technologic advances,
- increased need for genetic counselors,
- needs for diversification and
- role and interaction with ABGC.

The *internal* effectiveness of NSGC focused on leadership issues related to the Board of Directors and the Executive Director. Finances, programs and services, including publications, conferences, public education and awareness, were critically evaluated.

Overall, members expressed high satisfaction with their ability to obtain timely, ample and quality information from NSGC and are pleased with the leadership of the Society. The Membership Directory and *PGC* were listed as the most valued membership features.

INFORMATION AVAILABLE

The complete Strategic Plan Report produced by Unger Consulting is available in a 96 page report. Members may obtain a copy by writing to the Executive Office. A $15 fee to cover the cost of copying and postage must accompany your order. Please order by July 9.

FORMING THE STRATEGIC PLAN

The membership sent a clear directive, the Board listened and the outline of the strategic plan was created. Of the 21 targeted issues identified by the membership, the Board prioritized them into three categories representing timelines for action. *(See page 7 for topic summaries and responsible officers, committees or staff.)*

All 21 items would and could benefit from *your* input. Please call the committee chair or Board member responsible for action. Your ideas about how to acheive each of the goals is highly encouraged.

WORK, WORK AND MORE WORK

On Sunday, eight items were brought forward for a vote:

- STUDENT INVOLVEMENT: Bonnie LeRoy proposed that a student representative be added to the Board. Although deemed highly desirable, the Board voted not to create this position at this time. A fair system to represent all programs and provide representative voting were key reasons for the veto.
- PROFESSIONAL ISSUES: Wendy Uhlmann presented a series of documents. The Board adopted subcommittee and *ad hoc* committee guidelines, a new survey timetable and guidelines for quarterly reports. Three by-laws changes were proposed related to the Code of Ethics. One was adopted. Art. 13.2 was amended to read: The Certification of Incorporation, the By-laws *or the Code of Ethics* may be amended... .
- EDUCATION COMMITTEE: The Annual Education Conference Planning Manual was presented by Carol Strom and unanimously approved.
- SOCIAL ISSUES: The Cystic Fibrosis Position Statement was adopted as presented by Vivian Weinblatt. See page 9. She also introduced a proposal by Dr. Francis Collins that NSGC consider creating a database of translocation cases. The Board approved

ACTIVITIES OF YOUR PRESIDENT

■ *Represented NSGC at HGP Five Year Goal Setting Meeting.* PURPOSE: To develop ideas and direction beyond the initial five years. ACTIONS: 125 people reviewed the current status of the original project's goals; new director Dr. Francis Collins presented the budget, appropriation projections, and new intramural and clinical programs (including genetic counseling). INPUT: My contribution was to suggest that with each gene discovery, a fact sheet be made available, detailing clinical applications, testing sites and timeframes for access to testing.

■ *Represented NSGC at COMGO meeting.* PURPOSE: Update by Dr. Elizabeth Short, member of Health Care Reform Task Force. ACTIONS: Drafted genetic component to be included in proposed health care legislation. KEY DISCUSSIONS: Genetic counselors' ability to bill for service; genetic services to be provided by appropriately certified professionals; every state must provide universal access; children with genetic diseases to be covered by *basic* plan until age 18. INPUT: Once plan is made public, NSGC members are urged to provide feedback to Social Issues Committee for inclusion in NSGC formal response.

…by Board

further exploration via Dorene Markel, chair, Genetic Research Issues Subcommittee.

- FINANCES: Deposits and a double entry system will be handled through the Executive Office, effective January 1, reported Linda Lustig. Fiduciary responsibility will remain with the Treasurer.
- NOMINATING COMMITTEE: Joan Scott recommended and the Board approved a member increase to six plus Past President I to allow for broader representation and an added responsibility to include Board Leadership issues.
- REGIONAL REPRESENTATION: Betsy Gettig successfully introduced the restructuring of Region IV and V boundaries to coincide with CORN. Oklahoma, North and South Dakota are now in Region IV. All other NSGC regions remain intact.
- GENETIC SERVICES COMMITTEE: Karen Greendale proposed and the Board unanimously approved a new standing committee to address clinical and service issues, paralleling the American College of Medical Genetics. The *ad hoc* committees related to human resources and quality assurance will submit final reports this fall, be disbanded and become subcommittees of this new committee. By-laws changes related to this decision are as follows: <u>Section 3.1.Standing Committees:</u> …education, <u>finance and genetic services.</u>
  <u>Section 3.11. Genetic Services Committee. The Genetic Services Committee shall act with respect to provision and quality assurance of clinical services provided by genetic counselors.</u> ■

VISIONING THE FUTURE

Strategic Plan Overview

■ *NSGC's Strategic Plan has taken a major step toward achieving its vision. The following issues and priorities have been identified, as determined by those members who responded to the Strategic Planning Survey (included in January membership mailing) as well as in interviews with selected Board and general members and the Executive Director. To proceed, the active participation of the members is required. You are invited to contact the Board members to provide input into the next phase.*

GOALS TO BE ACHIEVED	BOARD/COMMITTEE RESPONSIBILITIES
■ IMMEDIATE RESPONSE REQUIRED	
The following list represents goals targeted for immediate attention.	
Restructure Financial Operations	Finance; Treasurer; Executive Director
Increase Member Involvement and Leadership Development	Executive Committee; Nominating
Respond to Health Care Reform	Social Issues; COMGO Representatives
Improve Board Communications	*PGC* Editor; Regl Reps; Executive Cte
Develop Policies re: American Board of Genetic Counseling	Professional Issues; Education
■ PLANNING AND STRATEGIZING REQUIRED	
The following list represents goals requiring intermediate attention.	
Explore Membership Recruitment	Membership
Establish Quality Assurance Guidelines *(based on final report from QA* ad hoc *committee)*	Genetic Services
Assess Executive Office Staffing Priorities and Growth Issues	Executive Director; Executive Cte
Redefine Function of Regional Representatives	Regional Representatives
Vitalize Genetic Counseling Research	Journal Editor
Explore Continuing Education	Education
Collaborate with Related Professionals/Organizations	Executive Director; Executive Cte
Create Public Relations Program	Genetic Services; Regional Representatives; Executive Cte
Study Genetic Services in Underserved Areas	Genetic Services
Create Member Recognition Program	Professional Issues
Address Human Resources Issues *(based on final report from Human Resources* ad hoc *committee)*	Genetic Services
■ NO ACTION REQUIRED; MONITOR	
The following list represents goals requiring long-range attention.	
Monitor Journal	Journal Editor
Develop Guidelines for Evaluating Educational Materials	Education; Membership
Assess Speakers Bureau; Connecting Links	Executive Director
Develop List of Potential Position Statements and Resolution Topics	Social Issues
Revisit Licensure	Committee Disbanded by Board Action; Final Report to Genetic Services Chair

Protocol for Ethics Consultations Established

The subcommittee on Ethical Codes and Principles is now a standing subcommittee of the Professional Issues Committee with responsibility for interpretation, review and revision of the Code of Ethics as it applies to an individual member's practice, as well as to the NSGC's relationship with its members and society at large.

How to Submit

Created as an educational and consultative resource, the Ethics Subcommittee is now accepting your ethical questions and dilemmas using the following protocol:

- Questions can be posed to an individual or to the entire subcommittee via the chair.
- Confidentiality will be maintained throughout the process, although requests will be shared with the entire subcommittee. Specific information about any part of the consultation, however, will never leave the subcommittee or be included in any reports.
- The subcommittee accepts both formal and informal requests. Formal requests must be written and should include all pertinent information, including a clear statement of the dilemma. Formal requests will receive a written acknowledgement, including an indication of the response time.
- Informal requests will be taken and responded to in phone consultations.

What To Expect

The Ethics Subcommittee will *not* give you directive advise or tell you how to solve your ethical dilemma. Rather, we will identify the ethical principles in conflict, interpret the NSGC Code of Ethics for you and refer you to those guidelines of the Code which we believe are most relevant to your problem.

Members are encouraged to use the Ethics Subcommittee as a sounding board. In some situations, your ethical dilemmas may be ones we have argued at least once during the six year development of the Code of Ethics. Other questions, especially those of a more general nature, may even lend themselves to workshops at future conferences.

Who to Contact

The five full members of the Ethics Subcommittee are Judith Benkendorf, MS, chair, Rose Grobstein, BA, Anne Matthews, RN, PhD, Susan Schmerler, MS and Vivian Wang, MS. There are also two *ex officio* members, the Professional Issues Committee chairperson and an ethics consultant. The Ethics Subcommittee meets at the Annual Education Conference and other regional meetings. Ongoing business is conducted via conference calls at least once a quarter. ■

Susan Schmerler, MS and Judith Benkendorf, MS

Student Corner

Inquiry Meets with Success; New Focus

One genetic counseling student had a positive experience when she publicized information regarding her master's project. Beth Peshkin, MS, University of Wisconsin, placed an announcement in the Bulletin Board (*PGC*, Vol.14:2).

"As a result of contacts made after publication of my idea, I refined my thesis from a reference to a training manual on cancer risk counseling. Thus, the format as well as the audience changed.

"I also made a number of new contacts and new friends. Their input helped me shape ideas, and they were also able to give me leads about jobs, since I am interested in cancer risk counseling after I graduate.

"In addition, I became part of the planning committee for the NSGC short course on cancer genetics."

Hopefully, the other students who list their topics will have similar experiences.

Name:	Leslie Cohen, MS
Program:	Northwestern
Topic:	"Ethnocultural beliefs about the causes of birth defects and genetic disorders"
Phone:	312-996-9134
Name:	Fiona Fields, MS
Program:	Northwestern
Topic:	"Informing children with neurofibromatosis of their diagnosis: parental choices and attitudes"
Phone:	312-996-4390

Rich Dineen, MS and Bonnie Hatten, MS

GeneBytes

Pedigree Software: Can It Meet Counselors' Needs?

Though they may be unsung, routine and sometimes sloppy, pedigrees form the core of our daily work. Indeed, the very existence of the genetic counseling profession hinges on pedigrees. You would think somebody would write a computer program to help with this daily, vital task.

Pedigree software programs exist, but they may not be exactly what you want. The pedigree programs mentioned below are capable of generating standard pedigrees but none are particularly genetic counselor friendly. Indeed, some of the programs assume the user has fairly sophisticated skills, such as knowledge of Fortran.

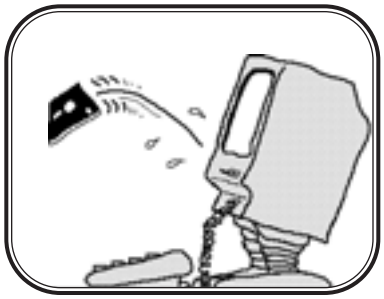
We experienced problems getting any of them to generate a simple pedigree. And each program has it's quirks, such as problems with drawing sibship order or lack of landscape printing. Of the listed programs, probably Pediplot, with its menu interface, is the least difficult to use.

In future columns, we will look at other programs, including one for Apple Macintosh. Readers are encouraged to share their views and experiences by writing either of us.

If you are interested in learning more about pedigree software, contact the companies or individuals listed below:

- Rodney C.P. Go
  Dept Epidemiology, University of Alabama, BHM, University Station, Birmingham, AL 35294-0008; 205-934-6107
  SOFTWARE: FTree.
- D. Curtis,
  Molecular Psychiatry Lab, Academic Dept Psychiatry, University College and Middlesex School of Medicine, Riding House St, London W1N8AA England
  SOFTWARE: Pedraw
  Note: Dr. Curtis is not equipped for large scale distribution of his software.
- Michael D. Badzioch
  Dept Molecular Genetics, MD Anderson Cancer Center, HM Box 209, Houston, TX 77030; 713-792-7595
  Software: Textped
- John Gersting
  UHH/CS, 523 W Lanikaula St, Hilo, HI 96720-4091; 808-933-3331
  SOFTWARE: Megadats
  Note: Not currently available; intended for very large complex pedigrees.
- Kirsten & Niels Baggesen
  Kristtornvej 19, DK 8200 Arhus N, Denmark; +45 86 10 20 55
  SOFTWARE: Pediplot

Robert Resta, MS
and Karen Wcislo, MS



Recommendations on Cystic Fibrosis Screening Added to Society's Position Statements

The following Position Statement on cystic fibrosis screening was approved by the Board of Directors on May 9 at the interim Board meeting, having received positive review by legal counsel.

To summarize, POSITION STATEMENTS reflect issues of universal nature to the practice of genetic counseling and *do not* require membership vote for incorporation. RESOLUTIONS, in contrast, are timely and may be temporal and change as laws or available services change. These statements *do* require a membership vote for incorporation. A complete text of all previously approved NSGC Position Statements and Resolutions can be found in *PGC* 14:3,6.

CYSTIC FIBROSIS SCREENING: The NSGC supports the following recommendations: 1) Individuals seeking genetic counseling who have a family history of cystic fibrosis (CF) or a relative who is a CF carrier should be offered CF carrier screening; 2) Pilot studies to explore the scientific, educational and counseling aspects of screening are necessary prior to instituting large scale population screening programs; 3) Clinicians should be encouraged to evaluate a laboratory's statistics with regard to accuracy, informativeness, specificity and sensitivity prior to sending specimens; 4) Genetic counseling services by a Board Certified/Board Eligible genetic counseling professional is an essential component of any CF screening program. *(Adopted May 1993)* ■

Vivian Weinblatt, MS
Social Issues Chair

The Huntington's Disease Gene: Current Information…

On March 23, an international team of six research groups announced the successful identification of the gene which causes Huntington's disease (HD) *(Cell* Vol 72, 921-983, Mar 26, 1993).

The new gene, IT15 (interesting transcript 15) was isolated in the 4p16.3 region and contains a polymorphic trinucleotide repeat that is expanded and unstable on HD chromosomes. The repeated nucleotides are $(CAG)_n$, which code for poly-glutamine. The protein product has been named "huntingtin." It is not yet known if the repeat is translated into protein product, and the function of the protein and mechanism by which the expanded repeat causes disease remain a mystery.

Huntingtin appears to be widely expressed throughout the body, yet cell death in HD is confined to specific neurons in particular regions in the brain.

Laboratory Specifics

At the time of the *Cell* paper, 75 independent HD families representing all different haplotypes and a wide range of ethnic backgrounds and 173 normal chromosomes had been analyzed. The normal range appeared to be 11-34 repeat units, with 98% demonstrating 11 to 24 repeats. The HD range was reported from 42 to greater than 66 repeat copies.

Newer information from Gusella's lab indicates that the normal range stops at about 34 repeats and the HD range starts at about 37 repeats, although indications from an international dataset are expected to show overlap. Also of interest are two cases of possible new mutations which were analyzed and found to have expanded repeats. Each of the individuals had a parent whose number of repeats (33 and 36) were in the high end of the normal range. Possible premutations?

This trinucleotide repeat region appears to be very unstable, with only 15% of HD patients inheriting the same number of repeats as their affected parent. Extreme increases were typically associated with male transmission. The largest HD repeat segments were found in juvenile cases where there is a known preponderance of male transmission.

Only General Conclusions

Although early reports were hopeful about a correlation between number of repeats and age of onset, researchers now caution that only *general* conclusions can be drawn. It is doubtful that this information will be specific enough to be used for counseling, with perhaps the exception of the extreme expansions seen in juvenile onset cases.

Looking at Implications

Persons involved in HD predictive and diagnostic testing met in Boston on May 17 to respond to some of the following questions:

■ ***Are we ready to begin clinical use of a HD gene test?***

Most said yes, but there are a few recognized gray areas, such as the overlap between normal and HD ranges and use of repeat number in prenatal diagnosis of juvenile cases.

■ ***Should predictive testing be offered to those at 25% risk?***

Although such testing cannot be prevented, the group suggested that a consensus try to be reached between the 25% risk offspring and the 50% risk parent. Counseling should be provided about the implications that learning one's predictive HD status has on other family members.

■ ***Should repeat testing be offered to those who have already gone through predictive testing programs?***

This is necessary, but a retest decision should be made freely, without pressure and *only* with consent of the patient.

■ ***Should this test be used to make or confirm a diagnosis?***

This would be an important use of the test, but primarily in those instances in which the diagnosis of HD has already been clinically made with some certainty. Testing for other referrals with a lower index of suspicion should be conducted under the guidelines used for predictive gene testing.

■ ***Will there be strict protocols for HD predictive testing?***

The major components of the current protocol (pretest counseling, genetic counseling, psychiatric/psychological evaluation, neurological evaluation and follow-up) used for linkage testing are still necessary, since the laboratory analysis has changed, but the psychological and social implications remain. Suggestions were made to form more general guidelines, and a summary of the recommendations are being documented to update the current guidelines.

■ ***Should minors be tested?***

Group consensus was that testing should be offered to

…You Can Use

persons 18 years or older, the only exceptions being when medically indicated, such as juvenile onset HD. Social indications, e.g., adoption, should not warrant predictive testing.

■ ***Should families continue to bank DNA on relatives?***

Yes. However, banking should be limited to the affected parent, when available, or another closely related affected family member.

As with any genetic condition, lab confirmation of the diagnosis in affected individuals is an *essential* component of analysis of extended family members. This is particularly important since a number of phenocopies for HD have already been discovered.

■ ***When will testing be available; how much will it cost?***

Probably within the next 6 months. Lab costs are expected to be considerably lower than linkage-based costs.

BE CAUTIOUSLY OPTIMISTIC

Although the identification of the HD gene is significant, it does not answer the question *When will there be a treatment or cure?* We don't yet know.

More research is necessary, but identifying a gene or even completely understanding its function and association with a disease process does not guarantee that treatments or cures are forthcoming.

It is important to be hopeful, but to not convey false promise to those HD families who continue to wait for the *real* breakthrough. ■

Dorene S. Markel, MS, MHSA
Human Genome Center
University of Michigan

12TH ANNUAL EDUCATION CONFERENCE UPDATE

THE TECHNOLOGY PARADOX: FACING THE CHALLENGES

REGISTRATION: This year's conference promises to provide first-rate education and professional growth. Register early to save your dollars for fun activities in and around Atlanta. Registration without late fee penalty is **August 1.**

EXPERIENCE THE REAL SOUTH: When planning your trip to Atlanta, consider extending your visit. Stay in Atlanta or visit Georgia to feel true Southern hospitality. *To the North:* a Bavarian village, majestic mountains and Babyland General Hospital, where Cabbage Patch kids sprout. *To the Southwest:* FDR's Little White House, Jimmy Carter's hometown and Callaway Gardens. *To the East:* Savannah, the country's largest Historic District, restored from the 1700s, and many beautiful and relaxing beaches. For information, call the Georgia Department of Tourism, 404-656-3590.

SHORT COURSE: The *The ABCs of Cancer Genetics* organizing committee is interested in obtaining information from genetic counselors who have used a laboratory for DNA studies, are providing genetic counseling or are involved in clinical or basic research projects for familial cancers. If you have these experiences, contact Maureen Smith, 901-528-6595.

SPOTLIGHT ON… The workshop, "Duty to Recall," will focus on our added responsibility because of the availability of new or improved tests for diagnostic, presymptomatic and carrier testing. The session will address decisions regarding: Which genetic disorders to target and when to recontact? Who and how to recontact: the individual, the referring physician …by phone, by letter? Who will pay for the costs of recontact and subsequent clinic visits? Legal, moral and ethical issues abound. If you have experience with recontacting families and would like to share or express a concern, contact: Robin Bennett, MS, Genetics, RG-25, UWMC, Seattle, WA 98195.

SPECIAL MEETINGS: Need to schedule a meeting or reception during the conference? Request an Ancillary Meeting Reservation Form from the Executive Office by **July 15** to assure your preferred space and time.

CALL TO ACTION: Janice Edwards and Shane Palmer, 1994 Conference co-chairs invite *you* to join the planning team. Reward yourself with the great feeling of knowing that your efforts helped make the 13th Annual Education Conference in Montreal one of the best ever! Call Janice, 803-779-4928, or Shane, 919-946-6481, now! ■

■ RESOURCES ■

A Silent Sorrow: Pregnancy Loss
authors: Ingrid Kohn, MSW, Perry-Lynn Moffitt
publisher: Dell Publishing, NY, 1992
price: $12.00 pb, 464 pp
reviewer: Carolee Watkins, MS, Mercer Medical Center

Through both personal and professional experience, Kohn and Moffitt came to the much written about subject of pregnancy loss and grief. The characteristics that makes this book distinctive and worth reading are its depth and breadth of coverage.

Common threads of emotion link the discussion of various types of losses, including: ectopic pregnancies, miscarriage, stillbirth, newborn death and pregnancy termination based on prenatal diagnostic information. The chapter about pregnancy termination is written in a non-judgmental and supportive style. The information in this chapter about genetic counseling and medical care is appropriate.

APPROPRIATE ADVICE

Throughout the book, there is an emphasis on self help. The authors provide appropriate advice about support groups and therapists and discuss responses of friends and family. They review options of seeing and holding the baby/fetus and creating memories. The authors correctly note that it is the genetic counselor's job to offer these options. Kohn and Moffitt discuss incongruent grieving in couples and emphasize that everyone, regardless of gender, has his or her own responses and needs.

The authors appear to have researched the medical portions of the book well and emphasize the importance of seeking medical advice. Touching personal stories are woven into each chapter.

While the literacy level required of the reader is high, *Sorrow* is worth recommending to patients experiencing all types of pregnancy loss, including termination based on information obtained from prenatal testing. ■

Shattered Dreams/Lonely Choices: Birthparents of Babies with Disabilities Talk about Adoption
author: Joanne Finnegan
publisher: Greenwood Publishing Group, Westport, CT. Fall 1993.
price: $22.95 hb, 173 pp
reviewer: JK Rucquoi, MS, Yale University Medical School

The Finnegans are a couple who took home their son with Down syndrome and began a search for information about adoption and a deep search of their own souls. As often happens when one searches, others are met along the path and bonds are forged. Joanne has written about her search and about others who traveled this path.

The book is comprised primarily of quotations from these couples about a variety of subjects, including: family issues, adoption and decision making. At the end of each chapter there is a paragraph summarizing the message.

There is information in this book for everyone: health professionals, counselors, social workers and parents of children with disabilities. The book is appropriate for the genetic counselor's library. ■

All God's Mistakes: Genetic Counseling in a Pediatric Hospital
author: Charles L Bosk
publisher: The University of Chicago Press, Chicago, 1992
reviewer: Jennifer Fitzpatrick, MS, The Hospital for Sick Children, Toronto, Ontario

All God's Mistakes is an analysis of the practice of genetic counseling from a sociological perspective. The University of Pennsylvania author/professor, defines himself as an "ethnographer of medical action."

His fieldwork was an observation in the late 1970s of genetic counselors in an elite, urban tertiary care facility. His objectives were to describe and interpret the behavior of the "natives" at work. The result is a fascinating outsider's perspective about the genetic counselors' roles and responsibilities.

ROLES HAVE CHANGED

The fact that Bosk did his fieldwork in the late 1970s and did not publish until last year is the book's most significant drawback. The counselors he observed were all physicians with responsibilities quite different from today's masters level genetic counselors. Bosk viewed his subjects as being limited in their approach to the psychological dimensions of the counseling process. He states that "counselors do not use questions to explore what the parents' values are or what they think they should do."

To his credit, in his closing

chapter, Bosk acknowledges that since the time of his fieldwork, many changes have occurred, notably the influx of masters trained personnel into the field and the concomitant increased emphasis on the psychotherapeutic nature of the genetic counseling process. Unfortunately, however, he does not describe these developments in enough detail to allow the lay reader to gain an accurate understanding of the roles and responsibilities of today's genetic counselors.

NONDIRECTIVENESS: A DISSERVICE?

Despite this serious limitation, Bosk identifies some problematic areas in clinical genetics that still trouble us. In describing how genetic counselors adhere to the ethos of nondirectiveness, he wonders whether this inability or unwillingness to offer advice might be an actual disservice to some patients, specifically those who need and ask for direction when faced with difficult choices.

Perhaps the physicians he observed were not particularly skilled in making patients feel comfortable with the burden of decision making, or perhaps he did not view the patients' airing of their frustrations as therapeutic in itself. Nevertheless, this is an issue which often surfaces in clinical genetics, and Bosk questioned whether nondirective counseling can sometimes be construed as patient abandonment.

PATIENT AUTONOMY DEPENDS ON CONSULTANT; SETTING

Bosk also emphasizes how strongly the notion of patient autonomy is upheld in outpatient situations but is usurped in inpatient encounters. In outpatient cases, the consultant is usually the patient, whereas in inpatient cases, the primary consultant is often the attending physician.

Bosk observed that when patients and attending physicians disagree about intervention, the geneticists would more readily abandon their defense of the patients' right to choice and defer to the attending physician.

Bosk provides a thoughtful sociological explanation for this phenomenon, shedding light on the geneticist's role as consultant in the hospital milieu, but he rightfully makes us wonder why inpatient cases are different from outpatient ones.

THOUGHTFUL READING

This is not a media influenced, reactionary piece of writing about the evils of "brave new world" technology, but a description of clinical genetics grounded in sound scientific research practice, complete with the author's acknowledgment of the limitations of his methodology. The prose is often difficult, and it is not written for laypersons.

It is not, as the book jacket describes, appropriate as "a source for informed decision making to the increasing number of people affected by the personal consequences of the new medical technology."

It is appropriate for students of medical sociology and those of us who wish to think critically about how we practice. ■

MEETING MANAGER

1993	
July 6 - 7	Region III NSGC Education Conference, "Unusual Serum Screening and Triplet Repeat Update," Sea Pines, Hilton Head, SC. Contact: Andy Faucett, 912-350-5970.
Sept 10 - 11	PacNoRGG, PSRGN and NSGC Region VI Continuing Education Conference, "Screening the Pregnant Client: Who to Screen and Why," Embassy Suites Hotel, Bellevue, WA. Contact: Connie Cox, 503-494-8342.
Nov 20 - 21	Alliance of Genetic Support Groups and National Organization for Rare Disorders joint meeting, Holiday Inn, Alexandria VA. Focus: health care financing. Contact: Alliance, 800-336-GENE.
1994	
April 11 - 14	Danish Council of Ethics, Copenhagen, Denmark. Title: "Ethical debate: public participation." Abstracts of up to 500 words are being accepted through October 1, 1993. Registration and abstract submissions: Else Marie Sejer Larsen, Chairperson, The Danish Council of Ethics, Ravnsborggade 2-4, 2200 Copenhagen N, Denmark.

■ BULLETIN BOARD ■

SLC Offers Awards for Counseling Tapes

The Human Genetics Program at Sarah Lawrence College is developing a video library of genetic counseling sessions. To encourage this effort, $1000 will be awarded for the best film of an entire counseling session; $500 will be awarded to the runner-up.

The object is to obtain a comprehensive counseling session incorporating a range of issues. Initial sessions are preferred.

The quality of the tape should enable students to learn from watching. It should be visible and audible, but does not need to be professionally produced. The length should be a minimum of 30 minutes, and hard copies of the pedigree should be provided.

Winners will be selected by a committee of SLC faculty and genetic counselors. The winning videos will become the property of Sarah Lawrence Genetic Counseling Program and used for teaching purposes only.

Please contact Joan Marks, 914-395-2371, for additional information. Tapes are due by October 1. The winner will be announced in November.

Ethical Dilemmas Wanted

The NSGC Ethics Subcommittee, ELSI fellow Julie Maley and Drs. John Fletcher and Thaddeus Kelly are compiling a case based ethics textbook. The book will be based on our NSGC Code of Ethics.

Genetic counselors and students are invited to submit cases in which ethical dilemmas have been identified. Short discussions of related ongoing ethical concerns not illustrated by an individual case may also be submitted.

Counselors whose contributions are included will be acknowledged and will receive a free copy.

For more information, contact Julie Maley, PhD, Dept Pediatrics, Div Genetics, Box 386, Health Sciences Center, University Virginia, Charlottesville, VA 22908; 804-924-2665; FAX# 804-982-3850.

Subcommittee Recruitment

The Ethics Subcommittee is recruiting three members for three-year terms starting October 1. Minimum requirements are full membership, interest in bioethics and the ability to attend committee meetings.

If interested, send your CV and a letter outlining your interest and experience in bioethics to: Judith Benkendorf, Dept OB/GYN, Georgetown Univ Medical Center, 3800 Reservoir Road NW, Washington DC 20007-2197 by August 6. Address questions to: Rose Grobstein, 503 Weatherstone, Paoli PA 19301; 215-889-7418.

Members Awarded CF Grant

The National Institutes of Digestive and Diabetes and Kidney Diseases (NIDDK) has awarded a two-year, $500,000 grant for the project, Cystic Fibrosis Carrier Screening Educational Materials, to Trish Magyari, MS, Principal Investigator and Ann C.M. Smith, MA, Project Director. The project will include the development of a package of public and professional educational, multi-media materials for use in population-based CF carrier screening programs for use in medical centers, public health clinics, community settings and private physician's offices.

Call for Applications

On March 16 - 20, 1994, the final phase of the ELSI project, "Genetic Counselors as Educators on Human Genome Issues," will conduct a "train the trainer" course in Chicago using materials developed for primary care professionals.

Twenty genetic counselors representing all six NSGC regions who can attend and will conduct the course in their areas are invited to apply. All expenses will be covered. Contact Beth Fine, 312-908-7713.

Study Break

If you are reading this in lieu of or in avoidance of studying for Boards, the entire group of already Board Certified members wish you good luck!

…Now back to work!

NSGC Nearer to Offering Liability Insurance

The most frequently asked question by members logged into the Executive Office is one regarding the availability of professional liability insurance. Finally, a broker who has been working tirelessly to locate a company willing to accept genetic counselors is meeting with success. If you are interested in updated information as it becomes available, please send a postcard or note to the Executive Office. Information will be made available to interested members as we learn more about the potential of offering this membership benefit. ■

■ EMPLOYMENT OPPORTUNITIES ■

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

■ **LOS ANGELES CA:** Summer/Fall 1993 opening for BC/BE Genetic Counselor. Exp, Spanish language skills preferred.
RESPONSIBILITIES: PN coun & AFP coord, CVS, early amnio; research oppty, med student educ.
CONTACT: Michelle Fox, MS or Peggy Kulch, MS, UCLA Medical Center, 300 Medical Plaza, #3102, Los Angeles CA 90024-6969; 310-206-8211. EOE/AA.

■ **COLORADO SPRINGS CO:** Immediate opening for BC/BE Genetic Counselor w/ MS in GC or BS in nursing. Exp pref.
RESPONSIBILITIES: PN diagnosis, MSAFP triple testing, commun educ, eval of newborn, ped & adult cases; outreach site for Denver geneticists.
CONTACT: Jane Congleton, MS, RN, Southern Colorado Perinatal/Genetics Ctr, Memorial Hospital, 1400 E. Boulder St, Colorado Springs CO 80909; 719-475-5960. EOE/AA.

■ **TAMPA FL:** Immediate opening for BC/BE Genetic Counselor. CV and 5 letters of recommendation required.
RESPONSIBILITIES: Wide range of GC oppty w/ significant respon for pt care: PN (amnio, CVS, U/S programs); satellite clinics; educ activities.
CONTACT: Boris G. Kousseff, MD, University South Florida, 10770 N 46th St, Suite C-900, Tampa FL 33617; 813-975-6900. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of PN & some ped GC: amnio, CVS, teratogens, U/S abnormalities, NICU & developmental ctr consults, preimplantation genetic dx. Coord CF carrier testing prog. Oppty for teaching & research.
CONTACT: Melody White, MS, Reproductive Genetics Institute, IL Masonic Medical Center, 836 W. Well-ington, Chicago IL 60657; 312-296-7095. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Work w/ clin geneticist/pediatrician and GC in tertiary care children's hosp w/ full range clin & lab genetic svcs. Counsel pts & families in myelomeningocele, CF, cleft lip/palate clins; assist w/ genrl genetics, metabolic, NF & skeletal dysplasia clins; inpt consults. Liaison between lab & referring MDs.
CONTACT: Joel Charrow, MD, Head, Clinical Genetics, Children's Memorial Hospital, 2300 Children's Plaza, Chicago, IL 60614; 312-880-4462. EOE/AA

■ **BOSTON MA:** Immediate opening for Genetic Associate with MS in GC or related field. Exp pref; not required.
RESPONSIBILITIES: Join busy PN program: molecular DNA dx prog, involvement in MSAFP; research oppty.
CONTACT: Aubrey Milunsky, MD, Ctr for Human Genetics, Boston University School of Medicine, 80 E Concord, Boston MA 02118; 617-638-7083. EOE/AA

■ **WORCESTER MA:** Immediate opening for BC/BE Genetic Counselor. Exp pref.
RESPONSIBILITIES: Bi-weekly comp Genetic Clinic, major respon for PN diag intake, coun & liaison between PNDx lab & pts/physicians. Close supt by exp med geneticist.
CONTACT: Philip L. Townes, MD, PhD, Director, Div Genetics, Dept Pediatrics, Univ Massachusetts Medical Ctr, 55 Lake Ave North, Worcester MA 01655; 508-856-3949. EOE/AA.

■ **CHARLOTTE NC:** Immediate opening for PhD BC/BE Medical Geneticist.
RESPONSIBILITIES: S'vise new clin genetics svc: plan & implement clin svcs, recruit & s'vise GCs, counsel pts, liaison between clinicians & genetic lab svc.
CONTACT: Sheila Davis, Personnel Dept, Presbyterian Health Services Corp, PO Box 33549, Charlotte NC 28233-3549; 704-371-4000. EOE/AA

■ **STATEN ISLAND NY:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Diverse PN & ped coun: amnio, AFP, teratogen, malformations, etc; dysmorph, fra X, cytogen in developmental disabilities clins; inpt, NICU consults; partic in lay & prof educ, nltr, advis council, family supt groups.
CONTACT: Susan Sklower Brooks, MD, Comprehensive Genetic Disease Program, New York State Institute for Basic Research in Developmental Disabilities, 1050 Forest Hill Rd, Staten Island NY 10314; 718-494-5240. EOE/AA

■ **TOLEDO OH:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Expand outreach genetic svcs primarily to children & families with/at risk for MR or developmental delay in NW Ohio area.
CONTACT: T. W. Kurczynski, MD, PhD, Dept Pediatrics, Medical College of Ohio, PO Box 10008, Toledo OH 43699-0008; 419-381-4435. EOE/AA

■ **PORTLAND OR:** One-year temporary opening for BC/BE Genetic Counselor, beginning 9/93: 3 mo FT; 9 mo 1/2 time w/ poss of continuing.
RESPONSIBILITIES: Provide GC for wide range of conditions, partic in PNDx prog, coord & admin clin svc in conjunc w/ MD/PhD genetics team.
CONTACT: Judy Parmenter, Kaiser Permanente, 2701 NW Vaughn, Suite 300, Portland OR 97210-5398; 503-721-3874. EOE/AA

■ **PHILADELPHIA PA:** Summer 1993 opening for BC/BE Genetic Counselor; limited travel to satellite clinics req.
RESPONSIBILITIES: Join 4 GCs on multidisc team w/ range of all aspects of PNDx: CVS, amnio, fetal reduction, Level II U/S; weekly ped & adult clins; opporty for teaching & research.
CONTACT: Marie Barr or Vivian Weinblatt, Medical Genetics, Suite 400, Thomas Jefferson University Hospital, 1100 Walnut St, Philadelphia PA 19107 215-955-5080. EOE/AA

■ **PHILADELPHIA PA:** Aug 1 opening for Part time BC/BE Genetic Counselor.
RESPONSIBILITIES: 10-14 hrs/wk at estab perinatal ctr in suburban Phila.
CONTACT: Mike Osborne, Genetics & IVF Inst, 905 Rutledge Ave, Horsham, PA 19044; 215-654-0212. EOE/AA

■ **COLUMBIA SC:** October 1 opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of PN diag coun: CVS, amnio, MSAFP, U/S detected abnorm; tchg oppty in MS Genetic Counseling Prog; partic in CDC Neural Tube Prevention (folic acid) 4-yr project.
CONTACT: Janice G. Edwards, MS, University South Carolina School of Medicine, Dept OB/GYN, Two Richland Medical Park #208, Columbia SC 29203; 803-779-4928. EOE/AA

■ **CHARLOTTESVILLE VA:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team of 4 GCs & 4 MDs in predominantly PN position: CVS, amnio, PUBS, AFP, teratology.
CONTACT: Rachel Baughman, MS, Dept Obstetrics, Div Genetics, Univ Virginia Medical Center, Box 387, Charlottesville VA 22908; 804-924-2500. EOE/AA

■ **RICHMOND VA:** September 1 open ing for BC/BE Genetic Associate/ Research Assistant. CV & 3 letters of reference required.
RESPONSIBILITIES: Multifaceted position with emphasis on PN coun; active outreach, family planning, fetal anomalies, pediatric specialty clins; GC training prog; collaborative research.
CONTACT: Joann N. Bodurtha, MD, MPH, Dept Human Genetics, Medical College of Virginia/Virginia Commonweath University, Box 33 MCV Station, Richmond VA 23298-0033; 804-786-9632. EOE/AA

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nsgc

233 Canterbury Drive
Wallingford, PA 19086-6617

Legislative Briefs

Hello from your new Legislative Liaison! I am thrilled to be assuming this position and plan to keep you informed of the exciting developments taking place here in Washington, DC.

My personal interest is in vision research with a focus on counseling for the visually impaired. I have the privilege of working at the Ophthalmic Genetics Department of the National Eye Institute, National Institutes of Health.

In the legislative arena, many changes have occurred since President Clinton took office on January 20th.

Just two days into his term, President Clinton commemorated the 20th anniversary of the landmark Roe V. Wade decision by issuing an executive memoranda:

- overturning the Title X "gag rule," which prohibited family planning clinics receiving federal funds from providing complete and unbiased counseling to low-income women;
- overturning the "Mexico City Policy," which prohibited nongovernmental organizations receiving federal funds from administering international family programs that encouraged or supported abortion "as a method of family planning";
- lifting the ban on the performance of abortions in overseas military hospitals for military personnel and their families, provided that individuals pay for the procedure themselves;
- mandating the review of the ban on importation of RU486 into the United States for personal use.

Everyone is anxiously awaiting the findings of the Health Care Reform Task Force, headed by Hillary Rodham Clinton. Abortion is anticipated to be a controversial area of the the health package, as the current thought is that Clinton intends to include abortion as part of the basic health plan.

Signs of increased pressure for both sides of the issue are evident. Pennsylvania Gov. Robert P. Casey (D) said in a speech that the health care package would be "dead on arrival" if it provides coverage for abortion. However, in a letter sent to Hillary Clinton, 31 female House members insisted that abortion be included in any proposal. Expected to be released sometime in July, a full review of the report will be included in the Fall issue of *PGC*. ■

Laura Wozencraft, MS
Legislative Liaison