

PERSPECTIVE S

in genetic counseling

Volume 15:3

Fall 1993

USING GENETIC SUPPORT GROUPS WISELY

by Barbara Lerner, MS, Genica Pharmaceuticals, Worcester MA

Most genetic counselors will refer a family to a genetic support group at some point in their professional lives. The value of the concept is well recognized, but there is little in the literature about evaluating the quality of the group to which the family is referred or ensuring the effectiveness of the referral. The following article represents the experiences of several genetic counselors in their quest to develop personal lists of support groups and make appropriate referrals.

BUILDING A REPERTOIRE OF SUPPORT GROUPS IN YOUR AREA

■ DEVELOP A REFERRAL CATALOG

"Being aware of the support groups in your area is one of the first tasks to tackle," suggests Karen Treat, Beth Israel Hospital in Boston. However, this can be difficult since groups are continuously created and disbanded. Additionally, some groups do not promote themselves.

continued on p. 6

MEET YOUR NEW BOARD

The following officers, committee chairs and regional representatives will assume their positions at the October general membership meeting. Newly elected or appointed persons are indicated with an asterick. Your Board is here to serve you. Please call on them to communicate your thoughts about their work or the work of the Society in general.

OFFICERS

Karen Greendale	518-473-8036	President
Bonnie LeRoy	612-624-0144	President-Elect*
Andy Faucett	912-350-5970	Treasurer*
Nancy Callanan	919-966-4202	Secretary
Betsy Gettig	412-578-7359	Past President I
Edward Kloza	207-883-4131	Past President II

COMMITTEE CHAIRS

Maureen Smith	901-528-6595	Education*
Linda Lustig	415-923-3046	Finance*
Rebecca Rae Anderson	402-559-6497	Genetic Services*
To Be Appointed		Membership
Ann Happ Boldt	317-274-1061	Professional Issues*
Vivian Weinblatt	215-955-4295	Social Issues
Vickie L. Venne	714-728-4310	PGC Editor
Deborah Eunpu	215-572-8636	JGC Editor

REGIONAL REPRESENTATIVES

Mary-Frances Garber	617-732-4208	Region I*
Jill Stopfer	215-456-8726	Region II
Shane Palmer	919-946-6481	Region III*
Kathy Delp	616-732-8664	Region IV
Amy Cronister	505-438-2164	Region V*
Robin Bennett	206-548-4030	Region VI

The NSGC thanks the 1993 nominating committee, chaired by Edward Kloza, and its members, Judith Benkendorf, Jacqueline Hecht, Vickie Hannig and Naomi Nakata, for a job well done!

**national society
of genetic
counselors, inc.**

nsgc

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

ON THE INSIDE

Health Care Reform: Will Kaiser be the Model?	2
Code of Ethics: More than a Silent Partner	3
Database Survey Follow-Up	4
New JGC Address	4
Visioning: Research in Nursing	5
Professional Issues; Genetic Services Committees	8
AEC Acknowledgements	9
HGP Update	10
Letters to the Editor	10
GeneBytes	11
AEC Update	11
Bulletin Board	12
Resources: <i>How to Break Bad News; Precious Lives Painful Choices</i>	13
Meeting Manager	14
Student Corner	14
Employment Opportunities	15

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

Committed to providing highest quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

HEALTH CARE REFORM — WILL KAISER BE THE MODEL?

by Lisa Fritzke, MS, Kaiser Permanente, San Jose CA

■ As the United States lumbers toward health care reform, those in medical institutions are looking closely at the Health Maintenance Organizations (HMOs) as possible prototypes for health care. It is important to consider what will become of genetics inside an HMO. Several genetic counselors from Northern California were asked to comment on their transition from a private or University setting to a Kaiser genetic department.

Working for Kaiser means being part of a team whose members include the local genetic department staff as well as those in the other genetic departments in the region. The regional genetic community works to maintain efficient and consistent service.

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Editorial Staff:

• Editor-in-Chief • Vickie Venne, Nichols Institute, 33608 Ortega, San Juan Capistrano CA 92690; 714-728-4310; FAX# 714-728-4979

• Karen Copeland, Central Texas Genetics, Austin TX

• Richard Dineen, Univ Illinois College of Medicine, Peoria IL

• Andrew Faucett, Memorial Medical Center, Savannah GA

• Susan Jones, Childrens Hospital of Philadelphia, Philadelphia PA

• Seth Marcus, Lutheran General Hospital, Park Ridge IL

• Kathryn Steinhaus, Univ California Irvine Medical Center, Orange CA

• Executive Director • Bea Leopold • NSGC Executive Office, 233 Canterbury Drive, Wallingford PA 19086; 215-872-7608; FAX# 215-872-1192

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

Publication Date, Next Issue: December 15
Deadline for Submissions: November 10

The opinions expressed herein are those of the authors and do not necessarily reflect those of the Editorial Staff or NSGC.

The group meets formally about every six weeks to establish protocols and share ideas and problems related to standard of care for their patients. In general, the system is well-organized, and the genetic counselor role is well-defined. Genetic counseling tasks are identified, and efforts are made to streamline them on a local and regional level.

The genetic counselors handle both prenatal and general genetic cases, with 60 to 70% being prenatal. They work closely with the geneticists on the general cases, while the prenatal cases are often handled independently. There is a built in and carefully maintained system for support, feedback and guidance.

THE GOOD

Kaiser counselors do not have to deal with financial matters for any services such as counseling, lab tests, patient transportation, interpreters or abortions. They do not assume the role of the social worker and can thus devote more of their time and energies to the work they were trained to do.

THE BAD

However, there is a tendency to keep responsibilities of genetic counselors the same, so there are fewer genetic counselors with particular specialties.

In addition, there is a sense of isolation from primary care and subspecialty providers. While much effort has gone into establishing the role of genetics and defining what is an appropriate referral, some of the camaraderie which comes from sharing or even turf wars with other departments is missing.

Also missing is the intellec-

tually stimulating atmosphere of the University setting. Some genetic counselors regret leaving behind the opportunity to work on new genetic technology and its applications. Having come to Kaiser, they feel as though they are losing their edge, that there is nothing in the external environment urging them to keep up-to-date.

IN EXCHANGE

In exchange, the genetic counselors found job security with higher salaries and better working conditions. The pressure to publish or write grants is gone. Kaiser Northern California has more money for clinical care, management and facilities than most university settings. It is clinically rather than research-oriented, so the money does not have to be divided or shared.

DO THE PATIENTS BENEFIT?

Does this money and clinical focus mean better patient care? Medical records can be easily obtained for the patient and, with permission, Kaiser family members. Patients are generally seen in a timely manner. Appropriate referrals to subspecialties within and outside of Kaiser can be made without concern about payment. Linkage analysis on samples from non-Kaiser family members can be financed, although this is reviewed on a case-by-case basis.

At Kaiser, the patient's interests are not compromised because of the cost of a procedure or a test. Clinical decisions are based on what is medically appropriate for the patient rather than what the patient or the medical center can afford. The genetic counselors also

continued on p. 14

THE CODE OF ETHICS: MORE THAN A SILENT PARTNER?

In 1991, the NSGC membership approved a professional Code of Ethics. Based on the four primary relationships of genetic counselors — relationships with themselves, their clients, their colleagues and society, there should rarely be a dilemma the Code of Ethics cannot help you resolve. The following article is the first in a series of four that will outline the application of our Code.

Do either of these two scenarios sound familiar?

SENARIO I: A client is referred at 16 weeks gestation because her obstetrician is worried about hemoglobin electrophoresis results that are difficult to interpret. You feel uncomfortable about handling this case alone without first having a diagnosis of carrier status established. The medical geneticist is unable to provide additional information, and the consulting hematologist also finds the results unclear and cannot help you unless family studies are done. You wonder how to handle the case.

SENARIO II: Your colleague is having personal problems that are impacting job performance. You contemplate intervening to offer support and suggest a decrease in patient load.

Who or where did *you* turn to the last time you faced similar conflicts? Was it your Code of Ethics? If not, please read on.

CODE OF ETHICS TO THE RESCUE

By adopting a Code of Ethics, the NSGC membership agreed to be guided by the Code and, in return, take responsibility for their professional conduct. The Code of Ethics reflects our collective beliefs, responsibilities and goals. In addition, our Code promotes our professional identity and the public's recognition of this identity.¹ In fact, the two scenarios above exemplify issues dealt with in the first section of the Code.

Section I addresses genetic counselors themselves. It documents the value we put in competence, integrity, dignity and self-respect. Guidelines 1, 3 and 4, for example, may be applied when counselors find themselves in over their heads.

In these situations, counselors should acknowledge their limits honestly, to both themselves and their colleagues, and strive to seek all relevant information, assistance or support to not compromise competence. If specific situations are repeatedly found to be difficult, the self-aware genetic counselor should consider steps such as continuing education in this area and should consult established practice standards.

Therefore, don't fret if you find yourself in scenario one. Tell the other members of the team that based on your profession's Code of Ethics, you believe it is unfair to the client to complete the consult without appropriate medical back-up.

TAKE CARE OF YOURSELF FIRST

Guideline 5, Section I refers to another area in which self-awareness is important for genetic counselors to be the best possible resource to themselves, their clients, their colleagues and society. To keep their physical and emotional health in check and not compromise professional performance, genetic counselors are encouraged to pull back when necessary and seek out activi-

ties and individuals who can contribute to their self-renewal. This includes heightening one's awareness of and/or confronting professional issues which affect one's personal life and impinge upon job performance. With such a commitment to self-care, it is expected that genetic counselors will make it their duty to empower themselves and colleagues to tend to their own physical and emotional health as needed. Therefore, don't shy away from reaching out to a colleague. You owe it to your colleague and to yourself to share your concerns.

USE IT

The members of the Ethics subcommittee ask you not to let your Code remain a silent partner. Develop a relationship with the Code and practice applying it to daily situations. We will be reviewing the three other sections of the Code in subsequent issues of *Perspectives*. As we do, and you begin to use the Code regularly, it will be apparent that the four relationships and their resultant guidelines are closely intertwined. Moreover, this will strengthen the fifth relationship of the Code — the Code of Ethics and you. ■

*Judith Benkendorf, MS and
Anne Matthews, RN, PhD*

- 1 Benkendorf, J.L., Callanan, N., Grobstein, R., Schmerler, S. and K.T. FitzGerald. 1992. "An Explication of the NSGC Code of Ethics," *JGC* 1(1):31-40.

NATIONAL ON-LINE DATABASE FOR GENETIC MATERIALS: SURVEY RESULTS

The Patient Literature Subcommittee of the Education Committee is involved in a collaborative effort to create an easily accessible, comprehensive database of genetic educational resources. This is a follow-up to the previous article and survey response card (*PGC*, 15:1). It reflects returns from 157 members; a 14% response rate.

CURRENT DATA BASE USAGE

The majority of survey respondents (72%) indicated that they are currently using one or more databases to access genetic resources and information. A list of 37 databases has been compiled and is represented in the accompanying table. The most frequently used databases are OMIM (48%), Reprotox (57%), Medline (37%), TERIS (13%), GratefulMed (13%) and POSSUM (10%).

COMPUTER USE AND ACCESSIBILITY

Most survey respondents (81%) reported that they were comfortable using a computer terminal and modem. A computer and modem in the workplace was reported to be available by 82% of respondents.

ON-LINE OR GRAPEVINE?

Desire for a genetic resource database was high. Ninety eight percent of respondents indicated that they would use a

database if it were accessible by modem. On a scale of 1 to 10, with 10 representing a computer accessible database and 1 representing a phone call, about 80% of respondents ranked 8, 9 or 10, indicating that they would prefer to directly access a database and print a list of resources rather than call a database coordinator or other source for information.

WHAT'S NEXT

Currently, funding is being sought for continued development of the project. A central access system is being established with the help of the OMIM experts at Johns Hopkins University. The colla-

borating organizations are collecting a comprehensive list of existing databases. If you are aware of any databases other than those in listed below, please contact Jannell Sloan, 304-842-4955.

SUMMARY

Thanks to the 157 counselors who responded to our survey. Based on their high degree of computer literacy, accessibility to hardware and interest in a database, we will continue to participate in this project which has the potential to reach and benefit a large portion of the NSGC membership. ■

*Jannell Sloan, MS and
Barbara Pettersen, MS*

DATABASES OF GENETIC INFORMATION OR PATIENT EDUCATION MATERIALS

ACOGNET	OSSUM
ALLIANCE	London Dysmorphology and Neurogenetic databases
Comp-U-Serve	Multilingual patient educational materials, Gisela Rodriquez, UMDNJ-NJ Medical School
Current Contents	MUMS (Mothers United for Moral Support, Inc)
Custom program in "Clipper"	NORD database
Database designed by Hedda Hunter, Canada	PAPERCHASE
Database developed by Dr. Susan Winter for dx metabolic disease	Poisindex
Dirline	POSSUM
Genetiware	Reprorisk
Genome database	Reprotox
GratefulMed	Rutgers Center for Ethnocul- turally Competent Materials
Great Plains Genetic Network	Shepard
HELIX	SOFT
IDENTIDEX	SYNDROME
Internet	TERIS
IRGS (Interregional Genetic Systems)	TexSearch
Medline	TOMES
NLM	Weaver's Prenatally Dx
OMIM	

JGC OFFICE CHANGE

Effective immediately, all correspondence and manuscripts for the *Journal of Genetic Counseling* should be sent to Deborah L. Eunpu, MS, P.O. Box 2145, Jenkintown PA 19046. The new *Journal* office phone is 215-572-8636.

RESEARCH: THE FUTURE FOR GENETIC COUNSELORS; THE PRESENT FOR NURSES



■ Research was one of many topics discussed during the development of the NSGC's strategic plan. The Journal of Genetic Counseling provides a forum for the publication of our research, the Jane Engelberg Memorial Fellowship funds innovative ideas and our profession is discussing doctoral programs. Additionally, an increasing number of employment opportunities incorporate research. However, a research committee is already a standing committee for our genetic nurse colleagues in ISONG. The chair of that committee was asked to share her thoughts regarding the development of research in genetic nursing with us.

Nursing, because of its broad range of services, requires a knowledge base paralleling the scope of its practice. That knowledge base is developed through research based on responses of individuals and groups to actual or potential health problems, the environments that influence health in humans and the therapeutic interventions that affect the consequences of illness and promote health. Within the discipline of nursing, the primary purpose of nursing research is to improve clinical nursing care of patients.

One event which provided impetus for nursing research was the establishment in 1986 of the National Center for Nursing Research (NCNR) within the NIH. The mission of the NCNR is to support basic and clinical research and research training in the science of health care relevant to nursing.¹ The research programs of the NCNR focus on health promotion and disease prevention, understanding and mitigating the effects of acute and chronic illness and disabilities and the delivery of nursing services.

HOW IS RESEARCH PERFORMED?

Nurses in all specialty areas may assume a variety of research related roles in the course of their practices. While some conduct independent research projects, others

collaborate with colleagues, use the findings in their practice, provide consultation, collect data or participate in other phases of the process.

Examples of the types of studies nurses in genetics might investigate include;

- adaptation to genetic conditions and birth defects;
- psychosocial impact of genetic technologies on women's health;
- examination of nursing interventions to assist with coping mechanisms in genetic conditions; and
- assessment of how factors such as family interaction and motivation are related to decision-making or symptom management caused by a genetic health problem.

BARRIERS AND RESOLVES

Time and money are important considerations for any research endeavor. Finding the time for research is one of the more challenging aspects. Developing a time table to direct the course of the study from start to finish as well as scheduling blocks of writing time without interruption are often helpful. Collaborative work may reduce the time demand on each person.

Examples of federal agencies that provide financial support for nursing research include the NCNR and National Institute of Child Health and Human

Development. Nursing research may also be supported by philanthropic, foundation and professional organizations such as the American Nurses Foundation and Sigma Theta Tau Nursing Honor Society.

PROFESSIONAL SUPPORT

The ISONG Committee on Research was established to support and foster nursing research among populations with or at risk for genetic health conditions. This research is focused on generating and using scientific knowledge to promote health, prevent disease, and improve the quality of nursing care delivered to genetic clients and families. In addition to promoting the conduct of nursing research in genetics, the committee also aims to facilitate networking among nurses in genetics about research issues, encourage genetic research collaboration among investigators and foster the utilization of research findings in nursing practice and education. ■

*Mira Lessick, PhD, RN,
Rush University College of
Nursing, Chicago
ISONG Research Committee Chair*

¹ U.S. Department of Health and Human Services (May, 1988). *NIH extramural programs: Funding for research and research training*. NIH Publications No. 88-33, p. 132. Washington, DC: National Institute of Health.

GENETIC SUPPORT GROUPS...

Maintaining a current list of active groups is an ongoing process. The ease of finding groups will vary, depending on the rarity of the disorder, the demographics of your community and the amount of professional support available to groups. Two organizations (Table 1) can help locate national groups and their chapters. Colleagues may also know of groups for which they can provide first hand knowledge.

According to Robin Blatt, Coordinator of the Massachusetts Genetics Program, Department of Public Health, developing connections with the local genetic related support groups is essential to providing comprehensive health care. "By establishing personal relationships with these groups and knowing what services and resources they have to offer, health care providers can make appropriate referrals that can potentially make a significant difference in a person's adaptation to his or her diagnosis, condition or general situation," she suggests.

Public health departments and other related professionals may be able to direct you towards local support groups (e.g., familial cancer support group may be located through an oncology unit).

■ DEVELOP A DOSSIER ON EACH GROUP

Finding the group is only part of our responsibility prior to making a referral. Two additional questions to consider are:

- *What is our role in screening a group prior to referral?*
- *How much quality assurance should we be expected to provide for our patients?*

A basic genetic counseling tenet is to strive towards a non-directive approach to counseling. As a result, many may not believe it is our role to determine which groups our patients should contact. The director of the Alliance of Genetic Support Groups, Joan Weiss, says there are no true quality assurance measures in place to evaluate support groups. However, she believes it is the patient's decision and choice to make, and it is our responsibility to find out as much about each group as possible. She believes that the counselor "cannot be held accountable for everything that goes on in the group meeting. We must give some responsibility to the patient."

Gail Brookshire, of Children's Medical Center in Dallas, thinks it is imperative to speak with the support group's contact person prior to making the first referral to ensure that the group's goals, mission and style

of operating can be accurately transmitted to the patient. This will help ensure a smooth and effective referral. Also, take time to read the literature distributed by the group to get a sense of their technical knowledge and social stance. "Without that effort on the genetic counselor's part," Gail says, "the referral may turn out to be a negative experience instead of a nurturing one for the patient."

Robin Blatt has developed questions (Table 2) as part of her genetic needs assessment program, currently called "Mapping Massachusetts." Incorporating these questions into your interview with the group's coordinator will help create a picture of a support group's operations. To keep track of the information, consider designing a catalog with an entry for each group.

MAKING A REFERRAL TO A GENETICS SUPPORT GROUP

Timing is crucial when referring to a support group. It is first necessary to determine the patient's readiness to hear about the group's availability. Is a referral into a group support structure appropriate or would the patient benefit from individual counseling first?

"Although the patient may not be able to retain information about the group at the initial counseling session," says Randi Zinberg, of New York City's Mt. Sinai Hospital, "we discuss it then, as well as in subsequent conversations. I also include information about the support group in my follow-up letter and tell the patient it's available when they are ready to consider joining a

TABLE 1

RESOURCE ORGANIZATIONS TO IDENTIFY NATIONAL GENETICS SUPPORT GROUPS

- Alliance of Genetics Support Groups
35 Wisconsin Circle, Ste. 440, Chevy Chase MD 20815
800-336-4363 or 202-652-5553
- National Organization for Rare Disorders
P.O. Box 8923, New Fairfield CT 06812
800-999-6673 or 203-746-6518

HOW TO IDENTIFY AND MAKE REFERRALS, from p. 1

group. This way, they can decide when the time is right for them."

Include the group's brochure as an additional reference. It is also important to allow the patient to make the first contact to the group. A call from the group may be considered an invasion of privacy or too confronting for the patient at the time. Most individuals need to decide to contact a group within the parameters of their own timeframe.

For most of us, referring to genetic support groups is as

routine as coming into the office. It remains a significant part of a very complex counseling process. Providing an out of date phone number or referring to a group with an agenda different from what is expected may reflect negatively on the person making the referral. Personal evaluation of a support group prior to making a referral can improve the service we provide. ■

1 Bennett, Robin L. In Support of Support Groups: The Role of Genetic Self-Help Groups in Medical Genetics. *Genetics*

Northwest. 5:3-5, Spring 1990.

2 Blatt, Robin JR, Peer Support Groups: Establishing a Relationship, Making a Referral. Unpublished.

3 Weiss, Joan O, Support Groups For Patients With Genetic Disorders and Their Families. *Pediatric Clinics of North America*. 39:13-23, 1992.

[EDITORS NOTE: PGC publishes information about national support groups based on space availability. We encourage counselors to screen groups prior to making referrals to ensure their appropriateness.]

TABLE 2

COLLECTING DATA FOR YOUR GENETIC SUPPORT GROUP REFERRAL CATALOG

■ GENERAL INFORMATION

Support Group Name:

Contact Name:

Address, phone, fax:

■ ORGANIZATIONAL STRUCTURE

When was the group founded?

Is the group a member of Alliance of Genetic Support Groups?

Is the group incorporated as a non-profit organization (501c3)?

Is the group a chapter of a national organization?

Does the group have an advisory board? Who?

What is the background of the contact person and/or officers?

■ MEMBERSHIP

How many members does the group currently have?

What are the criteria for joining the group?

What are the membership responsibilities?

■ FINANCING

How is the group financed?

Are dues required? How much are they?

Are donations solicited? From whom?

In what type of fundraising activities does the group engage?

■ MISSION AND GOALS

Is there a printed or stated mission for the group?

Is there a written philosophy for distribution?

What services does the group offer members and nonmembers?

■ COMMUNICATIONS AND MATERIALS

How does the group communicate with it's members?

What written material is available for distribution, and what does it say?

Can a sample of materials be obtained free of charge? (Include it in your catalog)

■ MEETING STRUCTURE

How often does the group meet?

When and where are the meetings?

Is there an outline for the meetings?

Are professionals invited to attend as members or speakers?

■ PEER SUPPORT FACILITATORS

Does the group have a staff?

Are the facilitators parents, professionals or a team?

Have the facilitators had specialized training in running a support group?

■ CONFIDENTIALITY

Does the group maintain a mailing list of its members, and is it kept confidential?

Has the group addressed issues of confidentiality with regard to issues that may arise in providing support?

■ QUALITY ASSURANCE

Is there a structure that enables clear lines of accountability or responsibility?

Are there mechanisms for evaluating the support group?

Developed by Robin J. Blatt, Massachusetts Genetics Program, Massachusetts Department of Public Health, 1993

SPOTLIGHT ON PROFESSIONAL ISSUES; WELCOME TO GENETIC...

The Professional Issues Committee was established to address issues pertaining to the professional interests of genetic counselors. Over time, the tasks of the committee have changed as the profession has evolved. If there is a project listed below (or not listed) that you would like to join (or establish), attend our committee meeting or contact the project chair. We welcome

your input, participation, ideas and energy!

PROFESSIONAL STATUS SURVEY

A key task of this Committee is the administration of a bi-annual survey to evaluate our professional roles and compensation. The survey results have been used to negotiate salaries, faculty status and other professional benefits. Committee members formulate survey questions; data entry and

analysis is performed by paid consultants. This year's committee will work on the 1994 survey.

"VOICES OF GENETIC COUNSELORS"

A brochure emphasizing the different work environments and career paths of genetic counselors needs volunteers. This brochure will be included in career packets, displayed at college fairs and used for public relations and general public education. We need about 100-150 word descriptions about your work, why you decided to become a genetic counselor or aspects of genetic counseling you find rewarding. In addition, the artistic design of this brochure could use your input. Contact Wendy Uhlmann for details. The deadline for contributions is October 31.

STANDARDIZATION OF FAMILY PEDIGREE PROJECT

Robin Bennett and Kathryn Steinhaus have spearheaded efforts to develop standard pedigree symbols to represent family information and relationships. A task force is working on nomenclature and educational materials to promote the use of these symbols by all health professionals. See the Bulletin Board (*page 12*) if you are unable to attend their Poster Session at the NSCG or ASHG meeting this Fall.

"NETWORKING" PROJECT

Debra Doyle has been developing of a list of professional organizations with interests that relate to our profession. This project will facilitate networking opportunities and collaborations with colleagues in other medical specialties.

WELCOME TO OUR NEWEST STANDING COMMITTEE

STANDARD (n): 1. Something considered by an authority or by general consent as a basis of comparison; an approved model. 2. anything, as a rule or principle, that is used as a basis for judgment. 3. an average or normal requirement, quality, level (*e.g. His work this week hasn't been up to his usual standard.*)

STANDARD OF PRACTICE (n): 1. Within a profession, the usual and customary provision of services by a prudent and competent practitioner. 2. a judgment of adequacy of care which may be influenced by many variables including location and type of practice, professed areas of specialty or complexity of the case. 3. one of the concerns of the newly established GENETIC SERVICES COMMITTEE.

Current trends in health care presage greater standardization — of access, coverage and care plans. In the rapidly evolving field of genetics, it is difficult to imagine how this will resolve. How are *basic* genetic services to be defined? How can we assure appropriate care for people in remote locations, with limited means or of differing ethnic heritage? Who should decide when a certain test, such as CF population screening, becomes standard procedure? When a special interest group, such as the International Huntington Association, articulates a protocol for testing or management of a genetic condition, what authority should it carry in the genetic community or the courts? What constitutes the practice of genetic counseling, and who should have the authority to do it? What standards should be applied in assessing the adequacy of an individual's practice? Issues such as these will be the focus of the newly organized Genetic Services Committee, chaired by Rebecca Anderson. It will take under its umbrella two *ad hoc* committees formerly engaged in similar inquiries: the Quality Assurance committee and the Human Resources committee. Members interested in wrestling with these challenging topics are encouraged to attend the committee meeting during the AEC or contact Becky Anderson. ■

...SERVICES

ETHICS SUBCOMMITTEE

This subcommittee serves as an educational and consultative resource and provides ongoing interpretation of the Code of Ethics. The subcommittee, chaired by Judith Benkendorf, has established an ethics consultation service.

Subcommittee members have teamed with Drs. Julie Maley, John Fletcher and Thaddeus Kelly to prepare a bioethics casebook for genetic counselors based on the Code of Ethics. All NSCG members are encouraged to submit cases.

INFORMATIONAL BROCHURE FOR HR PURPOSES

Human resources departments often have difficulty classifying genetic counselors and establishing a salary structure. A new project is the development of a brochure outlining the educational background, clinical training and board certification of genetic counselors to aid these processes.

PROFESSIONAL PUBLIC RELATIONS

In our quest to be the leading voice, authority and advocate for our profession, we must network with colleagues in other medical subspecialties. Another new project involves creating pamphlets specific to other medical disciplines describing how genetic counseling will benefit their patients and families.

For more details, contact Ann Boldt, or come to the committee meeting during the Annual Education Conference. ■

*Wendy R. Uhlmann, MS
Past Professional
Issues Chair*

*and Ann H. Boldt, MS
Professional Issues Chair*

WITH THANKS...

We wish to thank the following exhibitors for their support of the NSGC's 12th Annual Education Conference:

Alfigen — The Genetics Institute	Pasadena CA
Dianon Systems/Collaborative Diagnostics	Stratford CT
Genelex	Seattle WA
Genetic Design	Greensboro NC
Genica Pharmaceuticals	Worcester MA
Institute for Molecular Genetics at Baylor College of Medicine	Houston TX
Integrated Genetics	Framingham MA
Management Recruiters of Chattanooga	Chattanooga TN
March of Dimes Birth Defects Foundation	White Plains NY
Oncogenetics	Phoenix AZ
Oncor	Gaithersburg MD
Roche Biomedical Laboratories	Research Triangle Park NC
Silver Platter Education	Brookline MA
SmithKline Beecham Clinical Laboratories	St. Louis MO
U.S. Dept of Energy / Human Genome Program	Oak Ridge TN

and we extend a special thanks for the following conference support:

Arcade Publishing	New York NY
...for the donation of a book, <i>Anna, A Daughter's Life</i>	
Cherwell Scientific	Brookline MA
...for the donation of the software package, Cyrillic	
deGruyter-Mouton Advertising	Hawthorne NY
...for the donation 6 books, <i>Prescribing our Futures</i>	
Genetics & IVF Institute	Fairfax VA
...for an unrestricted donation	
GeneScreen	Dallas TX
...for a grant to cover printing the registration brochure	
Genetrix	Scottsdale AZ
...for an unrestricted donation	
Integrated Genetics in conjunction with	
Genetic Design	Greensboro NC
...for supplying totes, notepads and pens for this conference	
Integrated Genetics	Framingham MA
...for funding a breakfast seminar, "New Frontiers in Cardiovascular Genetics"	
MetPath	Teterboro NJ
...for supplying Sunday afternoon refreshments	
Roche Biomedical Laboratories	Research Triangle Park NC
...for a generous grant to cover the printing of the program book	

and we gratefully acknowledge the following companies for supporting Short Course Series #1: The ABCs of Cancer Genetics

Dianon Systems/Collaborative Diagnostics	Stratford CT
ONCOR	Gaithersburg MD
Metpath	Teterboro, NJ

...YOUR SUPPORT IS GREATLY VALUED!

WHAT'S HAPPENING WHERE? THE NINE GENOME CENTERS

■ *Although many researchers have HGP-related grants, nine academic institutions share the largest amount of NCHGR financial support. These facilities will provide the core of the scientific information expected from the 15-year project.*

MASSACHUSETTS INSTITUTE OF TECHNOLOGY, CAMBRIDGE (*est Oct 1990*) E. Lander. Constructing the genetic and physical maps of the mouse genome and a low resolution physical map of the human genome.

WASHINGTON UNIVERSITY, ST. LOUIS (*est Oct 1990*) D. Schlessinger. Constructing complete physical maps of human chromosomes X and 7; and participating in assembling YAC contigs of disease gene regions on other chromosomes.

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO (*est Oct 1990*) R. Myers. Constructing a complete physical map of human chromosome 4; sponsoring educational activities for teachers, students and support groups.

CHILDREN'S HOSPITAL OF PHILADELPHIA (*est May 1991*) B. Emmanuel. Participating in a consortium to assemble integrated physical and genetic maps of human chromosome 22.

UNIVERSITY OF CALIFORNIA, BERKELEY (*est August 1992*) G. Rubin. Developing a physical map of the genome of the fruit fly *Drosophila melanogaster*.

UNIVERSITY OF IOWA, IOWA CITY (*est Oct 1992*) J. Murray. Generating a high resolution, easy to use genetic linkage map of the entire human genome; studying ethical, legal and social issues; providing opportunity for teachers to attend the University of Iowa to study genetics

and the HGP and become catalysts in their communities.

UNIVERSITY OF MICHIGAN, ANN ARBOR (*est Oct 1990*) F. Collins. Improving technology to make the steps from "clinic to base pair" more efficient, faster and less costly; finding the gene for early onset breast cancer; developing educational programs for teachers and journalists.

BAYLOR COLLEGE OF MEDICINE, HOUSTON (*est Feb 1991*) C. T. Caskey. Assembling physical maps of human chromosomes

X, 6 and 17; providing a YAC screening service to the international community working on chromosome 17p.

UNIVERSITY OF UTAH, SALT LAKE CITY (*est Feb 1991*) R. Gesteland. Developing and implementing sequencing technology; identifying high quality markers for genetic mapping ("jumping genes"); focusing efforts on developing genetic markers for chromosomes not being actively studied. ■

JoAnn Inserra, MS

LETTERS TO THE EDITOR

TO THE MEMBERSHIP:

NSGC member Dr. George Tiller, shot in both arms by a fanatic who stalked him outside of the his women's clinic in Wichita, is well and working.

I called his office the day after the trauma to learn that he was "in surgery." Deeply concerned, and because I know the staff well, I took the liberty of asking his condition and was happily told that he was *performing* surgery, not *undergoing* surgery! The incident did not curtail his work, even for a day.

A donation has been made in his name to Religious Coalition for Abortion Rights by the NSGC for his speedy recovery, remarkable resilience and deep commitment to choice.

Betsy Gettig, MS, President

TO THE EDITOR:

We enjoyed reading the interview with Lori Williamson-Kruse, MS and Kimberly Harris, LCSW, ACSW (PGC 15:2). We especially appreciate the candor with which they shared all that went into developing their rich professional relationship.

The process they went through to resolve their differences superbly exemplifies Guidelines 3 (*Recognize the traditions, practices, and areas of competence of other health professionals and cooperate with them in providing the highest quality of service.*) and 4 (*Work with their colleagues to reach consensus when issues arise about the role responsibilities of various team members so that clients receive the best possible services.*), Section III, of the NSGC Code of Ethics.

As members of the committee responsible for framing the Code, it is gratifying to read an example of it in action.

*Judith L Benkendorf, MS,
Georgetown University, Washington, DC
and Nancy P. Callanan, MS,
UNC Chapel Hill, Chapel Hill, NC*

HELP FOR STATISTICAL ANALYSIS

Undertaking a research project is always difficult — busy clinic schedules, funding, departmental politics and inertia make it hard for projects to even get off the ground. If one successfully surmounts these obstacles, there still remains the intimidating hurdle of statistical analysis. After all, how many genetic counselors are comfortable applying aggression analysis, analysis of variance and confidence intervals?

Fortunately, an IBM-based computer program makes the statistical analysis of data easier. *Epi Info* was developed by the Epidemiology Program Office of the CDC and the WHO's Global Programme (*sic*) on AIDS. It is designed "for handling epidemiological data in questionnaire format and for organizing study designs and results into text that may form part of written reports." *Epi Info* helps in investigation design, questionnaire preparation, data entry and analysis of results. Some of the analytic techniques include ANOVA, means, frequency, cross-tabulations, regression analysis, confidence intervals, graphs and histograms. Files can be exported and imported to and from most popular formats. Different modules allow for data checking, entry validation and file merging.

GENETIC APPLICATION

Despite *Epi Info*'s epidemiological orientation, the program can be adapted to genetic research. For example, most studies on choroid plexus cysts focus on risks for Trisomy 18, but have also found a few cases of Trisomy 21. Even a weak association between Down syndrome and choroid plexus cysts could be clinically important. This association could be evaluated by comparing the choroid plexus cyst frequency of mid-trimester fetuses who are karyotypically normal to those who have Trisomy 21. *Epi Info* could carry out the entire research portion of the project.

System requirements for *Epi Info* (Version 5) include an IBM-compatible computer running PC-Dos or MS-DOS (Version 2.0 or higher), 512K RAM and a graphics adapter board for generating graphs. A tutorial, manual and sample files are included in the package. The current cost is \$38.00. Version 6 is due for imminent release. *Epi Info* can be ordered from USD, Inc., 2075-A West Park Place, Stone Mountain GA 30087; 404-469-4098. *Epi Map*, a related program also available from USD, can be used to generate geographic frequency maps and cartograms.

■ ■ ■

MORE PEDIGREE DRAWING PROGRAMS

As a follow-up to our previous column on pedigree software, we have heard of two others, both Windows-based. Cyrillic for Pedigree Drawing is available from Cherwell Scientific Publishing Ltd, 15 Auburn Place, Brookline MA, 02146; 617-277-4200.

Genetics Pedigree Database is being developed by G. Bradley Schaefer, MD, University of Nebraska Medical Center, Omaha NE 68198-5430 and should be available in January 1994.

Look for reviews of these products and an Apple-based product in future columns. ■

by Robert Resta and Karen Wcislo



THE TECHNOLOGY PARADOX:

FACING THE CHALLENGES

MEDIA RESOURCE CENTER

The Media Resource Center will highlight the impact that genetic testing, prenatal diagnosis and genetic counseling have on our society. In addition to videos currently collected, we are asking you to dig deep into your video cabinets to find programs you may have taped in recent years that would be of interest ...Oprah, 60 Minutes, Donahue, 48 Hours...even local programs reflect national sentiment toward our profession and impact how our work is perceived.

To contribute tapes, call Monica Alvarado, 818-375-2073, or Cynthia Kane, 510-658-4371.

ETHICS CASES TO BE HEARD

Ethics Subcommittee members will be available throughout the conference for *Ethical Troubleshooting: Curbside Consults*. This service will allow you to discuss situations with a member of the subcommittee who will help you apply the Code of Ethics to your case.

Additionally, Dr. Julie Maley will be available to accept your ethical conflicts for the casebook she is writing with the Ethics Subcommittee.

Got a problem? We'll be equipped to listen. See the information board at registration to schedule your session with a subcommittee member or Dr. Maley.

ABGC TO CONVENE IN ATLANTA

Plan to be at ABGC's first membership meeting on Monday, October 4 at 7:15 am to hear about the ABGC structure as well as the election results. ■



BULLETIN BOARD



NEWS FROM THE BELTWAY

Barbara Bowles Biesecker, MS and Don Hadley, MS have joined the Intramural Program at NCHGR this month to co-direct a new genetic counseling training program, create a multidisciplinary genetic counseling research center and coordinate an enhancement of clinical medical genetics services at the NIH.

Last January, Elizabeth Thomson joined NCHGR's ELSI project to coordinate the research portfolio related to genetic testing, education and counseling and manage the cystic fibrosis consortium.

BEYOND CIRCLES, SQUARES AND DIAMONDS

The Standardization of the Family Pedigree task force has been working diligently to establish standardized symbols for pedigree nomenclature. Their recommendations and a request for feedback will be presented at poster sessions during both the NSGC and ASHG education conferences.

We hope to see you there, since that will be the best opportunity to receive your valuable input. If you are unable to attend the conferences but are interested in providing feedback, contact Robin Bennett, 206-543-4030, Kathryn Steinhaus, 714-456-6873, or Stefanie Uhrich, 206-543-3767, to discuss the project.

PUBLIC AWARENESS: AN INVITATION TO BE INVOLVED

The Task Force for Public Awareness in New Orleans is looking for ASHG members to meet with local groups during their annual meeting, October 6-9. Volunteers will speak to a community organization about the scope of clinical genetics and the importance of reproductive choice for our patients.

Although the law banning abortions in Louisiana was overturned by a Federal Appeals Court in September 1992, ASHG is committed to emphasizing the importance of genetic services through a variety of activities during their

meeting. If you can contribute to this outreach by speaking to a local group, contact Dr. Mary Z. Pelias at 504-568-6151 or Dr. Peter Rowley at 716-275-3461.

MCH PUBLICATION AVAILABLE

The Department of Health and Human Services, Maternal Child Health Bureau, has recently published *Maternal and Child Health Research Program: Active Projects FY 1990 and 1991*. Single copies are available at no charge from National Maternal and Child Health Clearinghouse, 8201 Greensboro Drive, Suite 600, McLean VA 22102; 703-821-8955x254.

CALLING HIGH SCHOOL AND COLLEGE STUDENTS

For those of you who speak with students considering a career in genetics, three resources are now available:

■ *Solving the Puzzle*, a 24-page booklet published by GSA and ASHG, reviews many options in the field and features past president Joan Scott. Copies are available for \$1.00.

Call 301-571-1825.

■ *What's Ahead? Careers in the Human Genome Project* has been published by the Education Program, University of Michigan NIH Human Genome Center. This tri-fold brochure outlines some careers specific to the HGP.

Order copies from Paula Gregory, 313-747-2738.

■ Students who are specifically interested in a career in genetic counseling can order a high school or a college/career change level packet, *Is a Career in Genetic Counseling in Your Future?*, from the NSGC office.

IN MEMORIAM

The genetic counseling community lost a dear friend and colleague, Randi Kramer Fox, on June 15 of renal cell carcinoma. She was 39 and had graduated from Sarah Lawrence College in 1979.

Randi worked at The New York Hospital - Cornell University Medical College for more than 10 years. Her area of expertise was Marfan syndrome, and she was instrumental in organizing the original New York chapter of the Marfan Foundation.

A memorial is being established in her name at the new science center, now under construction, at Sarah Lawrence College. Anyone wishing to make a contribution in Randi's name can send a check to Swinford House, Sarah Lawrence College, Bronxville NY 10708. Please indicate that your donation is in memory of Randi Kramer Fox for a memorial in the new science building.

Randi was an extremely caring and thoughtful person and was a wonderful friend. She will be deeply missed.



How To Break Bad News

by: Robert Buckman, MD

published by: Johns Hopkins
University Press, Baltimore
MD, 1992, 223 pp

price: \$45.00 hb, \$15.95 pb.

reviewed by: Ginny Corson, MS,
Johns Hopkins Hospital,
Baltimore MD

This practical book is written for health care professionals by a medical oncologist who draws largely on his personal experiences. The author strives to increase the reader's ability to communicate bad news, comfort level with this task and sensitivity to feedback.

Although the book may be most useful to physicians and many of the examples used are from oncology settings, the skills and protocols described are applicable to a variety of professions and disciplines, including clinical genetics.

The author begins by describing social, patient and professional factors which contribute to the difficulty of breaking bad news. The special circumstance of dealing with the news of terminal illness is also considered.

General communication skills are illustrated with focus on listening, questioning and responding. This discussion leads to a six-step protocol for delivering bad news. A wide range of patients' general and specific reactions to bad news are then presented with options for the professional's response. Dr. Buckman compares the strengths and drawbacks of each closed, empathic, open or hostile response in various circumstances. The book closes

■ RESOURCES ■

with an examination of the interaction of the professional with family members and reactions of the health care team.

Most practicing genetic counselors will already be sensitive to many of the issues raised by Dr. Buckman. In spite of this familiarity, his very specific attention to the setting, semantics and the emotional aspects of communicating bad news make this book a unique resource for counselors interested in improving their skills. The book would also be valuable for students. For readers of all experience levels, the specific, short examples and their analyses will heighten awareness of one of the most challenging aspects of health care. ■

Precious Lives, Painful Choices: A prenatal decision-making guide

author: Sherokee Ilse

published by: WinterGreen Press,
Maple Plain MN, 1993, 88pp
price: \$7.50

reviewed by: Leslie Ciarleglio
MS, Univ Connecticut Health
Center, Farmington CT

As a prenatal genetic counselor and facilitator of a termination support group, I work with individuals, couples and families who are faced with abnormal prenatal diagnostic test results. Counseling these families at the time of abnormal test results is a challenge. Patients are often in shock, and it can be difficult for them to assimilate the amount of information we supply.

While it is usually possible to provide literature about a specific disorder, and even about

loss, grief and bereavement, there has been a paucity of written material for families who face loss by choice. *Precious Lives* is a self-help book geared specifically to these families, filling a long needed void.

Precious Lives guides families through the painful journey of receiving bad news, the perinatal options, the decision making process, coping skills and dealing with the future. The book is formatted with self-explanatory chapters: Getting the News, Deciding, The Options, Continuing the Pregnancy and Terminating the Pregnancy. They are written independently so readers can choose information without necessarily reading the entire book. In addition, the book includes an appendix and an annotated bibliography.

This book provides excellent practical advice with concrete guidelines which are needed for patients who tend to be very disoriented at this time in their lives. The text is interspersed with quotes from people who have "been there." While the majority of these are enlightening, there seems to be an overabundance in which a diagnosis that looked certain during pregnancy turned out to be wrong at delivery. I also sensed a subtle bias toward continuation of pregnancy.

Overall, *Precious Lives* is thorough, compassionate and practical. It should be made available to any family in this painful situation and should be on the shelf of every prenatal genetic counselor, support group facilitator, perinatologist and community obstetrician. ■



KAISER AS EXAMPLE from p. 2

have the freedom to see a patient for a follow up visit without worrying about who will pay. Nor do the patients wonder if their medical coverage will be dropped because of a particular diagnosis. For some of these patients, it is important that they continue with Kaiser, as they would not be accepted by other insurance plans.


In general, the genetic department functions as a consulting center responsible for coordinating patient care. The system works because Kaiser patients are willing to work within the system, keep their appointments (less than 1% no-show!) and take an active role in their health care.

THE ANSWER IS YES

The response of counselors working for Northern California Kaiser is mostly a positive one. Because genetic counselors spend a great deal of time coordinating with the other medical departments to provide care for their patients, they are in a unique position to evaluate whether the Kaiser system works. In fact, genetic counselors are often the ones who must see that it does work. As more individuals are identified as high risk for various conditions that have a genetic component such as heart disease or cancer, health insurance companies may respond by increasing the list of preexisting condition limitations, and more people will be left without proper coverage.

Hopefully Kaiser will be able to maintain its integrity and continue to provide all of its members with appropriate care, spreading the cost and encouraging both quality and efficiency. ■

Student Corner

 Student representatives from the various Region IV training programs met during the Spring 1993 Regional NSGC conference to compile a list of concerns and suggestions for improvement regarding the master's level training programs. They attempted to identify issues which applied to all or the majority of the programs. A complete list of their work is available from Michele Choe, 916-736-6888. The completed list was originally offered to program directory in Region IV only but may be useful to other programs and genetic counselors as well.

Students beginning the new school year are encouraged to submit their project or thesis topics as soon as possible to be considered for publication. Students may send their submissions to either Rich Dineen or Bonnie Hatten.

We look forward to hearing from all of you. ■

MEETING MANAGER	
1993	
Sept 29	The Institute for Genomic Research, George Mason University Center for Health Policy, <i>The Ethical Implications of Human Genome Research</i> , George Mason University Fairfax Campus, Fairfax VA. Conference Organizer: Charlene Douglas, PhD, RN. For information, call Geri Dolan, 703-993-1931.
Oct 21-22	<i>Law and Science at the Crossroads: Biomedical Technology, Ethics, Public Policy and the Law</i> , Boston. For more information, call C Wagan, 617-573-8627.
Nov 5-6	<i>First Genetic Marker - Blood Group Research, Race and Disease: 1900-1950</i> . Indianapolis IN. For information, call W Schneider, 317-274-3811.
Nov 20 - 21	Alliance of Genetic Support Groups and National Organization for Rare Disorders Joint Conference, <i>Health Care in Flux: How Will Families with Special Needs Fit In?</i> , Holiday Inn, Old Town, Alexandria VA. For information, call the Alliance, 1-800-336-GENE or NORD, 1-800-999-NORD.
1994	
Mar 13 - 15	March of Dimes 25th Clinical Genetics Conference, <i>Genes in Development and Cancer</i> , Hyatt Orlando, Kissimmee FL. Conference Directors: Arthur L. Beaudet, MD, Jessica G. Davis, MD and Rosalie B. Goldberg, MS. For information, call March of Dimes, 914-428-7100
Mar 15 - 17	American College of Medical Genetics First Annual Meeting, <i>A General Conference on Clinical Genetics and Clinical Laboratory Genetics</i> , Hyatt Orlando, Kissimmee FL. Conference Directors: Jessica G. Davis, MD and David L. Rimoim, MD, PhD. For information, call ACMG, 301-571-1825.



■ 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.*

■ **BERKELEY CA:** Civil Service Exam to be given in January 1994 for 2 Genetic Disease Program Specialists (GDPS IV & GDPS III). GDPS IV req 4 yrs admin in pub health genetic prog w/ rsrch, coun or tchg in genetics, genetic disease or closely related field; GDPS III req 3 yrs exp in same. GDPSIV: \$3827 - \$4618/mo; GDPS III: \$3486 - \$4205/mo.

RESPONSIBILITIES: GDPS IV serves as section chief of major statewide PN prog scrng approx 350,000 women/yr; develop & monitor stds for PNDx ctrs, cyto & molec biology labs; assist Chief in develop, implement, eval genetic disease prevention & control prog & policies. GDPS III provides consult & prog developmt to med community re: hereditary & congenital disease preven progs; devel prog objectives & stds, eval proj effectiveness, liaison & coord w/ lab svcs.

CONTACT: Application & announcement re: Civil Svc Exam, Maxie Spears, Genetic Disease Branch, Berkeley CA; 510-540-2613. [TDD 916-657-3042]. Apps must have return postmark by Nov 12. EOE/AA.

■ **LA JOLLA CA:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Rapidly growing academic ctr w/ wide range of clin & lab svc; wide range of GC oppty: genrl & repro genetics, amnio, CVS, teratogens, MSAFP screening.

CONTACT: Teri Richards, RN, University of California, San Diego, Div Medical Genetics, 9500 Gilman Drive, Box 0639, La Jolla CA 92093-0639; 619-597-2615. EOE/AA.

■ **PASADENA CA:** Immediate opening for BC/BE Genetic Counselor; special attn to candidates bilingual in Spanish.

RESPONSIBILITIES: All aspects of PN coun & case mgmt: CVS, amnio, U/S, terat & MSAFP. Involvmnt in ped/gen tchg & dev new clin programs poss.

CONTACT: Debra Cheyovich Tasic, DrPH, Alfigen-The Genetics Institute, 11 W. Del Mar, Pasadena CA 91105; 818-666-3300. EOE/AA.

■ **STANFORD CA:** Immediate opening for BC/BE Genetic Counselor w/ min 1 yr exp & Spanish language skills pref.

RESPONSIBILITIES: Join team w/ 3 GCs & 5 MDs in PN univ-setting: amnio, PUBS, AFP, teratogens, abnorm U/S, CVS, DNA analysis & genrl genetics; oppty for public & prof educ, clinical rsrch.

CONTACT: Robbie Tung, MS, Coordinator, Stanford University Medical Ctr, Dept GYN/OB, Stanford CA 94305; 415-723-5198. EOE/AA.

■ **SAVANNAH GA:** Spring/Summer 1994 opening for BC/BE Genetic Counselor. Salary range: \$32,000+; full hosp benefits; 10 meeting days/yr.

RESPONSIBILITIES: Join regl, diverse perinatal ctr w/ signif PN respon & independence. Provide educ for referring OBs, public, med students, residents; some newborn peds & satellite ped clins; oppty for rsrch.

CONTACT: Andrew Faucett, MS, Savannah Perinatology Associates, 4750 Waters Ave, Ste 202, Savannah GA 31404; 912-350-5970. EOE/AA.

■ **WEST DES MOINES IA:** October 1993 opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Range of genetic svcs in private perinatal practice.

CONTACT: Neil T. Mandsager, MD, Des Moines Perinatal Center, 3408 Woodland Ave, Ste 302, West Des Moines IA 50266; 515-222-3060. EOE/AA.

■ **CHICAGO IL:** December 1 opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Coord preconcept GC prog for public health family planning clin affiliated w/ UC; oppty for PN coun (amnio, CVS, U/S) & educ activ.

CONTACT: Amy Lemke, MS, The University of Chicago, Dept OB/GYN, MC2050, 5841 S Maryland Ave, Chicago IL 60637; 312-702-6621. EOE/AA.

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: All aspects of PN & ped GC: amnio, CVS, U/S abnorm, AFP, triple scrn, teratogens; wide range of ped disorders; educ & rsrch oppty.

CONTACT: Barbara K. Burton, MD or Karen Niedermeyer, MS, Ctr for Medical & Repro Genetics, Michael Reese Hospital, 2929 S Ellis Ave, Chicago IL 60616; 312-567-7340. EOE/AA.

■ **GARY IN:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: All aspects of PN coun, genrl GC: outrch clins, educ, nltr & advis bd partic; med student education.

CONTACT: Panayotis G. Iatridis, MD, DSc, Director, NW Ctr for Medical Education, 3400 Broadway, Gary IN 46408; 219-980-6555. EOE/AA.

■ **BOSTON MA:** Immediate opening for Full-time temporary BC/BE Genetic Counselor.

RESPONSIBILITIES: Join 2 GCs, 2 MDs to provide comp genetic svc to member & clin of lrg HMO. Broad range coun issues; strong PNDx prog: AFP2 & Tay Sachs co-coord; prof educ to HMO clinicians.

CONTACT: Martha MacMillin, MS or Susan Meccas-Faxon, MS, Harvard Community Health Plan, Genetics Dept, 185 Dartmouth St, Boston MA 02116; 617-859-5150. EOE/AA.

■ **BALTIMORE MD:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Join estab, active, growing PNDx ctr: CVS, amnio, triple screen, abnormal U/S, terat.

CONTACT: Theodore Baramki, MD or Sheila Traut, MS, Greater Baltimore Medical Center, Prenatal Diagnostic Center, Room 2312, Baltimore MD 21204; 410-828-2536. EOE/AA.

See Next Page

■ EMPLOYMENT OPPORTUNITIES ■

■ **BALTIMORE MD:** Immediate opening for BC/BE Genetic Counselor; Exp pref.

RESPONSIBILITIES: S'vise, coord, coun genetics inpt & outpt in tertiary care tchg hosp w/ active fellowship prog; oppty for educ & rsrch.

CONTACT: Karen Hofman, MD, Johns Hopkins Hospital, Ctr for Medical Genetics, 600 N. Wolfe St, Baltimore MD 21287; 410-955-3071. EOE/AA.

■ **GRAND RAPIDS MI:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Create, design, market & implement new MSAFP scrng prog; PN coun & involvment in educ health care community.

CONTACT: Terri Cargill, Human Resources, Butterworth Hospital, 100 Michigan NE, Grand Rapids MI 49503; 1-800-347-5455 or 616-732-2641. EOE/AA

■ **ST. LOUIS MO:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Join 4 GCs & 5 MDs in univ-based PNDx ctr offering CVS, amnio, PUBS, MSAFP + HCG, gen U/S, TIS; oppty for rsrch.

CONTACT: Heidi A. Beaver, MPH, Jewish Hospital, Div Genetics, 216 South Kingshighway, St. Louis MO 63110; 314-454-8168. EOE/AA.

■ **ST. LOUIS MO:** Immediate opening for BC/BE Genetic Counselor w/ interest in mental disorders. Half time w/ poten for FT.

RESPONSIBILITIES: Provide cognitive GC exclusively for mental disorders in newly estab psych GC clin; signif respon for coun & supt to adult pts & families w/ range of psych disorders (schizophrenia, bipolar, schizoaffective disorder, depression, alcoholism); liaison betw referring clinicians & commun supt grps; oppty for mktg, rsrch, tchg.

CONTACT: Steven O. Moldin, PhD, Washington University School of

Medicine, 4940 Childrens Place, Dept Psychiatry, St. Louis MO 63110; 314-362-9435. EOE/AA.

■ **ASHEVILLE NC:** Nov 1 opening for BC/BE commun outrch Genetic Counselor. Exp pref.

RESPONSIBILITIES: Interact w/ pub health and med genetic ctr staff in public health setting: coord satellite clin system; coun ped & PN pts; educ prof & lay grps; partic in overall prog plann & implementation.

CONTACT: Elizabeth G. Moore, MSW, Div MCH, Genetic Health Care Unit, Box 27687, Raleigh NC 27611-7687; 919-715-3420. EOE/AA.

■ **CHARLOTTE NC:** Immediate opening for BC Senior Genetic Counselor w/ min 5 yrs broadbased clin exp.

RESPONSIBILITIES: S'vise, plan & implement svc at lrg priv hosp: recruit & s'vise jr GC, coun pts, serve as liaison betw clinicians & genetics lab svc.

CONTACT: Sheila Davis, Personnel Dept, Presbyterian Health Service Corp, PO Box 33549, Charlotte NC 28233-3549; 9704-384-3067. EOE/AA.

■ **LEBANON NH:** Jan 1994 opening for BC/BE Genetic Counselor; Exp pref.

RESPONSIBILITIES: PNDx, outpt genetics clinics, inpt consults in tertiary care Childrens Hosp, some outrch; oppty for commun & prof educ.

CONTACT: John Moeschler, MD, Susan Berg, MS, or Eileen Rawnsley, BS, RN Ctr for Genetics & Human Development, Dartmouth Hitchcock Medical Ctr, One Medical Center Dr, Lebanon NH 03756; 603-650-7884. EOE/AA.

■ **MANSFIELD OH:** Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Coord satellite Genetics Prog: all aspects of GC, genrl adult & ped clins, PN & outrch ed; work closely w/ comp genetics ctrs in Cleveland, Akron & Columbus.

CONTACT: Robert C. Linstrom, Executive Director, Rehabilitation Service of North Central Ohio, Inc., 270 Sterkel Blvd, Mansfield OH 44907; 419-756-1133. EOE/AA.

■ **NORRISTOWN PA:** Immediate opening for BC/BE PT Genetic Counselor.

RESPONSIBILITIES: Share coord of MSAFP & Triple Test Programs for NE area US; client clin consult svcs, client visits & presentations; monitor tst prog & pt follow-up.

CONTACT: Patti Mathis, MS, SmithKline Beecham Clinical Laboratories, 400 Egypt Rd, Norristown PA 19403; 800-523-5447 x4563. EOE/AA.

■ **PHILADELPHIA PA:** Immediate opening for BC/BE Genetic Counselor. Exp pref; energetic, independent, self starter personality req. FT or PT job share possible.

RESPONSIBILITIES: Ped out/in-pt consults; all PN procedures & excellent Level II U/S; Cancer risk coun prog; Spina bifida clin; tchg res & med students; rsrch encour.

CONTACT: Jill Stopfer, MS, Albert Einstein Medical Ctr, Div Genetics, 5501 Old York Road, Philadelphia PA 19141; 215-456-8726. EOE/AA.

■ **FORT WORTH TX:** Immediate opening for BC/BE Genetic Counselor; fluency in Spanish helpful.

RESPONSIBILITIES: Join large, multidisc team to provide comp genetic svc to busy, hi-risk perinatology priv prac w/ growing ped caseload; partic in OB & FP resident tchg; involv exposure to wide range of genetic diseases in various settings; often req independ coun & case mngmt.

CONTACT: Martine Gould, MS or Kim McMillen, OB/GYN Consultants of the SW, PA, 1325 Pennsylvania Ave, Ste 450, Fort Worth TX 76104; 817-878-5298. EOE/AA.