PERSPECTIVES
in genetic counseling

Volume 16 Number 4 Winter 1994/1995

Ethical Issues in Genetic Testing

Prenatal and Childhood Testing for Adult-Onset Genetic Disorders

by Dorene Markel, MS, MHSA, University of Michigan, Ann Arbor
Chair, Genetic Research Issues Subcommittee

■ *NSGC Resolutions help communicate and clarify our views about the complex issues we face as genetic counselors. The Genetic Research Issues Subcommittee is developing a resolution on a controversial topic—predictive testing for adult-onset disorders in children. The Subcommittee seeks your input and reactions to this work-in-progress, so feedback can be incorporated into the final statement before it is formally presented to the membership for a vote.*

Testing for adult-onset conditions prenatally or in childhood is a topic of considerable and growing debate. When predictive testing for Huntington disease became available in the mid 1980s, policy statements limited testing to those 18 and older, or for pregnancies where parents would terminate a fetus with the HD gene. These guidelines were created in an attempt to:

- Preserve a child's opportunity to choose whether to be tested upon reaching adulthood.
- Prevent possible genetic discrimination.
- Protect against psychological harm since knowledge of genetic status might damage a child's self-esteem or alter parent-child relationships.

Childhood testing rarely impacts medical management, and generally does not improve predictive information for other family members. Supporters of testing cite parents' authority to make medical decisions for their children. Early knowledge may provide the child with an opportunity to adjust and incorporate genetic status into his or her self-image.

Testing for many other adult-onset genetic conditions is on the horizon—including common disorders such as breast cancer and Alzheimer disease. As genetic testing becomes more available, there will be more requests from parents or other parties to have predictive testing for children or fetuses.

Professional Societies Developing Guidelines

Other professional genetic organizations are addressing this issue. The UK Clinical Genetics Society published their report in October's *Journal of Medical Genetics.* A statement by the Social Issues Committee of the ASHG is being revised and is not yet available for review.

The Genetic Research Issues Subcommittee of the Social Issues Committee is developing a resolution to reflect NSGC's view regarding this type of predictive testing. The resulting resolution—incorporating our non-directive approach to genetic counseling—will provide members with an appropriate framework for evaluating such requests. It will impact the thinking and practice of other medical professionals receiving similar inquiries.

☛ Please read and consider NSGC's draft resolution on page 6 and contact us with your comments.

national society of genetic counselors, inc.

nsgc

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

On the Inside

NSGC acknowledges the following sponsor for a grant to support this newsletter.

Women's Health

Women's Health Care Services, Wichita KS, providers of late abortion care for fetal anomalies. George R. Tiller, MD, Medical Director.

Presidential Address

Shaping Our Continued Success In the Coming 25 Years

I have the wonderful fortune to be elected President in our 25th anniversary year. I am very proud to be part of the NSGC's rich history and look forward to a year of challenge and growth.

This year's education meeting was devoted to celebrating the past 25 years of the profession. We reflected on the contributions of those who shaped the field from the beginning. We shared our pride in our profession.

I believe we are at another beginning. We have been granted the opportunity to forge a strong, independent health care profession. Here are some steps we can take toward defining ourselves, setting our own standards of care and controlling our destiny.

• **Increase professional visibility.** I was excited to see a new high school Biology text with an entire chapter on genetics and genetic counseling, complete with pictures of Diana Punales. We can all play active roles in educating the public about our profession. These opportunities will often not come knocking—we must actively search them out.

• **Seek licensure.** We need to define ourselves in the health care system and actively seek recognition for our knowledge and skills. Licensure helps set standards to ensure patients seeking genetic counseling services receive appropriate care. This year the Genetic Services and Professional Issues Committees will be exploring national licensure options.

• **Continuing education.** To ensure professional credibility, we must demonstrate competence throughout our careers. An Ad Hoc Committee, chaired by Betsy Gettig, will begin establishing continuing education criteria.

• **Maintain high educational standards.** 25 years ago, a masters degree curriculum was developed for educating professionals who could provide technical information and help patients make difficult decisions. As the information and decisions become more complex, I believe we must adhere to our high educational standards rather than splinter the profession into different levels of educational backgrounds.

• **Mentoring.** Although it takes time and effort, we are the best role models and mentors for future genetic counselors—high school, college and graduate students. With all of us contributing, our future is sure to be full of bright creative professionals.

We have an exciting and challenging future ahead of us. I encourage everyone to find ways to get involved with NSGC and help shape that future. For me, NSGC provides a community, a strength and a vision I cannot have standing alone. I am honored to be in the position to help lead this organization and will do my very best to serve all of us now and in the future.

Bonnie LeRoy, MS
President

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More Welcoming Words

Wanted: Your Perspective

As incoming editor of our newsletter—appropriately titled *Perspectives*—I encourage you to share your unique points of view....about patient care, professional issues, our role in the health care system and society. Just as NSGC is "the leading voice" of our profession, you are the voices of NSGC.

Dialogue is the best way to understand others' perspectives, and ultimately your own. This newsletter is one way we can communicate among ourselves—it's never been easier to air your opinions (see page 7).

You rely on *Perspectives* to provide information, explore professional issues, and celebrate our accomplishments. Don't just read the articles, however, act on them: write a letter to the editor, or an elected official; dash off an e-mail or leave a message on the NSGC voice mail; contact a Board member or simply call another genetic counselor to talk. You will notice a "Call to Action" at the end of many articles.

I look forward to hearing from you—your perspective counts.

Liz Stierman, MS
Editor-in-Chief

Spotlight on

The Finance Committee: Pursuing a Secure Future

Finances...are they a bear? or a bull? NSGC members have a golden opportunity to gain management skills by learning about budgets, accounting principles, investments and more by participating in the Finance Committee—mastering concepts and terms like money market accounts, target asset mix, mutual funds, fiduciary responsibilities, laddering CDs, loads, dollar cost averaging, front-end, back-end...

What does the Finance Committee do? As part of the 1993 NSGC Strategic Plan, the Finance Committee and Treasurer have been overhauling NSGC's financial structure—both day to day financial transactions and the long-term investment planning.

Bank Change

NSGC had used a New York bank, causing logistical problems. After determining that a New York bank was not required, we switched to the PNC Bank in Philadelphia in early 1994. For the first time, NSGC has both a checking account and an interest bearing money market account.

We now route all monies through the Executive office, creating a dual system of checks and balances for safety. Copies of deposits and requests for payment are received, recorded and then forwarded to the Treasurer, who writes checks and maintains computerized financial records.

An Investment Strategy

The next challenge was evaluating NSGC's investments and creating a plan for the future. In the past, investment decisions were made solely by the Treasurer, without written guidelines.

To remedy this situation, NSGC sought outside expertise. In August, the Finance Committee reviewed proposals and selected the Legg Mason's ASAE Association Investment Program. With this program, NSGC created investment guidelines and strategies, ensuring continuity from one Treasurer to the next.

Out of these discussions came an NSGC Investment Policy Statement, approved by the Board of Directors in October. This document is currently being implemented by the Treasurer, Finance Chair, and Legg Mason advisors.

More Work to Be Done

1995 goals include assembling a financial policy handbook, refining the checks and balances process, designing computer records to coordinate with the budget, and providing investment education to the NSGC Board. The Board approved a change to elect the Treasurer one year prior to taking office to allow a training and transition period.

☛ The Finance Committee welcomes interested NSGC members.

Andy Faucett, MS
Treasurer

Health Care Reform Resolution Passes

96% of respondents voted to pass NSGC's Health Care Reform Resolution supporting national reform measures which provide universal access and coverage for genetic services, prenatal care, family planning services, safe and legal abortion, pediatric care, and psychological counseling.

One-third of eligible members returned ballots. NSGC by-laws require only a majority of respondents for passage of a resolution.

Board Meeting Highlights

NSGC's Board of Directors meets twice yearly to discuss issues of relevance to the Society as well as the profession of genetic counseling. Here are some of the key activities and decisions from October's meeting:

- Developing guidelines to ensure the best individuals are chosen as NSGC liaisons to other genetic and professional societies.
- Working on liability insurance options.
- Approved an investment program (Finance Committee).
- Considering an interdisciplinary group to develop practice guidelines for genetic counselors (Genetic Services Committee).
- Producing a genetic counseling recruitment poster targeted to high school and college students (Membership Committee).
- Developing a system for awarding continuing education units (Education Committee).
- Seeking member input for resolutions and policy statements as they are being developed (Social Issues Committee).
- Clarified membership requirements and categories.
- Discussed the strategic planning process.

Response

The Institute of Medicine Report: . . .

As a Member of the Institute of Medicine's Committee on Assessing Genetic Risks, I feel compelled to comment to my colleagues on the American College of Medical Genetic's Joint Committee on Professional Practice and their response to the IOM report (in the last issue of *Perspectives*).

The IOM Committee met for nearly 3 years, reading multitudes of papers, hearing testimony and inviting geneticists and counselors (among others) to present information on genetic testing. This comprehensive process provided opportunities for many voices to be considered in arriving at recommendations for the report, *Assessing Genetic Risks*.

ACMG's response criticizes the report for emphasizing testing's hazards rather than promoting its benefits. Yet, this was the charge given the IOM Committee: to evaluate the potential adverse outcomes of current and future applications of genetic tests.

Informed Consent

The IOM report endorses mandatory *offering* of established tests for diagnosing treatable conditions. It emphasizes that informed consent should be an integral part of any genetic testing situation, including newborn screening. ACMG's critique takes issue with the need for informed consent as this "might seriously undermine the overall benefits of such established efforts and unquestionably increase their costs."

As counselors, our objective is to support people in making voluntary informed decisions. It takes minimal time to distribute brochures and/or educate parents, ensuring they understand reasons for repeat testing and for later testing following early discharge from the hospital.

Further, making screening mandatory has not been shown to be necessary to identify affected newborns (Faden, 1982). The IOM recommendations reinforce an important standard for genetic testing: that it remain voluntary.

Carrier Status of Newborns

IOM's report recommends parents be informed *prior* to newborn screening if carrier status may be revealed through testing. Acknowledging other means for parents to learn their carrier status, the report supports parents' rights to decide whether to learn about the newborn's carrier status—following education and counseling about possible risks and benefits.

The ACMG Practice Committee claims this recommendation is "inconsistent with policies of full disclosure, parental rights and individual autonomy." Providing parents unsolicited information about their newborns' carrier status ignores their preferences. Full disclosure or parental rights

From the IOM Report

"Genetic counseling and education must be an integral part of genetic testing. Anyone who is offering (or referring for) genetic testing must provide (or refer for) appropriate genetic counseling and education prior to testing.

The goal of reducing the incidence of genetic conditions is not acceptable since this aim is explicitly eugenic; professionals should not present any reproductive decisions as "correct" or advantageous for a person or a society.

Nondirectiveness should always remain the standard of care for reproductive planning and decisions, and full informed consent before genetic testing will continue to be essential.

The genetic counselor, as the messenger of potentially devastating or discriminatory information, must honor the patient's desire for confidentiality except under rare special circumstances where breach of confidentiality is necessary to avert serious harm.

Research on the best ways to provide essential genetics education and counseling—by a variety of providers in a variety of settings—must precede efforts to streamline genetic counseling.

Since risk perceptions vary among individuals and among counselees and counselors, there is no one right way to present or interpret risk information; however, information must be balanced, and the process must be tailored to the client.

Ethnic and cultural sensitivity is particularly important—genetic counseling should be tailored to the cultural perspective of each client, with special attention to differing cultures between client and health care professional."

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. . . A Different Perspective

are not ignored when parents are allowed to make informed choices.

Childhood Testing

The IOM report recommends children be tested only for disorders for which a curative or preventive treatment exists and should begin during childhood. The ACMG Practice Committee's response to the testing of children illustrates the nature of this hotly debated topic, stating "parents may justifiably desire such information about their child to allay anxieties, for reproductive decision-making, or to plan for the health care needs of their child in the future."

Counselors are responsible for upholding peoples' right not to know information as much as their right to know. Testing in children should NOT be endorsed unless there are effective interventions. This protects children's rights to decide later, as adults, what information they seek. Allaying parents' anxieties is not sufficient justification for usurping this right.

Parents can be tested themselves in order to make reproductive decisions. Planning for children's future needs is a laudable goal but does not justify the potential harms involved. Further, attorneys on the IOM Committee do not agree that it is a legal parental right to have a child tested when no intervention is available.

(See pages 1 and 6 for more debate on the childhood testing issue.)

Support of Counseling

ACMG's Professional Practice Committee takes issue with several points in the IOM report, but ignores the important stance it takes on genetic counseling. The report devotes an entire chapter to genetic counseling, describing the importance of our professional role and setting a future research agenda. It repeatedly acknowledges our role in testing, recommending no patient be offered genetic testing without access to pre-test education and counseling. (See inset.)

Genetic counselors should feel a great sense of pride in the integral part we play in genetic testing and in the challenges before us. The IOM report's recommendations reinforce important issues for our profession: nondirectiveness, training of primary care providers, support for client confidentiality, research into strategies to streamline counseling for integration into new arenas, tailoring of counseling to clients' needs, and the need for culturally sensitive counseling techniques.

Form Your Own Opinion

Assessing Genetic Risks covers a number of issues beyond those addressed by ACMG: it includes unanimous recommendations regarding laboratory quality control; voluntariness, privacy, confidentiality and equity; public education; professional training; and policy issues.

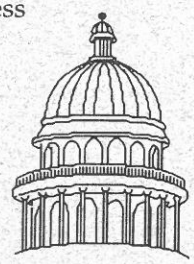
I encourage counselors to read the report for yourselves. You may wish to take a stand on these issues, publically or privately, and express your views.

☛ The Institute of Medicine's report, *Assessing Genetic Risks: Implications for Health and Social Policy*, is available for $44.95 plus tax and shipping through:

National Academy Press
2101 Constitution Avenue, NW
Washington DC 20418
Phone: 202-334-3313

Legislative Update

Changes in Congress



The 104th Congress was sworn in on January 4, 1995. The Fall elections resulted in a Republican majority in both houses—consequently, all committee chair and leadership roles have changed. Many committee assignments will be finalized in January.

Over one-third of the representatives in the 104th Congress have no more than 2 years experience.

Senate Majority Leader Bob Dole and Speaker of the House Newt Gingrich have promised a busy first 100 days. Priorities will be a balanced budget, crime reduction and welfare reform legislation. The future of health care reform is unclear at this time.

Promising to downsize the federal government, states will likely have increased responsibilities and powers, including federal fund allocation.

State Liaisons Sought

In an effort to keep aware of potentially major legislative issues at the state level, regional representatives are being identified among interested NSGC members. To become involved, leave a message for Lee Fallon on the Legislative Updates voice mail.

Changing announcements on the new voice mail system will keep members informed about late-breaking legislative news.

☎ 610-872-7608 Extension 5.

Lee Fallon, MS
Legislative Liaison

See story on page 1

Prenatal and Childhood Testing for Adult-Onset Genetic Disorders

NSGC Resolution Draft

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

1. Clients considering a pregnancy or who have a fetus or child at risk for an adult-onset genetic disorder should be made aware of applicable clinically available genetic testing technologies.
2. Childhood or prenatal testing of adult-onset disorders when there are no direct medical benefits in childhood should be undertaken cautiously. Genetic counseling should be provided to clients considering such testing and should include exploration of the psychological/social risks and benefits of early genetic identification from both the parents' and child's perspectives. The issues discussed should include the possibility of discrimination in insurance, education and employment. Parents should consider as well, whether the decision to test should be reserved for the child upon reaching adulthood.
3. Prenatal testing for adult-onset genetic conditions should be offered regardless of whether or not an affected fetus would be terminated. It is the role of the genetic counselor to educate clients as to the potential risks and benefits of pursuing prenatal testing for adult-onset conditions, but the choice must be the parents' to make.
4. Prenatal or childhood testing should not result in the disclosure of the carrier status of another individual who has declined this information (i.e. a 25% risk individual's status also giving the genetic status of their parent).
5. Caution should be exercised in the communication and documentation of test results. The child's parents should be made aware of their sensitive nature and the implications of sharing them with other professionals for whom the information is non-essential.
6. Genetic counselors are encouraged to consider both patient autonomy issues as well as the principle of nonmaleficence when requests are made for this type of testing and counseling situation. A genetic counselor should not be expected to offer a service that she feels uncomfortable providing and should be allowed to remove herself from such a case, or refer the case to another genetics professional.
7. Pilot studies are needed to assess the medical and psychosocial risks and benefits of testing for adult-onset genetic conditions in children or fetuses carried to term.

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UK Clinical Genetics Society. The genetic testing of children. *Journal of Medical Genetics*, 1994, 31:785-797.

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The Genetic Research Issues Subcommittee requests your feedback. Respond by January 31:

✍ Write or FAX: Dorene Markel, MS, MHSA, Subcommittee Chair, University of Michigan, Human Genome Center, 2570 MSRB II, Box 0674, Ann Arbor, MI 48109-0674; FAX 313-764-4133.

☎ Call NSGC Voice Mail—610-872-7608—and leave a message in mailbox 7.

Celebrating Ourselves

Congratulations to Award-Winning Genetic Counselors

■ **Brenda Finucane, MS,** the 1995 recipient of the JANE ENGELBERG MEMORIAL FELLOWSHIP, will use the year's support to identify and publish strategies for counseling women with mental retardation. In addition to interacting with mildly retarded people to gain insight into their motivation and decision-making skills, she will review literature in special education and related disciplines.

■ **Jamie Israel, MS,** received an award from NSGC's SPECIAL PROJECTS FUND to develop a comprehensive manual for genetic counseling on deafness. The manual—to be distributed to graduate training programs—will provide information on genetic forms of deafness, examine cultural and psychosocial issues, and discuss counseling strategies for working with deaf clients.

■ The Laboratories for Genetics Services/NSGC Speakers' Travel Fund has awarded grants to **Beth Fine, MS**, and **Amy Stein Schectman, MS**, for presentations at the June 1995 Association of Women's Health, Obstetric, and Neonatal Nurses conference. Their topics are: "Implications of the Human Genome Project: The Primary Care Nursing/Genetic Counseling Partnership" and "Early Onset Breast Cancer and the New Genetics" (BF) and "Teratogenic Effects of Common Exposures During Pregnancy" (AS).

■ **Beth Fine** is also the first recipient of the NATALIE WEISSBERGER PAUL NATIONAL ACHIEVEMENT AWARD, recognizing her dedication and wide-reaching volunteer efforts serving the genetic counseling profession.

■ REGIONAL LEADERSHIP AWARDS were presented to the following in recognition of their outstanding regional achievements and volunteer activities on behalf of NSGC and the profession:

Beth Balkite, MS, Region I
Rosalie Goldberg, MS, Region II
Lisa Amacker North, MS, Region III
Melonie Michelson, MA, Region IV
Christine Barth, MS, Region V
Bob Resta, MA, MS, Region VI .

Press 7 to Voice Your Views

NSGC has a new voice mail system. Designed to streamline requests for information and services, you can find out about NSGC activities and meetings, get legislative updates, revise your address in the member database/directory, or request job listings.

Have opinions to share or a gripe to air? You can also leave a message for the Board of Directors, *Perspectives* or the Society—choose option 7.

The system can only provide announcements and take messages. A new members-only Executive Office line is for those needing to speak to a real person.

☎ 610-872-7608 Voice Mail

Genetic Screening Position Statement

■ *Following approval of the Cystic Fibrosis Position Statement, NSGC's Board of Directors asked the Social Issues Committee to develop a statement addressing the more general issue of genetic screening. The following statement was approved and adopted at the October 1994 Board Meeting.*

The NSGC recognizes the increasing availability of laboratory screening tests which identify individuals who are carriers of gene mutations potentially resulting in genetic disorders in their offspring. The NSGC therefore supports the following recommendations:

1. Individuals seeking genetic counseling should be offered genetic screening tests after clinical research trials have been satisfactorily completed and the individuals:
   a) have a family history of a specific genetic condition for which testing is available, OR
   b) have reason to suspect a family history of a genetic condition for which testing is available, OR
   c) are members of a high risk subpopulation.
2. Pilot studies to explore the scientific, educational, counseling, social and ethical aspects of screening should be completed prior to instituting large scale screening programs.
3. Clinicians should evaluate test accuracy, informativeness, specificity, sensitivity, and laboratory proficiency prior to sending specimens.
4. Genetic counseling services by a Board Certified/Board Eligible genetic counseling professional should be an integral component of any genetic screening program.

Letters to the Editor

A World Without Genetic Counselors?

I am writing to share a disturbing yet eye-opening experience in my first year of genetic counselor training. As part of a cytogenetics rotation, I visited a hospital antenatal testing unit to observe an amniocentesis. The patient, a 37 year-old Caucasian woman, was a "routine" case of advanced maternal age. When I asked to sit in on the genetic counseling session, the doctor responded that pre-amnio counseling had recently been made optional at this facility, and thus was not covered by the patient's insurance plan. She, like most with lower incomes at this hospital, could not see a genetic counselor without paying out-of-pocket.

I also learned that the antenatal testing unit does not routinely give women patient education materials prior to amniocentesis.

The woman arrived for the amnio with her children: a 12 year old girl and a 9 year old boy. They were rambunctious; the boy fell to the floor feigning *hara-kiri* to symbolize the needle his mother was about to receive. The father, I learned, was sitting in the cafeteria.

As none of the staff asked the woman's permission for me to observe, I introduced myself and asked if I could stay in the room during the amnio. This prompted several questions from her children about genetic counseling, and the following comment from the 12 year old: "my mother didn't see a genetic counselor, it's only for people who are very scared."

The boy told me generally he was interested in medical procedures since he planned to be a doctor, but he was very close to his mom and did not want to watch her go through "something like that." He left the room quickly after the sonogram. As we waited, the mother and daughter talked about Down syndrome, but not about what might happen if the pregnancy was affected. If given the opportunity, it was apparent the woman would have been willing to discuss the procedure and its implications with a genetic counselor.

The daughter asked if her mother was required to have the amnio, and the woman replied "yes." She indicated her doctor had told her to have the test, then wondered aloud if it would hurt when the needle was inserted into her belly button. Once she learned the needle would not be placed in her navel, and ultrasound would be used to find a safe site, she said she felt much better.

The doctor arrived without introducing himself, stated "this is the consent form for you to sign" and left. The woman read it carefully, then paled. She asked if it was possible to have a cardiac arrest from an amniocentesis. I suggested that she check with the doctor. (The form she was reading was a general surgical consent form—other risks listed were tooth damage and infection, with no mention of miscarriage.) The doctor seemed surprised when she asked about the risk of a heart attack, and assured her it was not an issue, casually acknowledging the generality of the consent form.

The procedure itself went smoothly. As the fluid was being removed, the doctor asked to take a few extra cc's for a NY state laboratory quality assurance test, and she indicated that was fine. This may have been requested of her more formally at some other point, but this was clearly an inappropriate time to obtain any sort of "consent."

As the woman was getting dressed, the doctor left the room, walking past her son with the iodine-soaked paper covers but not stopping to explain to the wide-eyed little boy that it was not blood.

How pre-amnio counseling became optional at this institution is unknown to me. Of course, women who choose not to see a genetic counselor because it is unaffordable do not actually exercise any options. If the above experience is any example, it seems when genetic counseling is separated from "routine" amniocentesis for advanced maternal age, there is no one to fill the gap. It is imperative that genetic counselors find a way to ensure that all women receive appropriate services, not just those who can pay the bill.

As patient advocates, we must communicate the value of our services to colleagues in related health professions—from hospital administrators to nurses and physicians. A caring nurse with appropriate educational materials may have made all the difference for this woman, providing her much needed emotional and informational support.

The rising demand for testing is rapidly widening the delivery of genetic services beyond our specialized domain. This is the time to insist that genetic counseling and education remain integral components of all genetic testing services. In doing so, we can ensure that genetic counseling is both available and accessible to the people who may need it most.

Elinor Langfelder, BS
Sarah Lawrence College

■ *The case of a mentally impaired pregnant woman with untreated PKU was presented in the Fall 1994 issue, raising ethical questions about responsibilities to the patient and the fetus.*

Interference With the Reproductive Rights of Mentally Impaired Women

The concerns expressed by Bennett and Trahms regarding the burden to society of caring for a child exposed to high levels of phenylalanine prenatally are important. The authors question the decision-making capacity of the woman. However, as the case was presented, legally she is her own guardian. The case presenters propose to involuntarily hospitalize this woman in order to force feed her a diet she chooses not to follow.

Bennett and Trahms' views are not unique to genetic issues. They parallel the views of those who expect a woman to give up all her autonomy once she has chosen to be pregnant. The New York Times recently had a story illustrating this very clearly.[1] The Medical University of South Carolina ran a program in which pregnant women found to be positive for drugs were threatened with exposure and jail if they did not complete drug education programs. Over 40 women went to jail when they refused to be manipulated by the clinic staff.

In the history of our country many restrictions have been placed on who, when and how people could have children. Laws have been enacted that controlled the use and accessibility of contraception, abortion and sterilization, for example. However, procreation was recognized as a right by the Supreme Court in 1942.[2] In 1965 the Court decided that the right to privacy protects reproductive and family matters.[3] The government must meet very high standards in order to justify intrusion into these matters.

There are established mechanisms available that protect patients' rights while questions of their legal capacity are being evaluated. Bennett and Trahms may be more successful in attaining their goals by following those procedures.

Coercive intrusion into private, reproductive matters is a frightening infringement of personal, marital and reproductive freedoms. We must realize that any erosion of one element of hard won reproductive freedom can contribute to the loss of other essential reproductive rights.

Susan Schmerler, MS
UMDNJ-NJMS

1. Hilts P. Hospital put on probation over tests on poor women. *The New York Times* Oct. 5, 1994; B9.
2. *Skinner v. Oklahoma*, 316 U.S. 535 (1942).
3. *Griswold v. Connecticut*, 381 U.S. 479 (1965).

Authors' Response & Case Outcome

Schmerler's concerns regarding the reproductive rights of women and specifically those with mental impairment fail to acknowledge the responsibility women have to their unborn children, in this case a pregnant woman with untreated PKU. We did in fact honor this woman's reproductive rights over the health of her fetus although we investigated ways to hospitalize her to keep her under dietary control.

This case is different from the Medical University of South Carolina jailing pregnant women who refuse drug education. We were not requesting that our client be penalized for her actions; we were trying to maximize the outcome of a high risk pregnancy. Given her serum phenylalanine levels in early pregnancy she was at close to 100% risk to have a fetus affected by maternal PKU unless strict dietary management was maintained. This differs from pregnant women using drugs or alcohol where the fetal risks may be difficult to predict with any accuracy. One of the eight obstetricians seen actually placed a feeding tube with the patient's consent; however, she continued to surreptitiously consume food in addition to the phenylalanine-free formula given via the feeding tube.

This woman's voluntary and personal decisions have lead to the recent full term birth of a severely damaged baby. The child has profound microcephaly, micrognathia, broad nose, posteriorly rotated ears and congenital heart disease (situs inversus totalis with double outlet left ventricle, ASD, VSD, endocardial cushion defect and pulmonary artery hypoplasia). The brain abnormalities include absence of the corpus callosum and pachygyria/agyria. Most of these findings were evident on a 28 week ultrasound evaluation. The child was released to the care of the parents.

It is hard to reconcile the prognosis for this severely impaired infant with the mother's absolute reproductive right given this child may have had little impairment if the mother had chosen to provide a reasonable prenatal environment. How is this different from child abuse after birth which can result in lifelong physical or mental impairment?

We agree that it is important to protect a woman's "hard won reproductive freedom" and her "essential reproductive rights." But with personal freedom comes personal responsibility. And if not, what price freedom and for whom?

Robin L. Bennett, MS
Cris Trahms, MS, RD
Univ of Washington Medical Center

Bulletin Board

Successful Negotiators Sought

Have you used the Professional Status Survey to successfully obtain a salary increase, faculty appointment or improved benefits? If so, the Professional Issues Committee is interested in hearing your story for a workshop at the 1995 Annual Education Meeting.

☛ Contact Liz Hegarty, 516-663-2657 (M,T, Th, F); or 516-997-5089 (W, and evenings).

Genetics in Practice

Genetics in Practice—a newsletter for health professionals about genetic disorders and birth defects—is once again being published. Financial support is provided by the Allegheny Health, Education and Research Foundation. Currently, there is no cost for ordering.

☛ For more information, phone 412-359-6388, FAX 412-359-6488 or e-mail genprac@singer.asri.edu.

Consumers Needed for HuGEM Survey

The ELSI-funded Human Genome Education Model Project (HuGEM)—co-directed by Virginia Lapham of Georgetown University Child Development Center and Joan Weiss of the Alliance of Genetic Support Groups—is looking for consumer volunteers for 30 minute telephone interviews. Virginia and Joan are particularly eager to reach more representatives from minority groups.

☛ Call Joan Weiss with questions about the survey or HuGEM.

☛ Individual consumers can contact the Alliance office to be interviewed: 800-336-4363.

Abstracts for 1995

Look for the "Call for Abstracts" for the 1995 Annual Education Meeting in the January NSGC membership mailing. Submissions must be postmarked April 21, 1995.

Upcoming Meetings

February 22-23	NSGC Region III Meeting (prior to SERGG meeting), Atlanta GA. Contact: Shane Palmer, MS, 919-946-6481.
March 4-8	Feminist Perspectives on Bioethics course offered by the Kennedy Institute of Ethics at Georgetown University. Washington DC. Contact: Marc Favreau, 202-687-6771.
March 6-9	March of Dimes Clinical Genetics Conference/American College of Medical Genetics Meeting, Los Angeles CA. Contact: ACMG, 301-571-1825, FAX 301-571-1895.
March 23-24	NSGC Region IV Meeting (prior to GLRGG meeting), Columbus OH. Will include a cancer workshop. Contact: Rich Dineen, 309-655-7436.
April 26-27	American Cleft Palate-Craniofacial Association Meeting, Tampa FL. Preconference Symposium "Craniofacial Evolution, Development, and Syndromes." Contact: Nancy Smythe, ACPA, 412-481-1376; FAX 412-481-0847.
May 19-20	NSGC Region V Meeting, Santa Fe NM. Will include a cancer workshop. Contact: Amy Cronister, 505-438-2164.

Support Group Directory

The revised and expanded *Directory of National Voluntary Organizations and Related Resources*, supported in part by a grant from NSGC, will be available in mid-Spring. The Directory lists support groups for specific genetic conditions as well as disease registries, information offices of federal agencies and genetic networks.

Full NSGC members can purchase the 1995 Directory for $12, which includes postage and handling. Cost is $22 for all others.

☛ To order, send check with your name and address to:
Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase MD 20815

Health Education Catalog

The March of Dimes new Catalog of Public Health Education Materials describes low-cost print and audiovisual materials promoting reproductive awareness, including genetic counseling, nutrition and folic acid, alcohol and substance abuse prevention. Many materials are available in Spanish in culturally sensitive formats.

☛ For more information and a free catalog, call 800-367-6630.

Data Report Available

Birth defects rates and trends observed in 1.6 million ethnically diverse births are reported in *Birth Defects in California, 1983-1990*, available in January from the California Birth Defects Monitoring Program. This baseline data provides a national benchmark, as 15% of US births occur in California. Written by our own Liz Stierman.

☛ Free. Phone 209-224-2212 or FAX 209-224-0252.

14th Annual Education Conference

Genetic Conditions That Affect Adults: Implications for Genetic Counseling, Testing, and Public Policy

It's not too early to mark your calendars for the 1995 Annual Educational Conference, to be held **October 29-November 1** in Minneapolis, following the ASHG meeting. (No hotel could accomodate a group of NSGC's size prior to ASHG.)

New Challenges

The explosion of genetic information is creating unprecedented challenges and opportunities for genetic counselors. Change confronts us daily: from cloning of genes for common and not-so-common adult-onset conditions, to cutting edge assisted reproductive technologies, to discovery of "new" inheritance patterns.

- How should we respond to families requesting genetic testing of children for conditions that may not be manifested until adulthood?
- What do we tell the client carrying a fetus prenatally diagnosed with an untreatable disorder for which effective therapy may become available within the child's lifetime?
- How do we deal with discoveries we first learn of in the morning newspaper...which apply to a family scheduled for genetic counseling that same afternoon?
- How can professionals keep abreast of the "new" genetics and effectively manage change?

Adult-Onset Disorders

The 1995 Annual Educational Conference will focus on the implications of our newfound ability to provide counseling and testing for genetic conditions affecting adults. It will address genetic counseling, testing and public policy issues in several conditions as well as professional and personal management in a field encompassing an ever widening variety of settings. The Janus series will continue to provide new information on selected conditions long familiar to us.

Specialty Groups

An additional feature of this year's conference will be an afternoon session where counselors will meet with others working in the same specialty:

- Pediatrics
- Prenatal
- Public Health
- Cancer
- Neurogenetics
- Infertility
- Private Practice
- Commercial DNA Diagnostics.

These concurrent sessions will provide an opportunity to network, discuss specific clinical/professional issues and share resources.

☛ If you would like to help define issues covered in a specialty session, be a group facilitator, or add an additional specialty to the list, please contact Lisa Amacker North by February 1, 1995.

Wendy R. Uhlmann, MS
Carol Strom, MS
Conference Co-Chairs

Help Requested

Gathering Reimbursement and Licensure Strategies

A n ad hoc group led by Barbara Bernhardt and Debra Lochner Doyle, both members of ACMG's Billing and Reimbursement Committee, met to discuss issues relating to two important areas of concern to genetic counselors: reimbursement and licensure. The group's immediate goal is to gather experiences and resource materials—please contact them or contribute any written materials you have developed in these areas:

- **Form letters for third party payers** explaining procedures and/or genetic services for which patients have not been adequately reimbursed.
- **Successful strategies used by self-employed counselors** to obtain payment. They are very interested in hearing from those billing in their own names and/or whose patients are reimbursed by third party payers.
- **Negotiations with HMOs and managed care plans** resulting in agreements for payment for genetic services/procedures. Summarize details about contact people, services covered and plan limitations, "gatekeepers" and referral sources.
- **Explorations of credentialing** within your state. Who are government contact persons? How willing was the state to consider licensure? What are perceived benefits (or lack thereof) from the state's or counselors' view, especially with respect to third party reimbursement? Are you continuing to pursue licensure/certification—why or why not?

☛Call or send documents to:

Barbara Bernhardt, MA
Genetics/Public Policy Studies
550 N. Broadway, Suite 511
Johns Hopkins Medical Institute
Baltimore MD 21205-2004
410-955-7894; FAX 410-955-0241

Debra Doyle, MS
Maternal/Infant Health & Genetics
1704 NE 150th Street, K17-8
Seattle WA 98155-7226
206-368-4471; FAX 206-368-4468

Resources

■ Video ■

The CF Carrier Test: Is It for Me?

Produced by: Department of Molecular and Human Genetics, Baylor College of Medicine (1994)

Length: 15:35 minutes

Price: $45.00

Created to help persons with no family history of cystic fibrosis make informed decisions about whether to have carrier testing, this video discusses the frequency of the gene in the general population, inheritance, and screening methods. Two families discuss life with a child with CF, including breathing treatments, physical therapy, IVs, oral medications and cost for care. One child is a toddler; the other is a teenager.

The video accurately portrays the genetics of and carrier testing for CF. It also addresses the problems and difficulties faced by families of children with CF. A criticism, however, is that the video focuses on the negative side of family life. Quotes like these leave the viewer with a heavy feeling: it is a "24 hour a day job... can't just pick up and do something;" you "feel like the whole day you are fighting" to get the child to do therapy; "at one time statistically it had the highest divorce rate;" "the cost of caring for a CF kid is unbelievable."

The parents note it is an individual's decision whether to have carrier screening but go on to say knowing what they do now, they would have wanted screening for themselves. To show both sides fairly, the video should include families who declined carrier screening. The video makes the point that testing gives a couple "options" but these options are not discussed.

A video on carrier screening for CF is much needed, especially as more mutations are discovered and screened at a reasonable cost, paving the way for population carrier screening. Private physicians or genetic counselors wishing to offer CF screening but who are already pressed for time during counselling sessions may find this video helpful.

The video is technically excellent and very professionally done. As adjuncts to viewing, however, I recommend providing an explanatory introduction before showing the tape, time for questions and answers afterwards, and a brochure/fact sheet about CF screening for patients to take home.

Connie Stewart Motter, MS
Children's Hospital of Akron

The Social Issues Committee Comments

We encourage individuals purchasing this video to consider NSGC's position statement on CF screening prior to instituting population screening programs. It recommends that:

- Population screening should not be offered until pilot studies exploring the scientific, educational, and counseling aspects of screening have been done.
- Genetic counseling services by a Board certified/eligible professional should be an essential component of any population screening program.

Vivian Weinblatt, MS
Social Issues Committee

■ Support Groups ■

Moebius Syndrome

Moebius Syndrome Foundation
PO Box 993
Larchmont NY 10538
914-834-6008 OR

Contact: Vickie McCarrell
6449 Gerald Avenue
Van Nuys CA 91406
818-908-9288

Parent support group and fund-raising organization with 260 members. Quarterly newsletter plus information and a bibliography. Interested in funding research into causes and treatment.

Joseph Disease

International Joseph Diseases Foundation
PO Box 2550
Livermore CA 94551-2550
510-443-4600

Family support group providing information about Machado-Joseph disease and related disorders. Supports clinical research and refers patients to appropriate resources.

Urea Cycle Disorders

National Urea Cycle Foundation
PO Box 32
Sayerville NJ 08872
800-38-NUCDF (800-386-8233)
24-hour voice mail

Continuing Pregnancies

Abiding Hearts
Contact: Maria LaFond Visscher
Box 5245
Bozeman MT 59717
406-587-7421

Support before and after birth for parents continuing pregnancies prenatal diagnosed with fatal birth defects like anencephaly.

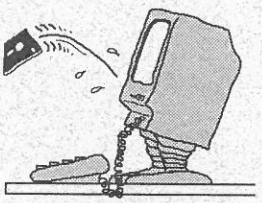
Organizing References—the Computer Way

Organizing articles into references for publication purposes can be laborious—authors' names are often difficult to transcribe correctly and spell-check is worthless for most last names and scientific terms. One more reason not to publish.

Bibliographic management systems are the solution. They have the ability to store and retrieve huge quantities of bibliographic data. The databases can be built by entering references—or by importing from a wide variety of on-line, CD-ROM or diskette-based services. Articles can be located rapidly, sorted based on authors' names or keywords, and edited for incorporation into the body and reference list of an article in the manner appropriate for the particular journal to which the piece is being submitted.

The most intuitive

Although many management systems exist at various price ranges, after previewing demonstration disks of the most common, Reference Manager for use in a Windows environment was selected. It is intuitive, but service and support can be obtained when needed. References can be added by keyboarding, however, they are more easily added with a Capture module which transfers references from selected database services directly into the Reference Manager database. The databases from which articles can be retrieved easily include, but are not limited to, BRS, Datastar, Dialog, Grateful Med, NLM and Silverplatter.



Once references are in the database, they can be retrieved quickly by a variety of parameters, including a word or phrase from a title or abstract. A Splicer module makes it easy to operate Reference Manager from a word processor program, which retrieves and marks references before incorporating the identifiers directly into the text. Many commonly used formats are available when altering bibliographic references in both the body of an article and in the reference section. The Windows version of Reference Manager is intuitive, and the Help key and users guide are well written and easy to understand.

Ordering Specifics

Reference Managers is available for IBM-compatible (both MS-DOS and Windows) and Macintosh computers. IBM systems require MS-DOS and 384K RAM or Microsoft Windows with 4 Megabytes to store up to 65,000 references. The Macintosh version requires at least 1 Megabyte of RAM to store up to 32,000 references. A module to capture references from databases is ordered separately, making the complete cost for any of the versions about $500.

A demonstration disk is available. Reference Manager can be ordered from Research Information Systems, 2355 Camino Vida Roble, Carlsbad CA 92009-1572, 800-722-1227.

Vickie Venne, MS, Robert Resta, MS and Karen Wcislo, MS

NSGC Aims for Cyberspace

Want to gently merge onto the information superhighway without being sideswiped by a '72 Chevy? To help you, a genetic computer resources subcommittee was formed at the recent education committee meeting in Montreal. Its initial goals:

- Develop an NSGC Internet address, enabling genetic counselors with common interests to form discussion groups for exchanging ideas. E-mail can be easily sent to all members of the group, (A student discussion group is already being formed.)
- Create an NSGC bulletin board on the Internet, for posting information and providing access to libraries of text files to read or download to your own computer.
- Locate relevant resources for genetic counselors on the Internet.
- Run training workshops at regional or national meetings.
- Identify computer mentors.
- Compile and distribute a list of NSGC members with e-mail addresses. (There are over 150 so far.) To add your name or update your e-mail address, contact the Executive Office or one of the committee members below.

☛Contact us with questions or comments:

Beth Conover • 402-559-5071
bconover@unmc.edu

Steven Keiles • 213-857-2074
pokeilss@scpmg.com

Jeff Shaw • 406-444-7533
jshaw@wln.com

Steven Keiles, MS
Subcommittee Member

Student Corner

Thesis Projects: Are basic science themes appropriate?

■ *In the last issue of Perspectives, training program directors responded to the comment that students' thesis projects "seem more directed to basic science than genetic counseling." A recent graduate adds her thoughts:*

I believe the purpose of a graduate thesis is to develop critical thinking skills and learn how to justify, design, complete and present experiments. Hopefully, after completing a thesis, the student has acquired skills for evaluating current information and knowledge, and for conducting research projects independently.

In basic science fields, students do a thesis under the tutelage of an expert—the principal investigator of the research (or another knowledgeable researcher). Counseling students are not likely to have access to genetic counseling experts who have time and knowledge to work with students to accomplish thesis goals. Perhaps, until the genetic counseling field has matured so research experts are available, students will be prepared best if they do a project with an expert in basic science, adding a counseling component.

There are other reasons why a basic science thesis may be appropriate. Genetic counselors need a good foundation in certain basic scientific knowledge. In addition, when we function as intermediaries between research groups and study participants, we need to understand how genetic research proceeds.

To agree on appropriate thesis topics, those in the field may need to clarify the purpose of the thesis in a genetic counseling masters program. It may be wise to examine recent theses and graduates, to determine if these goals were achieved. Hopefully, this ongoing discussion about thesis projects will contribute to high standards for genetic counselors and ensure that all students are well prepared.

Judy Miller, MS
Peoria IL

Internship Offered

The North Carolina Medical Genetics Association has a summer internship at Duke Medical Center for a genetic counseling student who has completed one year of an MS program. A $500 stipend is available.

Internships at other medical centers in North Carolina will be available in following summers.

☛For more information, contact Lorraine Fry-Mehltretter, MS, 919-684-3604.

ABGC Update

The Bulletin/Application for the 1996 American Board of Genetic Counseling Certification Examination was completed in October and has been sent to the National Board of Medical Examiners for printing. This document should be available from the ABGC Administrative Office by March, 1995. Sample copies of the Case Logbook Form and Instructions for Completion are now available and were distributed to Program Directors in Montreal.

Applications for the next examination cycle must be postmarked by December 31, 1995. The deadline for supporting documents for students still in graduate school will be specified in the application.

Completed applications will be reviewed by members of the ABGC Credentials Committee. Candidates approved for the Examination will be notified by letter of their "Board-eligible" status. Until receiving this notification, counselors should not describe themselves as "Board-eligible" to potential employers or colleagues.

The Examination will be given June 26, 1996, in Chicago, Atlanta, Philadelphia, and Los Angeles.

☛To request the Application or Logbook Form, write or FAX: Ms. Sharon Robinson, ABGC Office, 9650 Rockville Pike Bethesda MD 20814; FAX: 301-571-1895.

Ginny Corson, MS
Member, American Board of Genetic Counseling

Survey Coming

Personal Experiences with Genetic Conditions

Many enter our profession because of a personal or family experience with a genetic disorder. What issues do these counselors face? How do their personal experiences affect the counseling process?

Student Mary Martin of the University of Cincinnati will explore these basic questions with a survey of NSGC members, forming the basis of her masters thesis. The results could help guide training of future counselors.

☛ Please take the time to complete the survey, to be mailed in December.

■ 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.*

PHOENIX AZ: Immediate opening for BC/BE Genetic Counselor. Exp pref, not req.
RESPONSIBILITIES: Position for pediatric GC to coordinate pediatric genetic & metabolic clinics; follow-up abnormal newborn scrng results, partic in GC, med student, resident & fellow education.
CONTACT: Kirk Aleck, MD, Director, Univ Arizona Phoenix Genetics Program, Maricopa Medical Ctr, P.O. Box 5099, Phoenix AZ 85010; 602-267-5024. Send CV + 3 ltrs ref. EOE/AA.

LOS ANGELES CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: PNDx w/ some clinical genetic pediatric cases.
CONTACT: Rosetta Hassan, MD, King Drew Medical Ctr, 12021 S. Wilmington Ave, Los Angeles CA 90059; 310-668-4620. EOE/AA.

OAKLAND CA: Immediate opening for BC/BE Genetic Counselor - Supervisor. Supervisory & admin experience strongly preferred.
RESPONSIBILITIES: Join team of 2 geneitcists & 5 GCs to provide full range of PN & genrl GC: expanded AFP & NICU consults.
CONTACT: Cheri Loustalet, MS, Children's Hospital Oakland, Med Genetics, 747 52nd St, Oakland CA 94609-1809; 510-428-3550. EOE/AA.

SACRAMENTO CA: Immediate opening for experienced BC/BE Genetic Counselor.
RESPONSIBILITIES: Join busy private perinatal practice; all aspects of PNDx coun for amnio, CVS, abn U/S, terat, AFP, DNA in a CA State prenatal diagnostic center.
CONTACT: Judy Lampe, Practice Manager, Perinatal Associates of No. California, 5301 F St, #110, Sacramento CA 95819; 916-733-1755. EOE/AA.

STANFORD CA: Immediate opening for BC/BE Genetic Counselor. Experience and Spanish language skills preferred.
RESPONSIBILITIES: Join 4 GCs & 5 MDs in univ-setting PN position: amnio, PUBS, AFP, triple marker scrng, teratology, abnorm U/S, CVS, DNA analysis & genrl genetics.
CONTACT: Robbie Tung, MS, Coordinator, Stanford University Medical Center, Dept GYN/OB, Genetic Counseling Clinic, Stanford CA 94305; 415-725-2878. EOE/AA.

NEW HAVEN CT: June 1995 opening for BC/BE Genetic Counselor w/ masters in GC. Exp preferred.
RESPONSIBILITIES: All aspects of GC in busy genetic svc; many clin oppty & possibility of involvement in research proj.
CONTACT: Margretta R. Seashore, MD or Jodi Rucquoi, MS, Yale Univ School of Medicine, Dept Genetics, 333 Cedar St, PO Box 208005, New Haven CT 06520-8005; 203-785-2663. EOE/AA.

MIAMI FL: Immediate openings for 2 BC/BE Genetic Counselors @ Miami & Atlanta locations; 2-3 yrs clin exp req; ability to work independently, excellent org & interpersonal skills; bilingual (Eng/Span) for Miami position req.
RESPONSIBILITIES: Partic in all aspects of GC/client svcs: GC & follow-up families in large PN & triple marker scrng prog; educ non-tech staff; inservice in physicians offices.
CONTACT: Markey Burke, Human Resources, Integrated Genetics, One Mountain Rd, Framingham MA 01701; 508-872-8400x2266.

ATLANTA GA: *See Miami FL*

FORT WAYNE IN: Immediate opening for self-motivated, BC/BE Cytogenetic Counselor. 1-2 yrs experience in GC req. Salary Range: $32,800 - $47,600 depending on exp.
RESPONSIBILITIES: Client coun in lab division: genetics & chromosomal abnorm; respon for accurate, cost effective mngmt of State Dept Health grant & clinical activities.
CONTACT: Trisha Hayes, Human Resources, Parkview Memorial Hospital, 2200 Randallia Dr, Fort Wayne IN 46805; 219-484-6636 x2253. EOE/AA.

SCARBOROUGH (PORTLAND) ME: Immediate opening for BC/BE Genetic Counselor. Exp pref.
RESPONSIBILITIES: Provide comprehensive PN & genrl GC in regional ctr; inpt consults for large, nationally-known PN scrng prog; FraX referral prog; ongoing research, education incl: statewide CF, hemochromatosis demonstration proj; OB & Ped resident educ.
CONTACT: Richard A. Doherty, MD, Foundation for Blood Research, PO Box 190, 69 U.S. Route One, Scarborough ME 04070-0190; 207-883-4131. EOE/AA.

DETROIT MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active team in large, diverse, rapidly expanding repro genetic ctr: CVS, amnio, scrng, dx U/S, teratogens, novel fetal therapy & surgery; oppty for research, publications. Active involv in new GC Trng Prog.
CONTACT: Eric Krivchenia, MS or Mark Evans, MD, Hutzel Hospital, 4707 St Antoine, Detroit MI 48201; 313-745-7067. EOE/AA.

MINNEAPOLIS MN: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Carry out State Dept Health human genetics prog: consult to health professionals, education & information to genrl public; partic in selected state & natl activities to represent public health policy perspective; provide ldrship & coord for Newborn Scrng Prog in collab w/ lab div.
CONTACT: Human Resources Management, Minnesota Dept Health, 717 Delaware St SE, PO Box 9441, Minneapolis MN 55440-9441; 612-623-5401. Request announcement and application form. EOE/AA.

Continued on next page

national society
of genetic
counselors, inc.

nsgc

233 Canterbury Drive
Wallingford, PA 19086-6617

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

Employment Opportunities *from previous page*

Long Branch NJ: Immediate opening for Part time BC/BE Genetic Counselor.
Responsibilities: PNDx coun w/ some pediatrics.
Contact: Karen Methot, Monmouth Med Ctr, 300 Second Ave, Long Branch NJ 07740; 908-870-5196. EOE/AA.

Albany NY: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join 2 GCs, MD geneticist on multidisc team in tchg hosp setting: variety of GC oppty in PN, peds & adult spec & satellite clinics (SB, Hemo, NJ, HD, CF, CL/P)
Contact: Lenore Palladino, RN, MS, Albany Medical Center, 47 New Scotland Ave, Dept Pediatrics A-88, Albany NY 12208; 518-262-5120. EOE/AA.

West Islip NY: Immediate opening for Part time BC/BE Genetic Counselor.
Responsibilities: PNDx & counseling, triple marker scrng, teratogens.
Contact: T. Kramer, South Bay OB/GYN, 320 Montauk Hwy, West Islip NY 11795; 516-587-2500. EOE/AA.

Cincinnati OH: Immediate opening for BC/BE Genetic Counselor at Seton Center for Advanced OB/GYN. Excellent communication, organizational and follow-through skills required.
Responsibilities: Counsel patients with maternal/fetal diagnostic procedures, offer pre-conceptual counseling, professional & patient education.
Contact: Lisa Edrington, Employment Coordinator, Good Samaritan Hospital, 375 Dixmyth Ave, Cincinnati, OH 45220. EOE/AA.

Portland OR: Immediate opening for part time BC/BE Genetic Counselor (20/hrs/wk).
Responsibilities: Provide GC for ind & families w/ wide range of genetic conditions, partic in PNDx prog; coord & admin clin genetics svc w/ large, diverse genetics team in well-estab, successful HMO.
Contact: Judy Parmenter, Kaiser Permanente, 2701 NW Vaughn, Ste 300, Portland OR 97210; 503-721-3874. EOE/AA.

Philadelphia PA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join 5 BC GCs w/ emphasis on direct involvement w/ multidisciplinary genetics team affiliated w/ Genetrix cyto lab: involvement in neonatal genetics & dysmorphology; ample oppty & encouragement for academics, research, teaching, publications, support groups, commun educ.
Contact: Betti Bandura, Dept OB, Section Genetics, Pennsylvania Hospital, 800 Spruce St, 7th Fl, Philadelphia PA 19107; 215-829-3652. EOE/AA.

Salt Lake City UT: April 95 opening for BC/BE Genetic Counselor. Exp preferred.
Responsibilities: All aspects of repro genetics: PNDx; breast/ovarian CA; recurrent miscarriage; molecular diag; PN gene therapy. Oppty for research & prof development in Univ setting.
Contact: Elizabeth Young, Human Resources Dept, University of Utah, 101 Annex, Salt Lake City UT 84112; 801-581-6756. Refer to Job #EY5024. EOE/AA.

Charlottesville VA: Immediate opening for BC Genetic Counselor with interest in cancer genetics.
Responsibilities: Active role in dev cancer genetics unit in expanding cancer ctr: initial activities w/ breast/ovarian programs, progressing to other disorders: Identify & coun pts & fam; provide pt, consumer & public educ; involvement in clin rsrch; org computer registry
Contact: Susan Miesfeldt, MD or Pat Schnatterly, MS, UVA Health Sciences Center, Box 386 MCV Station, Charlottesville VA 22908; 804-924-2665 (PS); 804-924-9647 (SM). EOE/AA.