# PERSPECTIVES in genetic counseling

Volume 16:3 Fall 1994


## *Ethical Issues in Genetic Research*

## PROTECTING PATIENT AUTONOMY WHILE MAINTAINING EPIDEMIOLOGIC VALUE

*by Rosalie Goldberg, MS, Albert Einstein College of Medicine, Bronx, New York, and member, Genetic Research Subcommittee*

Recently, President Karen Greendale invited me to represent NSGC at a workshop, "Informed Consent for Genetic Studies on Stored Tissue Samples." It was called by the National Centers for Disease Control (CDC) and the Ethical, Legal and Social Implications Branch of the National Center for Human Genome Research (NCHGR) to discuss and examine current policies and ethical guidelines for studies that preceded informed consent for genetic testing.

Advances in technologies now make it possible to extract DNA from a variety of tissue samples. Specific consent was not obtained for many of these specimens to be used for future research purposes. In addition, no uniform institutional, state or federal policies exist concerning the use of these specimens. The CDC suggests that genetic counseling will

continued on p. 4

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With thanks to the 1994 nominating committee: Betsy Gettig, Chair, Kathryn Spitzer Kim, Eva Beller, Ken Loud, Wendy Uhlmann, Pat Ward and Stefanie Uhrich.

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### ON THE INSIDE


| | |
|---|---|
| Parting Thoughts | 2 |
| AEC Update | 3 |
| Untreated Maternal PKU | 5 |
| Social Issues Committee Spotlight | 6 |
| Health Care Reform | 7 |
| ACMG Response to Institute of Medicine Report | 8 |
| Student Page: Directors Respond; Student Projects; New Programs | 10 |
| Research Network: Pallister Hall, GSD type IV | 11 |
| GeneBytes: MacReview of Pedigree Software | 11 |
| Resources: Video: Secrets of the Code; Support Groups: Nevoid Basal Cell Carcinoma; Cystinuria | 12 |
| Bulletin Board | 13 |
| Letters to the Editor | 14 |
| Employment Opportunities | 15, 16 |


NSGC acknowledges our following corporate friend for a grant to support this newsletter.

*Parting Thoughts*

## A Year of Network-Building and Interdisciplinary Collaboration

From Latin America to Boston, Washington DC and Atlanta, many genetic counselors joined me as we represented NSGC this year. I see interdisciplinary network building as the key issue of my tenure.

During this year, Andy Faucett represented NSGC at a Centers for Disease Control meeting addressing the issue of chorionic villus sampling and limb defects. Rosalie Goldberg recently represented us at an ELSI/CDC-sponsored conference. *(See page 1.)* For the first time, NSGC flew our new banner over a booth at the National Association of Biology Teachers meeting.

At the interim Board Meeting, it was agreed that committee chairs would contact their counterparts in the American College of Medical Genetics (ACMG) to initiate communication and reduce duplication of effort. As one example of such collaboration, the Social Issues Committees of ASHG, NSGC and ACMG will be meeting together in Montreal.

Last month, ACMG invited NSGC to appoint a liaison to their Joint Subcommittee on Billing and Reimbursement. Barbara Bernhardt will fill this important role and, with Deborah Doyle, another member of the College subcommittee, take the lead on these issues within NSGC.

Francis Collins has invited NSGC to appoint liaisons to the National Advisory Council for Human Genome Research and to the ELSI Working Group. To quote Dr. Collins: ..."[NSGC] has consistently played a constructive and articulate role in [discussions relating to genetic testing and gene therapy], and in my view, continuing NSGC involvement is essential. Genetic counselors, by the nature of their dual training in the scientific and psychological aspects of genetics, have a unique viewpoint and a unique contribution to make."

We've also taken our unique viewpoint into the international arena. I attended a meeting sponsored by the March of Dimes to bring together representatives of international organizations concerned about birth defects prevention. Diana Punales-Morejon and I will present on the "Role of Master's Trained Genetic Counselors in the Provision of Clinical Genetics Services in the United States" and staff a booth at the 11th Congreso LatinoAmericano de Genetica in Puerto Vallerta.

The chair of COMGO, the umbrella organization comprised of all the medical genetic societies, rotates among the five steering committee organizations' presidents. I have been privleged to preside this year and to work with our sister organizations to strengthen COMGO, whose mission is to enhance networking and collaboration.

I wish Bonnie LeRoy a year similar to mine... challenging, but non-traumatic! Clinical genetics is receiving some long-overdue recognition among the policy-makers. Genetic counseling is at an exciting juncture in the evolution of our professional identity. Let's make sure that NSGC's voice is heard above the cacophony! ■

***Karen Greendale, MA, CGC***
***President***

*Perspectives in Genetic Counseling* is published quarterly by the National Society of Genetic Counselors, Inc.
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Publication Date, Next Issue: December 15
Deadline for Submissions: November 10



### Visioning the Future

#### NSGC Now Connected on the Superhighway

NSGC has entered today's technology by connecting with Internet. Members may use or refer others to NSGC with the following access:

**BEANSGC@aol.com**

NSGC is proud to benefit its members by offering speedy communications with the Executive Office and providing another way in which we are positioned for the future.

## "Twenty Five Years of Genetic Counseling: Expanding Roles, Extending Horizons"

Montreal, Quebec, Canada
October 15 - 18, 1994

With just weeks away, we look forward to a successful and productive educational conference.

*Special kudos to the hard work and diligent efforts of the planning committee...*

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*We we wish to thank the following exhibitors for their support of this conference...*

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Baylor College of Medicine Department of Molecular & Human Genetics

*...and we extend a special thanks to the following corporate friends for support of this conference:*

Aldine deGruyter...for the donation 2 books, *Prescribing Our Futures*

AT&T Canada...for a generous grant to provide special visual equipment for a platform presentation

Cherwell Scientific ...for the donation of the software package, Cyrillic

GeneCare...for an unrestricted donation for the conference

GeneScreen...for a grant to cover printing the announcement and registration brochure

Genetic Design...for an unrestricted donation for the conference

Genetrix...for an unrestricted donation for the conference

Integrated Genetics...for supplying totes, notepads and pens for this conference

Integrated Genetics...for funding a breakfast seminar, "Cancer Risk Counseling: Perspectives for Genetic Counselors," with Patricia T. Kelly, PhD

OncorMed...for funding a breakfast seminar, "How Will the Latest Genetic Discoveries for Malignant Melanoma Provide Key Information to Genetic Counselors? " with Ramone Fusaro, MD, PhD

Roche Biomedical Laboratories...for a generous grant to cover the printing of the program book

***Your support is greatly valued.***

# Another Role for Genetic Counselors in a Research Environment

continued from page 1

now be necessary as individuals are recontacted to obtain consent for their banked tissue samples to be used for research. It therefore becomes important that the genetic counseling community be involved in the policy concerns surrounding this issue before it becomes part of public practice.

*'...genetic counseling will now be necessary as individuals are recontacted to obtain consent for their banked tissue samples...'*

### Many Disciplines Represented

Workshop participants included lawyers, ethicists, public policy planners, NIH Division Chairs and consumer advocacy group spokespersons. In addition, representatives of NSGC, ISONG, ASHG, ACMG, NORD, The Alliance, The National Breast Cancer Coalition and CORN were present.

Dr. Francis Collins, Director of the NCHGR, introduced the theme of the conference "as a potential conflict between the need to add major health information from samples that were collected for other reasons on the one hand and to get appropriate informed consent without losing the epidemiologic benefits of those preselected populations on the other hand." If these positions are in opposition, research on important human diseases could be delayed.

### The Potential Problems

Participants presented cautious assessments of previous "new technologies" in which results were prematurely applied and subsequently proved as uninterpretable or incorrect. Screening inmates for association of XYY karyotype in criminality and mistakes regarding dietary interventions with PKU are two examples that were presented.

DNA is routinely extracted from whole blood, prenatal specimens and a variety of other tissues for immediate analysis. DNA can also be extracted from blood spots collected in the past as part of newborn screening programs as well as archived tumor biopsies obtained for pathologic evaluation from *any* surgery, including breast, ovarian or colon cancer.

Using the samples for DNA analysis without recontacting the donors and failing to provide the test results to them may result in "lookback" liability and may be interpreted as a violation of patient autonomy.

### The NHANES Study

One example with major national implications is the National Health and Nutrition Examination Survey (NHANES). The data accumulated from the six year study, which cost $30 million, includes valuable information about common diseases such as cancer and heart disease. In addition, baseline information about bone density, serological status and nutrition was collected. Blood samples were collected and DNA was banked at a time when their potential use was unclear. These samples are in demand today for a variety of research projects, including DNA analysis, and an additional $2 million is needed to recontact the 30,000 participants to provide appropriate counseling and obtain consent.

### One Area of Agreement

Consensus was reached regarding the collection of future samples and the role and responsibility of the Institutional Review Board (IRB) in requiring investigators to establish *in advance* what information will be revealed to whom and under what circumstances. Issues still to be resolved include the protection of anonymity of patient samples while assuring clinical usefulness of those specimens.

### What Can NSGC and Genetic Counselors do?

- Study the issues in our Genetic Research Issues Subcommittee.
- Be aware that data obtained from research may be made available to the donors or third parties, thus requiring special counseling strategies.
- Develop expertise in the ethical aspects of informed consent in accordance with NSGC's Code of Ethics.
- Gain representation on Institutional Review Boards.

Traditional physician/patient relationships may need to be modified as DNA analysis performed on individuals will have familial implications. When a sample is accepted for routine pathology evaluation and later used for research purposes, IRBs have to inform investigators that informed consent is required. Genetic counselors have the experience and ability to provide information and support around these issues. However, first they need representation on these Boards for their voices to be registered. ■

# When Intellect and Instinct Don't Agree: Untreated Maternal PKU

*THE CASE: Robin Bennett and her colleagues are following a mentally impaired woman with untreated PKU who presented at nine weeks gestation with a phenylalanine level over 30mg/dl. She apparently is her own guardian and had been referred by a family practice physician for evaluation and counseling because she refused to modify her diet. Several questions were raised regarding responsibilities to the patient, and also to the fetus. The issues include:d the patient's understanding of the serious harm that results from untreated maternal PKU, the feasibility of hospitalizing the patient for dietary control, the possible intervention of Child Protective Services on the part of the fetus and defining who has the follow-up responsibility. Several colleagues were asked to provide input regarding the issues, including Becky Anderson, Barbara Dixson and Sue Schmerler.*

## Comments from Colleagues

Of primary concern is the manner in which this woman was judged to be her own guardian and whether or not this was an official judgment from a mental health professional. If no official determination has been made, a professional opinion was suggested.

We cannot legally or ethically intervene in the care of this woman or her pregnancy and must respect her right to privacy, unless a legal guardian was appointed by the state. Since she currently is her own guardian, we, as health care professionals, have no legal jurisdiction over her actions.

## Remember the Code

Intervention by forcibly hospitalizing this woman would violate our Code of Ethics, which encourages us to respect our client's beliefs and suggests we enable our clients to make independent decisions, free of coercion. In 1992, our membership passed a Prenatal Substance Abuse resolution, which, although focusing on alcoholic and drug dependent women, advocated support services rather than punitive sanctions. Although hospitalizing for diet control is different from incarceration, both speak to not restricting a woman *solely* because she knowingly exposes her fetus to a teratogenic agent.

## Child Care After Birth

Another issue is this woman's ability to care for her infant after birth. Clearly, this is the role of Child Protective Services. They have already been notified and will keep the case on file. Several positive suggestions were provided, including attempting to maintain a relationship with the patient. Since this patient expressed the desire to keep her baby, emphasizing ways to maximize the baby's health may be a motivating factor for her to continue follow-up care.

The counselor was also encouraged to present information about contraception as a means of the patient avoiding the additional burdens of caring for more than one child. Unresolved are issues of finances, both during and after the pregnancy.

## In Summary

Parts of this issue have previously been presented in *PGC* and continue to be complex. In this case, it was agreed that the genetic professionals were not liable for this patient's decisions. We fulfill our obligation by providing necessary information to enhance a patient's personal decision-making. In spite of a gut instinct to protect the fetus from the harmful effects of untreated maternal PKU, this is an area in which we must allow intellect and training to rule. ■

***Fiona Field, MS***
***University of Illinois at Chicago***

## When Our Code of Ethics Presents Conflict

Our Code of Ethics addresses several different relationships: that with our clients and that with society. While respecting patient autonomy, this case presents unique problems in that this woman is both mentally retarded and mentally ill. She reported during her communications with us that she has seen eight obstetricians during this pregnancy, presented paranoid thoughts about their care and was non-compliant about staying on a PKU diet during her pregnancy. Clearly, dietary compliance would improve both the chances for her child and her own psychiatric health. Although the law recognizes her as her own guardian, her actions and comments demonstrated that she would be incapable of caring for a normal child, much less one who will have special needs. Using current financial information, this child will cost about $150,000/year in lifetime care, a cost born by society. We propose that in some rare circumstances such as this, it *is* appropriate to intervene.

***Robin Bennett, MS and Cris Trahms, MS, RD***

# SOCIAL ISSUES COMMITTEE: PAST, PRESENT...

The Social Issues Committee's (SIC) mission is to facilitate NSGC's response to ethical, social and political issues which impact our patients and our profession. Ann Walker, the first chair, and all those who have followed have witnessed the evolution of our Society's social conscience.

## FORMAL OPINIONS

The SIC has authored five position statements and three resolutions, which are our Society's method of addressing and responding to both potential and real social, ethical and political issues that may impact our patients and our profession. The position statements are:

- Access to Care
- Nondiscrimination
- Confidentiality of Test Results
- Disclosure and Informed Consents and
- CF Screening.

Two additional position statements are pending board review at the October meeting.

The resolutions have defined our stance on:

- Reproductive Freedom
- Prenatal Substance Abuse and
- Fetal Tissue Research.

## FASCINATING WORKSHOPS

The SIC also sponsors a workshop at each Annual Education Conference. Our most recent workshops in San Francisco and Atlanta addressed ethical and legal dilemmas as well as ambiguous results that we face with DNA testing. Both were met with enthusiastic responses.

The upcoming workshop in Montreal is entitled "Whose Choice is it Anyway? The Impact of Litigation on Genetic Policies." Participants will be divided into two groups and asked to develop and defend arguments for opposing sides of both real and fictitious legal cases. (We will even have a presiding judge!)

## WHERE THE ACTION IS

One of the SIC's first tasks was to inform the membership of political change during the Reagan-Bush era when the political assault on reproductive choice was at its zenith. Another instance of the SIC activating our organization surrounded the issue of holding the 1993 Annual Education Conference in New Orleans. At that time, the Louisiana legislature had adopted the most restrictive abortion statute, which has since been struck down by a federal court. We polled the membership, and despite ASHG's decision to hold its meeting in New Orleans, we made a decision of conscience and social responsibility to support our patients' right to reproductive choice.

## STANDING SUBCOMMITTEES

Much of the work of the SIC is accomplished by the two standing committees: the Legislative Subcommittee and the Genetic Research Issues Subcommittee. The current chair of the Legislative Subcommittee is Lee Fallon. This subcommittee continues to anticipate and monitor federal policy developments, and Lee communicates pertinent information to the membership through the Legislative Updates column in *Perspectives*.

This past year, she has spent most of her committee-related energies tracking the developments of health care reform. She is also in the process of establishing an Alert System so the membership may become better and more quickly informed about federal policies.

The focus of the more recently-formed Genetic Research Issues Subcommittee, chaired by Dorene Markel, is to address the ethical and social issues created by the explosion of new molecular diagnostics into our clinical practice. This subcommittee is currently working on position statements regarding genetic screening and presymptomatic testing. Committee members are also dealing with issues regarding the role of genetic counselors as

## NATIONAL HEALTH CARE REFORM RESOLUTION

The NSGC supports Health Care Reform measures which provide universal access to and guaranteed coverage for:

- Genetic services regardless of race or ethnic background, religion, socioeconomic status, disability, or sexual orientation.
- Prenatal care, family planning services, pediatric and long term care, and psychological counseling.
- Safe and legal abortion.
- Health insurance without respect to health status, including future genetic risks.

*Passed by the Board of Directors, April 24, 1994; pending Full membership approval (in progress)*

## ...AND FUTURE

research brokers.

### PLANS OF THE NEW CHAIR

I plan to continue previous efforts, including:

- approval of the pending position statements
- support of the efforts to establish the Alert System
- implementation of the new protocol for approving position statements and resolutions ('how a bill becomes a law').

On a personal level, I am interested in increasing access to genetic services. While we all believe that access is important, I'm skeptical as to how much action is taken to increase that access. While I am aware that some major barriers to increasing access (funding, resources) exist, I firmly believe that we *can* make a difference. Identifying both the barriers and all possible solutions is my first goal. *Action* is the next step.

Stay tuned, or better yet, get involved! The Social Issues Committee is energized by the ideas of our diverse membership. Come to the committee meeting in Montreal or call with your ideas. ■

*Lori Williamson-Kruse, MS*
*1994-1996 Chair*
*and Vivian Weinblatt, MS*
*1992- 1994 Chair*

### YOUR VOTE COUNTS!

If you are a Full Member of NSGC, we encourage you to meet the October 28 deadline for the National Health Care Resolution vote. A ballot is enclosed with this issue of *Perspectives*. ■

*Legislative Update*

## HEALTH CARE REFORM: POLITICS VS. ACCOMPLISHMENT

One of the political victims of Congress' crime bill appears to be comprehensive health care reform. When both the House and Senate returned to work September 12, they had just a month left in the legislative calendar to advance health care legislation. Speculation predicts that any attempt at comprehensive health care reform legislation may be postponed until the next legislative session, which will convene with the 104th Congress in January 1995.

With all of the House and 1/3 of the Senate up for re-election on November 8, health care reform may be a major policy issue which the public will use to make voting decisions.

### THE CURRENT COMPROMISE

A consensus health bill, where the current energy is being devoted, would eliminate many of the more controversial issues, such as requirements for employers to pay a percentage of employees coverage, federal regulation to control cost and Medicare reform. The consensus bill would likely target health insurance regulation, making health insurance easier to obtain and keep. Restrictions involving limitations on pre-existing conditions would be enacted. With the addition of federal supplements for Americans with low income, the consensus bill is estimated to provide insurance coverage to half of the 39 million Americans currently uninsured. It would not provide universal coverage, an issue President Clinton indicated last fall was non-negotiable. Other possible issues covered by the consensus bill could be a standard benefits package, malpractice reform, home care coverage and Medicaid reform.

### TIME TO QUESTION

Most of us are eligible to vote for Representatives to the House and some of us for Senate candidates, as well. Know the views of all candidates on these major issues:

- UNIVERSAL COVERAGE: Who and how many will be covered and by when?
- EMPLOYER MANDATED COVERAGE: Should employers be required to pay for or just offer health insurance?
- INSURANCE REFORM: Should pre-existing conditions be eliminated as barriers to health insurance?
- FEDERAL REGULATION: Should the federal government set limitations on reimbursement or covered services?
- STANDARD BENEFITS PACKAGE: Should certain health provisions be guaranteed to all insured, such as maternity care and abortion?
- MALPRACTICE REFORM: Would limits on monetary awards help control health costs?
- FINDING THE MONEY: What taxes should help cover additional health care costs?

Ask these questions of the candidates, and then ask them to describe the areas in which they are willing to compromise. Given their responses, you can define your voting strategy. Most importantly, make sure you are registered to vote, and then, *just do it.* ■

*Lee Fallon, MS*
*Legislative Liaison*

# ACMG's Joint Committee on Professional Practice...

*The prestige of the National Academy of Sciences' Institute of Medicine (IOM) is such that their publications are used by legislators and general policy makers and serve as a basis for decisions regarding the provision and delivery of health care services. The Joint Committee on Professional Practice of the American College of Medical Genetics has carefully reviewed one of their recent reports. A statement from that committee was recently sent to College members and identifies some areas of concern which caused the College to not endorse the report. The majority of NSGC members are not ABMG members.* Perspectives *editors thought it was important for our membership to be aware to be aware of such significant activities of our sister organizations. Therefore, with permission of Drs. Rimoin and Kaback, a majority of the statement is reprinted below.*

The American College of Medical Genetics (ACMG) welcomes the recent publication of the IOM Report "Assessing Genetic Risks - Implications for Health and Social Policy," which became available to the public in May (National Academy Press, Washington DC). This nine chapter volume represents the deliberations of a 20 member IOM committee comprised of geneticists, lawyers, ethicists, counselors, public health and health policy experts, as well as insurance industry and consumer representatives. During the two year deliberations which lead to this Report, numerous consultants in relevant areas participated in invited workshops and in an open public forum held in Washington DC in 1992.

The Report highlights many of the complex technical, social and ethical issues posed by dramatic recent developments in human genetic technology as well as other advances anticipated in the near future. It considers numerous laboratory and policy issues raised by genetic testing of individuals and screening of the population in general, or of high-risk population subsets for genetic disorders such as cystic fibrosis, Tay-Sachs disease, sickle cell anemia and Down syndrome. The Report also recognizes that rapid progress is being made in defining genetic alterations underlying or associated with more common disorders and conditions with onset much later in life such as Alzheimer disease, certain types of cancer and various cardiovascular disorders. It notes that the implications for individual and population-based testing and the development of health policies concerning these latter conditions are considerably more complex. The ACMG regards this Report as an important starting point in defining needed areas for further deliberation and exploration.

Unfortunately, however, as acknowledged by the IOM Committee Chairman in his published comments in the report ("Additional Views of the Chairman"), the Report primarily focuses on the potential problems raised by genetic testing and screening, with little emphasis placed on the values and benefits which such technologies surely will engender both for individuals and society. Genetic testing soon may provide us with the capacity to identify individuals who will develop specific disorders well in advance of initial symptoms. Such information, particularly if coupled with effective therapeutic or preventative intervention, may be of great benefit to many Similarly, the detection of certain genetic factors which predispose an individual to certain conditions (as distinct from assuring with certainly that the disorder will develop) may permit behavioral, dietary, or pharmacologic approaches which could greatly minimize the probability that the genetically predisposed illness will manifest in that individual at all. Clearly, enormous benefits in life quality, longevity, productivity and savings are likely to result from such discoveries and interventions. Moreover, individuals in families who perceive themselves to be at increased risk for various genetic disorders may, through testing, learn that they do NOT have such predispositions and, thereby, have their anxieties allayed and unnecessary interventions avoided, with considerable savings in health care costs.

In many areas the Report often suggests idealized solutions to the perceived problems. However, the Chairman's comments point out some major difficulties in the Report which concern many practicing medical geneticists. Many of the Report's suggested solutions are somewhat utopian and inconsistent, in varying degrees, with practical reality or well established current practices. To insist for example, that low-risk newborn screening for such disorders as phenylketonuria or hypothyroidism be provided only with fully in-

formed parental consent might seriously undermine the overall benefits of such established efforts and unquestionably would greatly increase their costs.

In another area, the Report's recommendation for withholding genetic testing results (eg, the identification of sickle trait status in a newborn as part of a screening effort directed to the identification of sickle cell anemia) from either or both parents is inconsistent with policies of full disclosure, parental rights and individual autonomy. Similarly, the suggested requirement that pilot studies be completed which prove the efficacy of a given intervention before any degree of broad scale genetic testing be conducted would deprive enormous numbers of individuals of useful medical information. For example, if testing to identity those who are genetically predisposed to colon cancer became available, it would require longitudinal studies stretching over decades to evaluated whether interventions including intense medical surveillance and/or dietary management would prevent and/or reduce morbidity and mortality.

Further, the recommendation that testing of children be carried out only where proven and effective interventions exist, regardless of parental requests, is also debatable. Certainly examples can be given where parents may justifiably desire such information about their child to allay anxieties, for reproductive-making purposes or to plan for the future health care needs of their child.

Finally, the Report's recommendations regarding how, and from what sources, regulation and oversight of genetic testing and screening might be achieved are problematic. Relatively little responsibility is delegated to established professional genetic organizations as major sources for recommendation in these complex areas. State jurisdiction (through health departments or regional bodies) is also given relatively minor focus. Rather, a newly created "National Advisory Committee and Working Group on Genetic Testing" is suggested by the Report at the primary oversight body. Such an entity, while achieving broad-based scientific and public participation, might well prove ineffectual (politicized), transient (like many federal commissions of the past) and overly restrictive. As is true in all other medical fields, the recognized genetic professional organizations representing the disciplines of medical and laboratory genetics and genetic counseling should be major (but not sole) sources of experience and wisdom in such deliberations.

There are, to be sure, myriad and complex issues raised by recent developments in medical genetics.

- How should genetic testing be introduced into the health care system and how should it be regulated?
- When should this occur? Under what conditions and with what prerequisites met?
- What requirements for professional competence and laboratory quality assurance must be met?
- How can adequate consent for testing be assured?
- Who will provide the pretest education and post-test counseling necessary to protect individual autonomy and sure appropriate understanding of testing results?
- How will confidentiality be maintained and privacy protested?
- What access to test result information should be available to insurance companies, employers and other family members?

These are issues which directly impact the practice of medical genetics. In fact they are some of the precise reasons for which the ACMG was formed. ... ... ...Its sister organizations are ABMG (which certifies doctoral-level clinical and laboratory geneticists and accredits training programs), ABGC (which certifies masters-level genetic counselors and accredits training programs), NSGC (the association of masters-level genetic counselors) and ASHG (which represents the genetic research community). The college and these sister organizations should be called on in the future to participate in and contribute meaningfully and substantially to deliberations at all levels — local, state and national — when issues raised in the IOM report are addressed. ■

*Michael Kaback, MD, Chair*
*William Conte, MD*
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*Karen Greendale, MA, consultant*

# DIRECTORS RESPOND TO COMMENTS ABOUT THESIS TOPICS

To the Editor:

I was pleased to see projects from students at the University of Cincinnati Graduate Program in Genetic Counseling listed in *Perspectives* (16:2, Summer 1994).

However, I did not find the comment "we noticed the nature of some topics seem more directed to basic science than genetic counseling" either supportive or encouraging.

Isn't having understanding of basic science a major part of genetic counseling? Some of our students choose "bench" over clinical projects because of interest or expertise in the area and/or availability of financial support for their research. All students are required to publicly defend their research and write a thesis. Clinical and genetic counseling implications are included as an integral part of the project.

Let's let the choice of master's projects be left to individual students, their advisors and graduate program faculty. We as genetic counselors ought to celebrate the rich diversity in ourselves and our training, just as we celebrate the diversity of the people we serve. ■

*Nancy Steinberg Warren, MS*
*GC Graduate Training Program*
*Cincinnati OH*

To the Editor:

The best reflection of a program is the performance of the graduate in the work environment, regardless of the thesis topic. Counseling skills and information are best acquired through the clinical training experience. Thesis topics revolve around two issues: the balance of genetics and counseling and the funding of master's level students.

The balance between science and counseling in a training program is an enduring challenge. An appropriate thesis can address any aspect of genetic counseling. Clearly, an understanding of the scientific foundation of clinical genetics is of great value. Likewise, a well done project on the art of genetic counseling is highly desirable. However, a well designed project in the science or art of genetic counseling which could involve scoring of videotaped or audiotaped counseling sessions tends to be costly. Current funding is better for 'hard science' than counseling oriented projects.

The University of Cincinnati is probably similar to my own institution where funding for our students is a major priority. To secure a graduate student research (GSR) assistantship at the University of Pittsburgh, a student must work 20 hours per week with a faculty member who pays a stipend of $945 per month with the institution providing tuition remuneration. As a result of the funding opportunity, students often choose a thesis topic with their faculty sponsor. Unfortunately, topics with a 'counselor focus' are seldom available, since extramural grant or institutional support for these topics is scarce.

To resolve the dilemma, genetic counselors and especially program directors should competitively seek grants which would support counseling research. Securing financial support for students is critical to all programs and the profession. Current funding mechanisms such as the GSR can serve the profession without altering the balance of genetics and counseling.

Thesis topic selection may in fact be related to funding issues for students. ■

*Betsy Gettig, MS, Director,*
*Genetic Counseling Program*
*University of Pittsburgh*

### STUDENT RESEARCH PROJECTS

SONJA EUBANKS, *University of South Carolina School of Medicine:* Utilization of Florescence *in situ* Hybridization (FISH) for the Elucidation of Small Structural Chromosome Rearrangements and Recombination Products.

KAREN HUELSMAN, *University of Cincinnati:* Modified Pulmonary Surfactant Protein-C as an Agent for Delivery of DNA to Airway Cells in Culture: An Approach to Gene Therapy for Cystic Fibrosis.

### NEWS REGARDING NEW PROGRAMS

Deborah Eunpu was named Director of the Beaver College Genetic Counseling Program, effective September 1. Beaver College is located in a suburb north of Philadelphia. They are preparing to accept students in the Fall of 1995.

Rumor has it that other new programs are developing in Michigan, Arkansas, Vancouver and at the NIH. ■

## Research Network

### Pallister Hall Syndrome

Researchers at NIH and UCLA have initiated a research program for patients affected with Pallister Hall syndrome (PHS). This disorder was thought to be sporadic and uniformly lethal but was recently reported to be inherited and compatible with long-term survival. The study goals are to determine the range of symptoms, the natural history of disease and the gene.

For eligibility criteria or to refer families, call Leslie Biesecker, MD, National Center for Human Genome Research, 301-402-2041; or John Graham, Jr., MD, Cedars-Sinai Medical Center, 310-855-2211. ■

### Glycogen Storage Disease, Type IV

The gene for type IV glycogen storage disease (GSD) has recently been cloned. Preliminary DNA studies indicate there is extensive heterogeneity. An International Registry for type IV GSD is being compiled to identify patients. This registry will identify patients for genotype/phenotype studies.

Participation requires a blood or skin fibroblast sample from the proband and a clinical history. If the proband is deceased, samples from parents or siblings will be accepted. Mailers for samples, medical release forms and reimbursement for appropriate medical expenses will be provided.

For more information contact: Allyn McConkie-Rosell, MSW or Y.T. Chen, MD, PhD, Division of Medical Genetics, Box 3528, Duke University Medical Center, Durham NC 27713; 919-684-2036. ■

*GeneBytes*

## MacReview of Pedigree Software

Welcome, Macintosh users, to the world of pedigree software. Pedigree/Draw (PedDraw), distributed by the Population Genetics Laboratory at the Southwest Foundation for Biomedical Research, can easily produce a professional quality pedigree using the symbols familiar to genetic counselors.

Information about an individual is readily entered with a dialog box. A unique identifying number is assigned, and gender and traits are selected. Multiple shading options exist to display traits, and "status symbols" include those commonly used by genetic counselors. Symbols can also be filled with a two letter code to denote a trait, such as "MR" for mental retardation. The program comes with designated two letter codes, but the user can add new ones. A snazzy feature not explored is the ability to fill the symbol with pictures (photos, graphs, drawings).

Placement in the pedigree is determined by the parents' identifying numbers. Siblings can be sorted by date of birth. A word of warning: the mapping algorithm may overlook birth order to create a "best fit" for the pedigree. Up to five comment lines can be placed beneath a symbol. These text lines can contain haplotype data. However, because there is no specific method of entering haplotypes, careful spacing and entry is required to display allele data in columnar format. This shortcoming can be compensated for by PedDraw's ability to save files in the "PICT" format. PICT files can then be edited in Microsoft Word, MacDraft, Powerpoint and other graphics software, since pedigree modification is much simpler in a graphics environment.

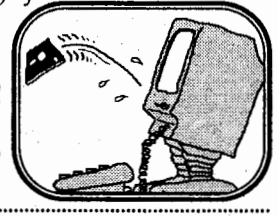
After entering individual records, display features can be varied to include mating line style (American vs. European vs. node), sibship compression, multiple mates, legend display on or off, generation numbering and size of the symbols.

Counselors involved with research on large pedigrees will appreciate PedDraw's ability to process up to 500 records in its standard format and 1000 records in extended format. Further help is provided by two utility programs: *Arbor* and *CountPed*. *Arbor* allows multiple unconnected pedigrees contained in a single file to be mapped and drawn with PedDraw. *CountPed* handles larger files (to a maximum of 2000 records) and will detect multiple unconnected pedigrees independently of PedDraw.

The user's guide describes PedDraw as a "work in progress." User feedback is actively sought and incorporated into revisions, which are generated every three to six months. Standard versions of *Arbor* and PedDraw run on any Macintosh with one MB of RAM; more memory is needed to run *CountPed*.

For further information, contact the Southwest Foundation for Biomedical Research, 210-674-1410 or FAX, 210-670-3317.

*Special thanks to Beth Hembold of the University of Michigan for sharing her PedDraw experience with large pedigree studies.* ■



***By Elaine Sugarman, MS, Integrated Genetics, Framingham MA with Robert Resta, MS and Karen Wcislo, MS***

# ■ RESOURCES ■

## ■ VIDEO ■

*Secrets of the Code*
*produced by:* Children's Television Workshop (1991)
*distributed by:* Sunburst Communications
*price:* $20.00 *length:* 30 min
*reviewed by:* Judy Capra, MA Middle School Life Science Project, Wheat Ridge CO

Quality videos for children that focus on basic principles of genetics are rare. Unlike most, *Secrets of the Code* is engaging, creative and targets fourth through sixth grades. It was produced specifically as an extension of the 3-2-1 Contact television program.

*Secrets* is an entertaining introduction to genetics. It focuses on a few basic concepts, reinforces them with examples and uses minimal technical vocabulary. It has visual and audio appeal via use of colorful graphics and student narrators. The program is organized in distinct content "blocks," each employing a different style to appeal to a wide range of young viewers.

Four children and four adults (two high school teachers and two nonscientists) provided input for this critique. We all liked the video but for different reasons. The children enjoyed the segment about cheetahs which showed the surgical removal of ovaries from the female. The adult nonscientists said that the review of basic genetics was clearly presented and interesting, while the science teachers were impressed by the amount of genetics that could be taught with so little vocabulary.

All four children learned the main concepts: that the 'recipe' for every living organism is found in its genetic code and that, because the 'details' of the code are different, every individual is unique. The video also introduces genetic engineering, explaining that by changing some details of the code, it might one day be possible to cure diseases and save endangered animals.

No video is perfect, and this one, too, has its problems. The adults were concerned that the messages in the cartoons could be confused with the science. I didn't like the insults about big ears and a big nose that were embedded in one of the cartoon segments. Similarly, in a segment when the genes found in marigolds and chimps were compared with those found in humans, the human genes seemed superior.

Some of the science could use strengthening. For instance, the relationship between genes and chromosomes is not adequately explained, and then the terms are used sloppily. There is also one phrase of concern: "Genes. You can mix them. You can fix them." Would this lead children with a genetic disorder think that their own genes could be fixed?

This video has classroom uses but is also appropriate for geneticists to use with their own children and should be considered a resource for families seen in genetic counseling clinics. It can be used as a conversation opener with younger members of the families while reviewing basic genetic concepts. The emphasis is on basic biology and normally functioning genes, and disorders are addressed only minimally. Parents should be encouraged to preview the film since there are views of fertilization and a segment about the relatedness of all living organisms. They are appropriately presented but the nature of the topics may be of concern to some parents. ■

## ■ SUPPORT GROUPS ■

***Nevoid Basal Cell Carcinoma Syndrome***

■ A national support network for those with Nevoid Basal Cell Carcinoma Syndrome has reorganized to provide support, treatment resource information, education and advocacy.

Contact: The NBCCS Support Network, c/o Penni Fischer or Susan Charron, 3902 Greencastle Ridge Drive #204, Burtonsville MD 20866; 301-847-1752 or 800-264-8099.

***Cystinuria Support Network***

■ The Cystinuria Support Network has been developed to provide a resource for connecting individuals for mutual support and practical advice. The forum includes: dealing with schools/ employers regarding drinking and medication requirements, ideas for encouraging consumption of large quantities of necessary fluids, the best approach to nighttime wake-up, mediations used to treat cystinuria and other issues of interest and concern.

For more information, contact: Cystinuria Support Network , c/o Jann Ledbetter, 22814 NE 21st Pl, Redmond WA 98053; 206-868-2996.

# BULLETIN BOARD

### IN YOUR MAILBOX SOON...

The long-awaited 1994 Professional Issues Survey will be mailed to all members along with other Society business in the membership mailing, due for distribution in late September.

Your 1995 Membership Directory will be mailed in early December, along with your 1995 dues statement. This varies from the system of the past several years in which the directory was distributed at the Annual Education Conference and mailed only to those members who were unable to attend the conference.

Directory changes will be accepted through October 1.

### MAILING ADDRESS CHANGES AND JOURNAL NOTIFICATION

The NSGC Executive Office supplies Human Sciences Press with the *Journal of Genetic Counseling* mailing labels. Therefore, you do not need to notify HSP of your address change. Prompt reporting of these changes made directly to the Executive Office will ensure that your flow of information is uninterrupted for *all* Society publications and mailings. Notification is requested in writing, by fax or E-mail. *(See page 2.)*

### WINNERS ANNOUNCED

- Beth Peshkin of Memorial Sloan-Kettering Cancer Center in New York had her bonus card selected from the many who returned their 1994 Professional Issues Surveys. Beth opted to have her 1995 dues waived as her reward.
- Jamie McDonald was granted the LGS/NSGC Speakers Travel Fund for her talk, "Genetic Counseling for HHT," given at the Hereditary Hemorrhagic Telangiectasia Foundation Annual Conference in July.
- Chantelle Wolpert presented "Genetic Gatekeepers: An Emerging Role of the Primary Care Provider," at the University of Kentucky Physician Assistant Program, also funded by the LGS /NSGC Speakers Travel Fund.

### FREEBIES TO NSGC MEMBERS

Two new publications, "A Young Mother's Guide to Pregnancy and Parenting," and "Making Choices About Sex" are available by writing to: Mary Anne & Bill Arnold, c/o Care Comm, Inc., POBox 417, 6902 Carslaw Court, Prospect KY 40059. Mention your NSGC membership to take advantage of a free single copy.

### DISCOUNT FOR ALLIANCE DIRECTORY FOR MEMBERS

NSGC has assisted the Alliance of Genetic Support Groups with a grant for the publication of their 1995 directory. In return, NSGC Full members will be entitled to a discounted rate when they purchase a copy. Contact the Alliance for an order form in early 1995 and don't forget to take advantage of your discount.

### GET INVOLVED!

If you are interested in working on the 1995 Annual Education Conference, come to the Planning Meeting on October 16 at 7:30 pm in the Argenteuil Room, LeMeridien Hotel, Montreal. If you are unable to attend, but would like to be involved, contact Carol Strom at 605-394-5110 or Wendy Uhlmann at 313-763-2532.

### NOTCH IN ONE MORE STATE

Anne C. Spencer has accepted a position in Boise ID, leaving only North Dakota unrepresented by genetic counseling services. Anyone interested?

## MEETING MANAGER


| | |
|---|---|
| Sept 28 - 30 | "Reproductive Genetics: Screening, Testing and Therapy: The Challenge and the Promise," The Western Pennsylvania Hospital, Hidden Valley PA. Contact: West Penn Hospital, CME Dept, 412-578-6926; FAX# 412-578-4839. |
| Oct 15 - 16 | National Tuberous Sclerosis Association 20th Anniversary Symposium, Arlington VA. Contact: Carolyn Wilson, 800-225-NTSA or 301-459-9888. |
| Nov 17 - 20 | "The Challenge to Change, " National Perinatal Association 1994 Clinical Conference and Exposition, sponsored in conjunction with the University of Wisconsin Medical School, San Diego CA. Contact: Contemporary Forums Conference Management, 510-828-7100x3. |
| 1995 | |
| Jan 5 - 7 | Legal, Medical and Ethical Issues in Women's Reproductive Health and Neonatology. Sponsored by American Society of Law, Medicine and Ethics. Naples FL. Contact: 617-262-4990. |

# LETTERS TO THE EDITOR

### PARENTS OF TWINS CAN USE MORE THAN 'CONGRATS'

Our first contact with a genetic counselor was six years ago when I had an amniocentesis scheduled. After the session, I had an ultrasound and received the remarkable news that we were having twins. Congratulations went all around but we didn't hear much of it — we were in shock. This is the moment when we could have *really* used a counselor. We had no idea of the difficulties that were in front of us. I encourage all genetic counselors to provide literature or referrals to couples who are having multiple births. The challenges and severe stresses of raising twins cannot be overstated.

For free professional literature, support, and a hot line staffed with professional counselors, contact Twin Services, 510-524-0863. The Mothers of Twins Clubs, 505- 275-0955, provides support and local meeting resources. On the death of a twin or twins, call 907-745-2706 for professional literature and out-standing support. ■

***Phyllis Hockett***
***Mother of 5-year old twins***

### PONDERING A TOUGH ISSUE

To the Editor:

*re: Third-trimester abortions and veteran counselors (PGC 16:2)*

The issue of third trimester abortions has provoked soul-searching discussions at my center, revealing a range of responses among all counselors, regardless of their years of experience. Increasing numbers of third trimester anomalies are being identified with increased ultrasound use. With the existence of private centers (such as the one in Wichita which funds our newsletter), it is possible to obtain third trimester abortions. Some hospitals perform them in-house.

While the availability of this service can be a blessing for some families, we are finding that the number of cases with "fuzzy" diagnoses raise some ethical dilemmas. The definition of "lethal" has also become "fuzzy."

Professionally, I am pro-choice. Personally, I don't always know exactly what that means. I believe every child should be a wanted child. But aborting a baby with Down Syndrome at 32 weeks feels different from aborting at 14 or 19 weeks. I struggle with whether the number of weeks should make a difference. Is the family's decision infanticide, abortion at 34 weeks or euthanasia? What if a family wants to abort for cleft lip and palate in the third trimester? Should genetic counselors be gatekeepers at all... ever...in what circumstances? The bigger question involves our willingness as professionals to continue an open dialogue about these unanswerable questions. We know at the outset that individual responses and experiences will make it impossible to create guidelines for everyone. However, do we leave the discussion up to the ethicists, the disability rights groups, the right-to-lifers, the students and the media?

For many of the veterans among us, the longer we are in the field, the more gray the ethical areas become. We embrace the complexities of each situation to such an extent that we become less sure of what is ethical and good for our society as a whole.

In our private discussions we often feel so ambivalent that we tacitly endorse the status quo at our own institution. The ethical issues in our jobs are incredibly difficult, and sometimes we tire of wrestling with them. Meanwhile, the issue of third trimester abortion occurs more frequently.

Let us begin to talk together, to hear one another's point of view and to wonder collectively about this relatively new development in prenatal diagnosis. ■

***Kathy Barnhart, MS***
***Kaiser Permanente, Oakland***

### ETHICS SUBCOMMITTEE RECRUITMENT

The Ethics Subcommittee is recruiting two members for three year terms beginning this fall with the following minimum requirements:

- full membership
- interest in bioethics and
- the ability to attend committee meetings held at the Annual Education Conference and by conference calls.

If interested, call Vivian Wang at 212-362-2330 or attend the Ethics Subcommittee meeting at the Annual Education Conference.

To apply, send your curriculum vitae and a letter detailing your interest and experience in bioethics to: Vivian Wang, Department of Counseling Psychology, Box 102, Teachers College - Columbia University, New York NY 10027 or fax to 212-678-4048 by September 30.

# ■ EMPLOYMENT OPPORTUNITIES ■

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

**LOS ANGELES CA:** Immediate openings for 2 BC/BE Genetic Counselors; excellent organizational & interpersonal skills; willing to travel to satellite clinics; Spanish helpful.
RESPONSIBILITIES: Provide GC support to families for clinical genetics program: PNDx, genetics clinic & subspecialty programs.
CONTACT: Noreen Brown, Human Resources, Cedar-Sinai Medical Center, 8723 Alden Dr, Los Angeles CA 90048; 310-855-5760. EOE/AA. Refer to Job #1940200.

**SACRAMENTO CA:** Immediate opening for BC Genetic Counselor. Minimum 1-2 yrs experience preferred.
RESPONSIBILITIES: Participate in all aspects of GC in university-based PNDx center; teaching responsibilities; expanded AFP & outreach clinics; many clinical opportunities.
CONTACT: Faith Betti, Dept OB/GYN, University California Davis, 1621 Alhambra Plaza Suite 2500, Sacramento CA 95816; 916-734-6930. EOE/AA.

**SAN FRANCISCO CA:** January 1995 opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Comprehensive care for 25% of No. Calif residents: PNDx & counseling, AFP, teratogen counseling, heterozygote screening, clinical & metabolic genetics, dysmorphology, newborn screening.
CONTACT: Bruce Blumberg, MD or Nancy Hanson, MS, Kaiser-Permanente Medical Group, 2200 O'Farrell St, San Francisco CA 94115; 415-202-2998. EOE/AA.

**SAN FRANCISCO CA:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of genetic counseling in a dynamic prenatal diagnosis center. Team includes clinical geneticist, genetic counselors and perinatologists. Hospital based program in OB Dept, California Pacific Medical Center: CVS, amnio, PUBS, teratogens, US abnormalities, AFP and triple marker screening and family history referrals. Counselors also work with CF clinic and Breast Health Ctr. Patients from varied ethno/cultural/socioeconomic backgrounds.
CONTACT: Linda Lustig, MS, Perinatal Services, 2100 Webster St, Suite 300, San Francisco CA 94115; 415-923-3637. EOE/AA.

**SYLMAR/LOS ANGELES CA:** Immediate opening for BC/BE Genetic Counselor. Fluency in Spanish helpful.
RESPONSIBILITIES: Join academic genetic service in public health setting: all aspects of PNDx case management, coordinate public & professional education; participate in clinical research, continuing education; opportunity for pediatric/general GC.
CONTACT: Valerie Rappaport, MD or Zina Tatsugawa, MS, UCLA Medical Center - Olive View, Prenatal Diagnosis Unit, Rm 3A101, 14445 Olive View Dr, Sylmar CA 91342-1495; 818-364-3474. EOE/AA.

**TORRANCE CA:** Immediate opening for BC/BE Genetic Counselor; bilingual in Spanish strongly recommended; flexible schedule.
RESPONSIBILITIES: Join 4 full-time GCs & 3 medical geneticists: provide PN counseling & genetic insvc to hospital & clinic staff at Harbor/ UCLA office. State-of-art telecommunications with colleagues & admin office in Fountain Valley.
CONTACT: Naomi Nakata, MS, Genetrix, Inc, 11160 Warner Ave #317, Fountain Valley CA 92708; 800-947-4363. EOE/AA

**NEW ORLEANS LA:** Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate active genetics program with variety of patient contact: inpatient hospital consultations, outpatient and statewide satellite clinics; patient intake interviews, coordinator of laboratory evaluation, follow-up counseling and referral to service agencies; education role includes presentations and teaching.
CONTACT: Emmanuel Shapira, MD, PhD, Human Genetics Program, Tulane Medical School, 1430 Tulane Ave, New Orleans LA 70112; 504-588-5229. EOE/AA.

**BOSTON MA:** Immediate opening for BC/BE Genetic Associate with MS in Genetic Counseling.
RESPONSIBILITIES: Coordinate busy molecular DNA diagnostic program; involvement in MSAFP; research opportunity avail able.
CONTACT: Aubrey Milunsky, MD, Center for Human Genetics, Boston University School of Medicine, 80 E Concord St, Boston MA 02118; 617-638-7083. EOE/AA.

**BRONX NY:** Immediate opening for BC/BE Genetic Counselor. Experience & Spanish preferred, but not required.
RESPONSIBILITIES: Join busy inner-city genetics team of BC MD & 5 GCs. Multi-culturally diverse pt population; all aspects of PN, pediatric and adult diagnosis & counseling services; ample & diverse research & educucational opportunities; professional, lay, community support groups.
CONTACT: Laura Miraz, MS, MPH, NY Medical College-Lincoln Medical & Mental Health Center, Pediatric Genetics Room 4-20, 234 E 149th St, Bronx NY 10451; 212-230-6452 or Metropolitan Hospital 212-230-6452. EOE/AA.

**NEW YORK NY:** Immediate opening for BC/BE Genetic Counselor. Excellent written & verbal communication skills necessary; Spanish helpful.

Continued on next page

national society
of genetic
counselors, inc.

nsgc

233 CANTERBURY DRIVE
WALLINGFORD, PA 19086-6617

# EMPLOYMENT OPPORTUNITIES *from previous page*

RESPONSIBILITIES: Neonatal, pediatric & hi-risk OB referrals; opportunity for independent work.
CONTACT: Dr. Kwame Anyane-Yeboa, Div Genetics, Columbia-Presbyterian Med Ctr, 622 W 168th St, PH 12West, New York NY 10032; 212-305-6731. EOE/AA.

**ROCHESTER NY:** Immediate opening for Part-time Genetic Counselor. Experience strongly preferred.
RESPONSIBILITIES: Join team to provide PN & multiple marker screening, genetic diagnosis and counseling in university-based clinic.
CONTACT: George B. Segel, MD, Div Pediatric Genetics, University of Rochester, 601 Elmwood Ave, Box 777, Rochester NY 14642; 716-275-5857. EOE/AA.

**PITTSBURGH PA:** Immediate opening for Senior Genetic Counselor with MS in Human Genetics or GC and minimum 5 years clinical experience.
RESPONSIBILITIES: Assist in development, implementation & evaluation of Cancer Susceptibility Analysis Program.
CONTACT: Pat Pope, Dept Human Resources, Allegheny General Hospital, 320 E. North Ave, Pittsburgh PA 15212; 412-359-6669. EOE/AA.

**DALLAS TX:** Immediate opening for Masters in GC, SW or related field and 2 years minimum experience in clinical genetics. Faculty Associate in Pediatrics.
RESPONSIBILITIES: Provide outreach services, information & education to local public health regional clinics & area high schools; act as liaison for pts & staff between genetic specialties at medical school & associated hospitals; support services to families.
CONTACT: Lewis Waber, MD, PhD, Dept Pediatrics, Univ Texas Southwestern Medical Ctr, 5323 Harry Hines Blvd, Dallas TX 75235-9063. EOE/AA.

**HOUSTON TX:** Immediate opening for Genetic Counselor with MS and 3 years experience as GC *or* MS, BC and 2 years experience. Experience must include risk assessment & counseling for adult onset diseases.
RESPONSIBILITIES: Design, implement and provide GC services for all assigned patients & at-risk individuals
CONTACT: Kelly Fitzpatrick, Dept Human Resources, University of Texas M.D. Anderson Cancer Center, 1515 Holcombe, Box 205, Houston TX 77030; 800-25-UTMDA. EOE/AA. Smoke-free.

## IN CANADA

**TORONTO, ONTARIO, CANADA:** Immediate opening for Genetic Counsellor with interest in PN diagnosis and research,
RESPONSIBILITIES: Join busy multidisciplinary parental diagnosis unit with variety of counselling opportunity: amnio, CVS, triple screen, fetal anomalies, teratogen counselling, develop adult GC clinic.
CONTACT: Colin Dawes, Human Resources Dept, The Toronto Hospital, 101 College Street, College Wing, 2nd Floor, Toronto, Ontario, CANADA M5G 1L7; 416-340-36812.