# PERSPECTIVES
## in Genetic Counseling

*newsletter of the* National Society of Genetic Counselors, Inc.

Vol. 10 No. 2 Summer 1988


## NSGC Elections to be Held

The nominating committee has been busy preparing a slate for the upcoming elections. The positions are: President-Elect, Secretary and Representatives for Regions II, IV and VI. Two candidates have been nominated for each position.

Information and ballots will be mailed to full members in good standing on or about July 15. If you are a full member and do not receive your ballot by Friday, July 29, please call the Executive Office.

Please exercise your voting privilege. Your vote counts!

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




## The Politics of Genetic Counseling

### A Feminist Views Prenatal Diagnosis

**by Ruth Hubbard, Ph.D., Professor of Biology, Harvard University**

Since women are the primary caregivers as well as childbearers, prenatal testing and counseling affect our economic and social circumstances, our experience of pregnancy, our health and the health of our children.

Fundamental to the concept of feminism is reproductive choice. Yet while we have entered a new era in which applications of genetics and prenatal testing offer unprecedented choices, opportunities for women to receive information about these choices depends on social and economic status. Even when it is provided, the information is often unbalanced and the range of reproductive alternatives is not adequately presented.

Because genetic professionals are trained within a medical model, they have a tendency to regard disability and disease as the enemy and to expect

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### Rights of the Disabled: A Message to Professionals

**by Marsha Saxton, Director Project on Women and Disability**

As a woman with spina bifida and as a disability rights activist, I challenge the supposition that having a disabled child is wholly undesirable and that the quality of life for disabled individuals is necessarily diminished. I also challenge the concept that we, armed with the new prenatal screening technologies, have the competence to decide whether some people are better off never being born.

Disabilities trigger fear in our able-bodied society, which upholds rigid standards of beauty, productivity and athletic prowess. The disabled person in our culture is often gawked at or avoided, pitied or resented, considered capable of vastly lowered expectations or held in awe. But the disabled person also faces more tangible barriers: employment discrimination, second-class

continued on p. 4, col. 2

### Sexual Harrassment as a Threat to Professional Status

**Name Withheld**

Sexual harassment is defined as "any unwanted sexual attention a woman experiences on the job, ranging from leering, pinching, patting, verbal comments, and subtle pressure for sexual activity, to attempted rape or rape."[1] Since this implies that it is the *recipient* of the attention and not the instigator that determines whether the attention constitutes sexual harassment, many interactions between males and females in the workplace can be classified in this manner.

*Sexual innuendo* is a form of sexual harassment that is difficult to classify and control because it is often condoned by female co-workers. My experience with sexual innuendo began with my hiring. I noted that the environment was unusually informal but at the time I didn't consider it to be threatening. In retrospect, however, I recall that even at my job interview I felt uncomfortable. I knew that my resume was thorough, but I expected more questions and less shoulder patting. After I was hired, sexual innuendo was subtle but constant.

I regard sexual innuendo as harassment even though it may be perceived as harmless

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## Corner Thoughts

This issue of *Perspectives in Genetic Counseling* begins an exciting new collaboration between genetic counselors and activists in the women's health movement. Our joint goal is to see that women and men have access to the information they need to make informed decisions about genetic tests and that individual reproductive rights are supported.

The timing of this forum is appropriate since issues of reproductive choice and control in genetic counseling and prenatal testing are being discussed worldwide by the media and various professional and consumer groups.

This issue features the comments of representatives of the Women and Reproductive Technologies group of the Committee for Responsible Genetics. They raise questions about the implications of prenatal testing, the genetic counseling relationship and the overall delivery of genetic services. The perspectives they offer are intended to be a synopsis of some of the issues that may benefit from further analysis.

As professionals working in human genetics, we constantly bear witness to the physical, emotional and spiritual effects of prenatal tests on the lives of women and their families. The impact can be profound and is growing as new technologies and protocols develop. I believe it is up to us, as health care providers and educators, to develop a model for "socially conscious counseling" and to re-evaluate and develop innovative methodologies to assist with prenatal genetic decision-making.

The premise is that genetic counselors, along with nurses and pregnancy and childbirth educators, often have the most prolonged contact with childbearing women. By broadening our views and working together, we can better serve them.

I look forward to ongoing discussions on these topics.

Robin Blatt

**Robin J.R. Blatt, R.N., M.P.H.**
**Massachusetts Genetics Program**

## Open Report

### Third Party Reimbursement for Genetic Services

**by Beth Fine, M.S., Illinois Masonic Medical Center, Chicago, IL**

In 1987, the Continuing Education and Training Project for Reimbursement of Medical Genetics Services was funded by the Division of Maternal and Child Health as a Special Project of Regional and National Significance (SPRANS).

The purpose of this Project, under the leadership of Robert M. Greenstein, M.D., is to improve access to genetic services, especially for low income, non- and/or under insured populations. To assist in this effort, a National Advisory Board (NAB) comprised of representatives of professional and consumer genetics organizations, the insurance industry, as well as public health and medical associations, was established.

One objective of the Project is to help develop a standard set of definitions of current and future genetics tests and services. The NAB concluded that the existing Current Procedural Terminology (CPT) codes for medical services, procedures and lab tests, as they apply to genetics, are adequate at this time. However, several issues regarding the descriptions of "genetic counseling" were raised. For example:

- How does an initial counseling session differ from an intermediate or complex session?
- How long should each take?
- Who should provide counseling?
- How should we bill for group counseling sessions? ...for extended family studies involving chromosome translocations or DNA linkage analysis?

Since the question of reimbursement for non-physician genetic counselors was not resolved, I am recommending that our Professional Issues Committee form a liaison with the appropriate ASHG committee to explore this issue.

At a recent NAB meeting, Mr. Barry Eisenberg, representing the American Medical Association (AMA), described the CPT code development. Because the ABMG and ASHG certify and include non-physicians, neither can represent genetics in the AMA's House of Delegates, from which the CPT Advisory

continued to p. 4, col. 1

## EdNotes

Are genetic counselors so focused on reducing disability that they have grown insensitive to disabled people? Are genetic testing technologies and services sold to an unknowledgeable public without adequate opportunity for discussion? ...reflection? ...decision? Does the male-dominated field of medical genetics oppress women genetic counselors?

These questions and others are posed to the NSGC by the authors of the lead articles in this issue of *Perspectives*. Presented here is a preview of some of the topics to be discussed in New Orleans in October—office politics (p. 1), institutional politics (p. 3) as well as state (p. 5), regional (p. 2) and national (p. 5) politics.

Genetic counselors may take issue with some of the ideas and opinions expressed here. Frankly, I'd be surprised if they didn't. But these viewpoints cannot and should not be dismissed. The criticisms presented here are meant to be constructive, as Robin Blatt points out in *Corner Thoughts*. She and other members of the Women and Reproductive Technologies Group of Boston's Committee for Responsible Genetics (CRG, 186A South St., Boston, MA 02111) are challenging the NSGC to consider their viewpoints as the profession and the application of genetic counseling evolve. Ruth Hubbard and Marsha Saxton have begun the dialogue here with articles that they wrote with the guidance of Rayna Rapp and Nachama Wilker. A future issue will feature comments by Laurie Nsiah Jefferson on genetic services and minorities.

There will be an opportunity to continue the discussion in New Orleans, and Trish Magyari recommends that Barbara Katz-Rothman's *The Tentative Pregnancy* be read as background (see p.8). Don't be content to just read the reviews (p. 5 and p. 9).

Anyone wishing to continue the dialogue in *Perspectives* is welcome and perhaps the Committee for Responsible Genetics will invite representatives of the NSGC to present our views in GeneWATCH, CRG's bi-monthly publication.

Lastly, a special thanks this issue to Robin Blatt, who coordinated the submission of some excellent material, to Betsy Gettig for some helpful ideas and to Fred Bieber for contributing some information to Ann Swinford's report on the fetal tissue transportation legislation.

**Ed Kloza**

## The Economic Impact of Genetic Service Provisions

**by Tillie Young, M.S., Hackensack Medical Center, Hackensack, NJ**

In the 12 years that I have been working as a genetic counselor in a 500+ bed New Jersey hospital close to New York City, I have observed some changes which may be part of a pattern in the evolution of genetic service provision.

The hospital, affiliated with one of the three New Jersey medical schools, is now a medical center, having undergone continuing expansion as part of an elaborate and expensive upgrade. There is keen competition among the several nearby suburban hospitals of similar size. Lucrative programs such as cardiac surgery and pediatric oncology are eagerly sought. While recognized as having PR value, genetics is not seen as an income producer, and other hospitals continue to refer cases out rather than support an in-house program. Consequently, ours is the only genetic service in the county.

The steady, rapid growth of our service in its first 10 years has leveled off to about 1200 referrals per year, half of which are for prenatal diagnosis. Although most of our prenatal cases involve advanced maternal age, an increasing proportion of younger gravidas are being referred. Currently, about 25% of our referrals involve abnormal MSAFPs, more often low than high.

The biggest change has been the movement of genetic diagnostic services, mostly prenatal, into the private practice area. MSAFP is part of standard OB office procedure. Successful marketing of office ultrasound and private laboratory services has induced most of our staff obstetricians to offer amniocentesis in private offices; genetic counseling is either bypassed or offered separately, either in-hospital or privately. While this may create moonlighting opportunities for genetic counselors, a potential for conflict of interest exists.

Many of these visible changes are the consequence of a major overhaul of the hospital finance system. Cost containment programs such as diagnosis related groups (DRGs) for in-patients are costly and add-on "reimbursement" charges for out-patient services are a way of making up lost revenue. As the private sector skims off the well-insured patients, hospitals are left to serve the less affluent. The increase in referrals from clinics and health centers is most likely

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# Case Report

Case Report No. 12

## Misdiagnosis Of Spina Bifida In A Normal Fetus

**by Beverly Tenenholz, M.S., West Penn Hospital, Pittsburgh, PA**

***Maternal serum alpha-fetoprotein (MSAFP) screening can be an extremely useful tool—ut it is not without its problems. 'False positive' results are among the difficulties frequently encountered. This case reflects the importance of appropriate follow-up of an elevated MSAFP.***

Mrs. K., a 29 year old Caucasian G2 P1, had an MSAFP result at 16 weeks gestation of 2.8 MoM. Mr. and Mrs. K. were counseled by her obstetrician, who recommended a repeat MSAFP or an amniocentesis as follow-up. Unfortunately, this discussion left them with the impression that undergoing an amniocentesis implied an agreement to terminate the pregnancy if the amniotic fluid AFP/ACHE result was abnormal. Since this couple would not consider terminating the pregnancy, they refused the procedure. An ultrasound was performed at 18 1/2 weeks and the radiologist identified an apparent widening of the vertebrae at level L5/S1, indicating a diagnosis of spina bifida cystica.

Mr. and Mrs. K. had copies of the ultrasound films sent for evaluation to Dr. B., a prominent physician with a spina bifida clinic in a large midwestern children's hospital. Dr. B also felt that the baby had spina bifida. He suggested that the couple deliver the baby in a large medical facility staffed and equipped to handle this situation. They then contacted Dr. C., a neurosurgeon and the director of the spina bifida program at our medical center, who referred the couple to our genetics department for counseling and case management.

When we saw Mr. and Mrs. K., she was 34 weeks pregnant. We reviewed the available information and reminded them that the diagnosis was without biochemical confirmation since an amniocentesis had not been performed. An evaluation by our prenatal ultrasonographer failed to demonstrate any suspicious area along the fetal spine. After a lengthy discussion regarding the importance of a confirmatory biochemical assay, the couple again declined amniocentesis, resigned to the diagnosis of spina bifida.

The issue of delivery was raised. There is continuing controversy regarding mode of delivery following prenatal diagnosis of spina bifida.[1-3] Although Caesarean section is most frequently used, some studies suggest that vaginal delivery is not contraindicated in lower level lesions where hydrocephalus is not apparent on ultrasound. A group including a perinatologist, ultrasonographer, neonatologist, clinical geneticist and genetic counselor met to discuss this issue in detail. A trial of natural labor was suggested, with a C-section as a back-up, *if* medically indicated. The couple agreed, although they again declined amniocentesis, this time recommended to determine fetal lung maturity.

We had become increasingly uncomfortable with the plan for this patient and at 39 weeks, a delivery date was set. Prior to induction, she was again encouraged to have an amniocentesis for fetal lung maturity. She consented. ACHE and chromosome studies were concurrently performed. The ACHE was negative, providing no confirmation of a diagnosis of open neural tube defect. The couple had a difficult time accepting the evidence, but agreed to a delivery at their local hospital. Not at all surprising to us, Mrs. K. delivered a normal, healthy baby with no signs of open spinal abnormalities.

This case raised concerns for us centering on the absence of confirmatory testing for the spinal lesion. Prenatal genetic counseling should allow the patient to choose her care based on appropriate and complete information. How could we have been sure that all available options and their advantages and disadvantages were clear to Mrs. and Mr. K? How comfortable should we have been with a diagnosis of spina bifida cystica by ultrasound alone? [4,5] How far can we or should we go to comply with the wishes of patients, even when we believe that those wishes are inappropriate? What would have been the consequences if a C-section were performed to deliver a normal, healthy baby without obstetrical indication?


1 Chervenak FA, *et al:* Perinatal management of meningomyelocele. *Obstet Gynecol* (1984) 63 (3):376-80.

2 Stark G, Drummond M: Spina bifida as an obstetric problem. *Dev Med Child Neurol* [Suppl] (1970) 22:Suppl 22: 157+.

3 Shurtleff DB: Meningomyelocele: a new or a vanishing disease? *Z Kinderchir* (1986) 41 Suppl 1:5-9 (Abstract only).

4 Lindfors KK, et al: Midtrimester screening for open neural tube defects: correlation of sonography with amniocentesis results. *AJR* (1987) 149(1),141-5.

5 Roberts CJ, et al: Diagnostic effectiveness of ultrasound in detection of neural tube defect. The South Wales experience of 2509 scans (1977-1982) in high-risk mothers. *Lancet.*(1983) ii (8358): 1068-9.

## Reimbursement, from p. 2

Committee is drawn. However, Dr. Rodney Howell was appointed to represent genetics professionals as an *ad hoc* (interim) member of the CPT Advisory Committee. Both the ASHG and ABMG are reviewing this issue.

A second objective of the Project involves the development of training materials regarding reimbursement issues surrounding current and future applications of genetic services. Aided by a Project Advisory Committee, Ed Kloza and Polly Haddow are members of the Project team which has designed and written the training manuals and is piloting the training sessions for consumers, genetic service providers, third party payors and public health administrators. Sessions were held in Connecticut and Maine this Spring and will continue in New York State and the rest of New England this Fall. NSGC members in these regions may be asked to participate in this "train the trainer" Project.

The NSGC has been asked for financial support for this Project. At the last meeting, the Board endorsed the Project, but a funding commitment is pending further review by the Finance Committee. Third party coverage of genetic services in general and for genetic counseling in particular should be a priority for the NSGC.

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## Economic Impact of Genetic Services, from p. 3

only partially the result of our educational efforts toward the underserved.

I was originally drawn to genetic counseling because it encouraged the counselor to take as much time with a case as a patient needed. Administrative requirements such as counting "units of productivity" (read: patients), now add to job stress and contribute to the risk of burnout in this helping profession. Gone are the days when we could afford to offer initial visits at no cost to publicize our services, when our modest salaries were covered by grants from the March of Dimes or other agencies. Hospitals must now pay for our space, staff, computers and other overhead out of revenues that our service generates, and our service must be cost-accountable.

Perhaps our genetic counseling training needs to incorporate some of these economic facts of life to better equip genetic counselors to deal with these inevitable changes.

## *Rights of the Disabled, from p. 1*

education and restricted opportunities for full participation in community life.

I do *not* argue that it is easy to raise a disabled child, even where resources and support systems are available. I *do* suggest that placing the blame for *any* difficulties the parents' encounter on the child's disability vastly distorts the picture. Very often, prospective parents have never faced the issue of disability until it is raised in relation to testing. Their exposure to disabled children has been so limited by the children's isolation that most people have only stereotypical views based on telethons and displays on drug store counters soliciting our pity and loose change.

### Sterotypical Images Foster Oppression of Handicapped Individuals

The major stereotype is that disabled persons' lives are filled with suffering. In my work, I've known severely disabled people...people with quadriplegia, multiple sclerosis, muscular dystrophy, cerebral palsy; people who are blind or who have hearing impairments, as well as many with "hidden" chronic diseases such as epilepsy and diabetes. Not unlike the rest of the population, some experience considerable difficulty in their lives while others do fine, hold jobs and enjoy a full and satisfying life. Most disabled people have told me with no uncertainty that the disability, the pain and the need for compensatory devices and assistance can produce considerable inconvenience, but that often these become minimal once the individual adjusts to the disability. It is, however, the discriminatory attitudes and thoughtless behavior that make life difficult: the oppression, the architectural barriers, the pitying stares, the frightened avoidance, the assumption that you can't do the job, can't order for yourself in a restaurant, can't find a mate or can't direct your own life. The *oppression* is what is disabling about having a disability.

There are disabled people who "suffer" with their physical conditions. There are those who have chosen to end their lives rather than continue in pain or with severe limitations. This is also true for nondisabled people who suffer from emotional pain and limited resources. Our limitations may be more visible, our need for help more apparent, but like anybody else, the "suffering" we may experience is primarily a result of not enough human caring, acceptance and respect. It is the disabled *themselves* who can and must address the issue of their own worthiness.

Finally, I challenge the assumption that we, as a culture and as individuals, have the competence to assess the quality of life of the disabled and to use this assessment to determine their fate. The medical system wishes to fix, to cure, to control, to improve, suggesting that no couple need settle for less than "perfect." Fear of malpractice rather than sound clinical judgment motivates many physicians to encourage prenatal screening and the quick solution of abortion following the diagnosis of a disability. But by the very nature of their work, health care professionals often see only those cases of disability associated with complications and problems with management or individuals in the terminal stages of an illness. Many clinicians never have the opportunity to see disabled individuals living independently, productively, enjoyably.

### Informed Choices Require Thorough Understanding

If I were to offer counsel to a woman considering prenatal testing, I would ask her if she has sufficient knowledge about the disability and an awareness of her own feelings about it to make an informed choice. Does she *know* any disabled adults or children? What was she taught about disability by adults when she was young? Is she aware of how much the posters, telethons and stereotypes distort reality? The major factors to consider should be the ability of the parents, the family and the community to support, love and encourage the child to reach its fullest potential. Accurate assessment of those abilities can come only with greater clarity about the real nature of disability.

It is unlikely that we will ever be able to eliminate disability. Our compelling and more profound challenge is to eliminate oppression. Acceptance of all people regardless of their differences will achieve the greatest enhancement in the quality of our lives.

### RESEARCH IN GENETIC DISCRIMINATION

Reports of cases in which chromosomal or genetic variation may have been a consideration in obtaining life or health insurance, employment, educational resources or other human services (legal, governmental or health) are being solicited for a study on societal attitudes involving genetics. Any incident of possible discrimination is of interest. Affected individuals or others aware of possible examples are encouraged to contact: Paul R. Billings, M.D., Ph.D., Director, Clinic for Inherited Diseases, Harvard Medical School, New England Deaconess Hospital, Boston, MA 02215; (617) 732-9719. Strict confidentiality will be maintained.

## Legislative Briefs

### IL Addresses Effects of Alcohol

Two bills in the Illinois legislature address a continuing effort to educate the public regarding alcohol use during pregnancy.

Senate Bill 1588 amends the Marriage and Dissolution of Marriage Act and the Alcoholism and Other Drug Dependency Act to require county clerks to distribute a Fetal Alcohol Syndrome pamphlet with each marriage license.

Senate Bill 1589 amends the Liquor Control Act of 1934. This bill requires that all retailers who sell any alcoholic beverages for consumption on the premises post, in a conspicuous place, a sign which clearly reads: "Warning: Drinking alcoholic beverages during pregnancy can cause birth defects." A violation of this bill would be a Class C misdemeanor punishable by a fine of not more than $100.

**Seth Marcus, M.S.**
**Region IV Representitive**

### Transportation of Human Fetal Tissue under Advisement

HR 1990 proposes to regulate the interstate transportation and storage of human fetal tissue or any biochemical product from any aborted human pregnancy.

Under this act, the source, ultimate destination and intended use of the tissue *must* be reported to the Secretary of the DHHS. This bill will require licensing of human tissue storage facilities which utilize interstate transportion and will also empower the Secretary to prohibit interstate transportation and storage of fetal tissue.

It is not clear whether an 'aborted' pregnancy as referenced in HR 1990 refers to spontaneously or medically aborted. If it refers only to non-spontaneous abortions, there are no provisions for such documentation or for preserving patient confidentiality. Presumably, this bill would require licensure for universities performing biochemical/molecular examinations on tissue from abortuses and which save samples for future use or for medical-legal reasons.

The relationship between this Bill and the recent moratorium on fetal tissue research declared by the DHHS is unknown. The NIH is convening an *ad hoc* committee this summer to consider the implications of human fetal transplantation on research.

**Ann Swinford, M.S., Editor**
**Professional/Personal Advancement**

## Book Bag

***The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood***
by Barbara Katz-Rothman, Penguin Books, New York, 1986 274 pp., $6.95 ppbk; $17.95 hdbk

*The Tentative Pregnancy* by Barbara Katz-Rothman explores the social and emotional ramifications of amniocentesis. The author raises many ethical and moral questions, some of which she attempts to answer. Many of the conclusions that the author draws cannot be considered valid because at times they are oversimplistic, inaccurate, biased and limited by the research methodology.

Ms. Katz-Rothman, Professor of Sociology at Baruch College in New York, has written another book, *Giving Birth: Alternatives in Childbirth.* In *The Tentative Pregnancy* she shifts her focus from childbirth to prenatal diagnosis. The author interviews 60 women who had amniocentesis and 60 women who did not as well as several genetic counselors. All but the genetic counselors were respondents from advertisements in *Ms.* or a magazine called *Mothering.* It is questionable whether the women who responded were biased in their motivation for responding, their geographic area and their selective recall after their experiences. Ms. Katz-Rothman acknowledges these biases.

While many of the issues raised in this book are worth considering, the tone of the book is strident and the content reflects the author's anti-scientific and anti-technologic bias. Ms. Katz-Rothman sees amniocentesis as part of a greater trend to commodify people and states that genetic counseling serves the function of "quality control." She advises women who would choose not to abort a fetus with an abnormal result *not* to take the test. Further, she advises women who *do* take the test not to find out about sex chromosome abnormalities or "diagnoses in search of syndromes." These recommendations illustrate how Ms. Katz-Rothman makes generalizations without considering the individuality of decision-making. That there may be a positive side to amniocentesis is a foreign notion to this author. Clearly, for Ms. Katz-Rothman, amniocentesis and the problems it poses is a symptom of technology gone awry and a symbol of society's misplaced values.

Ten percent of the women interviewed had to have "the tap" repeated; about 20 percent had some kind of undefined physical problem with the test. These numbers are much higher than usual, and our concern is that the average reader probably would not discount this or other misleading information in the book.

In exploring some personal biases of genetic counselors, Ms. Katz-Rothman fails to realize that counselors can have personal and professional biases *and that the two can be separated.* While any bias can subtly permeate through, the objective of the process of genetic counseling is non-directiveness. While Ms. Katz-Rothman acknowledges that counselors try to counsel non-directively, she basically describes us as handmaidens of physicians rather than advocates of patients. To illustrate her point, she recounts a pre-amnio counseling session in which an insensitive genetic counselor clearly ignores the wishes of her Hispanic patient.

Our biggest concern about *The Tentative Pregnancy* is that pregnant women who are considering amniocentesis and who may frequent the growing pregnancy and childbirth sections in book stores will buy this book since it is the only book we know of that is solely about amniocentesis. These women will most likely feel more troubled and ambivalent about the test after reading this book.

Genetic counselors should read this book so they are aware of what influences their clients. The ethical questions are important for us as genetic counselors to consider—it is imperative that we become aware of our own biases regarding raising ambiguous issues, how risks are perceived, what we feel to be the purpose of the test and what the legitimate reasons are for having or not having the test.

However, we would *not* recommend that a client read this book because it raises all the difficult questions without a clue about how to proceed in our imperfect world where women and children are undervalued and technology is a mixed blessing. We wonder who the author intends her audience to be. If it is prospective parents, it will only leave them feeling more tentative about their pregnancies. If it is genetic counselors, the inaccuracies and biases may infuriate them so much as to blind them to the book's value. It is time that a genetic counselor write this kind of book for the general public. *The Tentative Pregnancy* may serve as the necessary catalyst.

**by Kathy Barnhart, M.S. and**
**Andrea Fishbach, M.S.**
**Genetic Counseling Program**
**University of California at Berkeley**

## Sexual Harrassment in the Workplace, from p. 1

by others; the only difference between these and an overt pass is a matter of degree. Since the person making the suggestive remarks was my boss, I considered them oppressive, undermining my sense of professionalism in the work environment. While over 90% of genetic counselors are women, most of us work in a male-dominated setting, under physicians or geneticists whose professional expertise may spawn inflated egos. Fortunately, this is not a general phenomenon: many male geneticists/physicians with whom I have worked do not treat women subordinately.

After discussing my objections with my office colleagues, I was left with the impression that the boss's behavior is accepted as endogenous to his personality and was advised that it "shouldn't be taken too personally."

Another type of subtle sexual derogation came in the form of a seemingly complimentary remark. Being introduced to a patient or colleague followed by the remark "Isn't she cute?" undermined my professional standing and downgraded the patient's/colleague's perception of me from professional person to sexual object. Not only was everyone (except the harasser) uncomfortable amidst the sea of obligatory nods and an angry blush, but this also reduced my credibility as a counselor.

Studies of sexual harassment often depict harassers as older married men in a supervisory position and considered unattractive by their victims.[2] They are driven either by lust and the need for sexual gratification, the desire to flaunt economic power, the establishment of power differentials, social control...or any combination of the above. Power is usually behind all of these motives. A boss may use his economic power as "holder of the purse strings" to threaten the economic security of the female employee. Sexual harassment enables such a boss to augment his sense of superiority, masculinity and control over his estate.

Because I was new both to this job and to the role of victim of sexual harassment, I was unsure of what I should do. I concentrated on doing my job well, and I now feel my boss respects me for my professional abilities. Fortunately, the harassment has stopped, but not because I dealt with it head-on. Had I been more familiar with this issue, more confident in my abilities and more willing to stand up for my rights, I would have adopted a direct approach (see box).

Partially as a result of the sexual revolution, female sexuality has become socially acceptable and some men interpret this as an invitation to make sexually suggestive remarks and/or advances. This is particularly inappropriate in the boss/subordinate relationship because it ignores the power differential which interferes with the subordinate's ability to object. Men can choose whether or not to sexually harass women and we, as women, can choose to take action to minimize it's occurrence.

[1] Backhouse, Connie et al., *Fighting Sexual Harassment: An Advocacy Handbook.* Alliance Against Sexual Coercion, 1979.

[2] Horn, Patrice and Jack., *Sex in the Office.* Addison-Wesley Publishing Co., 1982

### Handling sexual harassment

- Confront the aggressor. Let him know that his remarks are neither appreciated nor flattering.
- Write him a letter listing the grievances in a factual manner. Include their personal and professional effects. Insist that he stop.
- Ask that a policy statement be written, if one does not exist.
- Inform the employer/hospital administrator in writing, since this is where ultimate liability for the conduct of the employees lies.
- Consider civil action. Employment discrimination on the basis of sex is prohibited under Title VII of the 1964 Civil Rights Act.
- In some states, claims for emotional suffering may also be brought.

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## Letters to the Editor

### Response to Clastogenic Exposures on Family DNA Studies

The concerns raised by Gale Gardiner (Clastogenic Exposures on Family DNA Studies, Vol. 10 No.1) regarding the possible effect of exposure to mutagenic or clastogenic agents are of interest. Certainly it may be helpful if such information can be provided to the laboratory about family members participating in DNA studies.

The specific concern of spurious indication of non-paternity need not be a serious issue in the DNA laboratory. When RFLP analysis at a specific locus implies non-Mendelian segregation (i.e. non-paternity) the possibility of new mutation always exists. Paternity is then analyzed using VNTR (variable number of tandem repeat) probes that map to chromosomes other than the test locus. This allows the differentiation of non-paternity and new mutation in the germ cell line.

Somatic cell mutations as a result of exposure to clastogenic or mutagenic agents should have little effect on DNA/RFLP analysis. DNA is prepared for RFLP analysis from a population of somatic cells; thus a mutation that occurs in a single somatic cell will be below the limits of detection using current technology. If the mutated cell is clonally expanded, the mutation may then be detected. However, in this case the clonal expansion is frequently seen as a tumor and can be compared to constituitive tissue (e.g. retinoblastoma) for verification.

**Katherine W. Klinger, Ph.D., Director**
**Genetic Reference Laboratory**
**Integrated Genetics**

## *Policy Statement*

# Vitamin A Exposure during Pregnancy

**by Karen Wojcik, M.S., University of Rochester (NY) Medical Center**

Recently, the Public Affairs Committee of the Teratology Society issued a statement on the use of vitamin A during pregnancy.[1] It is unusual for the Society to establish a position or make public statements, but the issue of excessive vitamin A during pregnancy is of concern to many teratologists.

Vitamin A occurs in two forms: beta-carotene and the retinoids (i.e., retinol, tretinoin, retinyl esters, retinoic acid). Beta-carotene is not considered a human or animal teratogen, and toxicity has not been demonstrated in animals or humans. The teratogenicity of some retinoids (etretinate, isotretinoin), however, has been well described in humans.[2]

Isotretinoin (Accutane), a synthetic retinoid used to treat dermatologic conditions, has been associated with several types of malformations (craniofacial, CNS, cardiac, thymic). Isotretinoin ingested during early pregnancy caused major malformations in almost 20% of exposed human fetuses, even at doses below the therapeutic range.[3]

Tretinoin (Retin-A) is used topically to treat acne and recently has been recognized as a potential treatment for wrinkles. The minimal amount of vitamin A absorbed into the skin with the typical dosage should not be teratogenic.

Non-therapeutic (dietary) amounts of vitamin A (beta-carotene and retinoids) are commonly obtained through daily diet and vitamin supplements. Beta-carotene is found in carrots, tomatoes and many other red, yellow and green vegetables. Vitamin A as retinol is found in fish oil, egg yolk, cheese, liver and butter.

The recommended daily allowance of vitamin A for pregnant women is 5000 IU/day. Surveys in the U.S. indicate that the average unsupplemented adult diet contains 7000-8000 IU/day of vitamin A, indicating that the average American woman may not need supplementation at all.

There have been several case reports of adverse pregnancy outcomes associated with a daily intake of vitamin A, of 25,000 IU or more, but these are likely to be biased reports due to the adverse outcome. Many infants described had malformations quite different from infants exposed to isotretinoin. Others had malformations that fit the recognizable pattern associated with isotretinoin exposure. Currently, no data are available to determine the risk of major fetal malformation following daily intake of any dose of vitamin A, and it is not possible to extrapolate from the known teratogenic dose of isotretinoin to an equivalent intake of vitamin A because of pharmacologic differences between isotretinion and vitamin A.

These issues have prompted the Teratology Society to make the following recommendations:

- Women who are at risk for becoming pregnant should consider their dietary intake of vitamin A before taking supplements and should be informed that excessive use of vitamin A shortly before and during pregnancy *could* be harmful to the fetus.
- Manufacturers of vitamin A (retinol/-retinyl esters) should lower the amount of vitamin A per dose to 5000-8000 IU and identify its source. Beta-carotene should be considered as the primary source of vitamin A for women in reproductive years.
- Warnings regarding excessive consumption of vitamin A (retinol/retinyl esters) and their possible effects should appear on product labels.
- Reproductive/developmental toxicity studies of vitamin A should receive national and international priority.

As genetic counselors, we need to appreciate the complexity of the current situation regarding vitamin A and counsel our patients appropriately. Clearly, more data are needed to accurately assess the effects of excess vitamin A use during pregnancy, and we must interpret the available reports with caution.

While there is no *substantiated* increased risk for fetal abnormalities in women taking vitamin A supplements, we should try to dispel the public perception that "if one is good, two is better" regarding vitamin supplements and communicate to patients that oversupplementation is not beneficial and may even be harmful. As always, we can continue to be perceptive and sensitive, especially in this controversial area.

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[1] Teratology Society Position Paper: Recommendations for Vitamin A Use During Pregnancy (1987), *Teratology* 35:269-275.

[2] Rosa, F.W. (1983) Teratogenicity of isotretinoin., *Lancet* 2:513.

[3] Lammer, E.J. et al. (1985) Retinoic acid embryopathy., *New England J Medicine* 313:837-841.

# CVS Study: Transcervical v. Transabdominal Procedures

**by Miriam Schoenfeld DiMaio, M.S.W.**
**Yale University School of Medicine**

Chorionic villus sampling (CVS) is becoming an attractive alternative to second trimester amniocentesis. Although CVS is widely available in the US, the safety and accuracy of the procedure are still under intense investigation. Early national experience is very encouraging. However, complete definition of the risks and the reliability of CVS will not be available for several years.

This article focuses on a study sponsored by the National Institutes of Health at a Yale-affiliated health center. It addresses the safety of the transcervical vs. the transabdominal approach, the two methods used to obtain chorionic villi.

Currently, no evidence exists identifying one method as safer than the other. In some cases, the approach depends on the position of the uterus and placenta. Very rarely, an obstetric contraindication such as active genital herpes or uterine fibroids may preclude one approach. Usually, either approach is equally feasible. In these cases, we request that the woman participate in the randomized study.

Women requesting CVS are informed that the procedure may be performed either transcervically or transabdominally and that they may be asked to participate in a randomized trial evaluating the relative safety of the two approaches. Informed consent is obtained before a woman is in the procedure room. If, after the initial ultrasound, the obstetrician states that the woman is eligible to be randomized, a sealed envelope containing the procedure assignment is opened.

Counseling about the study and randomization is straightforward and incorporated into the discussion of CVS. We remind the patient that randomization will take place only if an experienced obstetrician believes either approach is equally safe and appropriate for obtaining an adequate sample. Furthermore, women are reminded that a decade ago, pregnant women like themselves cooperated with investigators so that the safety of amniocentesis could be established.

Major medical institutions in the US dedicated to providing patient care and to gaining knowledge will ultimately enhance the quality of patient care. This NIH study is an example of how genetic counselors can play an important role in fulfilling the latter goal.

## Demands for New Program Addressed at Northeastern U

Funding is currently being sought by Northeastern University in Boston to develop a genetic counseling training program. This action is being taken to meet the growing demand for ABMG eligible genetic counselors.

The program, as proposed, will be based in the Department of Biology and will be co-sponsored by the Departments of Counseling & Education Psychology, Philosophy & Religion and Psychology. Requirements will include coursework in genetics, counseling and ethics. Successful completion of a comprehensive exit exam will be required. Clinical activities will be based at several hospitals in Boston.

Further information about this program will be published in *Perspectives* as it becomes available.

**Ann Swinford, M.S., Editor**
**Professional/Personal Advancement**

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## Social Issues Committee to Sponsor Political Workshop

Over the years, NSGC's Social Issues Committee has sponsored workshops at our Annual Education Conference focusing on contemporary issues in genetic counseling that have wide-ranging social implications.

Following the release of *The Tentative Pregnancy* by Barbara Katz-Rothman and the publication of various lay articles raising concerns on how prenatal diagnosis impacts on a woman's emotional attachment to her pregnancy, the NSGC Board of Directors suggested that we explore this issue.

To this end, Ms. Katz-Rothman will deliver a keynote address, *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood,* followed immediately by the workshop, *Coping with Prenatal Diagnosis: Personal and Political Strategies—Finding the Common Ground.* It will be co-facilitated by Beth Balkite and moderated by myself.

This workshop should provide an exciting opportunity for us to not only establish a dialogue with Ms. Katz-Rothman, but to also appreciate differing public opinions regarding prenatal genetic counseling and prenatal diagnostic techniques. Our goals are to explore areas of common concern and to develop professional guidelines for addressing these concerns.

The Social Issues Committee strongly recommends that you read *The Tentative Pregnancy*, especially the chapter on genetic counseling, prior to attending the keynote address or the workshop.

**Trish Magyari, M.S.**
**Chair, Social Issues Committee**

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## CHARGE Syndrome Booklet: How To Get Your Copy

Information on where to send for the CHARGE Syndrome Booklet was omitted from the last issue of *Perspectives*. To request a copy, write: CHARGE Syndrome Booklet, Quota Club, c/o Marion Norbury, 2004 Parkade Blvd., Columbia, MD 65202.

Genetic counselors and other professionals may request one copy free. The Quota Club requests a $1.50 donation for additional copies.

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## Membership Directories Mailed

Your 1988/1989 NSGC Membership Directory was mailed on June 20 via bulk mail. If your copy does not arrive by August 1, please call the Executive Office.

The Directory lists full, associate and student members in good standing as of May 1. We would like to apologize, in advance, for any errors or omissions. Our directory is only as current as your communication with us.

Please submit all address changes and corrections to Bea Leopold c/o NSGC's Executive Office.

**Luna E. Okada, M.S.**
**Membership Chairperson**

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## UT is Host to Region V Meeting

Ethics will be the topic of the Region V conference slated for August 9 in Park City, Utah. The meeting will immediately precede the Mountain States Regional Network.

Region V members wishing to become involved in planning or members from outside the region who are interested in attending are invited to contact Kathleen O'Connor (303-399-5393) or me (719-475-5406) for more information.

**Jane Congleton, R.N., M.S.**
**Region V Representative**

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## An Opportunity to Become Involved

Two positions on the editorial staff of *Perspectives* will be open this Fall.

Joan FitzGerald's term as Technology Editor ends this year and Ann Swinford will be entering medical school in September, leaving an unexpired term in the Professional/Personal Issues position.

Both editors are responsible for soliciting submissions, sending them for review and editing, as needed.

Please contact me by September 1 if you are interested in contributing to your newsletter in this capacity.

**Ed Kloza, M.S.**
**Editor-In Chief**

## Conference to Address Political Issues of Genetic Counseling

The Eighth Annual Educational Conference, *Strategies in Genetic Counseling: Political Influences from Society to the Workplace*, is scheduled for October 9 - 11 in New Orleans at the Hyatt Regency .

The program will focus on the effect of outside influences on the workplace with a special emphasis on the political survival of the genetic counselor. Discussions will include: an exploration of specific legislative influences, the politics involved in marketing genetic services, the challenges of office politics and how genetic professionals can take political action. A program brochure was mailed to every member in May. If you have misplaced your copy, a registration form is on p. 11.

The conference promises to be filled with information and resources that will enhance you professionally. In addition to plenery sessions, workshops and networking with colleagues, you can also look forward to meeting with the following vendors who have made early commitments to being there: **Collaborative Research, The Genetics Institute of Pasadena, Integrated Genetics, March of Dimes, Nichols Institute and Vivigen.**

# Books

***The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood***
***author:*** **Barbara Katz-Rothman**
***publisher:*** **Viking Press, 1986, 274 pp.**
***price:*** **$17.95 hardback; $6.95 paperback.**
***reviewed by:*** **A parent who terminated a pregnancy following the prenatal diagnosis of a neural tube defect, Akron, OH**

Sociologist Barbara Katz-Rothman's basic thesis is that "the new technology of reproduction puts many women into a difficult social state she terms as 'the tentative pregnancy'." She sees prenatal diagnosis as being not merely an individual matter but one with far-reaching economic, political and social consequences.

Her research is qualitative rather than quantitative; she bases it on discussions with genetic counselors and women responding to ads in *Ms.* and *Mothering* who accepted or had refused amniocentesis.

I first read *The Tentative Pregnancy* after receiving the results of prenatal testing which indicated a diagnosis of spina bifida. This book provided the reassurance that others had felt our pain and had struggled with our "tragedy of choice." This book validated our every experience and emotion. I was amused to see myself among the "well-educated, professional women" whom Katz-Rothman describes as taking pregnancy "as a reading assignment."

Katz-Rothman observes, "it ...often seemed that it was the husband who was sure, who knew the pregnancy had to be terminated, while the wife wrestled with the choice." Reading that, and the experiences of women who had lived it, afforded my husband and me greater insight into each other's positions.

The chapter that most affected me, and the one I asked my husband to read, was "Grieving the Genetic Defect," based on interviews with 13 women who had terminated their pregnancies. Katz-Rothman writes, "I want each person reading this to be able to feel it—I want you to hear the grief, hear the voices of the women who have experienced the new solutions brought on by the new technology." I read it both before and after terminating: the first time to learn and the second time to compare, to codify our own experience in the context of theirs. I am one of those women.

Reading the book while I was facing such a momentous decision, I found "Making Choices" (the decision to have amniocentesis) to be much ado about nothing and "On Fetal Sons and Daughters" almost frivolous—how could parents fuss so over sex selection when we were experiencing such conflict over our baby's very life? Now, two months after the termination, I view these chapters more kindly.

If there is anything I really regret about Katz-Rothman's book, it is that there is yet more to consider. MSAFP screening is a form of prenatal testing without medical risk. What impact will this have? Why are there no interviews with husbands? Our daughter, born alive, died in my husband's arms. Finally, why is there no companion chapter to "Grieving the Genetic Defect," containing interviews with parents who chose to carry their affected child to term?

Katz-Rothman cautions us that the new technology offers only "an illusion of choice," simply restructuring and limiting the choices actually available to us. How will the health of the fetus and maternal bonding be affected if woman don't commit to their pregnancies before the test results are available? (Women who choose amniocentesis report wearing maternity clothes later, announcing their pregnancies later and feeling the baby kick later than women who do not.) In its attempt to deal with existing risks, the new technology appears to create new ones.

# Audiovisuals

***Our Genetic Heritage***
***produced by:*** **March of Dimes, 1987**
***format & price:*** **1/2" VHS; 3/4" U-Matic (14 :20); $40**
***orders:*** **March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605**
***audience:*** **Nursing and allied health students, college or high school students, parents and other consumers**
***reviewed by:*** **Lee Ann Moore, B.S., Children's Medical Center, Dayton, OH**

Congratulations to the March of Dimes. In 14 quick minutes, this video clearly and accurately reviews topics ranging from inheritance patterns and pregnancy risks to CVS, gene mapping and gene therapy. It includes excellent, live footage of human gametes, fertilization, division, embryonic and fetal growth and birth.

Disorders which are sensitively portrayed include PKU, Huntington's disease, sickle cell, ADA deficiency, Lesch Nyhan and Down syndrome. Amniocentesis and genetic counseling are also explained in detail.

Viewers are told that as we study our "genetic heritage in reverse," we are clearly "doing to chromosomes today what medical men did to the human body in the 15th century," that is learning anatomy and physiology to understand better the functions of and interactions between genes, to determine what and why things may go wrong and to learn how to correct genetic problems.

Shortcomings of the video are minor and mostly related to its brevity. Other than Down syndrome, no explanation is offered regarding other numerical or structural chromosome abnormalities. Several diseases of adulthood are described simply as those to which our genes may predispose. No explanation of common birth defects or multifactorial inheritance is given. MSAFP screening is also left uncovered. Gene therapy, though well explained, is described in terms that suggest that it is currently generally available for curing certain genetic conditions.

Though brief, this video is packed with information yet is easily understandable. It is a wonderful aid to quickly review basics and spur discussion about genetic technologies, concepts and issues that the target audience is likely to face.

# Organizations

***Lowe's Syndrome Association, Inc.***

The Lowe's Syndrome Association, Inc. (LSA) is an international voluntary non-profit organization composed of parents, friends and professionals in 36 states, Canada, England, Australia and Japan.

The purpose of the organization is to provide information on Lowe's syndrome, foster communication among families and encourage medical research.

Resources supported by the organization include *On the Beam*, a newsletter published three times a year; international conferences on Lowe's syndrome, "Care Today...Cure Tomorrow," a 12 minute videotape for families and professionals and a new booklet, "Living With Lowe's Syndrome." This thorough booklet, written in understandable language, contains information on clinical features, genetics, research, development, education and the impact of Lowe's syndrome on the family. The first copy is free and additional copies cost 50 cents per copy.

To obtain a copy of the booklet or more information on the organization, write or call: LSA, 222 Lincoln St., West Lafayette, IN 47906; (317)743-3634.

# Classified • Classified • Classified

***THE JOB CONNECTION, NSGC's streamlined job search service, combines our* Perspectives' *classified section with our jobs hotline. The classified listings printed in this issue represent the most recent additions to the service. Members interested in complete or regional information may receive a computerized printout by contacting the Executive Office.***

**TUCSON, AZ:** Summer 1988 Opening for BC/BE Genetic Counselor.

Responsibilities: Prenatal diagnosis; MSAFP; CVS; teratogen & high-risk pregnancy counseling; community & professional education.

Contact: Lewis Shenker, M.D., University Medical Center, Dept. OB/GYN, 1501 N. Campbell Ave, Tucson, AZ 85724; 602-626-6636. EOE/AA

**FRESNO, CA:** Immediate Opening for BC/BE Genetic Counselor.

Responsibilities: General genetics, prenatal diagnosis, specialty clinics & education.

Contact: Susan Snyder, Preventive Services Coordinator, Central Valley Regional Center, 4747 N. First St, Suite 195, Fresno, CA 93726; 209-228-3061. EOE/AA

**PANARAMA CITY, CA:** Immediate Opening for BC/BE Genetic Counselor. Salary Range: $2166 - 2632/mo.

Responsibilities: Prenatal diagnosis & general genetics.

Contact: Gary Frohlich, M.S., North Los Angeles Regional Center, 14550 Lanark St, Panarama City, CA 91402; 818-997-1311. EOE/AA

**LOS ANGELES, CA:** Immediate opening for two Genetic Associates at major teaching hospital in prenatal diagnosis center. BC/BE preferred. Salary range: $29,000 - 35,000.

Responsibilities: CVS, MSAFP, structural ultrasound, teratology & amnio counseling. Participation in seminars and residency program encouraged.

Contact: Ann Garber, D.P.H., Director of Genetic Counseling, Cedars-Sinai Medical Center, Dept. OB/GYN, 8700 Beverly Blvd, Los Angeles, CA 90048; 213-855-3361. Include three references. EOE/AA

**OAKLAND, CA:** Position Available for BC/BE Genetic Counselor at Kaiser Permanente Medical Center, 20 minutes from San Francisco.

Responsibilities: Varied, including all aspects of clinical genetics & prenatal diagnosis. Top salary, excellent benefits.

Contact: Ronald Bachman, M.D., 280 W. MacArthur Blvd, Oakland, CA 94611; 415-596-6571. EOE/AA

**SACRAMENTO, CA:** Full/parttime immediate openings for Senior Community Health Program Representatives. Salary Range: $2007 - 2408/month.

Contact: Ann Peterson, R.N., M.N., UC/Davis, Prenatal Diagnosis Center, Dept. OB/GYN, 1621 Alhambra Blvd., Sacramento, CA 95816; 916-453-2124. EOE/AA

**NEW HAVEN, CT:** Immediate opening for BC/BE Genetic Counselor.

Responsibilities: Varied duties, including prenatal diagnosis.

Contact: Miriam Schoenfeld DiMaio, M.S.W., Yale University School of Medicine, Dept. Human Genetics, P.O. Box 3333, New Haven, CT 06510; 203-785-2661. EOE/AA

**MIAMI, FL:** Immediate opening for Adjunct Instructor. Masters degree in genetic counseling or related field and one year experience required.

Responsibilities: Establish county-wide satellite counseling program; provide professional education to community; teratology counseling & support services.

Contact: Laura Powell, Administrator, University of Miami, Dept. Pediatrics, Div. Genetics, P.O. Box 016820, Miami, FL 33101. EOE/AA

**TAMPA FL:** Immediate opening for BC/BE Genetic Associate. Salary Range: mid $20,000s, negotiable with experience.

Responsibilities: Varied, with wide exposure to genetic conditions & participation in specialty & outreach clinics.

Contact: Boris G. Kousseff, MD, University of South Florida, Box 15G, 12901 Bruce B. Downs Boulevard, Tampa, FL 33612; 813-974-3310. EOE/AA

**WEST PALM BEACH, FL:** Immediate opening for BC/BE genetic counselors. Salary Range: $27,000+ based on experience & credentials.

Responsibilities: Focus on 1st semester prenatal diagnosis at this rapidly-growing, free-standing center associated with a national network of leading medical geneticists.

Contact: Gene Manko, M.D. or Jay Trabin, M.D., The Genetics Institute of Florida, 1401 Forum Way, #210, West Palm Beach, FL 33401; 407-697-4200.

**SPRINGFIELD, MA:** Immediate opening for BC/BE Genetic Associate.

Responsibilities: Coordinate MSAFP screening program; general clinical genetic counseling; public and professional education.

Contact: Kathleen Walbridge, Dept. Human Resources, Bay State Medical Center, 759 Chestnut St, Springfield, MA 01199; 413-784-3667. EOE/AA

**DETROIT, MI:** Immediate opening for BC/BE Genetic Associate.

Responsibilities: Start-up Prenatal Diagnosis Program

Contact: Mary Helen Quigg, M.D., Hutzel Hospital, Dept. OBGYN, 4707 St. Antoine, Detroit, MI 48201; 313-745-7269. EOE/AA

**DETROIT, MI:** Immediate opening for BC/BE Regional Coordinator.

Responsibilities: Manage newborn screening & related genetic services.

Contact: Lester Weiss, M.D., Henry Ford Hospital, Medical Genetics, 2799 West Grand Blvd., CFP4, Detroit, MI 48202; 313-876-3116. EOE/AA.

**DETROIT, MI:** Immediate Opening for BC/BE Genetic Counselor at Wayne State University-affiliated center.

Responsibilities: Coordinate newborn screening program & community outreach.

Contact: E. Bawle, M.D., Childrens Hosptial of Michigan, Dept. Genetic Metabolism Disorders, 3901 Beaubien Blvd, Detroit, MI 48201; 313-745-4513. EOE/AA

**WINSTON SALEM, NC:** Immediate Opening for Masters-level BC/BE Genetic Associate in University-affiliated setting.

Responsibilities: PNDx & counseling; AFP; FAS; Maternal Age counseling

Contact: Barbara Burton, M.D., Bowman Gray School of Medicine of Wake Forest University, 300 S. Hawthorne Road, Dept. Pediatrics, Winston Salem, NC 27103; 919-748-4321. EOE/AA

**OMAHA, NE:** Immediate opening for BC/BE Genetic Counselor.

Responsibilities: Prenatal diagnosis & counseling; MSAFP; prenatal DNA studies; pediatric genetics; specialty clinics; public & professional education.

Contact: Warren Sanger, Ph.D., MCRI, University of Nebraska Medical College, 4420 Dewey Avenue, Omaha, NE 68105; 402-559-5070. EOE/AA

**CAMDEN, NJ:** Immediate Opening for Masters-level, BC/BE Genetic Counselor. Experience preferred.

# Classified • Classified • Classified

Responsibilities: Comprehensive service center, including prenatal diagnosis; pediatrics; AFP screening; teratology; Fetal Alcohol Syndrome; research; professional & community education.

Contact: Alice Lazzarini, M.S., University of Medicine and Dentistry of NJ-School of Medicine, 401 Haddon Ave, Camden, NJ 08103; 609-757-7812. EOE/AA

ALBUQUERQUE, NM: Immediate opening for BC/BE Genetic Counselor.

Responsibilities: Focus on dysmorphology, including intake evaluation, counseling, management & follow-up for a wide variety of dysmorphology and genetic patients; clinical coordination & travel to clinics throughout NM.

Contact: Jon M. Aase, M.D., University of New Mexico School of Medicine, Dept. Pediatrics, Surge Building, Albuquerque, NM 87131; 505-277-8631. EOE/AA

SYRACUSE, NY:Immediate opening for BC/BE Genetic Associate. Computer literacy helpful. Salary Range: $24,000.

Responsibilities: Join 2 genetic counselors in university-affiliated program, including perinatal & general genetics. Help develop sickle cell & other hemoglobinopathies program; community outreach opportunities.

Contact: Barbara Silverstone, Asst. Director, Central NY Regional Genetics Program, SUNY Health Sciences Center, WSK750 East Adams Street, Room 3109, Syracuse, NY 13210; 315-473-5884. EOE/AA

VALHALLA, NY: Immediate opening for BC/BE Genetic Counselor.

Responsibilities: Counseling, pediatrics & reproductive evaluation, case management; prenatal diagnosis; MSAFP; teratology.

Contact: Linda Higgs, MS, Medical Genetics, Westchester County Medical Center, Valhalla, NY 10595; 914-347-3011. EOE/AA

CLEVELAND, OH: Immediate Opening for BC/BE Genetic Associate.

Responsibilities: Prenatal diagnosis; amniocentesis; PUBS; CVS; community & professional education.

Contact: Irwin A. Schafer, M.D., Cleveland Metropolitan General Hospital, 3395 Scranton Road, Medical Genetics, Cleveland, OH 44109; 216-459-4323. EOE/AA

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Associate at University-affiliated teaching hospital.

Responsibilities: Management & follow-up of patients and families as well as consultation. Participate in specialty clinics. Services to the deaf and hearing impaired as well as genetic evaluation of children in foster care and adoptees is currently in start-up phase. Minimum prenatal counseling at present. Opportunity exists for lecturing.

Contact: Kathleen E. Toomey, M.D., J.D., Chief, Section Medical Genetics, St. Christopher's Hospital for Children, 5th and Lehigh, Philadelphia, PA 19133; 215-427-4430. EOE/AA

COLUMBIA, SC: Immediate opening for BC/BE Genetic Counselor.

Responsibilities: Amniocentesis; CVS; MSAFP; pediatrics; professional & community education.

Contact: S. Robert Young, Ph.D., University of South Carolina School of Medicine, Dept. OB/GYN, Two Medical Park Road #301, Columbia, SC 29203; 803-765-7316. EOE/AA

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**Don't Forget to Register**

**• National Society of Genetic Counselors • Eighth Annual Educational Conference •**
**••• Strategies in Genetic Counseling: Political Influences from Society to the Workplace •••**
**• October 9 - 11, 1988 • Hyatt Regency Hotel, New Orleans, Louisiana**

**Name (please print)** _____ **Degree** _____

**Preferred Mailing Address** _____

**City** _____ **State** _____ **Zip** _____ **Daytime Phone (  )** _____

**Receipt Requested** ❑ **Yes** ❑ **No** **Dietary Restrictions (specify)** _____

**Registration Fee Enclosed:**
- ❑ **$120 Members**
- ❑ **$145 Non-Members**
- ❑ **$ 40 Dinner Guest**
- ❑ **$ 85 Student**
- ❑ **$ 15 Late Fee (if postmarked after Saturday, August 27)**

- ➢ **Walk-In Registrations will be assessed a late fee of $30.**
- ➢ **Please make checks payable to NSGC, Inc., and send with this form to: Bill Herbert, Treasurer, 319 Cheyenne Drive, San Dimas, CA 91773. Please send U.S. currency, only.**
- ➢ **Payment must be received prior to the conference. If your institution pays your registration fee directly, and you anticipate a delay, please write a personal check and request reimbursement.**
- ➢ **Hotel reservations may be made by calling 1-800-228-9000. Mention "NSGC" for special rates.**
- ➢ ***REMEMBER: DEADLINE WITHOUT PENALTY is SATURDAY, AUGUST 27.***

reasonable persons to do everything in their power to avoid them. The medical community has often had trouble accepting pregnancy as a normal, healthy process. Prenatal testing offers opportunities for new kinds of intervention which women are expected to welcome. Providers frequently regard a decision *not* to take advantage of genetic counseling, screening or prenatal diagnosis as a sign of ignorance or misunderstanding.

How a woman views the possibility of bearing a child with a disability depends largely on her ethnicity, religious background, family circumstances and the value that childbearing and rearing have in her life. For some women, bearing a child with *any* degree of disability would be a major disruption which they would opt to avoid at all costs. Others would accept what comes. And still others want to accept whatever happens, but would take advantage of testing to be prepared.

As these tests become applied routinely, they significantly influence the experience of pregnancy. Women's confidence in their ability to produce a healthy baby is being eroded. As a result, many women gratefully accept insufficiently-tested prenatal technologies, despite the limited information about the risks and benefits. Women have begun to talk about "the burden of choice" along with the emotional and physical tension created by the new decisions they must make during pregnancy.

There are values implicit in the process of genetic counseling and in the information that is imparted. Even when counselors are careful not to interject their personal preferences, the genetic counseling relationship incorporates the biases of the counseling and medical professions regarding health, disability and disease. Information provided to pregnant women in the course of prenatal counseling and diagnosis may *not* be liberating when the process is based on an unequal and disempowering relationship between pregnant women and genetics professionals.

To help individuals make informed choices about prenatal tests and their potential impact on the outcome of pregnancy, providers need to offer a balanced perspective regarding the disabilities tested for or the diagnosis. Potential parents are entitled to a full description of the disability, the risks of its occurence, the range of expression, options for treatment and the range of response to therapy. Providers must be careful in their use of phrases such as "birth defect" or "gross malformation," which are value-laden and subtly directive.

To help clients understand the effect that a child with a specific disability may have on their lives, genetic counselors need to understand their particular situation and be aware of and sensitive to cultural differences. While genetic counseling programs provide a variety of classroom studies and experiential field work, most are geared toward training within the medical model and do not offer a broad social perspective or incorporate disability training awareness. Is it reasonable to expect that counselors can provide complete and balanced counseling when they have not had the opportunity to know a range of disabled children and their families?

Perhaps the time has come to take a personal and collective inventory, to consider the content and process of counseling and to identify areas for improvement. For genetic counselors and other women caregivers who are often in subordinate positions, it may be helpful to examine the stated and unstated goals, objectives, motivations and incentives. Does your protocol supplement verbal information in writing in a culturally and linguistically appropriate formats? Are women given sufficient time to consider their testing options?

Having healthy children involves economic and social support to which many women have only limited access. Limited financial and social resources, not genetic problems, are responsible for most infant morbidity and mortality worldwide. The individualistic focus of prenatal intervention must *not* be allowed to obscure this wider need.


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