PERSPECTIVES

in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 10 No. 3 Fall 1988

Election Results Announced

Beth Fine, Past President I and Nominating Committee Chairperson, has announced the results of the 1988/1989 elections. Congratulations to:

President-Elect.....Barbara Bowles, M.S.
Secretary.....Nancy Zellers, M.S.
Regional Representatives:
Region II.....Linda Nicholson, M.S.
Region IV.....Kathy Morris, M.S.S.W.
Region VI.....Kerry Silvey, M.A.

The committee is pleased to report that close to 60 percent of the eligible members voted for President-Elect and Secretary, a record response.

Thanks for a job well done to Committee members: Michael Begleiter, Michelle Fox, Betsy Gettig and Kathleen O'Connor.

on the inside

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

INTEGRATED GENETICS

The Genetic Reference Laboratory: Committed to providing highest quality DNA-probe based diagnostic testing, service and education.

Difficult Counseling Issues

Counseling Issues

Countertransference in the Counseling Setting

by Ann Swinford, M.S., Lorna Phelps, M.S.S.W., Jean Mather, M.S.W., A.C.S.W. A.S., J.M.: Michigan State University; L.P.: Children's Hospital of Buffalo

In the Break-out session of the 1987 NSGC conference in San Diego, we discussed personal issues and their impact on us as genetic counselors. Much of the material dealt with countertransference issues.

Countertransference defined

Countertransference is defined as "feelings, wishes and unconscious defensive patterns of the practitioner that derive from past relationships and interfere with objective perception and block productive interaction with clients."[1] Some practitioners believe that countertransference is not significant in single session or short term counseling situations.

But the issues that our profession deal with are so emotionally loaded that countertransference may come up often. For example, a counselor who had an alcoholic parent may be inappropriately angry with a patient who has an alcohol or substance abuse problem. An infertile counselor may be overly upset with a couple who is disappointed

See Countertransference, p. 4, col. 1

Legal Issues

Counselor Liability in Risk Communications

An Interview with Philip Reilly, J.D., M.D., Medical Director, Eunice Kennedy Shriver Center for Mental Retardation, Waltham, MA and Ruth Mickelsen, M.P.H., J.D., Director, Legal and Policy Affairs, Minnesota Department of Health.

• Part I of a two-part interview •

The legal liability of genetic counselors regarding responsibilities to their clients has not been defined either in statutes or judicial decisions. This interview is meant to provide legal opinion and general guidelines as well as stimulate further discussion. It is *not* meant to provide definitive answers.

If a patient refuses recurrence risk information, what is our obligation to comply with that request?

Philip Reilly: When a patient states that he/she does not wish to be informed about important recurrence risk information, the counselor should first attempt to ascertain why. Further discussion may lead the patient to reconsider that decision. Should the individual be adamant, however, I would acquiesce to the decision.

Two subsidiary issues surface. What if the individual's refusal to receive crucial risk information poses a risk of harm to a third person? Consider that when an individual rejects information he or she may foreclose access to it by a spouse. This, in turn, may deprive the couple of critical information concerning a risk in child-bearing. This

See Counselor Liability, p. 6, col. 1

Corner Thoughts

Next year marks the 10th anniversary of the founding of the NSGC, when a committee dedicated to organizing the members of a fledgling profession undertook the arduous task of creating a professional society *de novo*.

Over the course of that decade the NSGC has served as a structure for the continued growth and development of the profession, a vehicle by which the profession and its members have gained respect and credibility. But the work that the founders of the NSGC began is far from finished. Genetic counseling is still an evolving profession, and its future is still to be determined.

But who will decide its future? Surely both the ASHG and the ABMG will help to guide the profession's direction. It is critical, however, that the NSGC assume more leadership in developing long-term goals and objectives for the profession. It can begin by actively raising public awareness of genetic counseling, by developing professional guidelines and by examining ways in which genetic counselors can increase their professional recognition.

To this end I propose that the NSGC:

- Develop a mechanism to create, submit and display in the public media positive articles on genetic counseling.
- Take initiative in developing policy matters regarding genetic counseling, e.g., guidelines for genetic counseling related to Down syndrome screening.
- Pursue the issue of licensure as a means of gaining professional recognition and some degree of financial autonomy, i.e. the power to bill for services.
- Examine the feasibility of a Ph.D. program in genetic counseling.

The NSGC has wisely used these early years to grow to the point where it now has a formal budgeting process and first-rate annual educational meetings. This is not the time for it to be content with its accomplishments of the past ten years. It is time to seek out and meet the challenges and opportunities of the next ten. It must take the initiative by creating a vision of genetic counseling in the 21st century, and by providing the direction and energy that will transform the vision into reality.

Ed Kloza
GENESYStems

Open Report

Transvaginal Sonography: Indications and evaluation

by Joanne Malin, M.S., Lenox Hill Hospital, New York City, NY

Ultrasound is one of the most important technologic techniques introduced into modern obstetrics; its many uses have revolutionized the care of the pregnant woman and her fetus. Currently, the focus has turned to transvaginal sonography (TVS) due to its higher resolution and earlier diagnostic capabilities.

Physics, rather than genetics, provides the explanation for the scope and limitations of TVS. The sound frequency is higher than that of transabdominal ultrasound (6.5MHz vs. 3.5 MHz) and the distance between the probe and the target site is shorter, making the sound waves travel less distance. TVS, however, is *not* indicated past the first trimester, when the fetal size is such that the fetal anatomy is out of the focal range of the probe.

The following are the indictions for administering TVS in obstetrical patients:

- Infertility (evaluation and in-vitro techniques)
- Pregnancy confirmation (as early as 4 weeks, 1 day)
- Suspicion of ectopic pregnancy
- CVS (placental localization)
- Pregnancies at risk for fetal anomalies

The publication of data to support the ability of TVS to trace normal and abnormal fetal development is imminent. Viability can be documented by the sixth post-menstrual week when the fetal heart beat can be seen. The spine can be traced from its uppermost end to the sacrum by 9 weeks, 1 day. An anencephalic fetus with a high cervical anthoracic rachischisis has been diagnosed. Cranial anatomy with the partition is also well visualized by the ninth week making the detection of holoprosencephaly possible.

Recognition of limbs and digits is accomplished by 11-12 weeks. A pregnancy at risk for Jeune dystrophy was monitored for differential changes in limb growth beginning at the eighth week when limb buds are visible. The diagnosis was established by the fifteenth week. TVS may also be able to detect caudal regression, conjoined twins and hydrocephaly.

See TVS, p. 6, col. 2

EdNotes

A funny thing happened on the way to this issue of *Perspectives*: the editing began to get easier. The Editorial Board is helping to enforce new *PGC* guidelines regarding the length, content, and quality of submissions; more articles are being submitted on computer disk; and the Editorial Board is expanding, perhaps due to rumors that membership facilitates acceptance into medical school.

Both Ann Swinford (Professional/Personal Issues) and Carla Golden (Counseling Approaches [aka Case Reports]) leave the Board this month for medical school. On behalf of the rest of the Editorial Board, I wish Ann and Carla much success in their new roles and am grateful to them both for their tenure on the Board. Replacing Ann in the Professional/Personal Issues position is Karen Copeland from Baylor. Her interests are in developing *PGC* as a means for peer support and professional advancement and as a forum for constructive discussions. Vickie Venne will be covering Technology, which was formerly linked with the Book Review position. Vickie has had much experience in the area of education, and she recently joined the staff of the Nichols Institute.

Joan FitzGerald has requested to stay on for another term on the Editorial Board with the expanded duty of covering all Professional Resources-books, videos, software, courses-designed to aid the genetic counselor in education or performance. Finally, Trish Magyari has joined the Board as Legislative Issues editor. Based in Georgetown, Trish has recently been appointed Legislative Liaison for the NSGC and will be monitoring and participating in activities on Capitol Hill and in state legislatures.

There is a current opening on the Editorial Board for a Counseling Approaches Editor (see Bulletin Board). If you have ideas for *PGC* and want to help shape its direction, consider this opportunity. Or, if you think that a new Editorial Board position is warranted, find me in New Orleans or drop me a line.

Ed Kloza

Children With Handicaps: A Medical Primer

by Mark L. Batshaw, M.D. and Yvonne M. Perret, M.S.W., 2nd ed., 1986, Paul H. Brookes, Baltimore, MD 21285, 490 p., $24.95 paperback.

Originally conceived as a primer for non-medical professionals, this second edition contains some excellent updates and special features (glossary and list of resources for handicapped children), but there are some serious inaccuracies based on outdated materials as well as a few omissions I would like to see addressed, such as HIV in children.

The chapter on birth defects, prenatal diagnosis and fetal therapy has some particularly misleading information. For example, the discussion of CVS (referred to by the old term chorionic villus biopsy) quotes 1983 figures for the risk of miscarriage as being four times higher than that following amniocentesis. Also, no mention is made of the Baylor abdominal probe which increases the utilization rate of CVS to 94 per cent. Likewise, AFP testing is described as a test for women having amniocentesis rather than a screening test recommended in most pregnancies.

A new chapter containing information on public benefits, legal services and estate planning is helpful, but also has the problem of the rapidity with which SSI regulations, P.L. 94-142 (Education for the Handicapped) and Medicaid entitlements change. An appendix which nicely describes the various syndromes unfortunately includes material on the availability of prenatal diagnosis and disease incidence which somewhat guarantees a quick obsolescence.

The book provides separate chapters on subjects such as vision, language development, nutrition and dental care and an impressive array of illustrations and drawings which prove helpful to those who have children with handicaps or who provide services, but it suffers in other areas by the speed with which information changes and the need in the genetics field for the specialized language that makes the material accurate.

Gloria W. McNally, Ph.D., L.C.S.W.
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Case Report No. 13

Ambiguous Test Results and Counselor Bias

by Kathryn Barnhart, M.S., Children's Hospital, Oakland, CA

This case report addresses the concept of countertransference (see p. 1). Did the counselor's personal experience and biases interfere with her objectivity, or did her recognition of this phenomenon allow her to avoid influencing her clients? Compare this case report with Case Report No. 12 (Vol 10, No 2), which also involves contradictory test results.

I counseled Mr. and Mrs. A for a routine, maternal age (37) amniocentesis. Because they were both graduate students in genetics, most of the discussion centered on Mrs. A's strong feelings that she would not abort an abnormal fetus. She had been raised as a Catholic and felt that having an abortion for any reason would violate her feelings, though not primarily religious in nature, that life is sacred. She thought she would be able to cope with the stresses of raising a disabled child, as she had seen her sister deal with a child with epilepsy.

Though he was rather detached during the session, Mr. A supported his wife's position. They had tried for ten years to get pregnant with their first child, at that time 18 months old, and were happy to be pregnant again in such a relatively short time.

During the session, I was impressed by Mrs. A's strength. She was a rational, well-educated woman who loved being a mother and had given up her career in genetics to work full-time at raising her children. She was thoughtful in her reasoning about not wanting an abortion and not rigidly adhering to some doctrine. I had some doubts about their strength as a couple, but I didn't address these concerns.

The amnio procedure went well, and the results showed 46, XX/47, XX+f. In six out of 30 cells, with some in each of two cultures grown, was a large, unidentifiable fragment. We felt this might result in some cells that were in effect trisomic, so we called the couple in and discussed this ambiguous result. We gave them a 40-60 per cent chance that the baby would have some unpredictable problems, possibly major. The couple wanted a fetoscopy, which was done at another facility and which showed 100 out of 100 cells as normal fetal blood cells. The couple was not recounseled at our center, but found the fetoscopy results somewhat reassuring. Ultrasounds during the later part of the pregnancy continued to be normal and growth of the fetus brought the gestational age into the expected range. Mrs. A's obstetrician prepared for the possibility of a high risk birth or neonatal problems.

During the immediate period of decision-making, Mrs. A ironically flattered my counseling skills by saying that I was the only one she could talk to who didn't seem to be pushing her one way or the other. I was working hard, she said, to act "neutral."

However, as a mother of two young children myself, I was bothered that Mrs. A seemed too self-sacrificing. First she had given up her career in genetics and now she was willing to accept the lifetime responsibility of caring for a disabled child. I didn't think that her husband was supportive enough for her to take on so much responsibility. His fledgling business was requiring long hours and causing financial worries. During this pregnancy, the couple requested and was given a referral to a psychologist.

The case was difficult for me because I discovered my own personal and professional bias was clearly for the couple to abort this pregnancy. My colleagues and I thought the odds didn't seem high enough for them to have a healthy baby. Since all my previous abnormal amnio cases had elected for termination, though none had such ambiguous findings, I was preparing them and myself for the worst scenario.

In retrospect, this case was difficult for me for two reasons. Both my bias as a medical genetics worker about continuing abnormal pregnancies when the outcomes may be severe and my own personal ambivalence about motherhood and career led me to feel that the couple was making a mistake. I admired Mrs. A's commitment to motherhood, while, at the same time, I mistrusted her ability to cope with it.

I called Mrs. A weekly throughout her pregnancy, and as the due date drew near, her calmness seemed to develop into depression and anxiety. Naturally, we were all elated and I was very surprised that the baby was healthy and normal. At a four-month exam by our medical geneticist, she appeared normal. This couple had gambled and won. I had learned to keep my personal biases out of counseling.

Ambiguous amnio results can be the utmost test of parental strength and counseling skills.

with the fetal sex results. Or a counselor may become defensive toward clients who are "higher ranking professionals" (M.D., Ph.D.) based on insecurities in past relationships with authority figures.

Handling countertransference

Most experts suggest that the first step in the "cure" is becoming aware of issues that trigger countertransference reactions. Many of these factors are elusive. The checklist that follows this article should serve as a starting point for thought and discussion. If you think that countertransference is affecting your work, the following suggestions might help you deal with these issues:

- MAKE ARRANGEMENTS TO TRADE SENSITIVE CASES with another counselor. If July 12 is the anniversary of your child's death, have another counselor cover the NICU that day. This will require flexibility among counselors and will depend upon the availability of adequate staffing. However, it is in the best interest of the client for genetic counselors to take care of themselves. Try using a hospital staff social worker or other appropriate professional for backup if you are the only genetic counselor.
- CONSIDER RESTRUCTURING THE COUNSELING SESSION. Handle the issues with which you are comfortable and have a colleague handle what you can't, e.g. you handle the medical issues and a colleague can deal with psychosocial issues.
- INCREASE INFORMAL COLLEAGIAL INTERACTION. Discuss your difficult cases with other counselors who can help you to answer the question "was it real or was it me?"
- CONSIDER FORMALIZED SUPERVISION similar to that required for social work and other professional counseling certification. This often takes the form of reviewing cases with a senior person during weekly sessions.
- TRY "FANTASY DICTATION." Write the dictation you really want to write and then write the real one. Not only will you be able to vent your feelings, but you may get more insight into what triggers your reaction.
- CONSIDER THERAPY. If certain aspects of counseling become too difficult or too frequent in your case load, perhaps an issue has become too much for you to deal with alone. Professional help may become necessary to resolve issues which may be affecting you on and off the job.

[1] *Direct Social Work Practice: Theory and Skills.* 1982: DH Hepworth and JA Larsen. Dorsey Press, Homewood, IL. p. 426.

WHAT BAGGAGE DO YOU BRING INTO A COUNSELING SESSION?

1. YOUR PERSONAL AGENDA in the profession. Do you have a need to help, to please, to be the expert? What happens if your help or expertise isn't acknowledged?
2. OTHER EXPECTATIONS. How do you feel if these aren't met?
3. SURPRESSED EXPERIENCES that have affected you psychologically and may still be affecting you. Do you react differently to cases involving...
   - major losses (death, childlessness)
   - family history (genetic disorder, substance abuse)
   - family relationships (dependent, splintered, co-dependent)
   - family size
   - views of parenthood
   - relationships similar to those that have positively or negatively influenced you (friends, lovers, parents)
4. PET PEEVES, e.g., interrupters, welfare recipients, etc.
5. REACTIONS TO PERSONALITIES WHICH ARE DIFFICULT e.g., temperamental, know-it-all, helpless, hopeless, non-caring, intrusive, etc.
6. REACTIONS TO EMOTIONS WHICH ARE DIFFICULT e.g., anger, helplessness, fears.
7. STEREOTYPES of certain groups, e.g., cultural, religious
8. SELF ESTEEM ISSUES. Are you affected by...
   - an inability to deal with criticism
   - a lack of professional confidence
   - a poor self image
   - the "got to be perfect" syndrome
9. PERSONAL VALUES e.g., work ethic, religion, moral values
10. PERSONAL LIFE THEMES. Why do I keep meeting up with the same type of person, situation, relationship, job? What do I need to learn?

Letters ...

Lay advice: an issue of trust

To the Editor:

We want to share an interesting situation which may be happening elsewhere.

The former President of the Down syndrome League of Lansing has developed a local reputation for her expertise in Down syndrome. We recently learned that friends and community members from Michigan and out of state often contact her with their concerns regarding low MSAFP values. She is consulted about the interpretation of results, the value of repeat MSAFP testing and whether or not an amnio should be done. The people who call her are anxious and upset, so she is placed in the same difficult position with which we are all familiar.

This situation raises several questions for us: Why are these patients not calling a genetic counselor or their physician for information? Is there a way we can inspire greater patient trust? (We think trust may be reason patients are calling a friend.) Was there a problem getting an informed consent?

We have started a dialogue with representatives of the Down syndrome League and have provided complete information about MSAFP screening. As a result, they feel more comfortable with MSAFP screening and feel better able to help friends who call.

We'd appreciate your insight and ideas.

Michigan State University
AFP Program Staff

Response to sexual harassment as a threat to professional status

To the Editor:

The opening sentence of the article on sexual harassment (Vol. 10 No. 2) defined sexual harassment as "any unwanted sexual attention a woman experiences on the job...." Sexual harassment affects individuals and is not limited to women. Men are also subjected to sexual harassment; indeed, because of societal pressure, men may be even *less likely* to report such victimization.

Focusing only on women does a disservice to men in the workplace. Sweeping generalizations and stereotypes are what perpetuate such discrimination. As genetic counselors, we should be sensitive to and avoid such blanket statements. The issue is not one of sexual harassment of women *by* men, but one of power and authority *between* individuals.

Seeing this personal history in the

newsletter of a professional organization such as the NSGC is disquieting and illustrates a trend we have noticed over the past year or two. Genetic counselors, or genetic associates, are generally viewed as women working in a male-dominated field. This view is held by the profession as a whole, and by affiliated professions, but is an erroneous one.

Another example is the seminar sponsored by the NSGC at the 1988 meetings which is for female participants only. Focusing on women and women's issues in genetic counseling indicates this is one of the profession's main areas of concern and perpetuates the misconceptions of our field. The difficulties many of us face in our day-to-day experience do not stem from the issue of women versus men.

It is very easy to reduce our problems to this battle of the sexes, but it is only a superficial response. The issue is one of establishing respect, authority and autonomy as professionals in a given field. The problem is better served by discussions of issues such as: non-physician health care providers and their impact on patient care; steps which increase a counselor's visibility, responsibility and expertise when entering a new position; establishing some standards in career potentials and benefits for genetic counselors and genetic counselors serving as a role model for medical counselors which would expand our potential to all aspects of medical care, not only the field of genetics. These are only suggestions of positive areas of growth and change we should explore.

There are many men working as genetic counselors and the profession and we are enhanced by their membership. Genetic counseling does not deserve to be considered a "women's career." However, if we continue as a professional group to emphasize only the women's issues in the field, we will discourage men from considering genetic counseling as a career choice. This is a move which would hurt not only our profession, but the patients, *men and women*, we serve.

Karen Copeland, M.S.
Kristine Courtney, M.S.
Andrew Faucett, M.S.
Joy Redman, M.S.
Genetic Counselors
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PGC: No place for ideology

To The Editor:

With the publication of Vol. 10, No.2, *Perspectives in Genetic Counseling* appears to have taken off in anew direction, not only in format but in terms of policy, one that may have serious implications for the NSGC and one that troubles us greatly. We somehow had the impression that *Perspectives* represented the professional interests of the NSGC and are left wondering whether or not these new directions were approved by the membership or at least the Executive Board of the organization. In our opinion, this issue of *Perspectives* shows a decided shift away from professionalism to ideology. The publication of *Corner Thoughts* by Robin Blatt, of the *Ed Notes* which appear to sanction the view expressed in the lead articles and of the two articles under the byline of "The Politics Of Genetic Counseling," singly or in concert, portray genetic counseling as insensitive to clients' needs, totally medical model in approach, eugenic in outlook and part of the capitalistic-male dominated-egotistical-anti-woman power structure.

Once the simplistic fiction of the malevolence of genetic counseling is established, then, obviously, only the "good guys" on the outside can save the field from itself. It's an age-old tactic to garner notoriety and to sell books. It is not as if the authors of the two political articles have said anything new. Which student who has passed through one of the major genetic counseling training programs in the U.S. has not been exposed in their training and coursework to all the issues raised by these authors?

The articles in question are both filled with much we can agree with, but, nonetheless, they say things which are open to serious questions and are clearly more personal bias than substantiated scholarly fact. The purpose of publishing them at this point in time presumably was to be provocative in preparation for the New Orleans meeting. They should have been labelled as opinion pieces so as to differentiate them from professional articles, which they decidedly are not. To appear as they did without editorial explanation or context implies to the uninformed reader who might pick up the newsletter that this represents the mainstream thinking of NSGC and reflects the true state of affairs in the field.

This borders on the edge of irresponsibility on the part of the editors. Robin Blatt's statement about the new collaboration between activists in the woman's health movement and genetic counselors is particularly troubling. The NSGC is not a political action committee; its central purposes are educational and professional. To hitch its fate to ideologues and political activists is not only asking for trouble but is a sure fire way of eroding professional standards and professionalism and splintering the organization's efforts. This is not to say that political issues are irrelevant to genetic counselors. They are not. However, it is the obligation of the editors of *Perspectives* to elucidate all sides of the issues, not to provide a forum for only one point of view.

It is appropriate for genetic counselors to question current practices and standards of care. However, this should be done in a responsible way. We see no great merit in giving ideologues an opportunity in the NSGC's own forum to bash the profession and to present it to the outside world and to ourselves in ways that have little or no relationship to reality.

Joan H. Marks, M.S., Director
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Seymour Kessler, Ph.D.
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Editor's Reply:

PGC's *policy has been and will continue to be to provide a forum for ideas, a vehicle for information and communication and a helpful resource for the NSGC. As with any publication, readers will be selective about what is relevant or helpful.*

Ms. Marks and Dr. Kessler are correct in assuming that the theme of the Summer Issue reflected that of the New Orleans meeting. That the articles in question were opinion pieces should have been self-evident.

As mentioned in the last Ed Notes *column, I expected the Summer Issue to be a controversial one. Hopefully, NSGC members who feel that the profession has been unfairly portrayed will also become contributors to* PGC *by submitting articles and letters which illustrate the professionalism which better represents their view of the NSGC and of the genetic counselor.*

refusal must be documented, signed by the patient and witnessed. As with any consent form, this instrument should be clearly, simply and frankly written.

Ruth Mickelsen: The main responsibility of a genetic counselor is to assemble, evaluate and convey genetic information. Clients seeking genetic counseling expect accurate and understandable information. Nevertheless, competent patients may refuse information, just as they may refuse medical treatment. A counselor confronted with a client who refuses available recurrence risk information should attempt to assist the client in dealing with the fear and discomfort which may lie at the heart of the refusal. However, if a competent client persists in refusing the information, the refusal should be honored and carefully documented.

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What if a patient refuses to release information to family members regarding a diagnosis?

P.R.: The fundamental difference between the physician/patient relationship and that of the genetic counselor and client is that information discovered by the counselor is much more likely to be relevant to the well-being of third parties.

How, if at all, does this alter the degree to which this process should be cloaked in confidentiality? This tenacious question has received considerable attention over the years. There are two views: a majority insist that confidentiality is sacrosanct and must not be breached *at any cost*. A growing minority (myself included) favor making a limited breach of confidentiality when it is intended to alert a small number of persons of a real risk to their health or of bearing a child with a serious disorder. In my opinion, there is virtually no legal risk in making a limited disclosure to a spouse.

I do not think that there are any circumstances under which a counselor is *obliged* to break confidentiality although there are situations in which the counselor has a *right* to make a limited disclosure. Of course, the ground rules for disclosure should be discussed with the client in advance. (See Box, p. 7)

R.M.: No court has yet held that genetic counselors have an affirmative duty to warn relatives of possible genetic risks.

A few cases have upheld a physician's decision to inform spouses of medical information necessary to protect the spouse (venereal disease cases). At this point, it does not appear that a legal duty exists to inform relatives of genetic risks over a client's objections. Until a legal duty to notify relatives of genetic risks is established, in the vast majority of cases the client's right to confidentiality should be honored.

In certain very limited situations which satisfy the President's Commission standards, disclosure may be permitted. However, if a counselor voluntarily elects to notify relatives over a client's refusal, the counselor may be liable for invasion of privacy and/or breach of confidentiality.

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Is it sufficient to give a patient a letter to distribute among relatives explaining a genetic risk, or must we directly contact all family members?

P.R.: It is sufficient to provide the patient with a letter that clearly explains the particular problem as it may pertain to other family members and that advises them to seek appropriate counseling, including an offer to perform that service or provide a list of professionals in each individual's locale.

An alternative would be to have the patient provide the addresses of appropriate family members so the counselor can communicate directly with them. However, I think the relatives will feel less threatened and be less likely to think their privacy has been violated if the relevant information is transmitted to them by a family member. A system that permits at-risk relatives to initiate the contact with a counselor gives them a greater sense of control over the process.

If a patient/client incidentally reports to the counselor that he or she has been unable to contact a relative, that does not trigger an obligation to follow-up. Nor, however, does it prohibit the counselor from taking the initiative. I do not think it is necessary to send advisory letters by certified mail.

In general, I favor a system in which the counselor prepares the letter(s) and the patient sends them.

R.M.: There are no definite legal standards addressing the degree and type of contact which a medical professional should pursue with third parties when a patient has approved such contact. To some extent, the appropriate "standard of care" in this area will be developed by the profession itself. Basic notions of "reasonableness" will likely define the level of contact activity which is accept-

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TVS, **from p. 2**

ADVANTAGES VS. DISADVANTAGES OF OBSTETRICAL TVS

Advantages	Disadvantages
• Empty bladder (patient compliance)	• Safety not established
• Earlier diagnosis	• Limited to the first trimester
• Increased accuracy	• Diagnostic ability based on fetal position (time consuming)
• Patient acceptance	• Medical-legal considerations

In summary, transvaginal sonography is *not* meant as a replacement for transabdominal ultrasound, but rather as a procedure which can be complementary in providing comprehensive obstetrical care.

able. The provision of a letter to patients for distribution to relatives may be a reasonable way to contact third parties. However, if the patient has requested that his relatives be contacted, the counselor will not be able to verify that contact has occurred if the patient is relied upon to distribute written materials.

In general, the law shows a preference for written notice. Many statutes in other areas specifically provide that notice by first class mail, postage prepaid, is sufficient. If a patient has consented to the notification of relatives, it is the *patient* who presumably provides the counselor with a list of addresses. If the letter is returned as undeliverable, a "reasonable" response would be to contact the patient for more up-to-date address information. If the patient *cannot* provide accurate information, it is likely that the counselor's duty to contact relatives would be found to be satisfied.

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If a family history is vague, how far must we pursue it?

P.R.: The genetic counselor has an obligation to pursue important, but unexplained, questions raised by the family history. I assert that this is a quintessential counseling activity; it is an important reason why patients are referred to counselors. The question should be pursued to the point where the counselor feels that he or she has made a "reasonable" search. At a minimum, it should include obtaining copies of the medical records of the relative in question, unless that person or his or her guardian refuses to release them.

The patient should be asked to share in the search. Among tasks that he or she might reasonably accomplish is: obtaining addresses, reviewing family diaries and photo albums and searching for relevant legal documents (birth certificates, death certificates, wills). The ultimate duty, assuming a cooperative patient, falls on the counselor.

R.M.: A genetic counselor's ability to obtain an accurate and complete family history is, in many cases, inherently limited by the patient's knowledge.

Since medical records of family members will not be accessible to the counselor, the counselor must rely on the patient to obtain accurate information. If obvious information is lacking and the patient cannot provide it, the medical record should clearly note this deficiency and the fact that this deficiency has been conveyed to the patient.

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What is our obligation regarding recontacting a family with new information (DNA testing for DMD)?

P.R.: The counselor has an ethical obligation to alert patients of the existence of a new test that substantially alters the ability to provide important diagnostic information.

In medicine, when an important new test or treatment is introduced, the physician is obliged to inform his patients. Failure to inform may fall to the level of malpractice.

The potential legal liability depends on whether the new test is so superior to the old one that good practice demands retesting. A new probe that improves test accuracy by a few percentage points does *not* necessitate re-testing. A dramatic change in accuracy (from 70 to 95 percent) *does*.

The obligation may be satisfied by sending a form letter to relevant patients at their last known addresses.

R.M.: The rapid advances in genetic diagnostic testing raises the issue of a genetic counselor's duty to recontact former patients and advise them of the new implications of a previously rendered service.

There are no judicial decisions to date which address this issue. However, in recent years several courts have imposed liability on physicians for failure to inform former patients of newly discovered risks of past treatment (DES and Dalkon Shield patients). The rationale of these decisions has been that a physician is a "learned intermediary" between drug manufacturers and patients and thus has a *duty* to pass new information on to the former patient.

Courts have also acknowledged that patients have less access to new information and often lack the necessary skills to analyze the information. These legal arguments will likely form the theoretical basis of a judicial determination that genetic counselors also have a duty to recontact former patients when new genetic information becomes available.

Since a duty to recontact has not been firmly established, there is also no clear guidance as to what conduct constitutes a "reasonable" or "good faith" effort of renotification. Written notice by first class mail, postage prepaid, to the patient's last known address, is likely to be sufficient. In some cases, it may be advisable to attempt to contact a known relative in an effort to locate the former patient. If former patients cannot be located, reasonable efforts may include publishing a general newspaper notice, similar to the notices which appear in manufacturers' recall campaigns. It is likely that courts will not be persuaded by complaints concerning the administrative burden of recontacting former patients, if the recontact may prevent serious physical harm.

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"A professional's ethical duty of confidentiality to an immediate patient or client can be overridden only if several conditions are satisfied: (1) reasonable efforts to elicit voluntary consent to disclosure have failed; (2) there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm; (3) the harm that identifiable individuals would suffer would be serious; and (4) appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in questions is disclosed."

—from the President's Commission for the Study of Ethical Problems in Medicine and Biochemical and Behavioral Research

Conference Update

The Eighth Annual Educational Conference in New Orleans is weeks away.

If you plan to attend and have not reserved your place, please be sure to send your registration form *as soon as possible.* Walk-in registrants will be assessed a $30 late fee; registration materials, hotel rooms and entrance to the special event *cannot be guaranteed* for walk-in registrants.

If you are interested in becoming involved in the NSGC, you are invited to attend one or any of the following meetings:

• Sunday, October 9 •

The NSGC Board Meeting has been scheduled from 9:00 - 2:00 PM in the Rampart Room on the fourth floor of the Hyatt Regency. Please note that this is a change from the previously reported time in the program brochure.

The following Committee Meetings have been scheduled from 3:00 - 5:00 PM. All are in the Hyatt Regency and most are located on the fourth floor.

Social Issues.....Rampart Room
Professional Issues..... Rosedown Room
Education Committee... Buena Vista Room
Perspectives Editorial Board...Ashland Room
Finance Committee..... Oak Manor Room
Regional Representatives (Incoming and Outgoing).....Elmwood Room

• Wednesday, October 12 •

The following Meetings have been scheduled from 9:00 - 11:00 AM.

Board Budget Workshop.....Grand Room
1st floor, Regency Conference Center
1989 Annual Conference Planning Committee.....Woody Herman Room Annex, 2nd Floor

Also, please note that the workshop, "Coping with Prenatal Diagnosis: Personal and Political Strategies—Finding the Common Ground," will be given on Monday, only, and will *not be repeated* on Tuesday. Registrants wanting to attend this session should plan accordingly.

LuAnn Weik, M.S.
1988 Conference Chairperson

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Third Party Reimbursement Proceedings Now Available

The conference Proceedings on the Reimbursement for Medical Genetics Services is now available from: National MCH Clearing House, 38th and R St., N.W., Washington, DC 20057.

The theme of the conference, held on May 17, 1987 in Boston, was "The Challenge to Provide Genetics Services." Of the many factors that contribute to reduced accessibility to these services, reimbursement was the one examined at this conference. If you are interested in more information, please contact National MCH Clearing House.

Robert Greenstein, M.D.
UConn Health Science Center

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Media Resource Center is People Resource Center

The Media Resource Center (MRC) at the NSGC Educational Conference was developed to provide access to published materials which address topics important to our membership. This year, as in the past, the MRC will provide written information and other media presentations.

To fit with the theme, some of our own politically active members will be giving short presentations about their involvement in the political process.

We would also like to see the "slide swap" idea revitalized. If you have any slides to share, we would be very happy to display them. We can never have too many slides!

Your input will help make the MRC successful.

Bev Tenenholz, M.S.
Media Resource Center Coordinator
412-578-7350

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Perspectives *Needs You*

Carla Golden, who has been soliciting and editing case reports as the Counseling Approaches Editor for *Perspectives* will be entering medical school this September. Carla's departure from the Editorial Board leaves one year of her term remaining. Anyone interested in serving as Counseling Approaches Editor should contact me by October 15.

Books, pamphlets and video tapes directed at patient or client use should be sent for review to Melonie Krebs. Anyone interested in joining the list of reviewers of these resources should also contact Melonie.

Ed Kloza
Editor-in-Chief, *PGC*

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Membership Drive Begins

You will soon be receiving a mailing that will include your dues envelope. Because the NSGC has changed to a calendar fiscal year, you will be billed for the period covering August 1, 1988 - December 31, 1989. Please help us with our paperwork by responding in a timely fashion.

Luna Okada, M.S.
Membership Chairperson

Brochure Debut at Annual Educational Conference

It's been nearly two years since Debbie Collins, then chair of the Professional Issues Committee, thought it a good idea to update our NSGC informational brochure. Seth Marcus adopted the project, rewriting and updating the brochure to better reflect our profession and our organization. With the assistance of Scott Polzin's layout suggestions, Seth jockeyed it from Professional Issues Committee to Executive Board and back again...several times!

We are pleased to announce that our new brochure will be available this fall at our Annual Educational Conference in New Orleans. Thanks, Seth, for your professional expertise, your tenancity and your good spirit throughout the brochure's many additional revisions prior to publication.

Other Conference Bonuses...

Look for the following exhibitors at the conference: **Collaborative Research, GeneScreen, The Genetics Institute/Alfigen, Integrated Genetics, Learner Managed Systems, Robert Maciel Associates, March of Dimes, Nichols Institute, Pergamon Press** and **Perceptive Systems.** Also, our hearty appreciation to **Roche Laboratories** for funding the Conference Program Book and to **Vivigen** for funding the note pads that will be in your registration packets.

In Memoriam

We are saddened to announce the untimely death of Jane Engelberg, M.S., on August 29 in New York.

A 1973 graduate of Sarah Lawrence College, Jane had been employed at Schneider Children's Hospital of Long Island Jewish Medical Center since 1978.

Notes may be sent to her husband, Al, at 20 W. 64th Street, New York City, NY 10023. The family has requested that donations be made to the Chemotherapy Fdt., 183 Madison Ave., Room 403, New York, NY 10016.

Book

Difficult Decisions for Families Whose Unborn Baby has a Serious Problem
publisher: **Centering Corp., Omaha, NE, 1988, 16 pp.**
price: **NA**
reviewed by: **Laura Child, M.S., Perinatal Center, Syracuse, NY**

Written for parents who have recently received abnormal prenatal diagnosis results, this booklet provides guidelines for making the decision whether to continue or to terminate the pregnancy.

The format of the booklet is excellent. The main topics are highlighted in bold print and the sentences are short and to the point. Actual quotations one would hear from parents are used to support many of the points made by the text. Even the colors used— earthy tones of tan and brown— are soothing.

The booklet covers virtually all major issues that parents confront when faced with an abnormal prenatal diagnosis result. With a great deal of tact, it covers equally well emotional, medical and financial issues. The following topics are covered:

- Stages of bereavement
- The importance of partners and family caring for each other
- Telling children the bad news
- Important questions to ask professionals
- Which professionals may be of help
- Practical tips on how to best proceed whether parents decide to continue or to terminate the pregnancy and
- How to relate to and what to expect from family, friends and co-workers.

The use of language in addressing sensitive issues, such as termination of pregnancy, is particularly well done. The point that either decision, continuation or termination, is made out of love, is reinforced throughout the booklet.

A short glossary of common medical terms is included, and the definitions are generally very appropriate.

My only criticism of this booklet is that it does not address the issue of consent for autopsy. Many parents find it extremely difficult to sign for an autopsy, despite the valuable information it can provide. The pros and cons of autopsy should have been briefly discussed.

I highly recommend the use of this booklet by any professional involved in the practices of obstetrics, perinatology or genetics.

HMHB: A Well-Kept Secret

by Trish Magyari, M.S., Georgetown U Child Development Center, Washington

Past efforts to encourage NSGC members to utilize Healthy Mothers Healthy Babies (HMHB) have largely gone unheeded. The purpose of this article is to further elaborate the merits of an HMHB affiliation and encourage involvement by our members with this resource.

Have you grappled with these questions and issues?

- Who can help me produce and disseminate public education materials?
- Who can help me reach low income or low literate populations in my area?
- What organized groups share my concerns about maternal substance abuse? How can we work together?
- Who can help me lobby my state legislature for genetic service funding or pass bills mandating alcohol warning signs?
- How can other health professionals understand how genetic counseling fits into the larger Maternal and Child Health Care picture?

The answers to all of these questions can be found by tapping into the Healthy Mothers Healthy Babies Coalition.

Background and composition

HMHB is a national coalition of governmental, professional and voluntary organizations committed to improving maternal and child health and to working together toward this goal. The Coalition has grown to 92 member organizations, including: the American Medical Association, the American Academy of Pediatrics, the American College of Obstetrics and Gynecology and the March of Dimes. Although currently only two of the member organizations focus specifically on genetics services (NSGC and CORN), HMHB is committed to supporting genetics services as they relate to MCH care issues.

NSGC, an integral part of the overall structure

The NSGC is an active member of the HMHB. Jill Fonda Allen, M.S. and I provide the leadership for the national Genetics Subcommittee, one of eight standing subcommittees. This Subcommittee meets quarterly with the National Steering Committee meetings, publishes a newsletter and is pursuing several national networking projects.

Perhaps most important to us is that HMHB is organized into a network of state chapters. Some states have hundreds of members and an active Genetics Subcommittee while other states have few members and have not yet made contact with the genetics community. The state chapters provide the bulk of opportunity for genetic counselors to utilize the coalition to its fullest.

Professional benefits

HMHB is an established vehicle for the development, production and dissemination of educational products. Genetic counselors can benefit from HMHB's experience in many areas, including developing print materials for special populations (minority, low income, low literate), working with the media to produce PSA's and tapping into their community-based dissemination capabilities. As an NSGC member, you are entitled to attend all HMHB functions such as legislative hearings, forums and receptions.

Participation in HMHB has an added benefit: it allows other professionals to understand the important role we play in Maternal and Child Health. Likewise, it can dispel the feelings of isolation we sometimes experience. Moreover, HMHB has a large and broad constituency base and is potentially a powerful ally in the legislative arena, especially if we have established our role by becoming involved in their activities.

How to become involved

Clearly, an association with HMHB has much to offer NSGC members. To take full advantage of HMHB and help strengthen their link to the genetic counseling community, you are encouraged to:

- Contact the HMHB Executive Office at 202-863-2458.
- Join the Genetics Subcommittee or sign up to receive the newsletter (funding prohibits sending it to all NSGC members) by contacting Jill Fonda Allen 202-745-2187 or me 202-687-8635.
- Visit Jill and me at the HMHB information table in New Orleans.

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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.

CAMPBELL, CA: Immediate opening for Masters-level BC/BE Genetic Counselor with minimum 2 years experience.

Responsibilities: General genetics; specialty clinics; education and outreach.

Contact: Peggy Purvis, Personnel Representative, San Andreas Regional Center, 300 Orchard City Drive, Suite 170, Campbell, CA 95008; 408-374-9960. EOE/AA

SACRAMENTO, CA: January '89 opening for Masters-level BC/BE Genetic Counselor. Excellent salary & benefits. New position to work with 3 genetic counselors & 1 MD geneticist.

Responsibilities: Amniocentesis & CVS counseling; MSAFP counseling; teratology & other prenatal counseling; general genetic referrals & hospital consultations.

Contact: Mark Lipson, M.D., Kaiser Permanente Medical Center, 2025 Morse Avenue, Sacramento, CA 95825; 916-973-7374. EOE/AA

SAN FRANCISCO, CA: Immediate opening for BC/BE Genetic Counselor. Excellent salary & benefits.

Responsibilities: Prenatal & general genetic counseling; case coordination.

Contact: Kerry Silvey, M.S., Kaiser Permanente Medical Center, 2280 Geary Boulevard, San Francisco, CA 94115; 415-929-5712. EOE/AA

FARMINGTON, CT: Immediate opening for BC/BE Genetic Counselor with MS, MSW or RN. Salary Range: $25,000 - 30,000 depending on experience.

Responsibilities: Large, active program: general & perinatal genetics, satellite programs, teratology; prenatal diagnosis; group amniocentesis counseling; CVS counseling. Faculty appointment & research opportunity available.

Contact: Robert Greenstein, M.D., UCONN Health Science Center, Div Human Genetics/Pediatrics, Room L-5072, Farmington, CT 06032; 203-674-1465. EOE/AA

NORWALK, CT: Immediate opening for BC/BE Genetic Associate at Yale University School of Medicine-affiliated hospital.

Responsibilities: Coordinate amniocentesis patients; pediatric & genetic clinics; public & professional education.

Contact: Isabel E. Fawcett, Supervisor of Employment, Norwalk Hospital, Maple Street, Norwalk, CT 06856; 203-852-3110. EOE/AA

INDIANAPOLIS, IN: Immediate opening for Director, Genetic Services. BC/BE Genetic Counselor with minimum 3 years experience in counseling or genetic service. Clinical or Medical Geneticist, Cytogeneticist PhDs may substitute for experience. Salary Range: Low $30,000s.

Responsibilities: Direct all state MCH genetic services: newborn screening, specialty clinics, Regional Genetics Network.

Contact: Diane Downing, MSN, Director, Division of Maternal Child Health, 1330 W. Michigan Street, Indianapolis, IN 46206-1964; 317-633-8457. EOE/AA

COLUMBIA, MO: Immediate opening for Masters-level Genetic Counselor with BC/BE to join 3 medical geneticists, 1 PhD geneticist & 3 genetic counselors. No experience necessary.

Responsibilities: Case management of patients with metabolic disease; coordinate existing MSAFP program.

Contact: Judith H. Miles, MD, PhD, University of Missouri at Columbia Hospital Clinics, 1 Hospital Drive, Columbia, MO 65212. EOE/AA

OMAHA, NE: Immediate opening for Masters-level BC/BE Genetic Counselor.

Responsibilities: Pediatric genetics; specialty clinics; prenatal diagnosis & counseling; MSAFP; prenatal DNA studies; 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

HANOVER, NH: Immediate opening for BC/BE Genetic Counselor or Nurse with experience in genetics. Salary Range: $24,000-32,000 depending on experience.

Responsibilities: Coordinate outpatient clinics; genetics & dysmorphology program; inpatient consultation; prenatal diagnosis; MSAFP; professional education.

Contact: Susan Berg, M.S., Dartmouth Hitchcock Medical Center, Butler Building, Hanover, NH 03756; 603-646-8453. EOE/AA

MANHASSET, NY: Immediate opening for Masters-level BC/BE Genetic Counselor at tertiary care center affiliated with Cornell University Medical Center. Salary Range: $28,000+, depending on experience.

Responsibilities: Counsel prenatal & genetics patients; teach & supervise genetic counselors, medical residents & fellows.

Contact: Julie Potter, M.S., Marjorie Williams, M.S. or Gittel Silverberg, M.S., North Shore University Hospital, Division of Genetics, 300 Community Drive, Manhasset, NY 11030; 516-562-4610 or 4615. EOE/AA

NEW HYDE PARK, NY: Immediate opening for BC/BE Genetic Counselor with experience in counseling, diagnosis, clinical administration, research & teaching.

Responsibilities: All aspects of counseling & case management for broad range of genetic services: diagnosis, teratology; MSAFP; prenatal diagnosis.

Contact: Audrey Heimler, M.S., Schneider Childrens Hospital / Long Island Jewish Hospital, Division of Human Genetics, New Hyde Park, NY 11042; 718-470-3010. EOE/AA

NEW YORK, NY: Mid-October opening for Masters-level, BC/BE Genetic Counselor/MSAFP Coordinator. Experience preferred but not essential.

Responsibilities: Coordinate MSAFP program; prenatal diagnosis (amniocentesis & CVS); participate in active clinic.

Contact: Robert J. Desnick, Ph.D., M.D., Chief, Developmental Medical Genetics, Mt. Sinai Medical Center, Fifth Avenue at 100th Street, New York, NY 10029; 212-241-6947. EOE/AA

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor. Research skills helpful. Full or parttime work negotiable.

Responsibilities: Breast cancer research project: pedigree development & verification; follow-up; patient counseling;

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liaison between research staff & subjects.

Contact: Daniel Miller, M.D., Strang Clinic, 55 E. 34th Street, New York, NY 10016; 212-734-4838. EOE/AA

NEW YORK, NY: Immediate opening for Masters-level BC/BE Genetic Counselor.

Responsibilities: Obstetric & pediatric counseling; coordinate screening program. Opportunity for writing & teaching.

Contact: Kwame Yeboa, M.D., Director, Division of Genetics, Columbia-Presbyterian Medical Center, 3959 Broadway, New York, NY 10032; 212-305-6731. EOE/AA

VALHALLA, NY: Immediate Openings for BC/BE Genetic Counselors at University-affiliated hospital. Work on comprehensive genetics team.

Responsibilities: All aspects of counseling & case management: birth defects, mental retardation, reproductive evaluations; abnormal sexual development; prenatal diagnosis; MSAFP; teratology. Wide range of specialty clinics. Opportunity to participate in satellite clinics available.

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

PROVIDENCE, RI: Immediate opening for Masters-level, BC/BE Genetic Counselor as member of existing team of 2 genetic counselors and 1 MD geneticist. Some MSAFP testing & counseling experience preferred.

Responsibilities: Assist with statewide MSAFP program; preamniocentesis counseling for advanced maternal age & other disorders; teratogen counseling; birth defects and dysmorphology consultation; lecturing; participate in research & manuscript preparation.

Contact: Marshall W. Carpenter, M.D., Women and Infants' Hospital, Department of Maternal & Fetal Medicine, 101 Dudley Street, Providence RI 02905, 401-274-1100.

FAIRFAX, VA: Immediate opening for BC/BE Genetic Counselor.

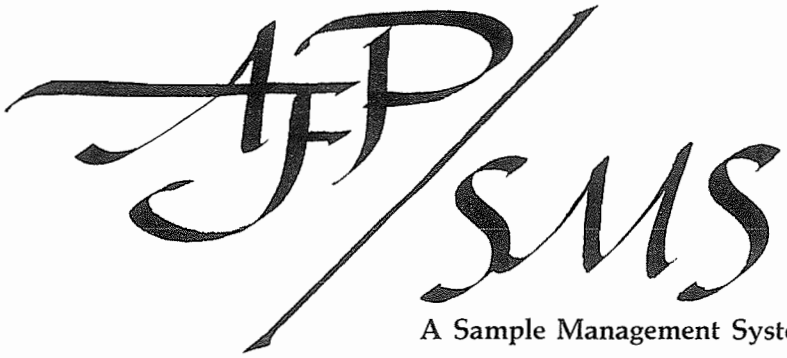
Responsibilities: Counseling pediatric & adult patients: CVS, amniocentesis, MSAFP, follow-up for large prenatal research project.

Contact: Shirley L. Jones, R.N., M.S., Genetics & IVF Institute, 3020 Javier Road, Fairfax, VA 22031; 703-698-7355. EOE/AA

RICHMOND, VA: January '89 opening for Masters-level BC/BE Genetic Associate/ Faculty Research Assistant. Strong teaching and organizational skills sought; computing skills preferred. Salary Range: $22,000 - 25,000, depending on training and experience.

Responsibilities: Professional education; track and counsel follow-up patients. Apply with 3 letters of recommendation by 10/31/88.

Contact: Dr. Joann Bodurtha, Medical College of VA, Dept. Human Genetics, Box 33, MCV Station, Richmond, VA 23298-0033; 804-786-9632. EOE/AA



A Sample Management System for Pre-natal AFP Screening

Your AFP Screening Program must work for the benefit of both the geneticist and the patient. To do that you need a fully-integrated system including accessioning, positive sample ID, data reduction, QC tracking, interpretive reporting, management reports, and a data base. AFP/SMS supplies all these and more!

- Interpretive reporting in plain English, and *you* compose the text;
- Calculation of MoM corrected for maternal weight, maternal race, insulin-dependent diabetes and twin pregnancies;
- Evaluation of the Down Syndrome risk.

AFP/SMS is brought to you by the creators of RIA AID and ELISA AID. For further information, including a brochure, call or write:

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Arlington, Massachusetts 02174-212
Tel: 617·646·3627 Telex: 910·350·0605 Fax: 617·648·7607
Contact: William B. Adams, PhD

Genetic Testing for Sperm Donors Sought

Senator Albert Gore (D-Tenn) announced in early August that he would ask the Food and Drug Administration to require sperm banks to routinely test donated semen for cystic fibrosis and Huntington's disease genes.

His remarks followed the release by the Office of Technology Assessment of a report on "Artificial Insemination Practice in the U.S." Gore added that he will be introducing legislation that would establish a data base of medical and genetic information on sperm donors. The information would be available but identities would be kept confidential.

NSGC Endorses Alcohol Warning Label Bill

Widespread public ignorance of the dangers of drinking during pregnancy coupled with an incidence of fetal alcohol syndrome (FAS) exceeding 1/1000 make increased public awareness of FAS imperative.

Congress is currently considering two bills, S.2047 and H.R. 4441, which would require warning labels on alcoholic beverage containers. One of the five rotating messages reads:

WARNING: The Surgeon General Has Determined That Consumption of This Product, Which Contains Alcohol, During Pregnancy Can Cause Mental Retardation and Other Birth Defects.

The NSGC has joined a broad-based coalition of over 100 organizations in supporting these bills. Recent activity centered on an August 10 hearing of the Senate commerce committee at which many coalition members, including the NSGC, submitted written testimony while Drs. Kenneth Jones and Sheila Blume gave excellent oral testimony regarding FAS. The hearings converted both Senator Hollings (Chair, Commerce Committee) and Senator Gore (Hearing chair) to supporting these bills and were devastating to the alcohol beverage industry which failed to testify.

S.2047 and H.R. 4441 are expected to come to vote prior to October 1 as planned attachments to an Omnibus Drug Bill. Write or call your legislators today. Include personal experiences with FAS and ask them to join senators Gore and Hollings in supporting these bills.

Address your letter to: Representative_____, U.S. House of Representatives, Washington, D.C. 20515; or Senator_____, U.S. Senate, Washington, D.C. 20510.

Long Range Supreme Court Composition to be Determined by 1988 Presidential Election

"For better or for worse, the 1988 election will be a significant one," says Supreme Court Justice Blackmun. "If Vice President Bush wins, the court could become very conservative well into the 21st century."

The three most liberal Justices, Blackmun, Marshall and Brennan, are at least 80, while no other justice is over 70. (Reprinted from RCAR Legislative Update, No. 88-16 and 17, August 1988).

The impact of your vote is far more reaching into the future than the next four years.

IMPORTANT REMINDER: To be eligible to vote on November 8th, you must register prior to the New Orleans conference. Please register today.

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