PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 11, No. 3 Fall 1989

WE'RE ALMOST THERE!

As of September 1, the SPECIAL PROJECTS FUND was closing in tightly on its goal to raise $20,000. This FUND was created to fund genetic counselors for independent projects that look toward the future of the profession and the future of the Society. We wish to thank those of you who have responsed to this appeal. If you have been intending to contribute, but just haven't gotten around to it, please send your check now, payable to NSGC Special Project Fund, to: Luba Djurdjinovic, 16 Leroy St, Binghamton, NY 13905.

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The Future of Genetic Counseling

Retrospections and Introspections ...and A Look Ahead

At the NSGC's 10 Year Anniversary, PGC is taking the opportunity to ask four counselors with unique perspectives — the Society's first president, a training program director, a male and an expert on genetic counseling career development — to speculate on the direction of counseling in the years ahead.

Ten years ago it was my hope that genetic counselors would become indispensable members of the medical genetics team. The demand for genetic counselors is primarily the result of exactly this achievement. In 1989, training programs graduated less than 50 board eligible/certified genetic counselors, a number inadequate to fill available positions. If this situation continues, employers may be forced to

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A Report from the *Ad Hoc* Committee on Codes of Ethics and Ethical Principles

A *PROFESSIONAL CODE OF ETHICS* is a set of principles by which members of a professional group agree to be guided in exchange for membership. A code of ethics provides the professional with guidelines for dealing with situations that pose ethical dilemmas. Ethical codes are *not* a series of rules and regulations. They are *statements of belief and guidelines for professional behavior.* They reflect the responsibilities, obligations and goals of a professional group, serve to unite a diverse membership and represent a consensus of standards and values. Professional codes of ethics can also be used by students and the community at large to

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Interphase Cytogenetics Implications for Prenatal Diagnosis

by Lorraine J. Fry, M.S., Integrated Genetics, Framingham, MA

As genetic counselors, we strive to provide our patients with the most current knowledge and support surrounding their individual genetic testing needs. We are, therefore, faced with the constant challenge of keeping abreast of innovative yet accepted technologies affecting the utility of cytogenetic, biochemical and DNA based studies.

CYTOGENETIC ANALYSIS has evolved tremendously from the discovery in 1956 by Tjio and Levan of the normal chromosome complement to the sophisticated, high resolution banding and imaging techniques which exist today. The current, broadly used cytogenetic techniques have enabled us to detect a high percentage of numerical and structural aberrations. However, improvements in speed, sensitivity and accuracy of chromosome analysis will further advance the capabilities of these diagnostic procedures.

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EdNotes

There's little doubt that as a professional association the NSGC is approaching maturity, an age where new responsibilities are assumed, especially for one's own future.

The observations offered by NSGC veterans Heimler, Scott, Resta and Corson clearly suggest that change will be a key word for this profession in the years to come: change in training, staffing, education and expectations. Joan Marks adds her perspective as well in a recent interview conducted by Seth Marcus. As part of our evolution, Judith Benkendorf suggests, on behalf of the *ad hoc* committee on Codes of Ethics and Ethical Principles, that the NSGC adopt a set of professional standards.

Perspectives is in for some changes as well. Immediate changes include the approval by the Board of Directors of Vickie Venne as Assistant Editor, and the appointment of Barbara Bernhardt from Sinai Hospital of Baltimore as the new Counseling Approaches Editor. In addition, Sylvia Mann from the University of Hawaii is joining the Editorial Board as Resources Editor. Our thanks to Jan Stryker and Melonie Krebs, whose terms on the Editorial Board expire this Fall. *Perspectives* accepts with regrets the resignation of Joan FitzGerald from her position as Professional Resources Editor due to increasing job responsibilities. Joan has been associated with *Perspectives* for many years and her contribution to this newsletter is much appreciated.

Finally, I'd like to thank everyone who responded to the recent survey regarding *Perspectives*. Over 200 were returned, most with very helpful suggestions or comments which the Editorial Board will consider in November. There were several unsolicited requests to begin a journal for the genetic counseling profession, and a gratifying number of responses included offers to assist in such an effort. We have already begun exploring the possibilities of launching a professional journal in 1991 which may compete with a new journal, *Genetic Counseling*, to be published in Europe next year. Your support of our efforts are especially needed if we are to be successful: a journal will be a testimony to our legitimacy as a self-governing profession.

Ed Kloza

Visions, Viewpoints &...

An Interview with Joan Marks, M.S.

Reproductive Technologies into the '90s

Joan Marks is Director of the Genetic Counseling Program at Sarah Lawrence College, Bronxville, NY

Joan Marks has been Director of the Sarah Lawrence Program in Human Genetics since 1972. She has authored* Genetic Connection: How to Protect Your Family Against Hereditary Disease, *and teaches a class in Issues in Genetic Counseling. Marks was instrumental in the creation of the genetic counseling profession and the National Society of Genetic Counseling.

WHAT DO YOU FEEL HAVE BEEN OUR MAIN ACCOMPLISHMENTS DURING OUR FIRST TEN YEARS?

The genetic counseling profession has achieved major goals during its first ten years as an organized, officially recognized society. Although the profession itself is 20 years of age, the NSGC, by establishing its national base throughout the country in the past ten years, has demonstrated the many different areas where genetic counselors participate in the delivery of genetic services. The Society has shown that genetic counselors represent well over a third of the professionals now providing genetic services in this country.

WHAT WERE THOSE START-UP YEARS LIKE? HOW MUCH DIFFERENT WERE THEY FROM TODAY?

The years between 1971, when genetic counselors trained at the masters level first received degrees and 1979 when the NSGC was organized, was a challenging and productive period in the evolution of this new health profession. Newly graduated counselors were "laboring in the fields" to gain recognition in the medical community. Program directors were continuously challenged to provide evidence that their curriculum was appropriate for the level of responsibility and range of services required of genetic counselors working as part of the health care team. Many leaders in the medical community felt strongly that the most appropriate candidates for training as counselors should be mature women who were parents, as well. There was serious doubt that non-physician counselors could be trusted to know their limitations. There was open skepticism that dealing with the emotional component of genetic diseases was either necessary or constructive. Men, first accepted to the Masters-Level Human Genetics Program at Sarah Lawrence College in 1977, were looked upon with even greater skepticism!

In view of the total lack of support for the training of genetic counselors from the Division of Maternal and Child Health, HHS, it is interesting to reflect that the field received essential generous support from 1969 to 1979 from the Division of Allied Health Manpower, Department of Health, Education and Welfare (HEW), to allow the curriculum and field training for genetic counselors to be developed. John Littlefield, M.D., former Chairman of Pediatrics at Johns Hopkins, Kurt Hirschhorn, M.D., Chairman of Pediatrics at Mount Sinai School of Medicine and Arthur Robinson, M.D., University of Colorado, Denver, were key advisors to Sarah Lawrence and should be recognized for their contribution to the development of the profession of genetic counseling. Kenneth Dumars, M.D., Professor of Pediatrics at the University of California, Irvine, clearly succeeded in gaining recognition of the field when he received support for the first Asilomar Conference in 1976 as an extension of the funding his department received as a University Affiliated Center. Also, the March of Dimes Birth Defects Foundation has consistently funded various aspects of the developing field of genetic counseling over the past 20 years.

OUR PROFESSION HAS SEEN TREMENDOUS GROWTH IN THESE SHORT TEN YEARS. DO YOU BELIEVE THAT WE CAN SUSTAIN THIS RAPID GROWTH OR DO YOU FORESEE A PLATEAU?

I view the field of genetic counseling as still in its developmental stages, despite the enormous growth of the past ten

years.The current shortage of trained genetic counselors indicates to me that the field needs to grow. It concerns me that the overall numbers of applicants for graduate training appears to have leveled off. Recruitment of high quality young people, and in particular minority candidates, needs to be rigorously addressed if the profession is to be able to meet the needs now recognized by the medical community.

HAS THE PROFILE OF APPLICANTS TO GENETIC COUNSELING PROGRAMS CHANGED?

A profile of recent applicants would be as follows: 85% women, recent college graduates, biology majors with psychology/sociology minors. Most have had some experience in at least one of the following: as resident dormitory advisors, Crisis Hotline counselors, working with retarded or disabled individuals or in cytogenetics labs. The remaining 15% are men or women in their 30's with experience in diverse fields such as teaching, psychology, cytogenetics or nursing.

WHAT SHOULD WE SET AS GOALS FOR THE NEXT TEN YEARS?

I would like to see the following achievements in the profession over the next decade:

- *RECRUITMENT OF QUALIFIED STUDENTS,* maintaining the high standards of the profession to assure the field's potential for further growth.
- *FURTHER PROFESSIONALIZATION,* including greater emphasis on clinical research publications with a focus on the process and effectiveness of counseling, *per se.*
- *ACADEMIC STATUS FOR GENETIC COUNSELORS.* ABMG-certified counselors should press for academic recognition within the medical community. Publications and teaching responsi-bilities should be the goal of some counselors and should lead to teaching appointments. Increasing recognition within the medical community will be accompanied by greater job satisfaction as well as higher salary levels.
- *CONTINUED DEFINITION OF THE PRINCIPLES* that guide genetic counseling.

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Case No. 17

Can non-directiveness be non-helpful?

by Karen Copeland MS, Baylor College of Medicine, Houston, TX

C. K. (age 38) and her spouse returned to our center for CVS. She had undergone CVS with us two years prior with normal results. Since she was thoroughly counseled in her previous pregnancy, the couple was scheduled for only a brief visit the day of her procedure. The CVS was performed without difficulty and C.K. experienced no complications.

The direct preparation results showed mosaicism involving 45,X/46,XX (16/20 cells) but in two cultures (40 cells) only 46,XX cells were observed. During follow-up counseling, we explained that it was unlikely that the 45,X cells were representative of the fetal karyotype since they were seen only in the direct and not in the cultures. However, we could not rule out the possibility of 45,X cells in the fetus which could result in the clinical manifestations of Turner syndrome, which we discussed in detail, with emphasis on the phenotype associated with a mosaic state.

The couple felt a child with Turner syndrome would not present any significant difficulties for themselves, their other daughter or the child itself and would only consider pregnancy termination if there was a significant chance of mental retardation. We then offered this couple the opportunity to clarify the results during this pregnancy, i.e. amniocentesis or PUBS, or to simply wait until delivery. Since no action could be taken for several weeks, the couple was to discuss this and contact us with their decision. When they left they were optimistic and considered the results of the CVS to be reassuring.

Over the next six weeks, C.K. and I spoke several times. While she still felt reassured, she expressed to me that she was not enjoying this pregnancy as much as she did her first. The ambiguous chromosome findings were clearly creating some anxiety. Her husband was comfortable waiting until delivery but was very sensitive to her concerns. She stressed that she was not concerned as much about Turner syndrome as she was that, given the questionable findings, she was not taking advantage of all the information that might be available to her. While she was anxious to confirm a normal phenotype, she did not want to put the pregnancy at additional risk just for her peace of mind; the couple had a history of infertility prior to their first pregnancy.

She repeatedly stated she did not know what to do. Several times during the counseling session and in our phone conversations she had asked what would I do if I were in her place. Explaining that there was no "right" decision or action, and that each couple must decide what is best based on their own personal, social, religious and economic needs only frustrated her more. She requested and trusted my opinion. I realized that this might be a conscious or subconscious attempt to delay or avoid making her own decision, but I felt that until this question was addressed she would not be able to move forward.

I told her what I would do, but carefully explained my reasoning: if I had to make this decision, it would be as a single woman with an accidental pregnancy. I would have a different perspective on probability figures since, as a genetic counselor, I would be biased by my exposure to situations and events considered "rare" or "unlikely." On the other hand, I explained, I have seen amniocentesis and fetal blood sampling performed many times more than the average patient would and have complete confidence in the obstetrician. Since my pregnancy would be a period of very high stress due to my social situation, I would not want the added stress of an uncertain diagnosis. I would want all doubt about the results removed as soon as possible.

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develop their understanding of the ethical obligations of the profession.

A professional code of ethics may cover specific duties or rights that differ from usual ethical requirements or may reflect the application of general ethical principles as they apply to specific professional activities. Often codes include statements that describe the overall aims or goals of the group. [1]

As a vehicle for professional identity, a code of ethics demonstrates to society that a professional group accepts some responsibility for...

- defining proper professional conduct
- sensitizing its members to important ethical issues and
- affirming professional accountability.

Traditionally, professional groups need to assure that their ethical principles and rules of conduct serve society's interest as well as the interests of the profession. [2]

Easy Answers Not Found

There are some limitations to professional codes of ethics and some problems are created by them. In developing a code, a professional group aims for universal representation and for consensus, a goal that may be difficult to achieve. Some issues and situations cannot be adequately covered by a code. Possible conflicts could arise between two codes, between personal values and code requirements or between the professional code and an institutional code. Finally, in developing a code, the issue of implementation and enforceability must be considered.

Diverse Codes Studied

To become more familiar with the organization and content of professional codes of ethics, the committee reviewed those of 12 professional organizations: American Association for Counseling and Development, American Dental Hygienist Association, American Nurses Association, American Psychological Association, American Speech-Language-Hearing Association, Association of Death Educators and Counselors, Health Educators, National Association of Social Worker, National Federation of Clinical Social Workers, North Carolina Society for Clinical Social Work, Physician Assistant Profession, and Current Opinions of the Judicial Council of the American Medical Association.

These were chosen because they represent human service professions with activities similar to or related to those of genetic counseling. The 12 codes reviewed represent a broad range of style and content. Some are very brief, with less than ten principles listed on a single sheet, while others are quite extensive, providing guidelines for very specific situations.

Common Qualities Noted

All of these codes provide guidelines covering four general areas:

- the practitioner
- the client or others affected by or affecting the client
- professional colleagues
- society. [3]

The primary ethical principle regarding the **practitioner** in all these codes is *competence*. In addition, most of the codes reviewed contained statements about quality of care, acceptability, integrity, impartiality in regard to whom they will serve, dignity, self-evaluation, continuing education and awareness of potential conflicts of interests.

Regarding the professional's relationship with **clients,** the codes emphasized the principles of *confidentiality, respect for client autonomy, informed consent* and *honesty* regarding the limits of the professionals' knowledge and the availability of other options and resources. The codes urged professionals to make appropriate referrals when necessary and required that the professional always act in the client's best interest.

Ethical guidelines for dealing with professional **colleagues** generally include principles that relate to *fairness* and *professional orientation.* The professional is encouraged to give and receive knowledge and to cooperate with colleagues. Specific responsibilities toward students are included in some codes and others provide guidelines for professional etiquette regarding research and publication.

Most of the codes contain statements concerning the professional's responsibilities towards **society** and require that the professional work to *advance the well-being and interests of society.* The professional is expected to exercise care in the use of his or her professional status and must be sensitive to social problems. Many codes recognize a professional responsibility to educate the public about the profession.

Recommendations

Mindful of both the utility and limitations of codes, this committee recommends to the Board that a professional code of ethics be developed for the NSGC. The construction process should include input from the membership and consultation with professionals in bioethics. Consideration should also be given to a mechanism for implementation of such a code and further studies of the strategies used by other professional organizations to implement a code of ethics should be undertaken.

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1 Mabe, AR and Rollin, SA. The role of a code of ethical standards in counseling. *Journal of Counseling and Development,* 64:294-297, 1986.

2 Chalk, R, Frankel, M and Chater, S. A.A.A.S. *Professional Ethics Project: Professional Ethics Activities in the Scientific and Engineering Societies.* December, 1980.

3 Levy, CS. On the development of a code of ethics. *Social Work* 19 (2): 207-216, 1974

4 Reiser, SJ. Codes of medical ethics. *Health Matrix* 11 (2) : 43-48, 1984.

5 Knight, JA. The essence of ethical codes and oaths. *Journal of Clinical Psychiatry* 42 (6): 222- 223, 1981.

The ad hoc committee on Codes of Ethics and Ethical Principles was appointed in 1986 by President Deborah Eunpu., M.S. Judith Benkendorf, M.S. chaired this committee from August 1986-October 1988. Since then it has been chaired by Nancy Callanan, M.S. The members of the committee are Rose Grobstein, M.S., Seymour Kessler, Ph.D. and Susan Schmerler, M.S. Their charge was to research the organization and content of professional codes of ethics.

For more information about the development of a Code of Ethics for the NSGC, or to provide input, please contact Judith Benkendorf, Georgetown University Hospital, Dept. OB/GYN, 3800 Reservoir Road NW, Washington, DC, 20007-2197; 202-687-8810 or Nancy Callanan, University of North Carolina at Chapel Hill, CB7250 / BSRC, Chapel Hill, NC 27599-7250; 919-966-4202.

Current Testing Limitations

Existing chromosome preparation and staining techniques can only be applied to relatively large numbers of rapidly dividing cells, thus necessitating one to four weeks of cell culture. This turn around time requirement poses particular concern to patients who are faced with considerable anxiety while awaiting test results or who may be approaching advanced gestational age and termination deadlines.

The high cost of chromosome analysis, which may prevent some couples from receiving services, is also the result of current cell culture and analytical procedures which do not lend themselves to full automation. Furthermore, they require highly skilled technologists who are in great demand, exemplified by recent employment data revealing that approximately eight positions are available for every cytogenetic technologist in the United States.[1]

Technical Breakthrough

A less labor intensive, less costly and more rapid procedure has been examined by a number of groups.[2-5] This method, termed *interphase cytogenetics*, is notably distinct from existing techniques in that analysis is performed on non-mitotic, interphase chromosomes. This technical capability means that it may be utilized as a rapid method for screening for certain cytogenetic abnormalities in uncultured amniocytes, chorionic villi, lymphocytes or other tissues.

A 24-48 hour aneuploidy screening device could provide patients with expedient results regarding chromosomes 13, 18, 21, X, and Y in the near future.

Interphase cytogenetics requires the creation of DNA probe sets which are specific for target chromosomes. Each probe set is fluorescently labeled and is hybridized *in situ* to slide preparations of interphase nuclei. The number of target chromosomes can then be simply counted to detect any numerical abnormalities of that particular chromosome.

To date, the generation of DNA probe sets specific for chromosomes 13, 18, 21, X, and Y are in the advanced stages of development. Interphase cytogenetics using the probe set for chromosome 21, for example, detects two fluorescent spots in cells from a normal individual, and three spots in Trisomy 21. The assay is chromosome-specific in that one probe set does not detect the presence of any other chromosomes; this is both a strength and a weakness in that the results are easy to read but do not detect non-numerical abnormalities, such as deletions or translocations.

...the integration of [non-invasive fetal sampling and interphase cytogenetics] could feasibly provide prenatal testing options to pregnant women regardless of age.

Near and Future Implications

One distinct feature of interphase cytogenetics is that analysis may be performed on a relatively small number of uncultured cells, an optimal situation for automation. In addition to current cytogenetic procedures, a 24-48 hour aneuploidy screen could therefore be offered to prenatal patients. This could provide some couples (for example, those primarily at risk for fetal aneuploidies due to advanced maternal age or family history of numerical chromosome aberrations) with rapid information that might minimize considerably the anxiety of awaiting test results. The combination of automation and chromosome counting simplification with interphase cytogenetics will require less subjective interpretation than traditional cytogenetic methods. Thus, the decreased cost of the procedure may provide more couples an opportunity to utilize prenatal diagnosis.

The concept of a rapid aneuploidy screen may become more of a reality as scientists begin to hurdle some of the existing obstacles of interphase cytogenetics. A 24-48 hour aneuploidy screening device could provide patients with expedient results regarding chromosomes 13, 18, 21, X, and Y in the near future. This method would detect greater than 90% of all medically significant, live-born chromosome anomalies.[6] However, until probe sets for entire chromosomes become available, structural and less common numerical abnormalities will not be detected consistently. Some researchers believe that probe sets which represent the entire genome will ultimately be developed, permitting the performance of a full *in situ* karyotype. Until that time, rapid and relatively inexpensive interphase screening methods could be offered only as an adjunct to traditional cytogenetic procedures.

Finally, interphase screening would play its ultimate role in prenatal monitoring if a non-invasive method of fetal sampling is developed. Because interphase cytogenetics requires a relatively small number of uncultured cells and a non-invasive sampling method obviates fetal risk, the integration of these two technologies could feasibly provide prenatal testing options to pregnant women regardless of age. These capabilities represent longer term research goals.

The eventual impact on genetic counseling may be astounding as the indications for prenatal testing, the procedures themselves and reporting methods could dramatically change. For the short-term, counselors need to keep themselves informed of the progress in this area as well as to prepare for providing educational support to patients as this and other technologies are introduced. Clearly, interphase methods will not initially supplant classical cytogenetics; however, rapid aneuploid screening procedures may have a prominent diagnostic utility in the near future.

1 Gasparini RP. Human resource data: national salary statistics for cytogenetics laboratories throughout the United States. *Karyogram J Cyto Tech.* 1988;14(6):102-111.

2 Rigas B, Welcher AA, Ward DC, Weissman SM. Rapid plasmid library screening using RecA-coated biotinylated probes. *Proc Natl Acad Sci USA.* 1986;83(24):1951-5.

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4 Julin C, Bazin A, Guyot B, Forestier F, Daffos F. Rapid prenatal diagnosis of Down syndrome with in situ hybridization of fluorescent DNA probes. *Lancet.* 1986; 8511(2):863-64.

5. Lichter P, Cremer T, Tang CJ et al. Rapid detection of human chromosome 21 aberrations by in situ hybridization. *Proc Natl Acad Sci USA.* 1988;85(24):9664-8.

6. Levitan M. *Textbook of Human Genetics,* 3rd ed. Chapter 3. (1988) Oxford Univ Press.

Book Bag

Co-Dependence: Misunderstood-Mistreated

Author: Anne Wilson Schaef

Publisher: Perennial Library, Harper Row, San Francisco, 1986, 105 pp.

Price: $7.95 paper

Reviewed by: June Peters, M.S., Tod Children's Hospital, Youngstown, OH

Co-dependence is a relatively new term in the field of chemical dependency treatment. Originally, the co-dependent was narrowly defined as the spouse of an alcoholic. Schaef (and others) have expanded the definition. In her book, Schaef speaks directly to counselors about our naive duplicity in perpetuating this syndrome. She cites the claim that 80% of all helping professionals are unaware of the addictive process and are not dealing with it in themselves. Her contention is that if we are not part of the solution, then we are part of the problem.

Schaef's model of co-dependence is described as a specific disease within the more generic addictive process. She identifies common phenomena within the heterogeneous fields of chemical dependency, mental health, the women's movement and family therapy and challenges us to look beyond our own narrow focus of care. Thus, an aware counselor taking a teratogen intake from a woman who has taken some laxatives might be alert to signs of alcohol or drug abuse, mental health problems such as bulimia or hints of a dysfunctional marital relationship. Despite time constraints, we may hear more of the real concerns behind the questions if we are actively listening for them in the way Schaef describes.

The heart of this book rests in Chapter 4 in which Schaef details the characteristics of co-dependence. She tells us that co-dependents are known for their caretaking activities, such as keeping the house or the department running, making themselves indispensable or being martyrs. They are typically workaholics at home and/or work. As a result, co-dependents often develop stress-related diseases such as headaches, backaches, ulcers and angina. Co-dependents also crave control to the point of addiction. They believe that nothing should get the best of them, no matter how sad, upsetting or chaotic. When they fail to have control of a situation, such as the risk of genetic disorder, they regard it as a personal failure. Co-dependents may deal with highly emotional issues on a regular basis, but they are not skilled at identifying and expressing their own feelings. Schaef observes, "Co-dependents often feel that part of their role in life is to find and explain answers for others. Interpretation is the practice of the disease of co-dependence."

The co-dependent is caught in no-win situations of attempting to control the uncontrollable; of wanting to "make everyone happy" while ignoring their own needs; of taking on others' problems, sadness and worries. This creates a lack of real intimacy in their own personal relationships. The end result of these dilemmas is physical, emotional and spiritual burnout.

Schaef concludes with treatment considerations and implications for becoming healthy and fully functioning persons and professionals.

A better understanding of co-dependency may help us, as counseling professionals, become more effective interviewers and support givers with families at risk for birth defects or experiencing genetic disease. For our families, it may sensitize them to the addictive processes which may be affecting their coping skills.

Reading *Co-Dependence* sensitized me to signs of the addictive processes in myself and my work. This book has the potential to awaken healthy conflict within ourselves and our community.

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Send case reports, resources, materials and books for review to appropriate editors; address changes, subscription inquiries and advertisements to Executive Director; all manuscripts and correspondence to Editor.

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Letter to the Editor

Airing Our (Professional) Linen: Risks Worth Taking

To The Editor:

A discussion at our regional conference of cases featuring ambiguous prenatal test results causes me to be concerned about genetic counselors' judgment in prenatal settings. This is especially troublesome where there is little or no supervision by medical geneticists, a commonplace situation for many counselors.

The responsibility of evaluating the variety of available prenatal tests — risks and benefits, rapidly changing indications, timing — and the level of understanding and concern of the patients can be overwhelming; good and timely communication among team members (geneticists, obstetricians, cytogeneticists, AFP lab directors, DNA lab directors, ultrasonographers) is imperative. With the advent of DNA technology and increased resolution of cytogenetics techniques and ultrasonography, we are more frequently faced with ambiguous results. Pitfalls include overly aggressive and perhaps inappropriate application of risky procedures, and harmful delays in application of already available technologies.

Just as "medical ethics committees" are appointed to quickly assemble and review issues concerning fetal viability after 24 weeks or medical care of a terminally ill individual, perhaps a similar committee composed of the above named team members should be formed (by genetic counselors?) to quickly assemble and discuss all aspects of a problematic prenatal case, insuring that all available resources are brought to bear on the problem.

I admire and support counselors who present their difficult cases to us. Oversights in medical judgment may be crystal clear to the audience, and the "counseling issues" may emerge as non-issues. But only through peer review may we gain the knowledge and perspective which enhances our contribution to the process of prenatal evaluation, less as technicians and more as professionals.

Name withheld by request

A Look Ahead... from p. 1

hire less qualified health professionals. This trend could undermine established standards for genetic counselors and patient care. Most training programs graduate less than ten genetic counselors per year, primarily because of the cost of the tuition, limited clinical training sites and lack of subsidized support for programs.

One solution is the funding of scholarships and support for training programs by potential employers in exchange for a guaranteed period of employment. Another option is funding by granting agencies. The NSGC should monitor this situation and take a leadership role in maintaining a balance between supply and demand.

During the next ten years our profession will approach the crossroad encountered in the social work and nursing professions when institutional staff size made self-supervision and administration realistic goals. This can be accomplished on the intradepartmental level or by autonomous departments of genetic counseling providing services by assignment to various medical departments. The NSGC should create a study group to learn from the models of other allied health professions.

And lastly, over the next ten years I would like to see the NSGC encourage the membership to have confidence and pride in their unique skills and body of knowledge, contribute to the delivery of medical genetic services and respected collaboration with medical and clinical geneticists. The NSGC could play an important role in promoting the philosophy of individual and collective strength derived from professional advancement and recognition. Programs at NSGC meetings should focus on the art of genetic counseling, including technique, policy, philosophy and education. Educational meetings on the national and regional levels should always include structured opportunities for small group discussions to provide the opportunity to share information, experiences and support. Genetic counselors should write about their work and body of knowledge to establish their expertise.

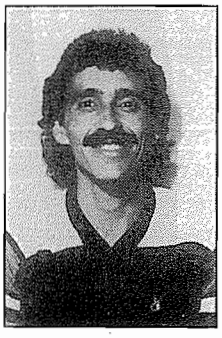
Over the years I have continued to be impressed with the outstanding quality of individuals attracted to the genetic counseling profession. The Society must take a leadership role to ensure that these brilliant and effective health professionals can realize their potential and experience career satisfaction within the profession.

Audrey Heimler, founding member and first president of the NSGC, currently is employed at Long Island Jewish Medical Center in New York.

THE TECHNOLOGICAL ADVANCES of the past few years have made a considerable impact on the clinical genetic services available to families. This will only increase as the genes involved in rare and common disorders alike are identified. As we look to the next ten years, I believe we must carefully consider what manpower and technical skills will be needed by genetic counselors to meet the service needs in this country. Our challenge will be to assure that there are enough appropriately trained professionals with the clinical and technical knowledge to move into new employment settings, provide services to families and educate the public.

Joan A. Scott has been the coordinator of the genetic counseling training program at the University of Colorado since 1984. She co-coordinated a recent conference of counseling program directors and related professionals, a meeting focused on future trends in training genetic counselors.

DESPITE OUR MIXED FEELINGS ABOUT IT, AFP is probably the best thing to happen to the profession since amniocentesis. More jobs, more responsibility, more pay, more patient variety, fewer genetic counselors going to medical school... and maybe this is just the tip of the iceberg. I predict that HCG/estriol/AFP screening will dramatically alter traditional referral patterns and will leave most obstetricians in the dust. Prenatal diagnosis counseling will become even more specialized and the connections to clinical genetic counseling will become more tenuous. All-purpose genetic counselors might become obselete.



Male genetic counselors? My crystal ball doesn't see a big increase in our numbers— maybe genetic counseling shouldn't have been written up in *Working Woman* magazine.

And, at least in the near future, we'll all be holding our breath every Supreme Court session.

Robert Resta, Swedish Hospital, Seattle, is a 10-year veteran of genetics and genetic counseling but insists that he still retains his initial charm, humor and sophistication.

THE POTENTIAL FOR CAREER DEVELOPMENT, as described in 1987 by an *ad hoc* committee of the NSGC, will continue in the areas of patient care, administration, research and education. In the general genetics clinic, new presymptomatic and carrier testing for single gene disorders will increase genetic counselor involvement with extended family members and at-risk individuals uncertain of whether they wish to know their status. On the prenatal front, explanations of the risk, timing and accuracy of alternative testing options will require added counselor energy and manpower. More specifically, new employment opportunities will be available in DNA laboratories and counselor training programs; genetic counseling will be sought increasingly for psychiatric disease; mass carrier screening for cystic fibrosis may become a reality; and greater political activity will be needed to support the option of pregnancy termination for genetic indications.

Virginia Corson has worked in Pediatric Genetics and the Prenatal Diagnostic Center at Johns Hopkins Hospital for 14 years. She was NSGC president in 1982/83 and chaired the NSGC ad hoc Committee on the Expanded Roles of Genetic Counselors.

Conference Notes

It's still not too late to register for the Annual Education Conference, to be held in Baltimore, Novmeber 9 - 11.

If your registration has fallen to the bottom of your "To Do" box, why not use the alternate form, printed on p. 11.

Some information that was inadvertently left off of the original brochure: for those of you who would like to bring a dinner guest to our Ten Year Celebration on Friday, November 10, the ticket price is $40. Reserving and paying for your guest in advance will enable us to plan appropriately. A limited number of tickets will be available at the registration table at the conference.

Finally, committee meetings will be held from 3:00 - 5:00pm on Thursday, November 9. Check the bulletin board at the registration area for the meeting locations.

On behalf of my co-chair, Beth Fine, and our supurb sub-committee chairs, we look forward to seeing you there.

Betsy Gettig
Co-Chair, Educational Conference

Child Health Theme Announced

The Office of Maternal and Child Health has reported that the theme for this year's Child Health Day is "Universal Access to Prenatal Care." The day-long symposium, which has been scheduled for Monday, October 2 in Washington, DC, will include topics related to financial and non-financial barriers to care, provider shortanges and delivery and quality of services.

— from newsletter of Health Mothers, Health Babies, 7/89

Alliance Workshop Set for Spring

The Alliance of Genetic Support Groups will hold its National Workshop on Peer Support Training Programs for Individuals and Families Affected by Genetic Disorders on March 30 - April 1, 1990 at the Georgetown University Conference Center and Guest House.

For information or to refer families, contact the Alliance, 1-800-336-GENE.

Joan Weiss
Coordinator, Alliance

Prof Resource Editor Needed

Joan FitzGerald has resigned from her position as Professional Resources Editor of *Perspectives*. This Editor is expected to solicit or identify books, videotapes, courses, software and other resources helpful to professional advancement as well as oversee written reviews of these resources. Anyone interested in serving the remaining two years of this term should write to me by October 20.

Ed Kloza

Response to GC Surveys Urged

Deborah Pencarinha, Nora Bell, Ph.D., and Janice Edwards, M.S., of the University of South Carolina Genetic Counseling Program are conducting a survey of MS genetic counselors similar to the survey published by Wertz and Fletcher in 1988. Addressing major ethical issues currently confronting our profession, this survey's results will be compared to those of the Wertz/Fletcher survey, which *excluded* MS counselors. All survey forms should be returned to USC before Friday, October 20.

BOOK

Choices, Not Chances An Essential Guide to Your Heredity and Health

Author: Aubrey Milunsky, M.D.

Publisher: Little, Brown and Company, Boston, Toronto and London. 1989, 488p.

Price: $22.50

Reviewed by: Leah Hoechstetter, M.S., Cincinnati Regional Genetic Center

Aubrey Milunsky's new book, *Choices, Not Chances,* is a fully updated, revised and expanded edition of his 1977 publication: *Know Your Genes.* This ambitious volume, written for the edification of interested consumers, tackles nearly every topic ordinarily addressed by standard medical genetics texts. Milunsky's style is quite readable and interspersed with the mandatory discussion of chromosomes and modes of inheritance is a treasure trove of "Fun Facts" in genetics. I found myself repeatedly interrupting my colleagues or my spouse to share some interesting tidbit of information. Unfortunately, though, since references are generally not provided, significant detective work would be required to identify sources.

Milunsky emphasizes a preconceptual approach, stressing the ideal of open, honest communication within families, knowledge of applicable screening options and cognizance of environmental risk factors once a pregnancy commences.

He includes a thorough discussion of prenatal diagnosis techniques (with the surprising omission of PUBS as an alternative to fetoscopy). It's interesting to consider that at the time of the original edition (1977), the MSAFP test was in its investigational stages and of unproven utility for screening NTDs. What a long, and unexpectedly complicated path we've since traveled.

There is a good section which addresses current knowledge about the genetic contribution to many common illnesses, including: cardiovascular disease, diabetes, cancer, mental illness and the biology of aging. Genetic counselors obtain information about the occurrence of these conditions from virtually every family seen; the chapters provide a concise summary and many useful tables. (For example, Empiric Risks for the development of diabetes in children of diabetics vs. nondiabetics, stratified by age of offspring.)

The author generally writes in a compassionate and understanding manner, but two distinct voices were apparent to my ears. In the chapter, "Genetic Counseling," Milunsky makes a good case for the practice of nondirective counseling, stating that a directive philosophy is a moral affront to individual privacy. There are innumerable examples throughout the text which imply otherwise; a few follow. "Morally, ...no person ...can ignore the new genetic discoveries and techniques for preventing genetic disease." "Society has a stake in your actions and how you perceive your responsibilities." "It is simply not possible for parents in this situation (having a child with a significant birth defect) to have sufficient energy and time to attend to their normal children...As a consequence of this neglect... emotional, behavioral and psychological problems develop in the normal siblings." I cringe upon reading statements like these and am truly sorry to see them in an otherwise fine text.

In Milunsky's view, genetic counseling should generally be provided by a clinical geneticist affiliated with a large, university medical center. A woman's discussion with her obstetrician is deemed sufficient prior to amniocentesis performed for older maternal age. He acknowledges the existence of master's prepared genetic counselors and states that they have an important role in a team with a physician geneticist, but there is no indication of what this role might be.

In summary, I feel this is a useful book for anyone interested in human/medical genetics. I would need to discuss and qualify some of the statements Milunsky makes as not necessarily reflective of the ideas and practices of other genetics professionals before recommending this book to a client or other interested consumer.

ORGANIZATION

The National Fragile X Foundation is taking a new direction with the group's recent decision to organize nationally through affiliations instead of chapters. Amy Cronister, the genetic counselor on the Foundation's Board of Directors and on staff at Denver's Fragile X Project, would like to hear from Fragile X groups interested in becoming an affiliate.

For further information contact: National Fragile X Foundation, P.O. Box 300233, Denver, Colorado 80203; 1-800-835-2246.

Case Report

from p. 3

Following my explanation, C.K. was quite relieved and excited. She understood the difference between our situations and the bases for our decisions. She finally realized that she was in a better position than I to make a decision for her. The right answer was the one that she and her husband would make. Without further hesitation, she said she would relax and enjoy her pregnancy, and wait until after delivery for testing.

In retrospect, I wondered how I could have handled this case differently to help C.K. reach her conclusion earlier. Clearly, I would answer the "What would you do?" question at a much earlier point. Patients frequently endow their counselor (or physician) with much more knowledge and wisdom than is warranted. While they understand they must make their own decisions, the professional opinion can carry significant weight. We know there is not a right decision for every couple, but some families may believe we can discern the right decision for them. By making sure that patients understand the personal reasons for our opinions we can demystify our "wisdom"; it allows them to see us as ordinary individuals who have no magic insights. This can release them from the pressure of trying to find the "right" decision.

Individuals who provide genetic counseling are frequently faced with this question from patients in a decision making crisis. Answering this question is usually not seen as appropriate when providing non-directive counseling. This is repeatedly discussed with genetic counseling students during their training. I would not have considered this approach when I first started in the field; however part of what we do is to teach patients how to make a decision, and I feel that this can be a helpful and appropriate technique. There is a fine line between discussing and persuading, so the counselor must be alert to personal biases and use caution. It may take time before a counselor is comfortable enough with personal feelings to share them with a patient. Since this case, I have utilized this approach with other patients and have found it can enable them to reach their own decision quickly.

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

PHOENIX, AZ: Immediate openings for 2 BC/BE Genetic Associates. Salary range: $30 - 35,000, negotiable with experience.
RESPONSIBILITIES: Wide range of genetic counseling opportunities: general and reproductive genetics, amnio, CVS, teratology, MSAFP screening, high-resolution ultrasound.
CONTACT: Daniel L. Harris, Administrator, United Genetics (includes the Genetics Center of Southwest Biomedical Research Institute and the Phoenix Perinatal Association), 1300 N. 12th Street, #316, Phoenix, AZ 85006; 602-258-7582. EOE/AA.

LONG BEACH, CA: Immediate opening for BC/BE Genetic Counselor with masters in human genetics or related field.
RESPONSIBILITIES: Prenatal, preamnio and general genetic counseling. Participate in State MSAFP screening and follow-up program.
CONTACT: Constance Sandlin, MD, Memorial Genetics Center, 2801 Atlantic Avenue, PO Box 1428, Long Beach, CA 90801; 213-595-2311. EOE/AA.

ORANGE, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team in children's hospital with private lab. Counsel in general genetics, hyperlipidemia and metabolic clinics; prenatal diagnosis (CVS & amnio); MSAFP abnormal results counseling; teratology; 20% outreach education.
CONTACT: Touran Zadeh, M.D., Director, Genetics Center, 1000 W La Veta, Orange, CA 92668; 714-667-0878. EOE/AA.

PANORAMA CITY, CA: Immediate openings for 3 BC/BE Genetic Counselors.
RESPONSIBILITIES: Join large team in expanding program, including amnio, CVS, high-level ultrasound; cytogenetics; teratogen counseling; MSAFP; newborn hemoglobinopathy screening; DNA-based diagnosis; dysmorphology; and craniofacial service.
CONTACT: Harold N. Bass, MD, Regional Coordinator, Genetic Services, Kaiser Permanente Medical Center, 13652 Cantara Street, Panorama City, CA 91402-5497; 814-908-2582. EOE/AA.

SAN FRANCISCO, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Full range of counseling in reproductive genetics, including: amnio, CVS, MSAFP, and fetal treatment program.
CONTACT: Kathy Drexler, MS, University of California, San Francisco, Room U-100A, San Francisco, CA 94143-0706; 415-476-4080. EOE/AA.

SAN FRANCISCO, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Comprehensive care for 25% of Northern California residents, including prenatal diagnosis and counseling, AFP screening, teratogen counseling, heterozygote screening, clinical genetics, dysmorphology, newborn screening and metabolic genetics.
CONTACT: Bruce Blumberg, M.D., Kaiser-Permanente Medical Group, 2200 O'Farrell Street, San Francisco, CA 94115; 415-929-5059. EOE/AA.

FARMINGTON, CT: Immediate opening for BC/BE Coordinator, Outreach Genetics Program with potential faculty appointment.
RESPONSIBILITIES: Coordinate 3 sites with monthly general genetics clinics, (pediatrics, adult, prenatal); develop and conduct lay and professional education in Public Health Genetics Program.
CONTACT: Robert M. Greenstein, MD, University Connecticut Health Center, Division of Human Genetics, The Exchange, Farmington, CT 06032; 203-674-1465. EOE/AA.

DOVER, DE: Immediate openings for 2 BC/BE Genetic Counselors (1 in Northern DE including Wilmington; 1 in Southern DE)
RESPONSIBILITIES: Conduct prenatal diagnosis counseling, including CVS; coordinate public health pediatric and genetics services; MSAFP screening; some community education.
CONTACT: Marihelen Barrett, Director Maternal Child Health, Delaware Division of Public Health, P.O. Box 637, Dover, DE 19903; 302-736-4785. EOE/AA.

BOYNTON BEACH, FL: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team in 350-bed community hospital setting, including: prenatal diagnosis, amnio, CVS; some pediatrics. Professional education opportunities available.
CONTACT: Lisa D'Augelli, MS, Bethesda Memorial Hospital, 2800 S. Seacrest Blvd / Suite 104A, Boynton Beach, FL 33435; 407-738-0448. EOE/AA.

INDIANAPOLIS, IN: Immediate opening for BC/BE Genetic Counselor with minimum of 2 years experience.
RESPONSIBILITIES: Prenatal counseling for CVS, amnio, PUBS; teratogen counseling; MSAFP screening; assist with ultrasound abnormalities.
CONTACT: James E. Sumners, M.D., Center for Prenatal Diagnosis, 1633 N. Capitol Ave #468, Indianapolis, IN 46202; 317-929-5475.

LEXINGTON, MA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIESS: Clinical position includes patient counseling and case management for amnio, MSAFP and general genetic counseling cases.
CONTACT: Barbara Thayer, MS, Prenatal Diagnostic Center, 80 Hayden Avenue, Lexington, MA 02173; 617-862-1171. EOE/AA.

DETROIT, MI: Immediate openings for 2 BC/BE Genetic Counselors.
RESPONSIBILITIES: Prenatal and pediatric counseling in field clinics; MSAFP; newborn screening.
CONTACT: Lester Weiss, M.D., Director, Medical Genetics and Birth Defects Center, Henry Ford Hospital, 2799 W. Grand Blvd CFP-4, Detroit, MI 48202; 313-876-3116. EOE/AA.

COLUMBIA, MO: Immediate opening for BC/BE Genetic Counselor. Experience not required.
RESPONSIBILITIESS: Join established genetics team to participate in general genetics counseling, outreach, prenatal diagnosis and metabolic clinics
CONTACT: Judith H. Miles, M.D., Ph.D., University of Missouri at Columbi Hospital Clinics, 1 Hospital Drive, Columbia, MO 65212. EOE/AA.

ST. LOUIS, MO: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIESS: Independent professional for amnio, CVS, PUBS, MSAFP screening, reproductive loss, teratology.
CONTACT: James P. Crane, M.D., Jewish Hospital of Washington University Medical Center, 216 S. Kingshighway, Dept. of OB/GYN, St. Louis, MO 63110; 314-454-7835. EOE/AA.

ST. LOUIS, MO: Immediate opening for BC/BE Genetic Associate in newly-funded position.
RESPONSIBILITIES: Rapidly-growing, academic center with wide range of clinical and laboratory services: clinical genetics; dysmorphology; inborn errors of metabolism; active cytogenetic, metabolic and molecular diagnosis laboratories. No prenatal diagnosis.
CONTACT: S. Bruce Dowton, M.D., Washington Univeristy School of Medicine, Division of Medical Genetics, Department of Pediatrics, 400 S. Kingshighway, St. Louis, MO, 63110; 314-454-6093. EOE/AA.

CAMDEN, NJ: Two immediate openings in newly state-funded Regional Birth Defect Program. 1) Program Coordinator must

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have BC with minimum 2 years experience, salary $34,500; 2) Genetic Counselor requires BC or BE, salary $28,560.
RESPONSIBILITIES: Program Coordinator: Coordinate, administer and manage program; Genetic Counselor: Provide multidisciplinary care in pediatric-oriented service (some adults) with multiple disabilities.
CONTACT: Cheryl Reid, M.D., Cooper Hospital, Division of Genetics, Camden, NJ 08103; 609-342-2157. EOE/AA.

NEW BRUNSWICK, NJ: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active prenatal diagnosis team, including: amnio, MSAFP; teratology; professional and community education.
CONTACT: Tressie Dalaya, MS, University of Medicine & Dentistry of New Jersey/ RWJMS, Professional Center, 97 Paterson Street, New Brunswick, NJ 08903; 201-418-8153. EOE/AA.

SANTA FE, NM: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate single-gene diagnosis; communicate test results to physicians; prepare educational materials.
CONTACT: Kirk Aleck, M.D. or Stirling Puck, M.D., Vivigen Laboratory, 2000 Vivigen Way, Santa Fe, NM 87505; 1-800-VIVIGEN.

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Opportunity to work independently in large prenatal diagnosis service; outreach to community hospitals.
CONTACT: Eva Kahn, MS, Prenatal Diagnosis Laboratory of NYC, 455 First Avenue, New York, NY 10016; 212-578-4712. EOE/AA.

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Large busy service, including: amnio, CVS, pediatrics, neonatology; opportunity for involvement in specialty clinics.
CONTACT: Jessica Davis, M.D. or Fred Gilbert, M.D., Co-Directors, Division of Human Genetics, The New York Hospital, Department of Pediatrics, 525 E. 68th Street, Room HT150, New York NY 10021. EOE/AA.

TOLEDO, OH: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Wide range of cases on active prenatal diagnosis service; involvement in clinical research; education and scientific presentations and reports.
CONTACT: Bea French, RN, MSN or T.W. Kurczynski, MD, PhD, Medical College of Ohio, Genetics/Pediatrics, P.O. Box 10008, Toledo, OH 43699-0008; 419-381-4435. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Prenatal and general counseling for amnio, CVS, MSAFP.
CONTACT: Michael Mennuti, M.D., Hospital of University of Pennsylvania, Dept. OB/GYN, 3400 Spruce Street, Philadelphia, PA 19104; 215-662-3232. EOE/AA.

PITTSBURGH, PA: Immediate opening for BC/BE Genetic Associate with minimum 6 - 12 months experience.
RESPONSIBILITIES: Comprehensive genetic service at large, academic hospital setting affiliated with University Health Center. Cleft palate center and satellite clinics; update birth defects information system; professional education.
CONTACT: Diana Long, Employment Manager, Magee Womens Hospital, Forbes and Halket Streets, Pittsburgh, PA 15213; 412-647-4290. EOE/AA.

DENTON, TX: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: General neonatal, pediatrics, hi-risk OB, infertility and adult patients in private tertiary care hospital.
CONTACT: Monica Kozak, Personnel, Genetic Screening and Counseling Service, PO Box 2467, Denton, TX 76202-2467; 817-383-3561. EOE/AA.

HOUSTON, TX: Immediate opening for BC/BE Genetic Counselor. Experience preferred, but not required.
RESPONSIBILITIES: Join team in academic setting; counseling & follow-up for amnio, CVS, MSAFP, PUBS, DNA & biochemical testing, teratology, ultrasound anomalies, hi-risk pregnancy and family history concerns; individual and patient education classes; education and research opportunities available.
CONTACT: Karen L. Copeland, MS, Coordinator, Prenatal Genetic Center, Baylor College of Medicine, 6550 Fannin, Suite 921 Houston, TX 77030; 713-798-4691. EOE/AA.

REPRODUCTIVE GENETICS AND NEW TECHNOLOGIES
REGISTRATION FORM

Name _____ Degree _____ Daytime Phone _____
Address _____
City _____ State _____ Zip _____
Receipt Requested ❑ Yes ❑ No Special Dietary Restrictions (specify) _____
Concurrent Workshop Choices (to be used for spacer planning, only)
A. Understanding our Infertile Genetic Counseling Patients, C. Shapiro, PhD and L. Djurdjinovic, MS
B. Issues Raised in Gene Linkage Studies, D. deLeon, MS and A. Lunstenberger, MS
C. Countertransference and the Genetic Counselor, A. Heimler, MS
D. Gamete Donation: Ethical, Legal and Medical Cionsiderations, sponsored by Social Issues Committee
E. Perinatal Bereavement Counseling in Genetics, S. Ilse, J. Benkendorf, MS and J. Fonda-Allen, MS
Workshop Choices: Friday ❑ A ❑ B ❑ C ❑ D ❑ E Saturday ❑ A ❑ B ❑ C ❑ D ❑ E
Fees: (must be enclosed)
❑ $130 NSGC Members ❑ $40 Extra Dinner Ticket ❑ Extra Donation to Special Projects Fund _____
❑ $155 Non-members ❑ Late Fee: $20 (if postmarked after Saturday, September 30)
❑ $85 Students ❑ Walk-in Penalty: $30 (on-site registration or postmarked after Tuesday, October 30)

- Remember: deadline without penalty is Friday, September 29.
- Checks or money orders should be payable, in U.S. currency only, to NSGC. Send this form or a duplicate to: Bill Herbert, NSGC Treasurer, 319 Cheyenne Drive, San Dimas, CA 91773.
- Payments must be received prior to the conference. If your institution pays your registraion fee directly, and you anticipate a delay, please write a personal check and request reimbursement.
- All cancellations are subject to a $25 administrative fee. After Tuesday, October 30, no refunds will be granted.

Substance Use During Pregnancy

One of today's most pressing public health problems is substance abuse during pregnancy. The specific answers being proposed to this question have broad implications for genetic counselors.

One proposed alternative is mandatory reporting of substance abusing women and their infants and criminalization of mothers. Another focuses on prevention, education and substance abuse treatment.

The newly formed Coalition on Alcoholic and Drug Dependent Pregnant Women and their Infants feels that the health care system, not the judicial system, is the appropriate place to address the needs of pregnant women with alcohol and drug problems. Comprised of 40 member organizations, including the AMA, APHA, ACOG, AAP, NSGC, and lead by the National Council on Alcoholism, the coalition aims to increase the number of treatment options for women and their infants. Treatment programs are currently non-existent in many states.

The coalition opposes S.1444, the Child Abuse During Pregnancy Act of 1989 introduced by Sen. Pete Wilson. Although this bill would allocate $10 million to treat drug addicted mothers, and it includes provisions for outreach, education and children, it also contains several objectionable provisions:

- health care providers must report cases to specified authorities,
- women who give birth to an addicted, impaired or injured infant as a result of prenatal substance exposure would face criminal charges which carry a mandatory sentence of three years in custodial rehabilitation, and
- testing would be mandatory on all newborns.

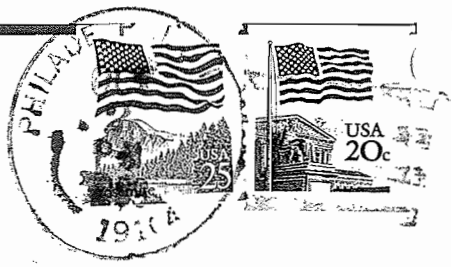
If S.1444 is passed, genetic counselors could be required to report drug and alcohol use during pregnancy or mothers of infants born with birth defects who used these substances. This may adversely affect the client relationship and keep women from seeking information regarding substance exposures during pregnancy, diagnostic services for their infants or genetic counseling services, in general, if lifestyle questions are part of the usual evaluation.

Please write to your Senator today (U.S. Senate, Wash., D.C. 20510) and express your concerns re: S. 1444.
Note: Similar bills are pending in six states (FL, NJ, MN, AZ, DE, and IL).

Pro-Choice Mobilization

The National Organization of Women is sponsoring a pro-choice rally on November 12, to be held at the Lincoln Memorial in Washington, D.C. If you will be attending the NSGC or ASHG meetings in Baltimore, this is an excellent opportunity to show your support for reproductive freedom. The rally will begin around noon on Sunday, the day between the NSGC and ASHG meetings. Public transportation by train from Baltimore to Union Station in D.C. is readily accessible. Details will be available at the NSGC meeting.

Trish Magyari
Legislative Issues



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10th Anniversary Year

Perspectives in Genetic Counseling

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