PERSPECTIVES

in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 10 No. 4 Winter 1988

Celebration slated in Baltimore

When professionals gather at the NSGC's Ninth Annual Education Conference in Baltimore next November, professional enrichment will be only part of the reason. Many will also attend to be part of a special celebration marking the Society's tenth anniversary.

Past Presidents and Founding Members Luba Djurdinovic and Deborah Eunpu have been appointed to plan a special commemoration marking the decade event.

"It's important for us to set aside time to reflect on our profession and on our achievements," said Debra Collins, President. "This commemoration will give us that opportunity," she added.

More information will follow in upcoming issues of *Perspectives*.

on the inside

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

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Social Issues

Membership Defined by Committee Survey Results

by Trish Magyari, M.S. and Robin Belsky Gold, M.S.

In November 1986, the Social Issues Committee polled the membership on a variety of personal and professional issues in conjunction with the 1986 Professional Status Survey. The purpose of the survey was to gather additional demographics (such as marital status, number of children and religion) as well as to ask questions related to our personal and professional views on reproductive options.

This survey asked new questions of our membership and the results give us some valuable baseline data regarding the NSGC membership in November 1986. There were 242 respondents. Reported percentages are based on the number responding to a specific item.

The results from Question 56 "Do you believe the NSGC, as an organization, should publicly support pro-choice activities?" were reported in the March 1987 *Perspectives* and led to the adoption of an NSGC pro-choice policy. Question 55 "Do you experience professional ethical dilemmas which you feel can be resolved?" was eliminated due to ambiguous wording. The remainder of the survey results (questions 45-54) are detailed here.

At that time, the majority of respondents were married (62.3%), while an equal

See Survey, 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 II 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.

In teratogen counseling, are we responsible for taking a complete exposure, pregnancy and family history or only for the teratogen mentioned?

P.R.: When a patient/client seeks counseling about a risk associated with a particular teratogen, the counselor is responsible for a thorough evaluation of the exposure to the particular teratogen. I do not think that the counselor's duty can be precisely determined and I do not advocate a broad duty to explore other issues. Nevertheless, exposure to one potential teratogen often suggests the possibility of exposure to several, especially workplace-related exposures. Thus, the counselor has a duty to ask general questions about other exposures, giving the client an opportunity to enlarge the field of concern. The answer will determine how the inquiry should proceed.

If the counselor notes some other obvious issue, such as advanced maternal age, the

See Counselor Liability, p. 6

Corner Thoughts

Over the past ten years, we have watched our profession become increasingly recognized as an integral part of health care to the point where even *Glamour* magazine listed it in its April edition as one of the top 20 careers for women in the 1990's. Our membership has been enhanced by the inclusion of individuals with backgrounds in social work, nursing, education and public health as well as those with formal training in genetic counseling. Although our work settings and responsibilities vary, we share the common goal of improving the lives of patients with genetic conditions and their families.

Diversity is one strength of our profession. Many creative ideas have come from members who have taken advantage of opportunities to expand their roles. Some members have been funded to direct studies. Others have developed new approaches to patient care, education or research incorporating new DNA technology. Many have ventured into new and challenging settings in private practice, industry or as directors of specialized genetic programs.

As we continue to test the limits of the profession, we have the responsibility to share ideas and information to benefit others who are exploring and broadening their experiences. The challenge to the NSGC is to keep abreast of all these creative activities. *Perspectives* and the annual education meeting are the principle forums for exchange of these ideas. The biannual professional status survey has also been a helpful vehicle for salary negotiation and elevation of job status.

This year, I challenge each of you to share your ideas and experiences with the NSGC by: • serving on a committee • writing an article for *Perspectives* • helping to plan a regional or national meeting and/or • submitting an abstract for a poster or platform presentation.

What you do is important and there are many opportunities for you to go beyond your perceived limitations. Don't be immobilized by fear of failure. To paraphrase the educator Henry Adams: "A genetic counselor's work affects eternity...You can never tell where your influence stops."

Debra L Collins

Debra Collins, M.S.
President

Open Report

Strategies and Risks of Early Amniocentesis

by Barbara Thayer, M.S., Prenatal Diagnostic Center, Lexington MA

Improvements in ultrasound and laboratory culture methods during the past few years have enabled us to attempt amniocentesis for cytogenetic testing at earlier gestational ages. Direct ultrasound monitoring of the needle insertion contributes to greater success in sampling smaller amniotic fluid volumes, and in situ culture methodology allows for analysis of these smaller volumes. We have performed approximately 100 early amniocenteses at 12-14 weeks gestation at the Prenatal Diagnostic Center. In addition, we process fluid samples obtained at early gestational ages by other physicians.

At this time, this procedure is particularly applicable for patients age or older at delivery, patients who have a child with a chromosome problem or who had a chromosomally abnormal fetus diagnosed in a previous pregnancy, or for patients who are carriers of a balanced chromosomal translocation. We have also performed the procedure on women between the ages of 35 and 40 who, after weighing the risks and benefits of amniocentesis at 12-14 weeks versus amniocentesis at 16, opt for the earlier procedure.

At the genetic counseling session which routinely precedes amniocentesis, the following information is discussed:

- THE ULTRASOUND EXAMINATION performed at 12-14 weeks in conjunction with the amniocentesis does not give as much information regarding fetal structures when compared to ultrasound at 16-18 weeks. For instance, visualization of fetal bladder, which is an indicator of fetal kidney function, is often not possible at 12 weeks gestation.
- WHEN COMPARED TO AMNIOCENTESIS at 16-18 weeks, which is over 99% successful at our center, early amniocentesis carries a slightly increased chance (approximately 3-4%) that an amniotic fluid sample will not be obtained. This failure rate includes patients who are not attempted because of uterine position or placental location as well as failed attempts.
- WE LIMIT THE AMOUNT OF AMNIOTIC

See Early Amnio, p. 7

EdNotes

As we prepare to finalize this year end issue of *PGC*, we can't help but reflect on this past year's accomplishments and take a look at the year ahead:

1988 saw the introduction of theme issues, a device which we will continue to use as a helpful way of organizing and presenting information. Next year's themes have been selected with reader's input. The spring issue will focus on "Adults with Genetic Disorders," and, to initiate thought regarding the annual education meeting, "Reproductive Technologies" will be featured in the summer issue. 1989 will mark the NSGC's first decade, and the fall issue will be devoted to the Tenth Anniversary. Tentatively scheduled for next winter is an issue directed at "Outreach."

The addition of Karen Copeland, Vickie Venne, Trish Magyari, Seth Marcus and Janice Stryker to the Editorial Board marks a much needed expansion of the PGC staff. This will allow us to expand the professional resources section to include reviews not only of books, but also of videos, software and other materials designed for professional use and to include an interview in each issue. The Board will be much more involved with selection and editing of articles than they have been in the past. *Letters to the Editor* will become, we hope, an increasingly utilized forum for responding to issues raised in *PGC*.

1988 also saw some of *PGC's* expenses underwritten by Integrated Genetics, and they have pledged to continue support through 1989.

The number of people who offered to review resources and articles for *PGC* is gratifying. We also had more than enough volunteers to review and index past volumes of *PGC*.

Finally, *PGC* had the difficult duty in 1988 to announce the untimely deaths of two colleagues, Jane Engleberg and Beverly Rollnick. Their example of involvement and professionalism should inspire us all. To that end, let us resolve for 1989 to accept Debra Collins' challenge [see *Corner Thoughts*] to share our energy and ideas through the many avenues (especially *PGC*) that are available.

Ed Kloza, M.S.
Editor

Book Bag

Antenatal and Neonatal Screening
Edited by: N.J. Wald
Publisher: Oxford University Press, 1984, 573pp
Price: $47.50
Reviewed by: Lynne S. Heckman, M.S., Dept. of OB/Gyn, Long Island College Hospital, Brooklyn, NY

This comprehensive text extends beyond the familiar review of screening for chromosome abnormalities, neural tube defects, metabolic and other genetic disorders to include a detailed technical summary of screening for respiratory distress syndrome, maternal infections, diabetes, hypertension and cervical cancer.

The section on procedures and tests covers the risks and benefits of not only ultrasound, amniocentesis, fetoscopy and fetal blood sampling, but also electronic fetal monitoring and placental function tests. For those working primarily in an obstetrical setting, useful information is presented for counseling in regard to genetic as well as associated obstetrical issues.

Most thorough is the chapter on open neural tube defects (ONTDs), covering every aspect of maternal serum and amniotic fluid AFP testing and ONTD diagnosis.

The chapter on amniocentesis includes an interesting summary and critical interpretation of the US NICHD, Canadian MRC and UK MRC studies.

The chapter on diabetes provides risk factors and recommendations for screening and treatment; however it does not discuss measuring glycosylated hemoglobin A levels to screen for glycemic control and risk of congenital anomalies.

The perspective of many of the British contributors is at times ethically and practically distinct from that which is generally accepted in the US. For example, the authors of the chapter on hematological disorders write that due to the variability of sickle cell disease "...antenatal screening for the purpose of making an antenatal diagnosis and offering elective abortion cannot be justified." (p.174) Also noted in several chapters is a risk associated with amniocentesis of 1% or greater.

Noticeable at first glance, *Antenatal and Neonatal Screening* neglects coverage of molecular genetic techniques, chorionic villus sampling, and maternal serum AFP as a screening test for trisomies in addition to ONTDs. Published in 1984, omission of these topics may be considered just one more consequence of the rapidly advancing field of medical genetics.

Case Report

Case Report No. 14

False Paternity and DNA Studies

by Seth Marcus, M.S.
Lutheran General Hospital Perinatal Center, Park Ridge, IL

In training, we are taught that we do not have the right to withhold information from a patient. The following case illustrates a situation in which withholding genetic information is brought into question.

A 27-year-old woman with cystic fibrosis wished to have DNA haplotyping performed on her husband in an effort to determine his likelihood of being a carrier. With her husband's consent, blood samples were drawn from him as well as his parents and a 20-year-old brother. To abbreviate the details, preliminary analysis of the DNA samples indicated the possibility of false paternity in the husband's brother.

Should I reveal this information?

There are several scenarios in genetics practice where withholding information from patients is debated, e.g. prenatal diagnosis of 47, XYY, determination of 46, XY chromosome complement in an adolescent female and sex following fetal chromosome analysis.

I was not aware of whether the brother's paternity status was questioned by anyone in the family. The family had not been informed prior to the testing that DNA analysis was capable of identifying false paternity. If I gave the brother the results, I might be violating his mother's right to keep that information confidential. There appeared to be no obvious benefit to the brother or family. In fact, revealing this information might possibly cause significant damage to the individual and to the family. Furthermore, the brother was not my patient and therefore I had no primary responsibility to him.

On the other hand, one must consider several arguments in favor of revealing the brother's non-paternity status: Everyone has a right to a knowledge of their genetic heritage. Withholding such information might be illegal or at least paternalistic. Doesn't the brother have the right to apprise himself of whatever genetic (or non-genetic) information is available about his biological father?

Withholding this information could establish a negative relationship with my patient. If I tell my patient that DNA analysis is uninformative and he asks why, what type of story would I need to concoct to conceal the truth of his brother's paternity? My role as a health care provider does not include being party to a family cover up.

It is also possible that providing this information to the brother may have a stabilizing effect on him, perhaps providing relief by confirming a suspicion that he may have had about his paternity. I also considered simply informing the mother of these findings, but the same arguments would apply.

Perhaps a consent form should be provided in advance of DNA testing forewarning the patients that false paternity might be detected by DNA analysis. But would such a consent form discourage use of DNA testing in certain families and thereby potentially do more harm than good?

While contemplating whether or not to inform the brother, I was notified by the DNA laboratory that more thorough testing did not raise any question of the brother's paternity, i.e. there was no doubt that the individual who submitted the DNA sample as the father was indeed the biological father.

The well-documented increase in DNA family studies and the not uncommon existence of false paternity suggest that genetic counselors involved with testing of this type will be faced with an increasing number of similar situations.

There have been questions raised in the medical community about whether medical technology is outpacing our ability to handle test results. Given that DNA technology is here and given its tremendous increase, in use we must address the issue of false paternity results.

number of them as not had children. Approximately 93% of our respondents are of Judeo-Christian religious background. At the time of the survey, however, only 10% of respondents considered themselves "very religious."

Career Motivation and Countertransference

Almost unanimous (95%) was the motivation to become a genetic counselor because of experience with a genetic disease or birth defect in themselves, a close friend or a relative.

This surprising finding may account for the high degree of empathy and understanding our profession has for persons with disabilities and our ability to act as patient advocates. On the other hand, it also makes the issue of countertransference raised in *Perspectives* (Vol. 10 No. 3) one to be seriously considered by our membership. The results also clearly show that our respondents are able to separate their personal from their professional views on the subject of reproductive choice and as a profession have made a commitment to presenting more than one reproductive option, even to couples who appear to have already made a choice.

Furthermore, although in their personal lives the respondents are more likely to uphold the right to abortion in some if not all circumstances, professionally they are most likely to present both abortion and continuation of pregnancy as options even when the counselees state they would unconditionally choose one option over another.

Recommendations

The SIC recommends to the Board that marital status and number of children be added to the list of standard questions on the Professional Status survey. In addition, the committee shall continue to develop new questions relative to social, political and ethical issues for future surveys.

To contribute to this project, contact:

Joanne Malin, M.S.
Chairperson, Social Issues Committee
Lenox Hill Hospital
Prenatal Testing Center
100 E. 77th Street
New York, NY 10021.

 # 45: (n=239) State your marital status.

A. Single	64	26.8%
B. Married	149	62.3%
C. D'vcd or Sep.	25	10.5%
D Widow/Widower	1	0.4%

 # 46: (n=200) State the number of children for whom you have significant responsibility.

A. 0 children	100	50.0%
B. 1 child	46	23.0%
C. 2 children	37	18.5%
D. 3 children	14	7.0%
E. 4 or more	3	1.5%

(Avg: 1.3 children per counselor or 2 children per 100 who have any children.)

 # 47: (n=239) Were you motivated to enter the field of genetic counseling because you, a relative or close friend had a genetic disease/birth defect?

A. Yes	227	95.0%
B. No	12	5.0%

 # 48: (n=241) State religion in which you were reared.

A. None	9	3.7%	G. Buddhist	0	0.0%
B. Atheist	2	0.8%	H. Other	7	2.9%
C. Catholic	50	20.7%	Unitarian	3	
D. Protestant	107	44.4%	Quaker	2	
E. Jewish	66	27.4%	Greek Orthodox	1	
F. Moslem	0	0.0%	Russian Orthodox	1	

 # 49: (n=239) State religion you currently practice.

A. None	72	30.0%	E. Jewish	62	25.9%
B. Atheist	3	1.3%	F. Moslem	0	0.0%
C. Catholic	22	9.2%	G. Buddhist	0	0.0%
D. Protestant	67	28.0%	H. Other	13	5.4%

 # 50: (n=237) Do you consider yourself to be religious?

A. Non Religious	52	21.9%
B. Not Very Religious	60	25.3%
C. Somewhat Religious	100	42.2%
D. Very Religious	25	10.5%

#51: (n=237) Do you attend religious services?

A. Never	48	20.3%
B. Rarely	67	28.3%
C. Irregularly	72	30.4%
D. Regularly	50	21.1%

 # 52: (n=308) Personally, do you endorse a woman's right to have an abortion under the limitation of the law? (Choose A, B or C; if B, check all that apply.)

A. Under no circumstances	1	0.3%
B. If a woman's life is endangered*	37	12.0%
C. Without restriction	197	64.0%
* • If the woman is a victim of rape/incest	33	10.7%
• If the fetus is diagnosed as having a defect/genetic abnormality	38	12.3%
• If the fetal sex is undesired	2	0.7%

 # 53: (n=233) Do you present abortion as an alternative to pregnancy continuation to a couple who states unconditionally that they are morally opposed to abortion?

A. Never	6	2.0%	D. Usually	58	25.0%
B. Seldom	14	6.0%	E. Always	130	55.8%
C. Sometimes	25	10.7%			

 # 54: (n=234) Do you present pregnancy continuation as an alternative to abortion to a couple who states unconditionally that they would abort a fetus if it had the abnormalities being prenatally tested for?

A. Never	7	3.0%	D. Usually	56	23.9%
B. Seldom	13	5.5%	E. Always	133	56.8%
C. Sometimes	25	10.7%			

Beverly R. Rollnick, Ph.D.

We are saddened by the untimely death of our friend and colleague, Dr. Beverly R. Rollnick, former president of the National Society of Genetic Counselors, of cancer, on September 23 in Chicago. Dr. Rollnick had played a key role in the inception of the genetic counseling profession and the founding of the NSGC.

Dr. Rollnick made a commitment to families with children with birth defects through her work for the National Foundation-March of Dimes. Between 1966 and 1971, she chaired the Education Committee and was a member of the Board of Directors of the Westchester-Rockland-Putnam Chapter. She also was a member and volunteer advisor of the New York State Executive Board. For this work, she was honored in 1968 and 1979 as Outstanding Volunteer.

In 1968, Dr. Rollnick earned a B.A. degree at Sarah Lawrence College, where Dr. Melissa Richter conceived the idea of a master's-level genetic counseling training program. Dr. Rollnick interested Dr. Virginia Apgar in this idea, and Dr. Apgar announced the proposed program in 1969. This announcement was instrumental in launching the first class of students at Sarah Lawrence College that same year.

Dr. Rollnick graduated and received a Master of Science degree in Human Genetics with this first class in 1971. She accepted a position as Genetic Counselor and Coordinator in the Division of Genetics at Children's Memorial Hospital in Chicago where she coordinated the midwestern section of the National Registry for Amniocentesis, a prospective study of the safety and accuracy of midtrimester amniocentesis.

For the past 12 years, she was Director of Genetic Counseling at the Center for Craniofacial Anomalies at the University of Illinois College of Medicine. She was recently promoted to Clinical Associate Professor of Genetics in the Department of Pediatrics. In collaboration with Dr. Celia Kaye, Dr. Rollnick was the first author of a major longitudinal study of children with ear malformations in association with other anomalies. She was also the author of the largest study of pedigrees of children with ear malformations. Additional analyses of this series of patients were in work at the time of her death, and will be completed by Dr. Kaye. Among her other significant contributions to medical literature, including more than 30 scholarly papers on a variety of topics, is her Ph.D. dissertation, *Federal Genetics Legislation: Bureaucracy, Politics and Policy*. She was an invited lecturer at numerous scientific meetings and academic programs.

In 1978, Dr. Rollnick was among the nucleus of genetic counselors who recognized the need for a national professional society, in her words, "to foster the professional genetic counselor through education, communication and other relevant activities and to promote the field of human genetics." She was representative to the founding Board of Directors of the NSGC for the membership region that included Illinois, and she was elected to become the second president of the Society in 1980.

She served the NSGC on many levels and in a variety of roles. She recorded and published the history of the Society, researched and wrote a position paper on the role of the Society in planning and enacting a continuing education program and participated in or single handedly completed countless other projects.

Dr. Rollnick was among the most prominent genetic counselors in the country. Outstanding among her accomplishments were her election to the Board of Directors of the American Board of Medical Genetics, on which she served as treasurer, the Board of Directors of the American Society of Human Genetics and the Board of Directors of the Genetics Task Force of Illinois. She was Consultant on Genetic Services to the State of Texas, and member of the Genetics Advisory Committee, Bureau of Health Care Delivery and Assistance of the U.S. Department of Health and Human Services. At the time of her death, she was president-elect of the Society for Craniofacial Genetics and a member of the Grant Review Committee, National Heart, Lung and Blood Institute, National Institutes of Health.

Dr. Rollnick never lost sight of her role as advocate and negotiator for the genetic counselor as a professional. She was dedicated to helping her profession by enhancing its reputation. She professed that the best way to do this was through the accomplishments and professionalism of each individual genetic counselor. She was an outstanding example of this principle. She was a role model and mentor for many genetic counselors who aspired to or achieved a leadership role.

Dr. Rollnick was committed to the following goals for genetic counselors. They were 1) high standards of performance for each genetic counselor in their work, publications and presented papers, 2) a strong sense of professionalism and 3) involvement in professional and scientific societies e.g. the NSGC, ASHG and ABMG.

For the NSGC, she was devoted to the following principles 1) membership criteria that would promote appropriate training for genetic counselors, 2) autonomy for genetic counselors in leadership of the NSGC and 3) a continuing education program planned and executed by the NSGC membership.

Beverly Rollnick was a beautiful, sophisticated, intellectually-gifted woman. She was committed to making a contribution that would make this world a better place in which to live. She was compassionate and gracious. Her sense of humor was an added gift to those who knew her well. While she was self-assured, she was always open to the opinion of others. She was a scientist, teacher, patron of the arts and devoted mother to her son, Stuart Ginsberg, and his wife, Lisa.

Her death has left a void for all of us who had the privilege to know her. It is important to keep her memory alive by remembering her plans, hopes and dreams for the professional genetic counselor and the National Society of Genetic Counselors and by honoring her dedication through ongoing commitment to the high standards of professionalism that were for her a reality and also an ideal.

by Audrey Heimler, M.S.
presented at 1988 Annual Education Conference, New Orleans, LA

individual must be alerted.

R.M.: The primary purpose of teratogen counseling is to provide information relative to the client's risk following exposure to a particular teratogen. It is generally agreed that the determinant factors in teratogenicity are the specificity of the agent, the exposure time, the genotype of the mother and the conceptus, the dosage and concurrent exposure to other agents.

Courts have often held that physicians will be liable for malpractice if the physicians, as an aid to diagnosis, do not avail themselves of all of the scientific means and facilities available to obtain the best factual data upon which to make a diagnosis. It is likely that a similar standard may be applied to genetic counselors.

Since each teratogen case is unique, a genetic counselor must use professional judgment to determine if all of the means available to obtain the correct assessment of a client's risk have been utilized. However, at a minimum, it appears that complete information concerning the determinant factors in teratogenicity should be obtained.

In prenatal counseling, are we required to address family history issues which do not directly effect the pregnancy ?

P.R.: No. The problem here is deciding which family history issues do or do not directly effect the pregnancy. Certainly a couple that approaches a counselor because of advanced maternal age need not be counseled concerning disorders the manifestations of which may be influenced by several genes.

When a patient consults an emergency room physician to repair a simple laceration, the history and physical is focused on the chief complaint. Similarly, the boundaries of a counselor's duty must be realistically drawn. The issue which brings the patient to the counselor usually will help draw that perimeter.

This is not to deny that a counselor should ask each patient a general set of open-ended questions in an effort to identify important health problems that are directly relevant to the pregnancy.

R.M.: Health care professionals are judged against the following standard: What level of care, treatment and skill, in light of all relevant circumstances, would be acceptable to a reasonable and prudent health care professional with similar training, experience and skill? If a counselor intends to limit prenatal counseling solely to possible genetic defects present in the fetus, it is advisable to inform the patient that the evaluation will not extend to family illnesses which do not directly impact the fetus.

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Letter to the Editor

Countertransference Issue Needs Closer Look

To The Editor:

Ann Swinford and I wrote the article on countertransference (Vol. 10 No.3) because we have seen little written about acknowledging one's personal experiences and dealing with them in the genetic counseling setting. However, the Social Issues Committee report presented in New Orleans indicates that a wide majority of NSGC members have a personal experience (eg. a sibling with Down syndrome, a mentally retarded child or even having a genetic condition themselves) influencing their decision to enter the field of genetics. Perhaps countertransference occurs more often than we thought.

Self-awareness of the possibility of countertransference would seem key to preventing this personal involvement from interfering with one's effectiveness as a counselor.

Lorna Phelps, M.S.S.W.
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FLUID withdrawn to 7-12 ml depending on gestational age, because of the smaller total volume of amniotic fluid. Withdrawing this smaller volume of fluid results in a slightly increased risk (about 2-3%) for cell culture failure, which can be compared to a 1% rate for amniotic fluid samples of approximately 20 mls.In our laboratory we routinely count the chromosomes in 15 cells from seven different colonies, do three analyses of chromosome structure under the microscope and cut two karyotypes. In talking with patients who opt for early amniocentesis, we discuss the increased risk that a complete study may not be possible. We also discuss the fact that results of the fetal chromosome analysis are usually available within 2 weeks, as with routine amniocentesis.

- BASED ON EXPERIENCE at the Prenatal Diagnostic Center and other medical centers offering this technique, the risk for miscarriage associated with the procedure is most likely .5-1%, which can be contrasted to a .25% risk associated with routine amniocentesis. In our follow-up of patients, we have not identified any increased incidence of birth defects in the babies delivered. Birth weights have been in the normal range.
- WE QUOTE A 99.4% ACCURACY RATE for chromosome testing performed on the amniotic fluid cells from early amniocentesis, the same as for routine amniocentesis. We discuss the fact that errors may occur due to maternal cell contamination, laboratory mix-up, low level mosaicism, or small rearrangements or deletions which are not detectable using current techniques.
- BECAUSE THE ACCURACY of amniotic fluid alpha-fetoprotein testing for neural tube defects in the fetus has not been firmly established for 12-14 weeks gestation, we recommend that patients who opt for an early amniocentesis have a maternal serum alpha-fetoprotein test at 16-18 weeks gestation.
- FINALLY, WITH ROUTINE AMNIOCENTESIS patients, our recommendation is that patients do no heavy lifting or vigorous exercise for 24 hours after the procedure. However for patients who opt for an early amniocentesis, we recommend that activity be much more restricted for 24 hours post procedure.

As with routine amniocentesis, a couple's decision to proceed with early amniocentesis is a matter of weighing risks and benefits. The appeal of early amniocentesis, as with CVS, is that results are available earlier in pregnancy. Early amniocentesis truncates the time frame during which many couples nervously await test results, possibly distancing themselves from and trying to conceal a pregnancy which they are anxious to acknowledge and share. In addition many women realize that, as traumatic as an abortion would be at any stage of pregnancy, an earlier one would be less emotionally devastating.

The increased risk for pregnancy loss may be the biggest deterrent to choosing an early amniocentesis or a CVS. Many women feel the need to select the safest procedure available because the pregnancy is so precious to them and the thought of a procedure-related loss so frightening.

In our discussion of amniocentesis a critical point to most couples is that the high degree of accuracy of the cytogenetic testing is retained. Obtaining the most complete and accurate information seems to be paramount to some couples. In fact it sometimes becomes an important issue to some couples that early amniocentesis is not as inclusive as a routine amniocentesis in that neural tube testing is not as confidently performed and ultrasound examination is not as definitive.

In summary, we have found that for patients who are anxious to get results earlier in pregnancy, amniocentesis at 12-14 weeks offers an alternative whose safety and success is being demonstrated. In addition, because the very high degree of accuracy of the cytogenetic testing is retained, the diagnostic dilemmas and patient anxiety which are sometimes generated by inconclusive results obtained after chorionic villus sampling are avoided.

As always, the choice of prenatal diagnostic technique depends on a couple's perception of their risk of having an affected child, their willingness to accept a level of risk to the pregnancy for the benefit of gaining diagnostic information, and the personal context within which they weigh these risks and benefits.

Key Elements in Secondary Genetics Education

At least one-half of the NSGC membership is estimated to include education as one of their responsibilities. For genetic counselors involved with educating high school students, the need to provide biology teachers with strategies has been recently addressed.

The current issue of *The American Biology Teacher* highlights six key concepts in human genetics determined to be most important for high school students to understand if they are to make informed decisions in this area of health. They are:

- There is human variability that is biologically controlled and can be understood.
- There are certain diseases (disorders) that are determined almost exclusively by one's genetic makeup (genotype).
- There are certain conditions that are interdependent on a person's genetic makeup and environment, including lifestyle.
- Chance has no memory. When two people who are carriers for the same recessive disorder have children, the chance of each child's having that disorder is 1 in 4. When a person, male or female, with an autosomal dominant disorder has children, each child has a 1 in 2 chance of inheriting that disorder.
- Carriers of recessive genetic disorders usually do not show symptoms of the disorder because carriers have only one gene for the disorder (along with a "normal" gene) and full expression of the disorder requires two "abnormal" genes.
- Individuals can contribute to their ability to have healthy children by knowing their own family histories. Avoiding exposure to or ingestion of certain products during pregnancy, and understanding the capabilities and limitations of prenatal diagnosis.

The authors, Paula Haddow, Deborah Eunpu, Niecee Singer, Daniel Brant and Margaret Ledwith, feel that these six concepts can be used as a framework around which a curriculum in human genetics can be planned. By including elements illustrative of each key concept into a human genetics curriculum, the authors assert that the curriculum "will contain the materials to provide students with a scientific working knowledge of the role of genetics in human development and medicine."

Haddow PK, Eunpu DL, Singer N, Brant DL, and Ledwith MB.(1988) "Introducing high school students to human genetics," *The American Biology Teacher*, 50 (8), 496-500.

Membership Directory in Preparation Stage

NSGC's 1989-1990 Membership Directory will be published this Spring.

We have received several suggestions for changes, including a request that only one address be listed. To address this request, "Let's Get It Right" cards will again be included in the January membership mailing. You will be asked to choose which address you prefer to have listed in the Directory. If we do not hear from you, we will automatically select your *preferred* mailing address.

If you have other suggestions regarding the directory, please write to me c/o University of Texas Medical School at Houston, Department of Pediatrics, P.O. Box 20708, Houston, TX 77225, *no later than March 1.*

Jacqueline Hecht, Ph.D.
Membership Committee Chairperson

Themes Announced for Vol. 11

The deadline for the Spring issue of *Perspectives* is February 10. The theme will be "Counseling for Adult Disorders." Tentatively scheduled are articles on counseling and management of adults with CF, alpha 1 antitrypsin deficiency, genetic screening in the workplace, identifying factors predisposing to familial lipid disorders, genetic counseling issues for mentally disabled adults and genetic counseling in an adult hearing impaired population. This issue's publication date is March 15.

Other themes and deadlines for 1989 are:

- SUMMER: "Reproductive Technologies," Publication Date: June 15; Deadline: May 10.
- FALL: "The History and Future of The Profession," Publication Date: September 15; Deadline: August 10.
- WINTER: "Outreach," Publication Date: December 15; Deadline: November 10.

Ed Kloza, M.S.
Editor

National Press for NSGC

Glamour Magazine's December 1988 Medical Report, " 'Will My Baby be OK?' New Genetic Tests Predict Diseases," featured information about CVS as a means of prenatal diagnosis.

Reporter Amy Mereson cited the NSGC and the National Tay-Sachs and Allied Diseases Association as resources "for information about where to seek genetic counseling." Of the dozens of calls the Executive Office has received to date, half have been for referrals to genetic counseling professionals and half have been for career information.

If you read articles in the popular press about genetic counseling, please forward a copy to the Executive Office and/or to Luba Djurdjinovic, NSGC Archivist, c/o Genetic Counseling Program, 16 Leroy Street, Binghamton, NY 13905.

Bea Leopold, M.A.
Executive Director

CAGC to hold Winter Meeting

NSGC's sister organization, the Canadian Association of Genetic Counsellors, will hold its third annual meeting in Winnipeg February 23 - 25. The meeting will coincide with the annual meetings of the Canadian College of Medical Geneticists and the Garrod Society.

For information about registration and accommodations, please contact Wendy Stoeber, Clinical Genetics, Health Science Centre, 685 William Avenue, Winnipeg, Manitoba R3E 0Z2.

Susan Creighton, M.S.
President, CAGC

AFP/SMS

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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!

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Contact: William B. Adams, PhD

Book

Searching for the Stork: One Couple's Struggle to Start a Family
Author: Marion Lee Wasserman
Publisher: New American Library, New York and Scarborough, Ontario
Price: $17.95
Reviewed by: Melonie Krebs, M.S.

This book is a very powerful first-person account of a couple's struggle with multiple pregnancy loss and genetic disease. There have been many similar books in the popular press but none which better communicates the feelings of jealousy, hostility and guilt commonly shared by couples who come up empty-armed in their efforts to have a child.

Marion Lee Wasserman reveals the innermost emotions she and her husband Dean experienced after severe fetal hydrops was prenatally diagnosed 5 months into their pregnancy. After a painful labor induction, a fetal autopsy revealed Gaucher's disease.

The couple conceived again and were anxiously preparing for CVS to prenatally test for Gaucher's when oligohydramnios was detected. Their third attempt at parenthood ended in a molar pregnancy. At 37, the Wassermans decided they were done with the "insanity" that pregnancy had become and decided to adopt.

The author has captured her reactions and thoughts on what it is like to go through prenatal testing, abortion, false hopes and the death of a dream child. Her descriptions of her feelings of jealousy and hostility towards friends, relatives and even strangers who have healthy children clearly reflect her pain.

She explains, "...since the world is made up of children and parents and expectant parents and grandparents, it wasn't possible to watch television or read a newspaper or book or to walk down a street without feeling jealous or angry."

"Dean and I were on different terms with the world than we had been before," she adds. These "different terms" will be familiar to parents who have experienced similar losses and may help to validate some of those feelings. They may also give new insight to genetic counselors and other health care providers who try to provide support to couples experiencing a similar loss.

This book is also unique because all the "right" things that genetic counselors advocate were done. The Wassermans had counseling prior to all prenatal tests, the support of sensitive physicians and nursing and social work intervention. They were encouraged to hold their dead baby and received support during and after their termination. From Wasserman's story, we learn that even when we do all the right things, our families' grief doesn't often personally touch us.

Wasserman's book may not be appropriate for every couple at every stage of loss, especially those who are in the middle of a crisis, but for most will provide the personal insight which can only come from those who have shared in the grief.

Audio-Visual

Support for Prenatal Decisions
Produced by: Support for Prenatal Decisions and Loma Linda University School of Medicine, Division of Genetics
Format/Price: 1/2" VHS (40:30) $95, purchase, $35, rental
Orders: Support for Prenatal Decisions, P.O. Box 1161, Bernadino, CA 92402
Audience: Professionals, allied health and paraprofessionals, parents and other consumers
Reviewed by: Jane Nichols, B.A., Bereavement Consultant, Regional NICU, Children's Hospital Medical Center, Akron, OH

Support for Prenatal Decisions is a rare find and much needed resource for genetic counselors who deal with parents experiencing pregnancy termination due to a fetal abnormality. Created by a parent support group for families in such circumstances, the stated purpose is for use in training programs designed to sensitize professionals to grief reactions and to the need for emotional support of parents before, during and after a genetic termination.

It begins with a warning about the sensitive nature of the content and how the video should be used only with an accompanying manual. The format is a panel discussion led by a genetic counselor with four women who have undergone a genetic termination. The husband of one of the women also participates. Points they make about their experiences include: feelings of being underprepared for and overly directed toward their decisions; the husband feeling left out; professional parents' use of a protective, clinical shield; and the consequences of getting bad news on the telephone or when alone.

Participants urge open communication about different types of grief response and the need for frank discussion about the various methods of termination and their potential complications. Aftercare issues such as photographing, naming and holding the baby as well as funeral arrangements are raised.

The primary limitation of the film is its one-sided view of parent reaction following a termination: the panelists talk about their personal, long-term grief and suffering and there is no representation from those who do not experience full-blown grief. Although the termination of a wanted pregnancy is certainly a difficult and fragile time, we do not have evidence to support the notion that every couple experiences grief to the magnitude represented in the film. This point and the fact that some of the parents generalize their reactions to include all parents, may promote guilt feelings for the parent who does not share the same depth of grief. It may also mislead the professional audience for whom the film is intended.

The video and booklet offer a concise summary of issues which arise for many parents faced with difficult prenatal decisions. When used with the balanced perspective of a wider gamut of post-termination reactions, these tools can serve to heighten healthcare providers' awareness of parental needs as well as to stimulate creative caregiving responses to those needs. The video could also be shown to parents who have terminated a wanted pregnancy as a way of validating their grief reactions, especially if a local support group is not available.

Organization

Pregnancy and Infant Loss Center, 1415 E. Wayzata Blvd., Suite 22, Wayzata, MN 55391; 612-473-9372.

The Pregnancy and Infant Loss Center (PILC) offers resources, education and support services for those who have experienced miscarriage, stillbirth and infant death. The center was founded in 1981 by nationally-known expert on pregnancy loss Sherokee Ilse to improve the care of bereaved parents and sensitize the public to their needs.

PILC services include resource refer-ral, parent advocate work and publication/distribution of perinatal bereavement literature and products as well as a newsletter, *Loving Arms* which includes regular columns for parent submissions as well as national news and events pertaining to bereavement.

Classified • Classified • Classified

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

TUCSON, AZ: Immediate Opening for Masters-level, BC/BE Genetic Counselor.
Responsibilities: Prenatal diagnosis; MSAFP; CVS; teratogen counseling; high risk pregnancy counseling; community & professional education.
Send Resume: Lewis Shenker, MD, University Medical Center, Dept. OB/GYN, 1501 N. Campbell Avenue, Tucson, AZ 85724; 602-626-6636. EOE/AA.

BERKELEY, CA: Immediate Opening for Part time (80%) Masters-level, BC/BE Genetic Counselor. One year experience in genetic counseling preferred; Sickle Cell disease experience desirable.
Responsibilities: Provide comprehensive care to sickle cell populations in multidisciplinary setting.
Send Resume: Yolanda Rooks, RN, Alta Bates Hospital, Adult Sickle Cell Center, 3001 Colby Street, Berkeley, CA 94705; 415-540-1609. EOE/AA.

LA JOLLA, CA: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Competitive longitudinal national research project for study of FSH Muscular Dystrophy including coordination; field diagnosis/assistance; data collation and case follow up.
Send Resume: Stephen Jacobsen, PhD, University of California San Diego, Dept. Pediatrics, M-009F, La Jolla, CA 92093; 619-534-6261. EOE/AA.

SAN FRANCISCO, CA: Immediate Opening for Part time (50%) Masters-level, BC/BE Genetic Counselor. One year experience and bilingual/bicultural background preferred. Salary Range: $2448/2948/mo, based on full time.
Responsibilities: New program serving underserved populations covering a wide range of genetics; newborn follow-up for variety of birth defects; some teaching in genetic counseling and medical school programs.
Send Resume: Ilana Mittman, MS, San Francisco General Hospital, Dept. OB-GYN, 1001 Potrero Avenue, Room 6D23, San Francisco, CA 94110; 415-821-3133. EOE/AA.

SAN FRANCISCO, CA: Immediate Opening for Masters-level, BC/BE Genetic Counselor. Excellent salary & benefits.
Responsibilities: Full range of counseling in reproductive genetics, including amniocentesis, CVS, MSAFP, fetal treatment program.
Send Resume: Mitchell Golbus, MD, University of California San Francisco, Reproductive Genetics Unit, Room U260, San Francisco, CA 94143-0720; 415-476-4157. EOE/AA.

SAN JOSE, CA: Immediate Opening for Masters-level, BC/BE Genetic Counselor.
Responsibilities: Prenatal diagnosis. Some travel to San Francisco and Walnut Creek.
Send Resume: John D. Stephens, M.D., California Prenatal Diagnosis Institute, 1390 S. Winchester Blvd, San Jose, CA 95128; 408-866-6266.

BOYNTON BEACH, FL: Immediate Opening for BC/BE Genetic Counselor in 350-bed community hospital setting.
Responsibilities: Prenatal diagnosis, amniocentesis, CVS; some pediatrics; professional education opportunity available.
Send Resume: Lisa D'Augelli, MS, Bethesda Memorial Hospital, 2800 S. Seacrest Blvd, Suite 104A, Boynton Beach, FL 33435; 407-738-0448. EOE/AA.

BOSTON, MA: Immediate Opening for Project Coordinator, Sickle Cell Newborn Screening. Position requires Masters-level professional; clinical experience preferred; knowledge of Sickle Cell Disease and newborn screening also preferred. Bilingual background helpful. Salary Range in low $30,000s.
Responsibilities: High visibility, high responsibility position includes supervisory & administrative duties; coordination of professional & lay education; overseeing hospital staff training; coordination of total screening program from patient recruitment to follow-up.
Send Resume: Marsha Lanes, MS, Massachusetts Genetics Program, Department of Public Health, 150 Tremont, 2nd Floor, Boston, MA 02111; 617-727-5121. EOE/AA.

WORCESTER, MA: Immediate Opening for Masters-level, BC/BE Genetic Associate with one or two years experience.
Responsibilities: Varied responsibilities, including active work as liaison with patients, professional & laboratory.
Send Resume: Mary Q. Lammi, Personnel Recruiter, University of Massachusetts Medical Center, 55 Lake Avenue North, Worcester, MA 01655; 508-856-2181. EOE/AA.

ROYAL OAK, MI: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Wide variety of responsibilities in pediatric & prenatal practice as part of expanding multidisciplinary team including 1 pediatric geneticist, 3 perinatologists & 1 genetic counselor.
Send Resume: Robert P. Lorenz, MD, William Beaumont Hospital, 3601 W. 13 Mile Road, Reproductive Genetic Program, Royal Oak, MI 48072; 313-288-1968. EOE/AA.

CAMDEN, NJ: Immediate Opening for Masters-level, BC/BE Genetic Counselor. Experience preferred.
Responsibilities: Comprehensive service center including prenatal diagnosis; pediatrics; AFP screening; teratology; Fetal Alcohol Syndrome; research; professional & community education.
Contact: Alice Lazzarini, M.S., University of Medicine and Dentistry of NJ-School of Medicine, 401 Haddon Ave, Camden, NJ 08103; 609-757-7812. EOE/AA.

BROOKLYN, NY: Immediate Opening for Masters-level, BC/BE Genetic Counselor. Some experience preferred. Salary Range: $32,000 negotiable with experience; excellent benefits including travel & education.
Responsibilities: Prenatal diagnosis & general genetics and specialty clinics on multidisciplinary team at hospital with excellent mental health facility; research opportunity available.
Send Resume: Ernest Lieber, MD, Interfaith Medical Center, Brooklyn Jewish Hospital, Div. of Genetics, 555 Prospect Place, Brooklyn, NY 11238; 718-935-7410. EOE/AA.

EAST MEADOW, NY: Immediate Opening for BC/BE Genetic Counselor. Bilingual preferred.
Responsibilities: Coordinate prenatal genetic service including amniocentesis, AFP; professional education including medical students & residents.
Send Resume: Mrs. M. Cosgrove, Nassau County Medical Center, 2201 Hempstead Turnpike, East Meadow, NY 11554; 516-542-2258. EOE/AA.

Classified • Classified • Classified

NEW YORK, NY: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Amniocentesis counseling; outreach to community hospitals.
Send Resume: Hody Tannenbaum, 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: Research in major study involving linkage studies of movement disorder group, including dystonia & essential tremors: Wide range of responsibilities from clinical to data base management. Opportunity for education, genetic counseling and facilitating support groups.
Send Resume: Deborah de Leon, MS, Neurological Institute, Box 77, 710 W. 168th St., New York, NY 10032; 212-305-5779. EOE/AA.

SYRACUSE, NY: Spring 1989 Opening for Masters-level, BC/BE Genetic Associate in Dept. Pediatrics at SUNY, Syracuse, NY.
Responsibilities: Coordinate pediatric clinic; counseling & follow-up patients with a wide variety of disorders; clinical research; some teaching.
Send Resume: *(until 4/1/89):* Christine R. Bryke, MD, Yale University School of Medicine, Dept. of Human Genetics, P.O. Box 3333, New Haven, CT 06510; 203-785-2660. *(after 4/1/89):* Dr. Bryke, c/o SUNY Health Science Center, 750 E. Adams Street, Syracuse, NY 13210; 315-473-5450. EOE/AA.

ASHEVILLE, FAYETTEVILLE & WINSTON-SALEM, NC: Immediate Openings for 3 BC/BE Genetic Counselor/Educators in Genetic Health Care Unit of the North Carolina Department of Human Resources, Division of Health Services.
Responsibilities: Coordination of genetic satellite services with major medical centers; case identification; broad range of preconceptional, prenatal & pediatric cases; professional & community education; consultation with other state programs.
Send Resume: Elizabeth G. Moore, Genetic Health Care & Newborn Screening Program Manager, Div. Health Services, P.O. Box 2091, Raleigh, NC 27602; 919-733-0385. Please include references. EOE/AA.

OKLAHOMA CITY, OK: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: All aspects of clinical genetics & prenatal diagnosis; service to outreach clinics.
Send Resume: Joyce Shissler, RN, MS or A. Garnica, MD, University of Oklahoma Health Sciences Center, Pediatrics/ Genetics, P.O. Box 26307, Room 2B275, Oklahoma City OK 73126; 405-271-3468. EOE/AA.

NASHVILLE, TN: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: General genetic counseling; teaching & research opportunities available.
Send Resume: Dr. D.N. Singh, Meharry Medical College, Div. Medical Genetics, Dept. Pediatrics, Nashville, TN 37208; 615-327-6786 / 6399. 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.
Responsibilities: Professional education; track and counsel follow-up patients. Apply with 3 letters of recommendation.
Send Resume: Dr. Joann Bodurtha, Medical College of VA - Dept. Human Genetics, Box 33, MCV Station, Richmond, VA 23298-0033; 804-786-9632. EOE/AA.

CORRECTION: The classsified listing in Vol.10, No. 3, erroneously listed the position at Mt. Sinai Hospital in New York City. The position is available in the Division of Medical Genetics.

Place Your Order Now!

Free Packets for National Alcohol-Related Birth Defects Awareness Week

MAY 14-21,1989

A free packet, designed to promote National Alcohol-Related Birth Defects Awareness Week, scheduled for the week of Mother's Day, May 14-21, 1989, is available from the National Council on Alcoholism. The packet contains action-oriented information for health professionals and other persons involved in educating the public about alcohol-related birth defects.

Supplies are limited. Interested persons should place their order no later than January 10, 1989, by completing the coupon on this page and mailing it to the National Council on Alcoholism, 1511 K Street, N.W., Suite 320, Washington, D.C. 20005. Orders for single packets will be taken as long as supplies last.

National Alcohol-Related Birth Defects Awareness Week Packet

I am involved in educating the public about alcohol-related birth defects and would like to receive a free packet. I understand that single orders will be filled on a first come, first served basis.

Name _____

Address _____

_____

Affiliation _____

Phone _____

Mail completed coupon to the National Council on Alcoholism, 1511 K Street, N.W., Suite 320, Washington, D.C. 20005. Thank you!

Alcohol Warning Labels Included in Omnibus Drug Bill

On October 22nd Congress passed the Omnibus Drug bill, including the NSGC-supported alcohol warning label bill (see *Perspectives* Vol. 10 No. 3). This is a clear victory for the NSGC and other members of the Alcohol Health and Safety Warning Labels coalition to increase public knowledge of alcohol-related birth defects.

Just one year after President Reagan signs this bill into law, the following label will be required on all containers of beer, wine coolers, hard liquor and wine sold in the United States:

GOVERNMENT WARNING:

- According to the Surgeon General, women should not drink alcoholic beverages during pregnancy because of the risk of birth defects.
- Consumption of alcoholic beverages impairs your ability to drive a car or operate machinery, and may cause health problems.

The final labeling bill was a compromise from the original proposal of five rotating warning labels. The Fetal Alcohol Syndrome warning was shortened and mention of mental retardation as a possible effect of drinking during pregnancy was deleted. The FAS warning did, however, retain a position of importance on the label and the Secretary of the Treasury is to report to Congress in two years on the need for additional or stronger labels.

NSGC members are urged to thank the main Senate sponsors: Senators Strom Thurmon (R-SC), Ernest Hollings (D-SC) and Albert Gore (D-TN), and to thank their own representatives for having (hopefully) supported the bill. NSGC members should also publicize this important victory in their community.

The FAS warning is likely to increase questions from the public about the dangers of drinking during pregnancy and there is a clear proactive role here for NSGC members to provide information and education. You might volunteer to speak to community groups such as your local PTA (also a supporter of bill), write a short article for your hospital or community newspaper or establish yourself as a local resource on FAS.

Prepare now for an increase in questions from consumers and obstetricians by educating yourself regarding FAS and becoming familiar with local resources such as a state FAS hotline or your state chapter of the National Council on Alcoholism.

Excellent free resources are available from the National Clearinghouse on Alcohol and Drug Information at (301)468-2600 by asking for the "Fetal Alcohol Syndrome Professional Materials" which includes comprehensive professional and patient publications.

In addition, a National Alcohol-Related Birth Defects Awareness Week Packet is available from the National Council on Alcoholism. (See p. 11.) This packet includes the extremely practical "Activists' Guide" of press releases, PSAs, fact sheets, resource lists, etc. as well as print materials for traditionally underserved populations.

This is a exceptional opportunity for the genetic counselor looking to develop an expanded role in public and professional education and to serve an important position in the community.

Trish Magyari, M.S.
Legislative Issues

Perspectives in Genetic Counseling
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Executive Office
233 Canterbury Drive
Wallingford, PA 19086