nsgc

PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 13, No. 3 Fall 1991

MEMBERSHIP VOICE

1991-1992 Election Results

Barbara Bowles Biesecker, M.S., chair, Nominating Committee is pleased to announce the results of the 1991/92 elections:

President-Elect ... Betsy Gettig, M.S.
Treasurer ... ... Linda Lustig, M.S.
Reg. Rep I ... ... Marsha Lanes, M.S.
Reg. Rep III ...Andrew Faucett, M.S.
Reg. Rep V .Janice Cox Palumbos, M.S.

Congratulations to the newly-elected Board members and thanks to the committee members for a job well done: Andrea Gainey, M.S., Diana Punales-Morejon, M.S., Rhonda Schonberg, M.S., and Alison Warner, M.S.

on the inside...

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

PATERNITY TESTING: A NEW ROLE FOR GENETIC COUNSELORS

by Wendy Uhlmann, M.S., Hutzel Hospital, Detroit, MI

As genetic technologies experience exponential growth, those involved with clinical applications must keep pace. The arena of paternity testing is one example. While the laboratory aspects of this new technology are highly refined, discussions about appropriate applications, delivery and social-ethical issues are frequently one pace behind. This article highlights some complexities of prenatal paternity testing and raises important issues which merit further discussions. — Karen L. Copeland, M.S.

Paternity testing referrals are cases genetic counselors tend to discourage, pass along to other colleagues or outright refuse. Although defining correct paternity is key in performing DNA analysis for genetic diseases, the role of genetic counselors in paternity testing for social (non-disease specific) reasons is debated. The focus of this article is *prenatal* paternity determination for social indications, since these cases usually involve a genetic center. Postnatal paternity testing need not involve genetic counselors since blood specimens can be obtained by the laboratory or by the patient's physician.

PRENATAL PATERNITY TESTING PRESENTS NEW OPTIONS

Traditionally, paternity determination has involved conventional blood testing methods and, with the exception of HLA studies, these methods restricted paternity determination to the postnatal period. Paternity testing became more of an issue for prenatal genetic counselors after DNA analysis techniques were developed. In addition to the general advantages of DNA analysis over conventional blood testing methods (greater accuracy in exclusion, multiple tests generally not required, lower costs and easier sample handling), DNA analysis can be performed on cells obtained through chorionic villus sampling (CVS) and amniocentesis. Genetic counselors are approached regarding prenatal paternity testing cases because they are knowledgeable about both DNA analysis and prenatal diagnostic procedures and are working in or aware of centers that offer these services.

There are many reasons women or couples desire prenatal paternity determination. Some women would consider terminating a pregnancy dependant upon the test results. The availability of early diagnosis by CVS makes this decision possible without public knowledge of the pregnancy. Paternity information may also prove useful for obtaining health care, maternity benefits and child support. Patients seeking paternity testing usually have complex psychosocial concerns, and counselors may have a greater opportunity to explore some of these concerns than they have in more traditional prenatal cases.

GENETIC COUNSELOR AS GATEKEEPER

Paternity testing cases can add a different dimension to the work of genetic counselors. The scenarios patients give for paternity testing are intriguing, and some cases tend to challenge our personal values, biases and stereotypes. The

• continued on p. 6 •

From a Different Perspective

Long Term Counseling at a Center for Individuals with Mental Retardation

Over the past six years, I have had the rare, if not unique, experience of being based full time at a center which offers a regional network of residential and day services to over 2000 developmentally disabled clients and their families. In contrast to a hospital setting, the main focus of our center is special education, vocational training and rehabilitation. I function as part of a medical department within the institution. More often than not, my day-to-day professional interactions are with teachers, social workers and physical and speech therapists.

A Different Approach

There is an ideal opportunity in the special education setting for long term follow-up and a comprehensive genetic counseling approach, one that includes the client not as the syndromal sum of his dysmorphic parts, but as a growing person, somebody's student, somebody's daughter, somebody's brother...someone whose birth has permanently changed the course of a family.

Much clinical work needs to be done, particularly on the diagnostic front. Many genetic conditions, such as fragile X syndrome, are greatly underdiagnosed among people with mental retardation, and their families are frequently unaware of the high risk for recurrence.

The psychosocial realm offers even more challenges to the genetic counselor, as many families have accumulated years of unalleviated guilt, misconception and chronic grief. With all due respect to Kubler-Ross' stages of coping, the "acceptance" of lifelong developmental disability is tenuous. Each phase in the disabled person's lifetime can mark a parent's return to depression, denial and anger, in no particular order or neat progression of emotional stages.

Early Equality

Consider the parents of a child with Down syndrome. Shortly after his birth, they go through the crisis of being told the diagnosis and of dealing with the inevitable denial, anger, guilt and sadness. Next is often a "golden age" of acceptance during preschool, when early intervention offers the promise of untold potential. Many developmental milestones are eventually celebrated, while the diapers and feeding battles, cute smiles and baby gurgles and basic joys of parenting remain intact. It is with tempered relief that parents realize their initial experience is not too different, after all, from "regular" parenting. The exaggerated ups and downs, high and lows, constitute a magnified version of "real" life.

"The genetic counselor's role [in a residential setting]...changes as the family evolves. New issues arise while others subside over the course of a lifetime."

When Reality Strikes

At about age five, when the child takes a noticeably divergent path from his peers by being enrolled in special education classes, the realization of difference is more emphatic. The slap in the face of the special education van taking a child to the special school while his peers climb aboard the regular school bus is the most tangible evidence of the road less traveled.

With schooling comes the frequent meetings, the constant vigilance, the sense that a wrong step educationally might mean a failure to drain every precious drop of potential from their child. Then, as graduation approaches and the family leaves the safe confines of mandated special education, there is the confirmation for some parents that their son or daughter is not, and never will be, able to live or work independently. At this point, the white noise of the "what-will-happen-to-Johnny-after-we're-gone" worry becomes deafening.

With age comes the high risk for Alzheimer's disease in people with Down syndrome, often with early onset, and a new crisis emerges as the family attempts to cope with their relative's decreasing independence and loss of hard-won skills.

Counseling Roles Evolve with Family Cycles

The genetic counselor's role in all this changes as the family evolves. New issues arise while others subside over the course of a lifetime. A family's concerns about recurrence, in future children and in grandchildren, may surface anew with each pregnancy. Parents struggle to balance the dichotomy of advocating for their existing child, while taking steps (carrier testing, prenatal diagnosis, limiting family size, etc.) toward the prevention of another. Siblings may harbor unspoken, and often unfounded, fears about recurrence, which they dare not broach out of respect for their parents' feelings. Meaty stuff for genetic counselors, and yet most of the families I see would not have sought genetic counseling outside of the safe, familiar walls of the mental retardation center.

Opportunities for genetic counseling at residential and school facilities will undoubtedly increase as knowledge about mental retardation is swept along into the genetics age. Given the severe shortage of genetic counselors in traditional roles, however, such positions are themselves likely to remain less traveled paths for a long time to come.

by Brenda Finucane, M.S.
Elwyn Institutes, Elwyn, PA

ASK A COLLEAGUE

Under what circumstance might you introduce two individuals at genetic risk who may be related?

Patient confidentiality and the duty to avert harm have been addressed in a number of forums, including *Perspectives in Genetic Counseling*[1]. We recently faced the question of whether to connect two pedigrees when an unusual balanced translocation was identified in a woman who was probably distantly related to a former genetics patient. The link with the other family was suspected due to the rarity of the translocation and the existence of a common surname in both pedigrees.

Both families had received appropriate genetic counseling regarding the translocation and the need to inform other relatives. However, the extended family was large and many individuals did not even know each other, so it seemed likely that some family members would not be notified. If a relationship was established, there might be a greater impetus to inform those relatives at risk, while those not at risk could be reassured, or not even contacted.

After discussions at our multidisciplinary case conference and with the hospital's legal office, we called the two translocation carriers, obtained further family history and discussed the possibility that each may be related to someone seen through our unit. Both individuals requested that the genetic counselor facilitate a contact, and written consent was received from both prior to sharing more specific information. These relatives had not personally known each other, and each was given the other's name and phone number with brief information about their ascertainment. This several stage process allowed us to keep the patients' identities confidential as we determined their interest regarding disclosure.

Whether additional family members will seek testing as a result of our intervention remains to be seen. Our hope was to avert harm by identifying at-risk individuals in this large pedigree. Consideration had been given to possible hostile feelings towards the distant relative by the recently diagnosed carrier who had suffered a neonatal death secondary to multiple fetal anomalies resulting from an unbalanced translocation. We felt, however, that both individuals would use the information constructively and to their families' best interest.

Virginia Corson, M.S.
Johns Hopkins Hospital
Baltimore, MD

1 Suslak, L. Patient confidentiality and the duty to avert harm. *PGC*, 12:1 Spring 90.

RESEARCH NETWORK

We are seeking families of individuals affected with **Wolf-Hirschhorn syndrome.**

A family member will be asked to complete a questionnaire on the family's experience with this syndrome. Some families will be asked to provide blood samples for DNA studies at no personal cost. Counselors are asked to submit a brief clinical summary and karyotype of the affected individual.

For more information, please contact: Susan Guckenberger, M.S., or Gilbert N. Jones, III, M.D., Dept. Pediatrics, Division Genetics, Southern Illinois University School of Medicine, P.O. Box 19230, Springfield, IL 62794-9230; 217-782-8460.

GENE BYTES

Computers are somewhat like AFP screening: like it or not, they are an integral part of our careers.

It is now necessary to learn at least *something* about computers, and many counselors are going through the long, slow process of learning lingo like "fonts," "relational database," "RAM" and the ever-popular "Abort, Retry, Or Ignore?"

We have spent the last 4 - 5 years developing computer applications within our respective genetics departments. Though separated by hundreds of miles and virtual ignorance of each other, we have shared some strikingly similar experiences and have developed systems that share many common features.

Neither of us had formal training in computers prior to on-the-job experience. We pretty much had computers thrust - more accurately "dumped" - upon us and were given the vague mission: *"COMPUTERIZE THE DEPARTMENT."* From scratch, and in a partial vacuum, we have more or less integrated computers into the daily management of patients, data and correspondence. Ultimately, the benefits have outweighed the sometimes considerable frustrations. It has, however, required a major investment of time and energy.

Among the topics we plan to cover in future columns: the overall advantages and disadvantages of "computerizing;" the available types of hardware and software; some specific areas within genetic counseling where computers are helpful; the psychological adjustment to computers; and the human and financial costs and benefits of working with computers. We view this column as an open forum to share questions and experiences. To that end, we welcome short tips and advice submitted by readers. Our experience is limited to IBM and compatible systems, but Macintosh users are encouraged to submit ideas, too.

• • • • •

KEY INPUT...The newest release of DOS (DOS 5) is clearly superior to its predecessors. Upgrade now while deals are still available....The best guide to DOS is Van Wolverton's *Running DOS 5* (Microsoft Press).

Robert Resta, M.S., Swedish Hospital Medical Center, Seattle, WA
and Karen Wcislo, M.S., Kaiser Permanente, San Jose, CA

VIEW...

ViewPoint addresses two questions related to genetic counseling for advanced maternal age. Susan Schmerler suggested that we discuss whether age 35 should remain the lower limit for "advanced maternal age." That issue is examined in an interview with Dr. Joe Leigh Simpson. Also, there is some uncertainty in the genetic counseling community as to the efficacy of offering MSAFP/triple screening to women of advanced maternal age, an issue addressed by Dr. George Knight.

Both interviews were conducted by Amy Stein Rissman, a genetic counseling student at Northwestern University in Chicago.

We welcome your feedback.

Seth Marcus, M.S.
ViewPoints/PointCounterPoint

Should Amniocentesis be Offered to Women under Age 35?

An interview with Joe Leigh Simpson, M.D., Chair, Department of Obstetrics and Gynecology, University of Tennessee, Memphis, TN

WHY WAS AGE 35 SELECTED AS THE AGE AMNIOCENTESIS IS OFFERED?

Age 35 is an arbitrary, but very reasonable point to offer amniocentesis. During the 1960's and 1970's, the risk figures for Down syndrome were given in 5 year pentads because they were not known specifically for individual years. At that time, the risk at age 35 (up and through 39) was 1 in 330 and the risk at age 40 (and up) was 1 in 100. Given the risks of amniocentesis to be 1 in 200, age 35 was a plausible age to select. After the age was selected, cost-benefit analysis was done which reaffirmed that age 35 was a good age at which to offer amniocentesis.

"If the guidelines are changed, we will simply be creating new dilemmas."

DURING A RECENT ACOG MEETING, LOWERING THE RECOMMENDED AGE FOR AMNIOCENTESIS WAS CONSIDERED. IT IS OUR UNDERSTANDING THAT THE GENERAL CONSENSUS WAS *NOT* TO ALTER THE STANDARD. DO YOU FORESEE THE AGE BEING LOWERED?

I am aware of no groundswell to lower the age at which patients must be informed about the option of prenatal diagnosis. Before the age is lowered, there needs to be scientific evidence indicating that the risks associated with amniocentesis or chorionic villus sampling have dramatically decreased. Thus far, this has not been done.

HAS THE USE OF ULTRASOUND DURING THE PROCEDURE AS WELL AS EXPERIENCE PERFORMING AMNIOCENTESIS LOWERED ITS RISK?

Many people believe that the loss rate is lower than 1 in 200, but this has not been proven. In a 1976 study conducted by the The NICHD National Registry for Amniocentesis Study Group[1], the background loss rate was 3.2% for controls and 3.5% for amniocentesis. This study helped set the risk figures for amniocentesis at 1 in 200. However, the rate of 3.2% for controls is higher than that which is expected at 16 weeks. (We would expect a rate of only 1-2% at 16 weeks.) This may have reflected selection bias for the control group. A later, well controlled study by Tabor *et. al*[2] failed to show the rate of loss to be any lower than the rate shown in the prior study. In fact, Tabor's study found a 1% risk due to the amniocentesis procedure, even higher than we originally believed it to be.

DO YOU THINK THAT THE RISK OF THE PROCEDURE SHOULD BE TAKEN INTO ACCOUNT WHEN ESTABLISHING THE AGE AT WHICH AMNIOCENTESIS IS OFFERED?

The comparison between the absolute rate of Down syndrome at a particular age and the procedural risk is not a valid one, in my opinion. It is like comparing apples to oranges. These two risks are separate issues and should not be made to seem equivalent.

WHAT DO YOU BELIEVE THE RESULT WOULD BE IF THE AGE WAS LOWERED?

More women would have the procedure, of course. However if the age is lowered, the same problem that exists now for 33-34 year olds will exist for women a year or two below whatever arbitrary age is selected as the new cutoff. If the guidelines are changed, we will simply be creating new dilemmas.

IF THE AGE IS NOT LOWERED, WHAT DO YOU SUGGEST FOR WOMEN UNDER AGE 35?

Anyone interested in amniocentesis or chorionic villus sampling would be able to avail themselves of these procedures. I, therefore, support increased education about amniocentesis for all women. As a result, women will be able to ask questions concerning the procedures and make informed decisions about whether to have an amniocentesis at ages less than 35 years.

[1] The NICHD National Registry for Amniocentesis Study Group, Midtrimester Amniocentesis for Prenatal Diagnosis, Safety and Accuracy. *JAMA*, Sept 27, 1976, 236:13

[2] Tabor A., Philip J, Madsen M., Bang J., Obel EB, Norgaard-Pedersen B Randomized controlled trial of genetic amniocentesis in 4606 low-risk women. *Lancet* 1986 Jun 7, 1(8493): 1287-93.

...POINT

Should Triple Test Screening for Fetal Down Syndrome be Offered Routinely to Women 35 and Older?

An interview with George Knight, Ph.D., Director, Prenatal Screening Laboratory, Foundation for Blood Research, Scarborough, ME

HOW DOES THE TRIPLE TEST COMPARE WITH THE TRADITIONAL USE OF MATERNAL AGE FOR FETAL DOWN SYNDROME DETECTION?

The projected detection rate for fetal Down syndrome using the triple test (AFP, unconjugated estriol, human chorionic gonadotrophin in combination with maternal age) for women of all ages is 60-70%, with 5-8% of the total pregnancy population having a positive screen test result. For women 35 years or older, it is projected that 85% to 90% of cases of fetal Down syndrome could be detected by the triple test with 25% to 30% of this group having a positive test result. Thus, 70 to 75% of older women could be classified at low risk and thereby avoid amniocentesis, but 10-15% of cases of fetal Down syndrome will be missed. If traditional maternal age criteria were applied to older women, 100% of cases would be detected if all women age 35 and above had amniocentesis.

"...maternal age can no longer be considered the most important determinant for assigning risk."

For example, if 1500 women age 35 and older all had amniocentesis, 10 fetuses with Down syndrome would be diagnosed. If these same women were screened using the triple test, 9 of the 10 fetuses would be detected, but only 450 of the 1500 women would require amniocentesis. The number of amniocentesis performed for each case of Down syndrome identified for the triple test is therefore only 1/3 that required using maternal age screening.

WILL MULTIPLE MARKER SCREENING DETECT OTHER CHROMOSOME ABNORMALITIES ASSOCIATED WITH AMA?

The ability of the triple screen to detect chromosome abnormalities other than Down syndrome has not yet been defined. Consequently, other abnormalities may not be detected. Individually, these abnormalities have a much lower incidence than Down syndrome. Collectively, they have a combined risk equal to that of Down syndrome. The Foundation for Blood Research and several other centers are prospectively evaluating a protocol for detecting a significant percentage of trisomy 18 cases. Until the performance characteristics of the triple test are defined for other chromosome abnormalities, however, older women should be made aware that the triple test is for fetal Down syndrome screening only.

SHOULD TRIPLE SCREEN BE OFFERED ROUTINELY TO OLDER WOMEN?

When used along with the three biochemical markers, maternal age can no longer be considered the most important determinant for assigning risk. From a public health perspective, triple test screening is sound because a high detection rate is maintained with a significant reduction in the amniocentesis rate with its attendant risk of miscarriage. The triple test, therefore, provides the older patient considering amniocentesis a better estimate of her risk for carrying a fetus with Down syndrome. It is essential, however, that women in the older age group are adequately counseled regarding the limitations of the triple test and be made aware that the test is not a substitute for amniocentesis.

IF WE RELIED UPON TRIPLE TEST SCREEN, WOULD THE OPTION OF CVS BE LOST?

CVS is performed in the first trimester of pregnancy while the triple test is used for screening in the second. It thus offers another option for women who did not have CVS.

HOW IS THE TRIPLE TEST PERFORMING?

The performance of the triple test is now being prospectively evaluated in a number of screening centers in the United States. The FBR is currently conducting two large collaborative studies.

The first involves collecting data on the use of the triple screen when applied to women of all ages. The enrollment phase of this study has been com-pleted, and it is anticipated that data on 25,000 screened pregnancies will be available for analysis this year. A second study, a collaborative effort between the FBR and the State of California, focuses on high risk women referred to prenatal diagnostic centers, where the majority of indications for amniocentesis are advanced maternal age. In this study, women are asked to provide a serum sample prior to amniocentesis, which is then assayed for the three markers, and a risk for fetal Down syndrome is assigned. The results from the chromosome studies are then collected and linked with the risk results. This study will answer the question of how the triple test performs when applied to older women. In addition, information will also be obtained on the usefulness of the triple test as a screen for chromosomal abnormalities other than Down syndrome. Although these collaborative studies are not yet complete, preliminary results indicate that the performance of the triple test is meeting expectations.

Paternity Testing: New Role for Genetic Counselors

from p. 1

married woman who has had an affair and the woman with multiple partners are both asking the same question, "Who is the father in this pregnancy?" yet some counselors may judge these women very differently.

A woman with a genetic indication for prenatal diagnosis in addition to her primary motivation of paternity determination may be allowed to proceed with paternity testing while a woman who does *not* have a medical indication is refused. Some centers allow paternity testing in cases of alleged rape or incest, considering this a legitimate reason. What makes these cases potentially problematic is not knowing whether rape or incest actually occurred and the fact that charges may not have been officially filed. Some women may file charges pending the results of such testing.

The above points demonstrate that the lines are not clear-cut in deciding what is an "acceptable" social indication for paternity testing, placing genetic counselors in the role of moral gatekeepers.

Professional Demands

Prenatal paternity testing presents specific problems which the genetic counseling field may need to address. While there are several commercial laboratories that actively advertise paternity testing services, the primary limiting resources for the *prenatal* analysis is the availability of genetic counselors to provide counseling and physicians to perform prenatal diagnostic procedures.

Many genetic centers are understaffed with excessive patient volumes, and some genetic counselors would rather schedule counseling appointments with patients who have genetic concerns. In addition, the counseling and coordination of paternity testing cases is particularly time consuming.

Shortcuts have Long Implications

One possible approach for genetic counselors is to treat paternity testing as single issue cases and not as "genetic" cases, so that a genetic intake and the genetic laboratory analysis could be omitted. Such an approach would be contrary to our standard of care which has emphasized obtaining a complete history, since patients frequently do not realize that a condition in their family is inherited. What would our liability be after prenatal testing for paternity determination if a chromosome analysis was not performed or her family history had not been obtained and a woman has a child with Down syndrome or a son with Duchenne muscular dystrophy? The issues of genetic counselor liability and patient confidentiality need to be examined in these types of cases given that a genetic counselor could be summoned for testimony if criminal or civil charges are filed.

Professional Responsibilities

If genetic counselors and centers choose *not* to handle prenatal paternity testing cases, what are the alternatives for families? Some possibilities to consider are:

- train single gene (issue) counselors
- have the obstetricians handle the cases and provide them with a list of laboratories
- have these cases handled by the laboratory personnel who would also make arrangements for the prenatal diagnostic procedures.

If we approach prenatal paternity cases on a case-by-case basis, we leave patients vulnerable to an individual counselor's moral judgment. Even a center-by-center approach may not be the best way to address some of these questions. Perhaps the genetic counselor's role in paternity testing is to actively participate in developing policies in both our individual centers and in our profession.

• • •

[Ed. Note: The PGC Editorial Board recognizes that genetic counselors usually lead busy lives and appreciates the time and energy devoted to the articles solicited for this newsletter. A special acknowledgement to Wendy Uhlmann, who completed this article the weekend before delivering Rachael into this world and helped edit the final version just one week after delivery! — V.V.]

Reproductive Genetics Center, Hutzel Hospital Suggested Guidelines for Prenatal Paternity Testing

Currently, our center handles paternity testing on a case-by-case basis. We have developed the following guidelines which may be of use to genetic counselors who accept paternity testing cases.

- **Spend** a few minutes on the telephone to save significant time later. Most inquiries do not reach the counseling phase and even fewer enter the testing phase since the majority of patients are deterred by the cost.
- **Schedule** a consultation first since there is a significant amount of information to discuss. Emphasize the availability of pre- and postnatal testing and work with the patient to determine which best suits her needs.
- **Ascertain** why paternity testing is being requested and the likelihood of different persons being the father. This information may prove useful later when communicating test results.
- **Establish** clearly how and to whom the results are to be communicated, both in verbal and in written form.
- **Review** all paperwork and consent forms carefully since they vary among laboratories.
- **Obtain** a genetic history on every person involved, whenever possible.

HUMAN GENOME UPDATE

THE HUMAN GENOME PROJECT is a major scientific endeavor that promises new opportunities for genetic counselors. In an effort to be proactive, the NSGC has appointed a standing subcommittee of the Social Issues Committee to deal with issues related to the Human Genome Project. One goal of this subcommittee is to keep the NSGC membership informed.

NAMES & PHONE NUMBERS TO KNOW

- **BETH FINE, M.S.,** Chair, NSGC Human Genome Subcommittee, 312-908-7441
- **ERIC JUENGST, PH.D.,** Ethicist and Program Director, ELSI Working Group of the HGP, 301-496-7531.
- **RON WORTON, M.D.,** Chair, ASHG Human Genome Committee; 416-598-6385.

ABBREVIATIONS TO RECOGNIZE

NCHGR: National Center for Human Genome Research
DOE: U.S. Department of Energy
HGMIS: Human Genome Management Information Systems
ELSI: Ethical, Legal & Social Issues
HGP: Human Genome Project

PUBLICATIONS TO ORDER

For written publications, contact Sandy O'Connor, NCHGR Communications Office: 9000 Rockville Pike, Bldg 38A, Room 617, Bethesda, MD 20892; 301-402-0911.

- *Understanding Our Genetic Inheritance,* The U.S. Human Genome Project:The First Five Years, FY 1991-1995
- *The Human Genome Project Fact Sheet,* May, 1991 (Excellent)
- *NCHGR Ethical, Legal, and Social Issues Program Has Successful First Year -* Backgrounder, 10/90

DATES TO NOTE

- October 18 - 19: *The Societal Impact of Human Genetic Engineering,* Oak Ridge, TN. N. Brown, 615-483-4357
- October 21 - 23: *Human Genome III: The International Conference on the Status Future of Human Genome Research,* San Diego, 212-730-1050.
- October 26: *Science Journalism III. Genes & Human Behavior: A New Era?* Harvard Med School, Boston, J. Beckwith, 617-432-1920.
- Nov 8 - 9: *Justice and the Human Genome,* Chicago, Sue Talbert, 312-996-4631.
- Nov 21 - 23: *Prenatal Genetic Testing: The Impact on Women,* NIH, Karen Rothenberg, 301-496-4121.

JoAnn Inserra, M.S.,

The Human Genome Project

produced by: Office of Communications, NCHGR
format, length: VHS, 23 min., *loan program information:* 1-800-243-6877
reviewed by: Yezmin Perilla, M.S., and Helen Travers, M.S.

The stated purpose of this video is "to inform the public about the goals of [Human Genome Project] and the impact it will have on our health and daily lives." Dr. James Watson, project director, and several other leaders in the field describe the processes of mapping - both genetic and physical - and allude to how this information may be used. We are urged to carefully consider ways to safeguard information obtained from the project.

The overall quality of the production is very good. The creative use of graphics illustrates and clarifies the rather technical discussions. Unfortunately, the use of graphics is not extensive, and is overshadowed by lengthy, somewhat unfocused conversations, so that the implications of what is being said may be lost to viewers not already familiar with the project. How the Human Genome Project will impact everyone's lives becomes secondary to the complexity of the technology used in this enormous project.

The illustration of the techniques applied to the localization of the relatively unknown (to the general public) Aniridia-Wilms Tumor is quite clear. But many people will not be particularly concerned with such a rare disorder. The power and potential of the Human Genome Project is lost when the viewer cannot see any personal relevance. "How will the Human Genome project affect me?" is not addressed directly enough to pique the interest and excitement of an uninformed viewer.

The NCHGR plans to distribute the video to schools, patient advocacy groups, legislators and consumers. This video could serve as the starting point for a lecture by an enthusiastic speaker who could focus the points begun in the tape. However, it is difficult to imagine this tape being well accepted and understood by the general public if used alone.

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc.
Editorial Staff:
• *Editor-in-Chief* • Vickie Venne, Nichols Institute, 33608 Ortega, San Juan Capistrano, CA 92690; 800-642-4657
• *Assistant Editor* • Karen Copeland, Perinatal Services, 2100 Webster St, San Francisco, CA 94118; 415-923-3046
•Andrew Faucett, Memorial Medical Center, Savannah Perinatology, 4750 Waters Ave, Suite 202, Savannah, GA 31404; 912-351-5970
• Susan Jones, Childrens Hospital, Div. Human Genetics, 219 Bryant St., Buffalo, NY 14222; 716-878-7545
•Trish Magyari, Macrosystems, 8630 Fenton St., Silver Springs, MD 20910; 301-588-5484
• Seth Marcus, Lutheran General Hospital, Perinatal Center, #325, 1875 Dempster St., Park Ridge, IL 60068; 708-696-7705
• Sylvia Mann, Shriners Hospital, 1310 Punahou St., Honolulu, HI 96826; 808-948-6872
•Kathryn Steinhaus, Univ California Irvine Medical Center, Dept. Pediatrics, Div. Human Genetics, P.O. Box 14091, Orange, CA 92613-4091; 714-634-5780
• *Executive Director* • Bea Leopold • NSGC Executive Office, 233 Canterbury Drive, Wallingford, PA 19086; 215-872-7608; FAX# 215-872-1192

Send case reports, resources, materials and books for review to appropriate editors; address changes, subscription inquiries and advertisements to Executive Director; all other correspondence to Editor-in-Chief.
Publication Date, Next Issue: December 16
Deadline for Submissions: November 11

Bulletin Board

JGC Set for Early '92

The first issue of the *Journal of Genetic Counseling* will be published and distributed to all NSGC members in early 1992.

Manuscripts that address *any* issue relevant to genetic counseling will be considered for publication. Genetic counseling case analyses, research reports, essays and review articles are all appropriate for submission. The Editorial Board is particularly interested in assisting first time or developing authors and encourages NSGC members to take advantage of this resource.

Instructions for authors are available from the editorial office, c/o Deborah L. Eunpu, Center for Developmental Medicine and Genetics, Albert Einstein Medical Center, 5501 Old York Rd, Philadelphia, PA 19141; 215-456-8706. ***Please Note:*** The 1992 membership dues will include a modest increase of $25 to cover additional expenses related to publishing and distributing the *Journal.* The Editorial Board and Board of Directors worked diligently to select a publisher who could provide the best quality publication at the lowest price to our members. Considering the current cost of other journals, we believe the added cost for this quarterly journal is quite reasonable. We trust you will, too.

Deborah L. Eunpu, M.S.
Editor-in-Chief, *JGC*

'92 AEC Committee Named

The site, topic and committee chairs for the 1992 Annual Education Conference have been set. All that is missing is you! Attend the planning meeting at the ICHG on Sunday, October 6 at 4:00, Ramada Renaissance TechWorld, Room 2. If you cannot attend, call one of the following committee chairs to offer your assistance:

Co-Chairs: Ann Happ, M.S. Albany Med Ctr, Albany, NY; 518-445-5120 and Lynn Hauck, M.A.. U Ariz Health Sci Ctr, Tucson, AZ; 602-795-5675

Logistics: Monica Wohlferd, M.S.S.W., UCSF Med Ctr, SF, CA; 415-731-1070

Program: Andrea Fishbach, M.S., Kaiser Permanente, SF, CA; 415-929-5712

Workshops: Kathy Keenan, M.S., Albany Med Ctr, Albany, NY; 518-445-5120, or Ellen Limber, M.S., Albany Med Ctr, Albany, NY; 518-445-5120 and Kathleen O'Connor, M.P.S., Repro Genetics Ctr, Denver, CO; 303-399-5393

Abstracts & Contributed Papers: Wendy Uhlmann, M.S., Hutzel Hospital, Detroit, MI; 313-745-7066

Communications: Maureen Smith-Deichmann, M.S., Northwestern Mem Hosp, Chicago, IL; 312-908-7441

Curbside Consultations; Lavanya Marfatia, M.S., U Florida, Gainesville, FL; 904-392-4104 and Rosalie Goldberg, M.S., Montefiore Med Ctr, Bronx, NY; 212-920-4781.

Meeting Manager

Oct 5 - 6: *Developing Genetic Technologies: Implications for Nursing Research and Practice,* ISONG, Washington, DC. Info: Shirley Jones, GIVF Institute, 3020 Javier Rd, Fairfax, VA 22031; 703-698-3948. *Update on developing genetic technologies and their implications for nursing research and practice; forum for communication and sharing among an international community of nurses involved in providing genetic health care services.*

Code of Ethics Approved

This summer, the full membership voted on the adoption of a society-wide Code of Ethics. The final committee-recommended and Board-approved Code of Ethics document and ballots were sent to 695 Full members. The response was 450, or a resounding 64%. Here are the results of that ballot:

In favor, 423 (94%); Against, 9 (2%); Abstain, 10 (2%) ; Ballot returned, but not completed, 8 (2%).

The NSGC extends appreciation to the ad hoc Committee on Ethical Codes and Principles for five years of diligent effort on behalf of the NSGC and the profession: Judith Benkendorf, M.S., (Chair); Nancy Callanan, M.S., Rose Grobstein, B.A., Susan Schmerler, M.S. and Kevin FitzGerald, S.J.

Member Input

Results Reported...

In the last issue of *PGC* (13:2), the Annual Education Conference (AEC) subcommittee conducted a membership survey to determine your preference for holding the AEC in conjunction with other groups or on its own. Results are as follows:

Total Surveys Mailed	901
Responses Received	
Full	334
Associate	14
Student	20
Total Responses	368
Total % Responses	41%

Of the responses received, the membership voted as follows:

Hold AEC *with ASHG*	
Full	69%
Associate	71%
Students	55%
Hold AEC *with March of Dimes*	
Full	17%
Associate	29%
Students	35%
Hold AEC *on its own*	
Full	9%
Associate	0%
Students	12%

...and Another Response Requested

Currently, the NSGC's 1993 Annual Education Conference is scheduled to be held in conjunction with the ASHG in New Orleans. At this time, the NSGC has *not* made a financial commitment to the City of New Orleans for this conference.

Louisiana's recent passage of one of this country's strictest anti-abortion laws prompted the Board to direct this committee to again poll the membership. The issue is:

How many of you would boycott the NSGC's 1993 AEC as a political statement?

Options for your opinion are given on the enclosed post card ballot. Please review it carefully and respond by Friday, October 18. Results will be reported in the Winter issue of *Perspectives.*

Susie Ball, M.S., Chair
AEC Subcommittee

Resources

Books

Genethics: The Clash Between the New Genetics and Human Values

authors: D. Suzuki and P. Knudtson
publisher: 1990, Harvard University Press, Cambridge, Mass
price: $12.95 ppbk, 372 pp
reviewer: Susan Schmerler, M.S., St. Joseph's Hospital, Paterson, NJ

The basic premise of *Genethics: the Clash Between the New Genetics and Human Values* is that the public must take an active role in the development of policies regarding the applications, regulations and monitoring of the new genetics. By presenting moral guidelines ("genethic principles") based on past experiences found in science, the authors hope to initiate a public dialogue to address these issues.

The first genethic principle presented is that a basic understanding of the subject is necessary *before* one can address complicated questions. Therefore, the first five chapters comprise a mini-course in genetics. The subjects of evolution and cell biology as well as basic genetics are described as an elegant "dance of the genes." The use of this metaphor greatly enhanced the presentation of basic concepts. However, the general public, those who need the education most, will have difficulty comprehending the sophisticated explanations. If the target audience of the book had been a college educated public, fulfilling the goal of the first genethic principle would have been successful.

The remaining chapters are each devoted to illustrating the basis for a specific principle. Chapter 7, on genetic screening in the workplace, proposed: "information about an individual's genetic constitution ought to be used to inform his or her personal decisions rather than impose them." Genetic screening programs, in the workplace and in health care centers, are reviewed and well presented with details that illustrate the benefits and problems that can arise from such tests.

The issues raised are important, especially when social injustice (targeting only specific populations for testing) and unfounded applications (restricting job opportunities rather than cleaning the workplace for everyone) ensue. These are topics that warrant a public forum. However, I am not sure this book has provided that for the majority of the public. I found the material interesting, but would not expect most of the population I serve to understand the background information.

Some information included in the text was distracting. Why quote an incidence for Tay-Sachs disease for northern European Jewish marriages when the Ashkenazi Jews of eastern Europe have a higher carrier frequency? And I don't agree that an incidence of XYY karotypes found in liveborn males is rare. Finally, if I told my patients that amniotic fluid is extracted from the fetus as is stated, none would opt for amniocentesis. When presenting information with the goal of education, there is an obligation to be accurate.

I finished *Genethics* feeling dissatisfied. The authors did not achieve their goal of heightened awareness for the general public. More needs to be said in language that can be understood by the average reader.

• • • • •

Understanding Breast Cancer Risk

author: P. Kelly
publisher: 1991, Temple Univ Press, Philadelphia, Pa.
price: $17.95pb, $39.95 pp. 157
reviewer: Jill Stopfer, M.S., Albert Einstein Medical Center, Phila. PA

Patricia Kelly states in the introduction that her book is intended for "health professionals who provide care to women with a breast concern." As one such professional, I found segments of this book to be quite insightful, while other chapters were too simplistic to be useful for the genetics professional.

The book covers: patients' risk perceptions, familial and epidemiologic factors that may contribute to an individual's risk of breast cancer, descriptions of benign breast diseases and noninvasive cancers and suggestions for helping patients with their breast concerns.

Chapters titled "The Patient's Perspective," and "Helping Patients with a Breast Concern" are the most useful parts of the book for the professional. The genetic counselor will recognize some basic counseling techniques applied to sessions in which anxiety-inducing information is being presented. These segments read like sensible advice from a colleague who has worked with women at increased risk for breast cancer rather than as a textbook presenting the results of scientific research in this area. While this format is certainly useful, Dr. Kelly fails to reference any of the published studies.

I found the chapter titled "Evaluation of Breast Cancer Risk" somewhat frustrating. Using sketchy "guidelines," a patient who has a mother and maternal grandmother with breast cancer is informed that she has a lifetime breast cancer risk of 20%. However, as with other risk figures, there was insufficient information provided as to how this figure was derived. Although a lay-person may be satisfied with a skeletal explanation, it is inadequate for a health professional who may be interested in learning how to compute the risk.

Although this book is fraught with omission of the well acknowledged and valuable scientific studies in this field, none is so clearly and deliberately self-promoting as "Appendix A." It is here that Dr. Kelly lists the "Breast Cancer Risk Analysis Services" available nationally. She fails to mention any but her own and two others where she personally trained the counselors. Other fine programs exist, such as the ones at Creighton University, University of Wisconsin at Madison, Strang Clinic and Johns Hopkins.

My recommendation to any genetic counselor interested in providing risk assessment for breast cancer is to perform the necessary literature searches, contact and work with others in the field and perhaps refer to this book as an introduction.

LETTERS TO THE EDITOR

CVS AND LIMB ANOMALIES

To The Editor:

Earlier this year, Firth and colleagues[1] in the U.K. reported five infants with severe limb malformations among 289 pregnancies in which transabdominal chorionic villus sampling (CVS) was performed at 8-9.5 weeks gestation. Four of the five infants had the hypoglossig-hypodactylia syndrome; two had CNS anomalies as well. In subsequent issues of *Lancet,* letters appeared from groups in Italy and China[2] supporting the existence of a relationship between CVS and limb malformations. In Chicago, we recently encountered four cases of terminal transverse limb anomalies among 309 infants born to women undergoing CVS at our institution. None of these infants had other anomalies. Three of the CVS cases were transcervical; one was transabdominal. The procedures were performed at 9, 9.5, 10.5 and 11.5 weeks gestation.

A number of mechanisms have been proposed to explain the occurrence of limb malformations and perhaps other anomalies following CVS. The most likely is thrombosis at the sampling site with subsequent embolization to the fetus or generalized decreased perfusion of the fetus resulting in ischemia and necrosis of the distal parts. Both are quite plausible based on previous demonstrations in both humans and animal models of such a vascular origin of limb anomalies.

In contrast to our observations and the others recently reported, several large series have failed to reveal a clear increase in the incidence of limb malformations among CVS patients. Data from two large U.S. collaborative studies were recently reviewed by Mahoney[3] and were interpreted as showing no more limb anomalies overall than anticipated based on available data from general population incidence. Therefore, the issue is clearly not settled. Further data are urgently needed.

In response to the suggestion by Firth *et. al* that the risk of limb anomalies might be confined to the gestational period prior to 9.5 weeks, some U.S. centers have begun to restrict CVS to 10 weeks gestation or beyond. In view of the fact that two of our four patients had their procedures after 10 weeks gestation, however, I do not believe we can feel confident that such an approach will eliminate any increased risk. Until this issue is resolved, patients considering CVS by either the transcervical or transabdominal approach, regardless of gestational age, should be counseled that there *may* be an increased risk of birth defects, specifically limb malformations, associated with the procedure.

Barbara K. Burton, M.D.,
Humana Hospital Michael Reese
Chicago, IL

1 *Lancet* 1991; 337:762-63
2 *Lancet* 1991; 337:1091-3
3 *Lancet* 1991; 337:1422-23

EDITOR'S NOTE: We thank Dr. Burton for bringing this issue to our attention. It is apparent that additional knowledge is neccesary to resolve this question. Genetic counselors should take this opportunity to evaluate their own center's experience with the effects, if any, of CVS on pregnancies and to critically review the available literature.

CULTURAL VALUES V. MORALITY: *NOT* A DILEMMA

To the Editor:

I read with interest and concern the articles "The Dilemma of Sex Selection" *(PGC*13:2).

The editor and both authors have made every effort to be understanding. I certainly agree that each of us should strive to understand the request for sex selection from the patient's perspective. Through careful questioning and discussion, we can hope to help them comprehend that in this country abortion for purposes of sex selection is generally not acceptable. I imagine that this approach is one that most genetic counselors would find reasonable. But, in this effort to be understanding, let us not lose sight of the issue: *abortion of fetuses solely for the purpose of sex selection is morally wrong.* That another culture views this behavior as acceptable does *not* validate it. Morality is *not* relative to culture.

We must strive to help these families, but we must also never forget that there are behaviors that are just plain wrong.

Michael L. Begleiter, M.S.
Children's Mercy Hospital
Kansas City, MO

VISIONS OF OUR FUTURE

A vision is a living image.

An *organizational* vision is that living image transformed into what a membership *wants* their organization to "look like in the future."

An *ideal* vision grows and changes with new technologies and trends, builds organizational strengths and capitalizes on its uniqueness.

Visions are *big.* They are based on ideas people commit to over the next 2...5...or 10 years.

An organization with a clear, compelling vision engages its members to work together, transforming it from image to reality. What is *your* vision for the NSGC? Think about values, professional status, image, reputation, size, composite of membership and marketplace. Then make it a point to sign up for one of the **LONG RANGE PLANNING FOCUS GROUPS,** scheduled every day at lunchtime during the ICHG, October 7 - 11 in the NSGC Administrative Office, Room 17, Convention Center. Box lunches will be provided, courtesy of Vivigen.

Reading materials will be available to familiarize you with visioning concepts prior to your session.

Sound intriguing? Space is limited. Please sign up early. Can't be at the ICHG but have some thoughts? Contact a Committee member: Virginia Corson, M.S., Chair; Debra Collins, M.S.; Andrea Fishbach, M.S.; Ann Happ, M.S.; Trish Magyari, M.S.; Mimi Riesch - Donnelly, M.S.; or Bea Leopold, M.A.

• CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED •

SAN DIEGO, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Oppty for indepen in i'disc setting; consult from UCSD & Childrens; coun & coord PN svc; prof & commun outrch & ed; coord dysmorph clinics; liaison w/ other gen clinics.
CONTACT:Raymond M. Peterson, MD, San Diego Regl Ctr for Developmentally Disabled, 4355 Ruffin Rd, San Diego, CA 92123; 619-576-2961. EOE/AA.

STANFORD, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Oppty to work indep w/ diverse, multi-ethnic caseload: genrl & PN coun for MSAFP, prof & pt educ.
CONTACT: Cindy Soliday, MS, Genetic Counseling Clinic, Dept Ob/Gyn. Stanford Univ Med Ctr, Stanford, CA 94305; 415-723-5198. EOE/AA.

WASHINGTON, DC: Immediate opening for BC/BE Genetic Counselor with possible faculty appt.
RESPONSIBILITIES: Independent, active role in all aspcts of antenatal tstg unit: CVS, amnio, MSAFP, fetal anomalies on large, multidisc team w/ close ped/gen dept interface. Active AMBG-certified training site; research.
CONTACT: Judith L. Benkendorf, MS, Georgetown Univ Med Ctr, 3800 Reservoir Rd NW, Dept. Ob/Gyn, Washington, DC 20007-2197; 202-687-8810. E O E / A A .

BOYNTON BEACH, FL: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team in community hosp setting: amnio; CVS; teratogen coun; genrl/post level II u/s genetic coun; oppty for ped coun avail.
CONTACT: Genetic Services, Bethesda Memorial Hospital, 2800 S. Seacrest Blvd Ste 104A, Boynton Beach, FL 33435; 407-738-0448. EOE/AA.

ATLANTA, GA: Immediate opening for BC/BE Genetic Counselor. Min 3 yr clin exp req w/ emphasis on PN.
RESPONSIBILITIES: Genetic consultation support & tech asst to physicians for pts w/ abnormal results; pt consults.
CONTACT: Brenda Jones, Human Resources, Genetrix, 6401 E. Thomas Rd, Scottsdale, AZ 85251; 800-333-GENE. EOE/AA.

NEW ORLEANS, LA: Immediate opening for Clinical Coordinator/Genetic Associate w/ Genetic Counseling or related degree.
RESPONSIBILITIES: Coord active program from intake to coord of lab eval to follow-up coun and referral with variety of patient contact: inpt hospital consults, outpt clinics & statewide satellite clinics. Ongoing activities involve comprehensive mngmt of PKU families. Public & prof ed.
CONTACT: Richard Greene, Asst. Director Personnel, Tulane University School of Medicine, 1430 Tulane Ave, New Orleans, LA 70112. EOE/AA.

BALTIMORE, MD: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: PN coun on large, multidisc team for amnio, CVS, MSAFP, triple scrn, teratogen, fetal anomaly follow-up; ped coun in outrch clins; ample educ & rsrch oppty avail. ABMG-appvd trng site, PhD Human Gen prog.
CONTACT: Maimon M. Cohen, PhD, Div Human Genetics, U Maryland School Medicine, 655 W. Baltimore St, Baltimore, MD 21201; 301-328-3480. EOE/AA.

LEXINGTON (BOSTON), MA: Immediate opening for BC/BE Genetic Associate.
RESPONSIBILITIES: Assume significant respon in pt coun & case mngmt in clin-oriented svc offering full range of clin svc: genetic coun, routine & early anmio, consult u/s; MSAFP & cytogen lab svcs; facilitate preg loss support grp; liaison between physicians & ctr.
CONTACT: Barbara Thayer, MS, or Christine E. Ford, Prenatal Diagnostic Center, 80 Hayden Ave, Suite 200, Lexington, MA 02173; 617-862-1171. EOE/AA.

SCARBOROUGH (PORTLAND), ME: Immediate opening for BC/BE Genetic Counselor. Exp pref.
RESPONSIBILITIES: Comprehensive regl genrl genetics & PN svcs; large MSAFP (triple marker scrn) & preg loss/trtmt prog in conj w/ Maine Med Ctr; ongoing rsrch & ed proj; OB/Ped resident educ.
CONTACT: Richard Doherty, MD or Ed Kloza, MS, Foundation for Blood Research, PO Box 190, Scarborough, ME 04070-0190; 207-883-4131. EOE/AA.

LANSING, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active, expanding Perinatal Ctr: genetic, preconcept, hi-risk preg, amnio, CVS, MSAFP coun; partic in prof medical & nursing ed.
CONTACT: Susan Karam, MS, Perinatal Ctr, Sparrow Hospital, 1215 E. Michigan Ave, Lansing, MI 48909; 517-483-2004. EOE/AA.

ST. LOUIS, MO: Immediate opening for BC/BE Genetic Counselor in rapidly expanding, univ-affil genetics program.
RESPONSIBILITIES: Coun in genrl & subspec clins; consults at primary & satellite sites; oppty for prof & commun ed activ.
CONTACT: Dr. Sue Chen, Acting Director, Div Medical Genetics, Cardinal Glennon Childrens Hosp, 1465 S. Grand Blvd, St. Louis, MO 63104; 314-577-5639. EOE/AA.

HELENA, MT: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: New position includes: ped & adult general genetics, outreach clinics to Native Americans, fetal pathology, PN screening & diagnosis; oppty for prof & public ed.
CONTACT: Joan FitzGerald, MS, Shodair Hospital, PO Box 5539, Helena, MT 59604; 800-447-6614.

LONG ISLAND, NY: Immediate opening for parttime (26 hrs/wk) BC/BE Genetic Counselor. Experience & Spanish pref; strong interest in coord & partic in prof & commun educ.
RESPONSIBILITIES: PN & ped coun to outrch clin in Nassau & Suffolk Counties as well as clinics in local commun hosp. Affil w/ NY Hosp-Cornell U Med Col.
CONTACT: Barbara Miller, MS, Genetics, St. Charles Hospital, 200 Belle Terre Rd, Port Jefferson, NY 11777, 516-474-6374. EOE/AA.

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor. Exp. pref; Spanish helpful. Excellent oral & written communication skills necessary.
RESPONSIBILITIES: Work independently on clin genetics team w/ varied respon incl: neonatal, peds & high-risk OB referrals.
CONTACT: Dr. Kwame Anyane-Yeboa, Columbia-Presbyterian Med Ctr, Presbyterian Hosp, PH12-1276/W, 622 W. 168th St, New York, NY 10032; 212-305-6731. EOE/AA.

CLEVELAND, OH: Immediate opening for BC/BE Genetic Counselor at univ-affiliated hosp.
RESPONSIBILITIES: Join active, expanding multidisc team for broad range of coun & educ activ: PNDx, birth defects & dysmorph; PN scrng for AFP, HCG, UE; terat risk assessmt; biochem/molec dx. Participate in prof & commun educ at all levels expected; oppty for clin rsrch avail.
CONTACT: Lois H. Dickerman, PhD, Genetics Center, Case Western Reserve University, UCRCII, Suite 510, Cleveland OH 44106; 216-844-3936. EOE/AA.

PORTLAND, OR: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coun on multidisc team srvg adult & ped population w/ some consults in spec clinics; located at univ-based facility in expand acad rsrch dept.
CONTACT: Karen Kovak, MS, CDRC, Oregon Health Sci Univ, PO Box 574, Portland, OR 97207; 503-494-8344. E O E / A A .

DANVILLE, PA: Immediate opening for BC/BE Genetic Counselor. Exper req.
RESPONSIBILITIES: PN, peds & adult coun in large teaching hosp.
CONTACT: Dr. Michael Ryan, Geisinger Clinic, Danville, PA 17822-1339; 717-271-6440. EOE/AA.

PHILADELPHIA, PA: Immediate opening for parttime indepen BC/BE Genetic Counselor. Exper strongly pref.

continued on next page

RESPONSIBILITIES: Dev & coord PN gen svc in tertiary care ctr: CVS, amnio, dx u/s, PUBS, MSAFP, terat coun w/ cyto & molec gen labs on-site. Ample support from multidisc genetics team. Resident ed & commun outrch; resrch encour.
CONTACT: Robert Reardon, Administrator, Dept. OB/GYN, Albert Einstein Medical Ctr, 5501 Old York Rd, Philadelphia, PA 19141; 215-456-6994. EOE/AA.

PITTSBURGH, PA: See Genetrix, Atlanta, GA

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor. Min 2 years exp pref.
RESPONSIBILITIES: Ped & adult genrl GC in acad setting w/ tchg & rsrch opporty.
CONTACT: Dianne Abuelo, MD, Genetic Counseling Center, Rhode Island Hospital, 593 Eddy St, Providence, RI 02902; 401-277-8361. EOE/AA.

CHARLESTON, SC: Immediate opening for BC/BE Genetic Associate. Exper pref.
RESPONSIBILITIES: Autonomous position on team in free-stdg univ-affil PNDx ctr.
CONTACT: G.S. Pai, MD, MUSC, Childrens Hospital, 171 Ashley Ave, Charleston, SC 29425-3310; 803-792-2620. E O E / A A .

BURLINGTON, VT: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Teratogen coun in reg'l ctr; some peds & PN coun.
CONTACT: Barbara West, MS, Vermont Regional Genetics Center, Dept. Pediatrics, Univ Vermont, Burlington VT 05405; 802-658-4310. EOE/AA.

NORFOLK, VA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: PN coun and coord for large referral base.
Contact: Deborah L. Smith, M.S., or Donald L. Levy, M.D., Div Maternal Fetal Medicine, Eastern Virginia Medical School, 825 Fairfax Ave, Norfolk, VA 23507-1912; 804-628-7300. EOE/AA.

RICHMOND, VA: Immediate opening for BC/BE non-tenure track Lecturer in Genetic Counseling Training Program. Teaching experience and organizational skills preferred; must be willing to travel to referring hospitals & satellite clinics.
RESPONSIBILITIES: Teach graduate, medical, dental and nursing students and assist in the direction of the genetic counseling instructional track; counsel and follow-up patients of all ages with variety of genetic disorders; develop educ materials & programs for students, professionals & pts.
CONTACT: Dr. Joann Bodurtha, Dept. Human Genetics, Box 33, MCV Station, Richmond, VA 23298-0033. Send 3 ltrs of ref and CV by 10/31/91. EOE/AA.

LEGISLATIVE BRIEFS

PRO-CHOICE CAMPAIGN TARGETS LOUISIANA POCKETBOOK

The ACLU Reproductive Freedom project has spearheaded a campaign to boycott Louisiana as a means of expressing displeasure over its virtual complete ban on abortion services. They are urging pro-choice groups to pull their events out of the state and cancel personal trips to the state.

So far, this campaign has been extremely successful: the New Orleans Tourism and Convention Commission announced that less than a month after the law's enactment, the city had already lost an estimated $41 million from canceled conventions. This figure is in addition to the estimated $31 million the city would have received from four meetings over the next 20 years of the American College of Obstetricians and Gynecologists, who recently voted to remove New Orleans from their standard rotation of cities. The American Public Health Association also recently voted to do the same. NSCG members can support this effort.

- CALL 1-800-33-GUMBO, the Louisiana Tourism Board, to express your displeasure over their abortion laws;
- RECONSIDER any planned personal trips to the state;
- BOYCOTT professional meetings and other events to the state;
- EXPRESS your opinion regarding the planned NSCG meeting in New Orleans in 1993 (see article on p. 8 and enclosed postcard ballot);
- EXPRESS your opinion to the ASHG president regarding the 1993 meeting and the ASHG's planned designation of New Orleans as one of three permanent meeting sites.

NSCG BOARD SOLICITS MEMBERS EXPERIENCES WITH THE GAG RULE

Is the Supreme Court's ruling that prohibits programs receiving Title X funds from counseling women about abortion (ie., the GAG RULES) having an effect on genetic counselors? If these regulations are influencing your practice, please relay your experiences to your Regional Representative. They have been asked to gather this information and report back to the Board at the October meeting.

SCHOOL READINESS ACT OF '91

A comprehensive bill to expand medical, educational and social services to underserved pregnant women and preschool children has recently been introduced as the School Readiness Act of 1991 (S911) by Senator Edward Kennedy. This bill has several components that expand access to care for high risk groups of women and children:

- HEALTH CENTER'S INITIATIVE — Expands prenatal and early childhood health services through community, migrant and homeless health care centers;
- SMOKING CESSATION IN PREGNANCY PROGRAM — Provides technical assistance to establish smoking cessation programs as a routine part of prenatal care via state and local health departments;
- HOME VISITING PROGRAM FOR AT-RISK FAMILIES — Provides grants for home visits to high risk pregnant women and infants with birth defects or developmental delay;
- HEAD START ENTITLEMENT — Expands access to Head Start for all income-eligible children.

Please contact your Senator to support this bill, c/o U.S. Senate, Washington, D.C. 20510, or call the U.S. Capitol switchboard at 202-224-3121.

— Trish Magyari, M.S.
Legislative Liaison