PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 11, No. 2 Summer 1989

Mailings Key Society Business

The NSGC is alerting members of three important summer mailings.

- The 9th annual educational conference brochure was mailed on June 19.
- Full members, only, will be receiving ballots and candidate information in late July.
- The 1989/1990 Membership Directory, generously funded by Nichols Institute Reference Laboratories, will be sent via bulk mail in early August.

If you do *not* receive these mailings, please call the Executive Office, 215-872-7608.

on the inside

Reproductive Genetics & New Technologies

DNA Analysis

Professional Responsibilities and Counseling Issues

by Patricia A. Ward, M.S., Baylor College of Medicine, Houston, TX

As the rapidly expanding field of molecular genetics provides increased opportunities for the diagnosis of genetic disorders, it also creates new challenges for the genetic counselor. The nature of DNA analysis, particularly those studies involving linkage, raises a number of questions about professional responsibility and counseling issues related to privacy of decision making and confidentiality of medical information.

KNOWLEDGE + OPTIONS = RESPONSIBLE COUNSELING

The American Society of Human Genetics statement, drafted by the *ad hoc* Committee on DNA Technology, addresses the specific responsibilities of the health care professional who provides genetic counseling.[1]

Genetic counseling which involves discussion of DNA analysis requires current knowledge about the availability of testing, potential usefulness to the particular case, costs and whether testing would be performed on a diagnostic or research basis. Since new mapping data, mutation detection and linkage data are constantly becoming available for other genetic disorders, it is critical that genetic counselors keep current regarding these advances and their impact on clinical testing. This information can generally be obtained by contacting a DNA diagnostic lab.

Once the genetic counselor has the information, the next challenge lies in sharing it with the client. Most clients

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Obstetricians' Choices for Reporting MSAFP Test Results

by Barbara Bowles Biesecker, M.S., Past Clinical Coordinator, MSAFP Testing Program; SmithKline Bio-Science Laboratories, St. Louis, MO

As genetic counselors, we are aware that discrepancies often exist between the expressed needs of patients and needs they demonstrate. A commercial laboratory that delivers genetics services through intermediaries — physicians and hospital laboratories — must satisfy these clients from a business perspective while providing a quality service to their patients. This report describes a conflict that arose when we attempted to satisfy the perceived vs. expressed needs of our clients.

BACKGROUND

In updating its MSAFP screening program in 1987, SmithKline Bio-Science Laboratories surveyed obstetricians regarding their preferences for MSAFP test report format. Thirty physicians from selected key obstetrical practices in three cities were

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EdNotes

I suspect that for many people the fascinating thing about genetics is the technology. *Genetic engineering. CVS. Polymerase chain reaction.* Evoking scenes of bespectacled, wiry-haired scientists in white lab coats peering through microscopes or into racks of test tubes, these terms capture the imagination of the public. Between the serious weekly news magazines and the supermarket tabloids, the image of genetics — and geneticists and genetic counselors — will be shaped for better or for worse.

Let's face it: the technology that we use as genetic counselors is far more glamorous than the activities that we perform. And while this issue of *PGC* and the theme of our meeting this Fall focus on technology, we can't let the relationship between genetic technology and genetic counseling become distorted — technology represents the tools available to our clients in their attempt to manage risk or disease. We can help our clients understand how the tools work, their risks and benefits and how to make use of the finished products. But we're not tool salespeople; we can't serve technology. It must serve us.

Pat Ward shares her rich experience in DNA testing in our lead story, stressing its impact on genetic counseling. As our second lead, *PGC* is pleased to present Barbara Bowles' summary of MSAFP reporting from industry's angle, balancing commercial and patient needs. Dr. Eugene Pergament's account of preimplantation technology, as reported in an interview with Seth Marcus, may represent another quantum leap in the area of prenatal diagnosis.

Finally, as an organization and as a profession, we should be very concerned about the situation in Ohio reported by Nancy Warren and Leah Hoechstetter in a *Letter to the Editor*.

Special thanks this issue to Vickie Venne for her extra efforts, and if you see Seth Marcus in Baltimore, buy him a beer and ask him to tell you about the technical problems with "the one that got away."

Ed Kloza

Visions, Viewpoints &...

An Interview with Eugene Pergament, M.D., Ph.D.

Reproductive Technologies into the '90s

Dr. Pergament is director of Reproductive and Medical Genetics, Illinois Masonic Medical Center, Chicago, IL

The natural history of prenatal diagnosis demonstrates a clear trend toward identifying disorders earlier and earlier in pregnancy. Amniocentesis, once available only to identify Rh iso-immunization late in pregnancy, is now often done earlier than the 14th week. CVS brought prenatal diagnosis to around the 9th week, as did high resolution ultrasound. Dr. Pergament's work introduces the availability of prenatal diagnosis at virtually the earliest point in pregnancy — prior to implantation.

PREIMPLANTATION GENETIC DIAGNOSIS...WHAT IS INVOLVED IN THIS NEW TYPE OF RESEARCH?

For the past three years, our research goal has been to develop techniques that will lead to preimplantation genetic diagnosis of high-risk pregnancies. Experiments have primarily involved human triploid embryos rejected for transfer. Two approaches have involved biopsy of the pre-embryo at the four cell and blastula stages of differentiation. As with any new prenatal diagnostic technique, the safety of the procedure and the accuracy of the genetic analysis require investigation.

WHAT OPPORTUNITIES DO YOU SEE FOR ITS CLINICAL APPLICATION?

Human triploid embryos biopsied at the four-cell and blastula stages appear to continue their usual developmental pattern. For genetic analysis at the four-cell stage, the polymerase chain reaction (PCR) has permitted sex-determination as well as identification of genes associated with alpha-1-antitrypsin and sickle cell anemia. For those genetic conditions diagnosed at the blastula stage, chromosomal, enzymatic and DNA analyses should be possible.

HAVE LEGAL RESTRICTIONS HAD AN IMPACT ON YOUR RESEARCH, PARTICULARLY IN REGARD TO OBTAINING EMBRYONIC MATERIAL OR USING GENETICALLY-ALTERED CELLS?

The legal restrictions placed on preimplantation genetic studies are the same that apply to all human clinical research programs. Our approach has been to use human embryos rejected for transfer for reasons totally independent of the research project. These embryos could be used at all stages prior to implantation; however, because of the genetic imbalance present, these embryos are not expected to proceed beyond the blastula stage.

With high-risk pregnancies which plan to continue following preimplantation genetic diagnosis, conventional in vitro fertilization (IVF) procedures require that only three or four fertilized embryos be transferred in any one cycle. If more than three or four pre-embryos are available, they will be cryopreserved and maintained in accordance with standard IVF protocols.

Preimplantation genetic diagnosis does not involve genetic alteration of the pre-embryo, but rather the identification of those pre-embryos carrying a normal gene versus those with the mutant genes. If experiments are to be conducted involving genetic alteration of human pre-embryos, the use of abnormal embryos unacceptable for transfer would again appear to be an acceptable approach...morally, ethically and legally.

WHAT BARRIERS, TECHNICAL AND NON-TECHNICAL, DO YOU SEE TO ROUTINE AVAILABILITY OF PREIMPLANTATION GENETIC DIAGNOSIS?

The technical limitations of preimplantation genetic diagnosis involve the multifaceted requirements to conduct such a program: the need for a high-quality IVF program, for embryologists trained in micromanipulation technique, and for the geneticists to have access to laboratories proficient in PCR, enzymatic and DNA technology.

The non-technical drawback to preimplantation genetic diagnosis is the potential expense to the patient. Comparison with the current methods of prenatal testing generates the following

costs: for high-risk pregnancy undergoing CVS or amniocentesis, the cost of testing is approximately $1,000. If a genetic abnormality is detected, the cost of an elective termination would range between $1,000 and $2,000, depending on the length of gestation. The maximum total cost in an established pregnancy undergoing conventional prenatal testing would be $3,000. For one IVF procedure, the cost is $5,000 and the possibility of a successful pregnancy is only 25%. If the procedure of preimplantation genetic diagnosis is to have any value to at-risk parents, its cost must be reduced considerably.

AS OTHER NEW REPRODUCTIVE TECHNOLOGIES ARE CONSIDERED, HOW DO YOU SEE THEIR RESEARCH OR CLINICAL APPLICATIONS BEING REGULATED?

There does not seem to be any reason for changing the present way in which original research is developed and conducted, even that involving embryonic/fetal research. In general, research proposals evaluated by institutional review boards and, in certain instances, by committees on ethics, have served the public welfare. The limiting factor is the funding of research projects. For example, there is a moratorium on embryonic research by the National Institutes of Health and this moratorium is primarily based on political rather than scientific considerations.

The key to questions concerning abnormal development, e.g., the etiology of congenital malformations, lies in our understanding the normal pattern of human embryonic development. Techniques are now available to begin to accomplish this goal but, unfortunately, embryonic and fetal research have become political issues. Moreover, the public is confused over the nature of embryonic research, its purpose and goals. Unless the public is better informed, research on human embryonic development will progress slowly.

Dr. Pergament has been invited to deliver a plenary session focusing on the future of genetic reproductive technologies at the 1989 NSGC Annual Educational Conference.

Seth Marcus
Interviews Editor

Case No. 16

Huntington disease: Inability to confirm diagnosis and risk

by Susan M. Jones, MS, The Children's Hospital of Buffalo, Buffalo, NY

Mrs. D was referred for genetic consultation by her infertility specialist because her family history suggested that her deceased father possibly had Huntington disease (HD). The referring physician wanted Mrs. D to understand the genetic implications of the family history before she underwent surgery for treatment of endometriosis.

Mrs. D was an intelligent woman whose family circumstances made confirmation of the diagnosis of HD difficult. She was the youngest of six siblings; her mother had remarried and had six more children by her second husband. Mrs. D had been raised with her half-brothers and sisters; she barely knew her full siblings and had never known her father.

The inadequate and conflicting medical records on the deceased father failed to mention HD but strongly suggested the possibility of a progressive neurological disorder. Also of concern was a report that Mrs. D's oldest full sibling, a brother in his 40's, had suffered for six years from an unspecified degenerative neurological disorder that according to some relatives was "the same as his father's." Mrs. D felt that it would be impossible for her to approach her brother, a stranger to her, to request information about his medical status.

Mrs. D was provided risk counseling for HD but was informed that without further documentation we could not be sure that either the diagnosis or the risk were correct. She seemed to dismiss the genetic information as not significant and stated that nothing but "absolute proof" of a diagnosis of HD in her father would cause her any concern. Stating that "this could be nothing at all or something that isn't genetic," Mrs. D proceeded with surgery.

Six months later, a woman referred for genetic counseling from the same rural area as Mrs. D's brother named him as a relative affected with HD. She subsequently decided not to pursue genetic evaluation; however, the call raised our suspicion that Mrs. D was indeed at risk for HD. During a follow-up call to Mrs. D, she reiterated her previous position that she was "not going to worry about this unless someone can tell me for certain that my father had Huntington's." Since the recent contact from the newly referred relative still could not confirm the diagnosis of HD, we decided not to share this information with Mrs. D.

A year later, Ms. R presented for genetic counseling, pregnant by a man reportedly with HD — Mrs. D's brother. She had cared for her disabled partner for approximately two years and told us that a diagnosis of HD had been made by a neurologist. Ms. R had decided to leave her partner after he suffered personality changes and became physically abusive. She refused our request to help obtain medical records on her partner; she was psychologically exhausted from caring for him and emotionally distraught over her pregnancy and her decision to leave him during his illness. She remained unwilling to help even when informed that the medical information might also be useful to another relative seeking genetic counseling.

We recontacted Mrs. D and told her that we had further undocumented information from independent sources that her brother had HD. Stating that "this is just hearsay so far," she remained unconcerned about the family history and unwilling to contact relatives and explore the diagnosis further.

This case posed several dilemmas for the genetics staff. First, Mrs. D's response to her potential risk appeared to be inappropriately casual. It was impossible to tell if she was trivializing her possible risk out of fear of its implications or if she was normally a person who did not worry about unconfirmed hazards. My feeling was that the latter was correct, but I remained conflicted about whether the patient's unwillingness to further explore her possible risk was in her best interest. Second, we had difficulty determining if and when we should share undocumented information from individuals unknown to her. We eventually decided to share this information because of staff sentiment that Mrs. D was entitled to know that further evidence supporting the diagnosis of HD had surfaced.

This case illustrates some of the challenges in the provision of genetic consultation when family circumstances and lack of medical information do not permit confirmation of a genetic diagnosis.

invited to participate in group discussions and private interviews. They were presented with samples of three different report formats and commented on convenience and speed of reading, ease of explaining the results to the patient and legal liability as implied by the text.

Format A featured the results in nanograms per mL and MoM corrected for gestational age, maternal weight, race and insulin dependent diabetes. It also highlighted the interpretation (low, normal, high), included reference ranges for 15 - 20 weeks and a description of the interpretation with detailed recommendations.

Format B also provided a MoM corrected for the four variables, but interpreted the results in terms of the numerical risk of twins, ventral wall defects, open spina bifida and Down syndrome. It also quoted a risk of 1 in 200 of serious complications associated with amniocentesis, but provided no recommendations.

Format C adjusted the results for gestational age, race and diabetes, and reported the results in "risk units" rather than MoMs. A flow chart was used to compare the prior risk of twins, open spina bifida, anencephaly, ventral wall defects, total risk of anomalies and Down syndrome to a revised, posterior risk. No recommendations were provided for follow-up.

Physician Preference

The physicians expressed a clear preference for Format A, citing its ease of reading compared to the other two reports which they considered cumbersome and confusing. They liked the highlighting of abnormal values and the inclusion of reference ranges in the first report. The other two formats were criticized because they emphasized risk, which could further increase the apprehension of patients by underscoring potential abnormalities and possibly increase the physician's legal liability as well. The unpopular formats lacked normative data for comparison and were judged difficult to read. The physicians were unable to interpret "risk units" which were utilized in the third format.

Comments on "Comments"

The physicians were asked for suggestions to improve the preferred format. Their recommendations:

- ***Keep it simple and straight forward.*** Avoid redundant information and keep comments to a minimum. Many patients request to see their MSAFP test report and pregnant women are especially emotional. Therefore, any increase apprehension caused by lengthy or detailed comments could prolong the time spent with the physicians, who are concerned about effective time management.
- ***Provide options for follow-up.*** If physicians choose a course of action different than one recommended on the report, then the documentation in the patient's chart (i.e. the report) will not parallel her care. This could increase their legal liability. The physicians suggested that alternative follow-up approaches should be offered, acknowledging that differences of opinion exist among competent professionals.
- ***Assume that physicians understand follow-up protocols.*** Avoid text which tells physicians exactly what to do. Physicians who order MSAFP tests should be familiar with appropriate follow-up. Any information on the report beyond whether the result is within normal limits is unnecessary since patients with abnormal results are referred to genetics centers. There, the patients will be provided with any further details by the geneticists. Alternatively, they suggested that information in the comment section could be provided through supplementary materials; paradoxically, the physicians added that information on risks of low birthweight, prematurity, fetal demise and renal abnormalities should appear on the report as well.

...the physicians' suggestion to list alternative follow-up protocols (was) in direct conflict with their desire for a concise, easy-to-read statement.

Discussion

There were conflicting messages from this group of responding physicians. They wanted the interpretive comments minimized, yet suggested more information to include. While they felt that the comments were not useful, they did not demonstrate clear understanding of the test or appropriate follow-up. Furthermore, the physicians' suggestion to list alternative follow-up protocols would result in a more lengthy and potentially cumbersome comment section, in direct conflict with their desire for a concise, easy-to-read statement.

In response to this survey, we considered the impact of the respondents' suggestions. Minimizing the comment section in regard for the participants' concerns for legal liability and time management would have created a conflict between our desire to please the clients and our commitment to provide a comprehensive program, with clear recommendations for follow-up.

As far as we are concerned, there are not several professionally endorsed alternatives for appropriate follow-up. Our protocol describes an algorithm for patient care in accordance with guidelines established by the American Society of Human Genetics and other professional organizations. Deviating from the protocol, in our view, may not be appropriate to providing the best possible patient care. Although the responsibility for follow-up may be delegated to genetics centers, there are several initial steps which may be carried out by the primary physician.

We ultimately modified the comment section in a manner considered less binding on the physician. This was achieved by using phrases such as "sonographic studies may be helpful" rather than "should be performed." This and other modifications represent a balance between the client's preferences and our desire to provide a complete MSAFP report.

Conclusions

While no general conclusions regarding obstetricians' preferences could be made on such a small sample, the results of the market research provided us with insight into potentially sensitive areas and assisted us in designing a report format which addresses the needs of our clinician clients without compromising our role in caring for patients.

For a copy of the sample formats used in this survey, please write to: Barbara Biesecker, M.S., University of Michigan, Dept. Pediatrics, D1109 MPB, Ann Arbor, MI 48109.

OH Law Negates Genetic Counseling as Profession

To The Editor:

The "Genetic Counselors" in the state of Ohio have a problem we wish to bring to your attention.

We are not permitted to use the title "Genetic Counselor" in reference to ourselves or "Genetic Counseling" to describe our primary responsibilities because of our exclusion from a recent state law mandating licensing of counselors and social workers. Since our training and job responsibilities are unlike those specified by the law, we are unable to qualify for licensing without the addition of another two years of Masters-level coursework in counseling as well as three years experience supervised by a licensed professional counselor (as defined by the State).

The Counselor and Social Worker Board has decided that if one cannot be licensed, one cannot use the term "counselor" in one's title or "counseling" in reference to one's activities.

The law is intended to protect the public from charlatans, quacks or others who might hang up a shingle claiming expertise as a counselor without any training or credentials.

Ohio is one of 33 states which have passed legislation regulating the practice of counseling. From our review, it would appear that Ohio's law may be the most stringent. Ohio feels it is on the cutting edge, leading the nation in protection of its citizens. We view it as the denial of a *bona fide* profession, for which we have been duly academically trained, experienced and nationally certified.

We are interested in learning if any of you have had any interactions, positive or negative, with similar state licensing laws. We would be happy to hear your suggestions as to how we might resolve the problem as we plan our strategies to contest the application of this law to genetic counselors in Ohio. We can be reached at (513) 559-4760.

(on behalf of our Ohio colleagues)
Nancy Steinberg Warren, M.S.
Leah Hoechstetter, M.S.
Children's Hospital Medical Center
Cincinnati, Ohio

Reaching Out to Underserved Populations

To The Editor:

Are genetic counseling services appropriately reaching underserved populations? According to the conclusions of a three-day working symposium on Genetic Services for Underserved Populations held in May, the answer is definitely *NO*.

Among the disturbing and far reaching conclusions reached was that "a large proportion of the United States population receives inadequate health care because of one or more of the following factors: ethno-cultural distinctiveness, geographic isolation, language barriers, religious beliefs, personnel shortages, racial differences and economic disadvantages."

Furthermore, medical genetics services are often inaccessible because they are largely preventive, relatively new, rather sophisticated in nature, restrictive in time allowed for some interventions *and* their high cost is poorly reimbursed.

In the United States, about one in four to five individuals is either a member of an ethnic racial minority group or is foreign born and thus faces ethno-cultural barriers in accessing health care. More than 53 million Americans are underinsured or have no insurance for important primary and preventive health services. Of these, nearly 14 million women are in their child-bearing age.

As providers, we need to educate ourselves about the ethno-cultural identities of patients and their special needs so that our services can be more meaningful, sensitive and supportive. In addition, genetic counselors need to work together to effect both state and federal policies regarding funding for genetic services so that our services are not restricted only to those who can pay.

Ilana Mittman, M.S.
San Francisco General Hospital

[Ed Note: This issue was addressed in Case No. 15 (PGC: Vol. 11, No. 1, Spring 1989). Judith Benkendorf made the point that Fetal Alcohol Syndrome is particularly high in urban, public hospitals where underserved populations are predominant.]

Low AFP Protocol Revision Suggested

To The Editor:

I would like to suggest that consideration be given to including a sonographic screening examination for features of Down syndrome in all pregnancies evaluated for a positive low MSAFP result.

In California, patients do not routinely have an ultrasound performed either prior to or in conjunction with MSAFP screening as it is mandatory for physicians to offer their patients the blood test only. When the patient is given the MSAFP results she is "counseled" by an AFP coordinator who is also a genetic counselor and is given a statistical risk of bearing an infant with Down syndrome.

It is my opinion that the patient would benefit substantially from sonographic examination specifically to identify the presence or absence of the nuchal fold sign and an evaluation of femur length. Such an examination should also include documentation of the presence of a normal heart and stomach, and should check the fifth finger for clinodactyly or hypoplasia of the middle phalanx.

Perhaps the inclusion of information regarding sonographic evidence of Down syndrome may assist the couple in their decision regarding genetic amniocentesis.

John D. Stephens, M.D.
California Prenatal Diagnosis Institute

Benacerraf, BR, Barss, VA and Laboda LA. A sonographic sign for the detection in the second trimester of the fetus with Down's syndrome. *Am J Obstet Gynecol* , 1985, Apr 15; 151(8):1078-9.

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Elias, S. and Annas, GJ. Routine prenatal genetic screening [editorial] *N Engl J Med* 1987 Nov 26; 317(22):1407-9.

Hegge, FN, Prescott GH, Watson PT. Sonography at the time of genetic amniocentesis to screen for fetal malformations. *Obstet Gynecol* 1988 Apr; 71(4):522-5.

Editorial Policy for 'Letters to the Editor'

Letters to the Editor are welcome and encouraged.

All letters must be signed and must include a professional affiliation as well as a daytime telephone number.

The author may request to have his/her name withheld.

The decision to publish letters will depend on the availability of space, the timeliness of the issue and the relevance to the readership as determined by the Editor.

Workshop Focuses on Genetics for Allied Professions

"Genetic Applications for Health Professionals" is an intensive three-day workshop developed by the University of Colorado (UC) Schools of Nursing and Medicine to educate community and school nurses, social workers and others in the principles of human genetics and the provision of genetic services.

This Denver-based program trains regional coordinators by offering instruction on course administration. Through contract or license, the developers of the course supply all materials, including flyers, detailed lesson plans, videotaped presentations, slide sets, disc tutorials and student study guides. A textbook developed for the course is available separately at a bulk rate of $17.95 or individually for $29.95. The coordinators are, therefore, fully equipped to administer the course in their local area.

Under the contract, students pay tuition to UC for professional continuing education ($90.00) or graduate credit ($120.00). The coordinator may charge and retain an administrative fee of up to $50 per student. Course content is basic, yet detailed enough to introduce students to a large number of concepts without being overwhelming. UC maintains control over content through lecture outlines but also allows flexibility in presentation by allowing guest lecturers and the options of using videotapes or slides. The course is designed to be offered over several weeks, allowing students ample time to absorb the information. There are opportunities to review concepts in class discussions and daily review sessions.

The text is generally high quality and provides useful margin summaries on nearly every page. However, it lacks the continuity in style provided by one author and could benefit from expansion of the section on molecular application. Disc tutorials allow independent review, and students are required to pass a final exam.

References to applications are frequent and especially effective in a family consumer panel discussion and an individual case study project. The textbook and discs, a good pair for limited independent study, are available directly from the publisher.

This course is a powerful package which is simple to employ in diverse locations. It will provide other professionals the requisite information they have awaited.

Katherine Berry, M.S.
Shodair Hospital, Helena, MT

For more information, contact Ann N. Smith, Ph.D., Project Director, Genetic Applications, University of Colorado Health Sciences Center, School of Nursing, 4200 East 9th Avenue, Box C-287, Denver, CO 80262; 303-270-8733

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DNA Analysis...

from p. 1

can feel overwhelmed by the amount of information covered in these sessions, especially if a woman is pregnant and the session includes an in-depth discussic of options for prenatal diagnosis. Timing of the DNA analysis can be important, since the data may dramatically alter the risk determined previously or the presumed risk assessment by the family. Acceptance of this new information takes time and the use of this information for decision making may not be immediate. Allowing adequate time for the session is critical and discussion of carrier or presymptomatic testing *before* a pregnancy is advantageous.

Communicating Complicated Concepts

The use of visual aids, such as pop-beads, to demonstrate informativeness, linkage and recombination, can be invaluable in explaining these concepts. The mathematic aspects of the DNA data analysis can be complicated and the explanation of this information requires careful assessment of the client's understanding of these concepts. It is helpful to compare the calculated risk *prior* to DNA analysis with the possible risks considering several hypothetical outcomes of the study. This exercise not only demonstrates how the analysis m clarify risk, but it also demonstrates th possibility of ambiguous results due to recombination, lack of informative markers or false paternity.

In addition to the sheer volume of information, the issues raised by the need for family cooperation in DNA linkage analysis and the information potentially obtained as a byproduct (e.g., false paternity) can represent a major obstacle in the utilization of these services.

Dealing with Noncompliance

Noncompliance by key family members with the request to participate in DNA analysis is frequent. Often, the reasons for this refusal stem from the major impact that the occurrence of a genetic disease has on family functioning. In some instances, refusal to participate may be based on fear of identification of false paternity. The fact that nonpaternity is identified in these studies at all suggests that the individuals involved do not understand the basis of the tests. In our DNA laboratory experience, the majority of cases with paternity conflicts involved individual who had *not* participated in the genet

counseling process.

Another aspect which may inhibit compliance is concern that presymptomatic studies may be positive and the impact that these positive results may have on insurance coverage and employment status. Lack of family compliance can have significant implications with regard to the accuracy of DNA analysis and in some instances, can make it impossible to perform the study.

Some women decide to postpone the DNA analysis until additional information is available...or not to pursue the DNA family study at all...

The need for extended family involvement also represents an invasion of the client's privacy, particularly when decisions about prenatal diagnosis and selective abortion are involved. Some women decide to postpone the DNA analysis until additional information is available, (e.g. fetal sex for X-linked disorders) or not to pursue the DNA family study at all because of their desire to maintain privacy in these decisions.

Confidentiality as a Counseling Issue

Once the DNA diagnostic testing is completed, information is available for the client and often for other family members. Counseling conducted before DNA analysis should address the issue of willingness of family members to share information about genotypes in order not to breech any individual's confidentiality.

Part of the ASHG statement addresses the question of confidentiality of this medical information as follows: "The process should avoid needlessly informing individuals who do not wish to learn their genotype or informing one family member of another family member's genotype."[1]

Appropriate notification of other family members with data can be complicated by location and level of compliance. Perhaps the best approach would be similar to notifying relatives when a chromosome translocation is identified in a family member, sending a short letter to the individual indicating that results are available and offering to assist them in finding a genetic counselor in their area. Making arrangements for the primary client to release the report is also required.

Genetic counseling for which medically useful information can be gained by DNA analysis will become more common as rapid advances continue in the study of the human genome.

Genetic counselors should accept the challenging responsibility of maintaining current information about availability of testing, providing education about this new technology to families and other professionals and facilitating provision of these services through coordination efforts and counseling support.

1 *Ad hoc* Committee on DNA Technology, Am. Soc. Hum. Genet. DNA banking and DNA analysis: Points to consider. *Am. J. Hum. Genet.* 42 (5): 1988, pp. 781-3.

A Primer of DNA Technology

by Corrine D. Boehm, M.S., Johns Hopkins University, Baltimore, MD

Genetic counselors need to educate themselves about the relatively new molecular technology and update themselves to maintain knowledge of a current list of disorders which are diagnosable by these techniques. With identification of new technologies and probes for providing more accurate and rapid diagnoses, genetic counselors will face the challenge of learning this information in order to be responsive to their patients' needs. Following is a review of the most common DNA methods currently used for diagnosis of genetic conditions.

DNA BASED GENETIC TESTING is currently carried out for single gene disorders either as prenatal, carrier or presymptomatic testing. A diagnosis is achieved either through *linkage analysis* using restriction fragment length polymorphisms (RFLPs) to track the inheritance of a disease gene within a family or through *direct detection* of a genetic lesion.

LINKAGE ANALYSIS is used in situations where it is neither possible nor feasible to detect the mutation directly. Probes detecting RFLPs near or within the gene of interest are used in family studies. If an informative marker is not found, a diagnosis may not be possible. Two types of errors are unique to linkage analysis:

- misassumptions about the biological relationships of individuals in the study (e.g. non-paternity)
- recombination between the RFLP marker being used for diagnostic purposes, the actual genetic lesion responsible for the disease and how closely linked the informative markers are to the mutation.

DIRECT DETECTION of a mutation is possible when:

- the mutation alters a restriction endonuclease recognition site
- the mutation is due to a gene deletion, or
- DNA sequences encompassing the mutation have been determined so that an oligonucleotide probe sequence to the mutation can be synthesized.

Direct detection methods are inherently more accurate than linkage studies since non-paternity and recombination errors will not be made. However, direct detection methods can only be used when the type of molecular defect responsible for a disease has been characterized.

POLYMERASE CHAIN REACTION (PCR) is a new technique used in DNA diagnostic testing for genetic disorders. While this does not provide new diagnostic capabilities, it has dramatically simplified many of the procedures which were already in use and allows diagnoses to be made more rapidly than by traditional methods. With PCR, one can rapidly synthesize millions of copies of a discrete DNA sequence *in vitro*. By amplifying the target DNA sequence of interest, the detection schemes are much easier and allow simpler, more rapid diagnostic capabilities with smaller amounts of sample.

HMHB Conference Slated

The bi-annual national Healthy Mothers, Healthy Babies Coalition conference will be held October 13-15, 1989 in Washington, DC.

The Genetics Subcommittee will co-sponsor two workshops, "Preconceptual Prenatal and Postnatal Strategies for Substance Abusing Women and their Infants" and another on AFP screening.

A pre-conference focusing on developing low literacy materials will be held on October 12.

For more information contact: Healthy Mothers Healthy Babies (202) 863-2458.

Jill Fonda Allen and Trish Magyari
NSGC Liaisons to HMHB

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I'natl Pregnancy and Infant Loss Awareness Event

To celebrate the first year anniversary of Former President Ronald Reagan's Proclamation that October is Pregnancy and Infant Loss Awareness Month, an international gathering of parents, health care professionals and support group leaders is slated for October 12 - 15 in Washington, DC. The event has been slated to coincide with the bi-annual HMHB (see above) and RESOLVE meetings.

The activities for awareness weekend include: a walk to remember and service of remembrance; networking/resource sharing opportunities; task force meetings and round table discussions.

One special event will be the tying together of hundreds of baby blankets which have been made in memory of miscarried and stillborn babies as well as newborns. Parents may send a baby blanket, which will be returned, without being present at the event.

For information, contact PILC, 1421 E. Wayzata Blvd, Suite 40, Wayzata, MN 55391; 612-473-9372.

Judith Benkendorf

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Slide Swap to Expand at '89 Educational Conference

Based on the successful Slide Swap interchange last year, the Media Resource Center committee will be adding an Electronic Software and Video Share at the 1989 Educational Conference in Baltimore.

Members are being asked to bring slides, videos and public domain (non-copyrighted) data management-based software to share.

Please note that all slides and videos involving patients *must* have signed consent forms. If you have resources to share *or* you need to create a release form, please call me at 313-493-6060.

Robin Gold
Media Resource Committee Chair

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Last Call: 1988 Proceedings

The Proceedings of the 1988 Annual Education Conference, "Strategies in Genetic Counseling: Political Influences from Society to the Workplace," held in New Orleans last October, is currently being prepared for publication. The members' and non-members' registration fee for the conference included advance purchase of the Proceedings. Copies will be mailed to those registrants this Fall.

A limited number of books will be available for purchase by interested individuals who did not attend the conference and by students. To order a copy, please send a check or money order for $30, payable to "NSGC," to the Executive Office. Please indicate your name, mailing address and a daytime phone.

Please note that orders will *not* be processed without prepayment.

LuAnn Weik
Conference Chairperson

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Call for *PGC* Editors

Two positions will become available on the *PGC* Editorial Board this Fall. The terms of Melonie Krebs, Resources Editor and Janice Stryker, Counseling Approaches Editor, will expire in October.

The Resources Editor is expected to solicit or identify books, pamphlets, videotapes, organizations and other resources designed to be helpful to patients. This editor oversees written reviews of these resources and is responsible for their inclusion in *PGC*.

The Counseling Approaches Editor is expected to solicit or identify case reports which focus on genetic counseling issues. This editor will oversee written reviews is responsible for their inclusion in each issue of *PGC*.

Interested applicants should write to me *no later than* August 15.

Ed Kloza
Editor in Chief, *PGC*

New Genetic Counseling Training Programs Accept Students for Fall

Two genetic counseling training programs, one in Texas and one in Minnesota, are slated to begin taking students this fall.

Jacqueline T. Hecht, PhD., has been named Director of the newly-created, ABMG-accredited Genetic Counseling Program affiliated with the University of Texas Health Sciences Center Graduate School of Biomedical Sciences. In addition to a focus on all aspects of genetics and genetic counseling skills, the program will emphasize new molecular techniques and applications. Additional information may be obtained by calling 713-797-4581.

The University of Minnesota has developed a program designed to balance studies in genetics, psychosocial counseling and bioethics. Meeting all of the criteria set by the American Board of Medical Genetics, the program was granted accreditation in April 1989. For information, contact Bonnie S. LeRoy, M.S., Assistant Program Director, at 612-624-0144.

Member Awarded Barbara Bush Commemorative Grant

Congratulations to Trish Magyari, who has been named recipient of the first Barbara Bush Commemorative Grant by the March of Dimes National Capital Area chapter. This $5000 award will ensure continuation of her ongoing work to develop literature on maternal and prenatal substance abuse for low literate minority women.

BOOK

Prenatal Tests
Author: Robin J.R. Blatt
Publisher: Vintage Books, 1988
Price: $9.95 pb
Reviewed by: Barbara Bernhardt, M.S.
Sinai Hospital of Baltimore

Prenatal Tests is written for any pregnant (or potentially pregnant) woman who will be making decisions about prenatal testing— thus, all pregnant women. The book's strength is in empowering women to make decisions about their health care, highlighting the voluntary nature of testing and raising questions women need to ask themselves and their health care providers.

After introducing the purpose of the book, the author devotes the next 80 pages to reviewing MSAFP testing, ultrasound, amniocentesis, CVS and PUBS. Each chapter concludes with a self-awareness checklist of the pros and cons of each procedure.

Chapters on genetic and environmental risks follow. The information here is generally correct and most readers will be able to determine if they have something specific about which to be concerned. However, some information is erroneous: it is stated that "imperfect" appearing embryos for IVF can be discarded before implantation and that cocaine is an "unlikely" teratogen. The errors are not always simply due to outdated information.

The book concludes with two chapters on individual decision making. An appendix lists descriptions of selected genetic conditions and birth defects, support groups and the offices of the state genetic services programs.

The chapters on MSAFP testing and ultrasound caution women to carefully consider each test before it is done. The AFP chapter unfortunately may lead readers to believe that an abnormal MSAFP value is almost always associated with incorrect dating, a fetal anomaly or a laboratory error. The concept of AFP testing as a screening tool isn't clear.

The amniocentesis, CVS and PUBS chapters each accurately describe the procedures and provide an exhaustive, sometimes exaggerated summary of the risks. Although some of the information presented is incorrect or outdated, most of the material presented is factual and clear. The reader is not reminded to specifically seek updated information.

The chapters on abnormal results and abortion are sensitive, thoughtful and clearly presented.

About two-thirds of the way through this book, I began to wonder why genetic counseling was not mentioned more often as a resource for information and support. In the chapter on *Prenatal Self-Assessment,* I discovered why. The author believes that "while counselors are supposed to be non-directive and to support you in any decision that you make, many professionals have biases in favor of prenatal testing." Later, she states "many counselors...may not always fairly portray the range of expression of the [disabling] condition." A "balanced" perspective on an assortment of genetic conditions is therefore provided in the appendix. All descriptions are brief. As an example, Hurler syndrome, included in the section on X-linked disorders, is described as a condition in which "life expectancy is shortened" with no mention of the extraordinary amount of care affected children eventually need. Hydrocephalus is described as a condition in which "with early diagnosis and treatment, physical and mental development can be expected to be normal."

This book would be appropriate for a couple who, after having had genetic counseling, asks for reading material which might provide additional enlightenment. However, this book was not intended for people *after* they have had genetic counseling, but rather to help women decide if they want or need prenatal testing. In that regard this book generally will be helpful because it contains mostly accurate information, is clearly written, helps women formulate questions and lets them know that they, not their health care providers, should be making the decisions about testing.

I wish that genetic counseling had been presented as a more valuable resource and hope that people who read this book will not be tempted to avoid our services.

AUDIOVISUAL

THREE APPROACHES TO AFP SCREENING

AFP Testing/Patient Info (National Version)
Produced by: Abbott Diagnostics, Rainbow Productions, Abbott Park IL; 1987
Time/Price: 10:45; No Charge

Alpha Fetoprotein Screening
Produced by: Milner-Fenwick, Timonium, MD; 1988
Time/Price: 9:46; $250

AFP Screening
Produced by: Golden Door Productions, Berkeley CA; 1989
Time/Price: 11:20; $229 (vol. discounts available)
Reviewed by: Kathie Foss, RN and Paula Haddow, MAT, Foundation for Blood Research, Scarborough, ME

In evaluating patient education videos, one looks for clarity, simplicity, accuracy and audience appropiateness. Of the three videos, the Golden Door video fulfills all of these criteria completely; the Abbott and Milner-Fenwick videos to a lesser degree.

Both the Abbott and Milner-Fenwick videos use a narrator to describe AFP and the meaning and significance of high and low values. They both use easy-to-understand graphics, including representations of spina bifida and Down syndrome. The Abbott video spends less time describing low AFP levels and Down syndrome than it does elevated levels and spina bifida. The relationship between low levels and Down syndrome needs to be covered in more detail, especially since this is the area of AFP screening that is often the most confusing to patients. The Milner video, in addressing elevated AFP levels, states (and lists in print on the screen), that "in addition to neural tube defects, high levels of AFP can point to other abnormalities in the skin, liver, kidneys and intestine." Although this is true, there are not enough data on risk for these disorders with elevated AFP, and this could lead to undue anxiety in the patient. Also, the Milner video states that Down syndrome is a condition "caused by an abnormality in one of the body's chromosomes."

The video by Golden Door uses an entirely different approach. There is a narrator to describe the details of AFP screening. However, the video also interviews patients, each of whom has different feelings as well as experiences with AFP, ranging from declining the test, discovery of twins, discovery of anencephaly and finding a low value, to those who had the test and would/would not terminate the pregnancy in the event of an abnormality. The video shows real children with spina bifida and Down syndrome when describing these conditions. As one lay person concluded after seeing these videos, "You come away from this video feeling good about AFP screening, no matter what you decide to do."

Classified • Classified • Classified

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

CHANDLER, AZ: Immediate opening for Masters-level, BC/BE Genetic Associate. Salary: $28,000 - $30,000, possibly negotiable w/ experience. Excellent health & travel benefits.
RESPONSIBILITIES: Preconceptual & prenatal diagnosis & counseling: MSAFP; CVS; amniocentesis; congenital malformation & pregnancy management education; teratology; opportunity for community & professional education.
CONTACT: Gary F. Simpson, M.D., Arizona Institute for Genetics and Fetal Medicine, 3200 N. Dobson Road, Suite E2, Chandler, AZ 85224; 602-897-0234. EOE/AA.

FRESNO, CA: Immediate opening for Masters-level, BC/BE Genetic Counselor. Some experience preferred.
RESPONSIBILITIES: Join MD geneticist, fellow, 4 GCs & 4 nurse clinicians in new position at comprehensive regional service center: prenatal diagnosis, AFP & newborn screening programs; sickle cell & satellite clinics; pregnancy loss project.
CONTACT: Marcy Masumoto, MS, Valley Children's Hospital, Genetics Prenatal Detection Unit, 3151 N. Millbrook, Fresno, CA 93703; 209-225-3000 x 1434. EOE/AA.

LOMA LINDA, CA: Immediate opening for BC/BE MSAFP Coordinator/Genetic Counselor. Experience preferred.
RESPONSIBILITIES: Coordinate state-funded MSAFP program; professional and family outreach.
CONTACT: Olga Kalbermatter, RN, Coordinator Genetic Service, Loma Linda University Medical Center, Pediatrics/Genetics, Room A527, Loma Linda, CA 92350; 714-796-7311x2838. EOE/AA.

OAKLAND, CA: Immediate opening for Regional Perinatal Screening Coordinator of Genetics. BC/BE or RN/MSN with CA license required; experience in genetics, health education, administration and/or pediatrics strongly preferred. Salary Range: $29,880 - $39,720.
RESPONSIBILITIES: Coordinate existing & new perinatal screening & hi-risk programs; follow-up & monitor Regional Metabolic Center Clinic; some work in MSAFP program, when needed.
CONTACT: Gloria Flores-Garcia, Personnel Dept., Kaiser Permanente, 280 W. MacArthur Blvd, Oakland, CA 94611; 415-596-6175. EOE/AA.

OAKLAND, CA: Immediate opening for BC/BE Genetic Counselor (Full/Parttime negotiable.)
RESPONSIBILITIES: Join team in HMO setting with diverse opportunities: prenatal counseling; general genetic specialty clinics (spina bifida & metabolic) & perinatal screening.
CONTACT: Dr. Ronald Bachman, Kaiser Permanente, 280 W. MacArthur, Oakland, CA 94611; 415-596-6571. EOE/AA.

OAKLAND, CA: Immediate opening for BC/BE with Masters degree in GC, nursing, public health or related field. Experience in developmental disabilities preferred.
RESPONSIBILITIES: General developmental disabilities counseling; professional & family education; inservice & liaison to community; some local travel required.
CONTACT: Phyllis Young, Personnel Coordinator, Regional Center of East Bay (serving Greater Bay area), 2201 Broadway, 5th Floor, Oakland, CA 94612; 415-451-7232. EOE/AA

STANFORD, CA: Fall 89 opening for BC/BE Genetic Counselor. Parttime temporary with potential of permanancy.
RESPONSIBILITIES: General genetic counseling in department of Pediatrics/Birth Defects and in specialty clinics; inhouse consultation.
CONTACT: Susan Seto, MS or Susan Schelley, MPH, Stanford University Hospital, Genetics Center A345, Stanford, CA 94305-5119; 415-723-6858. EOE/AA.

NEW HAVEN, CT: Two immediate openings for BC/BE Genetic Counselors interested in research & professional education activities & opportunities. Generous benefits package.
RESPONSIBILITIES: Exposure to diverse pathologies in research-oriented university environment: amniocentesis, CVS, fetal blood sampling; fetoscopy, MSAFP.
CONTACT: Eileen DuBois, Human Resources, Yale University, P.O. Box 1404 Yale Station, New Haven, CT 06520; 203-432-5702. EOE/AA.

WASHINGTON, DC: Summer 1989 opening for BC/BE Genetic Counselor. 1 - 2 years experience preferred.
RESPONSIBILITIES: Coordinate & counsel prenatal patients: CVS, amniocentesis, MSAFP, PUBS; teratology counseling; weekly travel to DC public health clinic.
CONTACT: Melvin J. Austin, Administrator, George Washington University, Dept. OB/GYN, 2150 Pennsylvania Ave NW, GA-430, Washington, DC 20037; 202-994-8283. EOE/AA.

WASHINGTON, DC: Immediate opening for BC/BE Genetic Counselor. Parttime with fulltime potential.
RESPONSIBILITIES: Coordinate and provide case management for pediatric genetics outreach program; conduct professional education; opportunities for research exist.
CONTACT: Trish Magyari, MS, Georgetown University, Child Development Center, CG52 Bles Building, Washington, DC 20007; 202-687-8635. EOE/AA.

AUGUSTA, GA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team of 2 MD clinical geneticists and parttime social worker with primary responsibility for clinical service: routine genetics clinics; inpatient consultations; CF, hemophilia (NF pending) clinics; opportunity for medical student education.
CONTACT: David B. Flannery, MD, Medical College of Georgia, Div of Medical Genetics, Department of Pediatrics, Rm BG121, Augusta, GA 30912; 404-721-2809. EOE/AA.

CHICAGO, IL: Fall 1989 opening for BC professional with Masters in Genetic Counseling and minimum 5 years experience in start-up position as Director, Graduate Program in Genetic Counseling.
RESPONSIBILITIES: Provide curriculum design, administration and instruction in new genetic counseling training program; participate in patient counseling activities.
CONTACT: Connie Wolf, Northwestern University Medical School, Dept OB/GYN, 333 Superior Street, Suite 1176, Chicago, IL 60611; 312-908-3302. EOE/AA.

INDIANAPOLIS, IN: Immediate opening for BC/BE Director, Genetic Services with minimum 3 years experience in genetic counseling or genetic service. Clinical or medical geneticist, cytogenetic PhD may substitute for experience. Salary Range: Low $30,000s.
RESPONSIBILITIES: Direct all state MCH genetic services: newborn screening, specialty clinics, Regional Genetics Network.
CONTACT: Diane Downing, MSN, Director, Division of Maternal Child Health, 1330 W. Michigan Street, Indianapolis, IN 46206-1964; 317-633-0758; EOE/AA.

BALTIMORE, MD: Immediate opening for Parttime BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team in large, community hospital-based Prenatal Diagnostic Center.
CONTACT: Theodore A. Baramki, MD, Greater Baltimore Medical Center, 6701 N. Charles St, Room 1506, Baltimore, MD 21204; 301-828-2753. EOE/AA.

BOSTON, MA: Immediate opening for BC/BE Genetic Associate with masters in genetic counseling or related field. Some experience preferred, but not required.
RESPONSIBILITIES: Coordinate prenatal diagnosis & molecular DNA diagnosis programs, involvement in MSAFP; research opportunity available.
CONTACT: Aubrey Milunsky, MD, Boston University School of Medicine, Center for Human Genetics, 80 E. Concord Street, Boston, MA 02118; 617-638-7083. EOE/AA.

SPRINGFIELD, MA: Immediate opening for Masters-level BC/BE Genetic Counselor. Salary Range: $28,000 - $35,000, negotiable with experience.
RESPONSIBILITIES: Comprehensive service center: MSAFP, prenatal & hi-risk counseling; teratology; professional & community education.

CONTACT: Lynn Fogg, Recruiter, Baystate Medical Center, 759 Chestnut Street, Springfield, MA 01109; 413-784-3667. EOE/AA.

WORCESTER, MA: Immediate opening for Masters-level BC/BE Genetic Associate with 1 - 2 years experience.
RESPONSIBILITIES: Varied genetic counseling responsibilities; active liaison with patients, professional & laboratory.
CONTACT: Maureen Langevin, University of Massachusetts Medical Center, 55 Lake Avenue North, Worcester, MA 01655; 508-856-2181. EOE/AA.

MINNEAPOLIS, MN: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Perinatal center with wide variety of counseling: prenatal diagnosis, NICU, hi-risk OB; monthly general genetics clinic.
CONTACT: Barbara Kunz, MS, United Hospital, 333 N. Smith Ave, Room 2474, Minneapolis, MN 55102; 612-220-6270. EOE/AA.

ST. LOUIS, MO: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team to provide genetic, prenatal consultation & counseling services; involvement in specialty clinics & outreach activities; participate in medical student & resident education.
CONTACT: Su-chiung Chen, MD, Cardinal Glennon Childrens Hospital, 1465 S. Grand Blvd, St. Louis, MO 63104; 314-577-5639. EOE/M/F/H/V.

CAMDEN, NJ: Immediate opening for BC/BE Genetic Counselor. Experience preferred.
RESPONSIBILITIES: Comprehensive services: prenatal diagnosis; pediatrics; MSAFP; teratology; FAS; research; professional & community education.
CONTACT: Alice Lazzarini, MS, University of Medicine & Dentistry New Jersey School of Medicine, 401 Haddon Ave, Camden, NJ 08103; 609-757-7812. EOE/AA/M/F/H/V.

NEWARK, NJ: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join genetics team covering all aspects of genetic counseling: prenatal diagnosis, MSAFP, teratology, dysmorphology, biochemical genetics; opportunity for teaching & clinical administration.
CONTACT: Franklin Desposito, MD, New Jersey Medical School, Division of Genetics, 185 S. Orange Street F546, Newark, NJ 07103; 201-456-4477. EOE/AA.

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join genetic counseling team; diversified, flexible responsibilities in academic setting.
CONTACT: R.J. Desnick, PhD, MD or Judith P. Willner, MD, Mt. Sinai School of Medicine, One Gustave L. Levy Place, Division of Medical & Molecular Genetics, New York, NY 10029. EOE/AA.

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor in research position. Computer knowledge helpful.
RESPONSIBILITIES: Coordinate longitudinal study for International Fanconi Anemia Registry: maintain & update patient & family information with extensive patient & family contact in University-research environment.
CONTACT: Arleen D. Auerbach, PhD, The Rockefeller University, 1230 York Avenue, New York, NY 10021; 212-570-7533. EOE/AA.

STATEN ISLAND, NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Wide variety of services in comprehensive genetic diagnosis program.
CONTACT: Susan Sklower, MD, New York State Institute for Basic Research, 1050 Forest Hill, Staten Island, NY 10314; 718-494-5240; EOE/AA.

DURHAM, NC: Immediate opening for BC/BE Genetic Counselor in Research Position. Full or parttime negotiable.
RESPONSIBILITIES: Linkage study involves collecting data for inherited motor neuron disorders; extensive family & patient contact.
CONTACT: T. Siddique, MD, Duke University Medical Center, Div. Neurology, Box 2900, Durham, NC 27710; 919-684-5650. EOE/AA.

WINSTON-SALEM, NC: Immediate opening for BC/BE Genetic Counselor. Experience not required.
RESPONSIBILITIES: 50% MSAFP/50% hi-risk OB/GYN; education opportunities available.
CONTACT: Jeannette Bensen, MS, Bowman Gray School of Medicine, 300 S. Hawthorne Road, Pediatrics, Winston-Salem, NC 27103; 919-748-4321. EOE/AA.

EUGENE, OR: Aug opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: General genetics, specialty clinics, prenatal diagnosis and counseling for Southern Regional Oregon; administration and education in Regional Center of ORHSU.
CONTACT: Robert Nickel, MD, Child Development and Rehabilitation Center, Oregon Regional Health Science University, 901 E. 18th Street, Eugene, OR 97403; 503-686-3575. EOE/AA

PHILADELPHIA, PA: Fall 1989 opening for BC/BE Genetic Counselor with 3 years experience in prenatal and/or pediatric genetics.
RESPONSIBILITIES: Newly-created position will provide opportunities for professional development and independence on genetics team with molecular diagnostic and full-service cytogenetics laboratory: general and prenatal diagnosis clinics; growing MSAFP screening program; participate in research projects.
CONTACT: Deborah L. Eunpu, MS, Center for Developmental Medicine & Genetics, Albert Einstein Medical Center, York & Tabor Roads, Philadelphia, PA 19141; 215-456-6786. EOE/AA.

PHILADELPHIA, PA: Immediate opening for two BC/BE Genetic Counselors.
RESPONSIBILITIES: General genetic & teratogen counseling; MSAFP; PUBS; CVS; early & routine amniocentesis; intrauterine surgery; travel to satellites required.
CONTACT: Lynn Godmilow, MSW, Director of Genetic Counseling Services, Genetiks, Ltd, 301 S. 8th Street, Suite 3C, Philadelphia, PA 19106; 1-800-336-5633. EOE/AA.

DALLAS, TX: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Full range of pediatric genetic patients. Primary responsibility for coordinating metabolic diagnostic service; opportunity for developing & expanding research program at major medical center; interact with large active genetics team.
CONTACT: Lewis Waber, MD, PhD, University of Texas Southwestern Medical Center, Division Pediatric Genetics and Metabolism, 5323 Harry Hines Blvd, Dallas, TX 75235; 214-688-8996 or 6796. EOE/AA.

MADISON, WI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate state teratogen project with occasional responsibilities in general and prenatal genetics clinics.
CONTACT: Renata Laxova, MD, PhD, University of Wisconsin, Waisman Center, Room 337, 1500 Highland Ave, Madison, WI 53705-2280; 608-263-2510. EOE/AA.

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TORONTO, CANADA: Immediate opening for professional with training in genetic counseling or related science/ nursing degree w/ genetics background.
RESPONSIBILITIES: Expansion of prenatal diagnosis program; patient interviews & counseling & follow-up; review laboratory results; assess need, develop & implement new prenatal services.
CONTACT: Dr. Elaine Hutton, Toronto General Hospital, Prenatal Diagnosis Unit, 4 Norman, Urquhart Wing, Room 142, Dept. OB/GYN, 200 Elizabeth Street, Toronto, CANADA M5G 2C4; 416-598-6387.

TORONTO, CANADA: Immediate opening for BC/BE Genetic Counselor or masters in nursing degree.
RESPONSIBILITIES: Assist with inpatient consultation service & manage follow-up clinic; some involvement in prenatal diagnosis & specialty clinics.
CONTACT: Dr. J. T. R. Clarke, Head, Division, Clinical Genetics, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, CANADA M5G 1X8; 416-598-5753.

Roe v. Wade: Reaction or Pro-Action

In response to the Supreme Court case *Webster v. Reproductive Health Services*, Social Issues Chair Joanne Malin and Legislative Liaison Trish Magyari met with representatives from RCAR, NARAL, the Alan Guttmacher Institute and several Congressional and Senate offices in early March.

The following recommendations were made for the NSGC membership:

- We need to become proactive in educating legislators, pro-choice groups and the public about the genetic counseling profession as misconceptions and lack of information are prevalent; and
- We must urge our members to become involved in pro-choice legislative activities on the state level now. If *Roe v. Wade* is overturned, each state will decide who, if anyone, will be eligible for a legal abortion. To find out what restrictions might apply in your state, contact your local NARAL office.

To that end, "NSGC Supports Reproductive Freedom" contains information on the NSGC, genetic counseling and the reproductive needs of our patients; refutes many commonly held myths regarding genetic services; and emphasizes that the NSGC supports all reproductive options. This special publication will be printed by NARAL. Plans to disseminate the fact sheet to NSGC members, legislators and pro-choice groups are being finalized.

Amicus Brief

Organizations wishing to provide information to the Supreme Court do so by filing an *amicus brief* or "Friend of The Court" document.

Regarding the *Webster* case, the NSGC signed on to the amicus brief drafted by the Association of Reproductive Health Professions which emphasized the need to keep all reproductive options available, especially for families at increased genetic risk.

Urgent Need To Increase Federal Genetics Monies

The Senate Appropriations Committee is now considering allocating surplus funds to the MCH Block Grant program. Traditionally, only a small fraction of these funds go to genetic services.

Please contact your legislators and request that any surplus funds be earmarked for state genetic services and allocated to the Genetic Services Branch, Bureau of Maternal-Child Health.

[Ed Note: For related information see Ilana Mittman's Letter to the Editor in this issue.]

NSGC Participates in Pro-Choice March

Approximately 20 NSGC members marched under the NSGC banner in support of reproductive freedom on April 9. The NSGC was one of several hundred organizations to officially co-sponsor the march.

Trish Magyari
Legislative Briefs Editor

1979 NSGC 1989
10th Anniversary Year

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