PERSPECTIVES

in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 12, No. 1 Spring 1990

Society to Introduce Journal

The *ad hoc* committee on the establishment of a journal of genetic counseling has recently reviewed proposals from three publishers: Lawrence Erlbaum Associates, Plenum / Human Sciences Press and Mary Ann Liebert, Inc. The recommendation of the committee, chaired by Ed Kloza and including Deborah Eunpu, Beth Fine, Joan FitzGerald, Vickie Venne and Bea Leopold *(ex officio)* are expected to initiate negotiations which will lead to the premier of the official journal of the NSGC in early 1991.

Members wishing to serve on the editorial board are reminded to contact Ed Kloza as soon as possible.

on the inside

Genetic Counseling Services for Patients with Craniofacial Anomalies

by Susan M. Jones, M.S., Division of Human Genetics, Children's Hospital, Buffalo, NY and consultant to J. Sutton Regan Cleft Palate Foundation and Craniofacial Center of Western New York

Craniofacial disorders, collectively considered, represent common birth defects. Clefts of the lip and/or palate occur in one out of every 700-800 births. Orofacial clefting may present as an isolated malformation of multifactorial etiology or as an associated finding in over 250 syndromes of known (chromosomal, Mendelian, teratogenic) and unknown etiology. Many syndromes associated with craniofacial anomalies are variable in expression and may not cause all findings in all affected individuals. Accurate diagnosis is requisite for the provision of appropriate genetic counseling for such patients and their relatives.

Correction of the anatomic and functional problems of patients with craniofacial disorders is a multidisciplinary effort. Specialists participating in the care of affected individuals include, but are not limited to, genetic counselors, medical geneticists, audiologists, dentists, orthodontists, otolaryngologists, plastic surgeons, prosthodontists, psychologists, social workers and speech pathologists.

In Buffalo, diagnostic services for patients with cleft lip and/or palate traditionally have been provided through a multidisciplinary cleft palate clinic attended by the genetic counselor. Patients are triaged by the counselor to the genetics department for evaluation by a dysmorphologist; consultation is provided by the counselor after a medical diagnosis is established. Recently, a craniofacial team was established to evaluate and treat patients with more complex anomalies; diagnosis and consultation for this service is also accomplished jointly by the dysmorphologist and genetic counselor.

A number of complex medical and genetic questions commonly arise when

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Counseling for Cystic Fibrosis: What do I do today?

by Vickie L.Venne, M.S., Nichols Institute Reference Laboratory, San Juan Capistrano, CA

Some days, it's not easy being a pioneer.

Many individuals choose careers in genetic counseling because of the excitement of a developing field. A few genetic counselors have specifically sought the pioneering opportunities — those working with the development of chorionic villus sampling or those in research programs. However, counseling when a significant discovery is first announced means that you are challenged to interpret an unfinished story, which usually involves uncertainties that require additional time to resolve. The recent identification of the major mutation of the cystic fibrosis (CF) gene[3] has presented most practicing genetic counselors with such a challenge. Many genetic counselors who deal with prenatal diagnosis face patients who are asking for clarification of CF information that is now being published in the lay press. Patient need for clarification means that the new information has to be understood and incorporated into an already busy counseling session.

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from the President

"Cheshire Puss," she began, rather timidly, as she did not at all know whether he would like the name. "Would you tell me, please, which way I ought to go from here?" "That depends a great deal on where you want to get to," said the cat. "I don't much care where," said Alice. "Then it doesn't matter which way you go," said the cat.

In these familiar words, Lewis Carroll challenges us with two concerns regarding the future of *our* profession: where we hope to go and whether we look to the cat for that direction.

In our early development, we have looked to the cat. I suggest we should be looking more towards ourselves. We are embarking on a future which we can influence, create, expand and discover.

We have some professional trends to consider in terms of where we hope to go. There are more positions available than genetic counselors can fill. Genetic assistants are being trained to provide alternative services. Simultaneously, genetic counselors suffer from a public relations problem. State governments are limiting reproductive options for our patients. And we continue to face the professional issues of licensure and direct billing for services. Each of these challenges us.

The NSGC should take action on these issues. The Society is *you.* It should function under your direction and as a result of *your* efforts. I urge you to get involved and to influence the response of the Society. Impact your professional future. Serve on a committee; recognize your political power and communicatewith your legislators; educate yourself about the training of single disease counselors and discover ways to get involved; write a book or arrange an interview with the media; publish professionally. Perhaps the most important challenge I offer you is to help recruit bright, energetic people to enter this field. If you are enthused by the unique contribution you have to make to the health care community, spread the word.

I am struck by the energy and intelligence of the genetic counselors in the Society. We have a passion for our profession. That passion breeds opinions about our profession and our Society. Make your opinions known to those of us who represent you. I hope the issues outlined have begun discussion and even some controversy that launches you into a responsive second decade.

Thank you for the honor of serving as your president.

Barbara Bowles Biesecker, M.S.
— Excerpts from Presidential Address

Asilomar Conference Review

Genetic Counseling Education into the '90s

by Barbara Bowles Biesecker, M.S.

Overview of Conference

For the first time in 10 years, a national meeting convened to discuss the future of training programs in genetic counseling. Initiated by the NSGC and organized by Wendy Blake, Beth Conover, Luba Djurdjinovic, Joan Scott, Ann Walker and Barbara Bowles Biesecker, the September '89 Asilomar Conference had a three-fold purpose:

- to re-evaluate the 1979 training program guidelines established at a meeting held in Williamsburg, VA;
- to discuss alternatives to Master's level training; and
- to review implications of post-Master's education.

The responses of 315 genetic counselors and nurses in genetics to last summer's survey about their professional training provided valuable background information.

Thirty-five participants were invited, including representatives of the 15 current genetic counseling training programs, five clinical genetics nurse specialists programs, the ABMG, the March of Dimes Birth Defects Foundation, MCH, CORN, the CORN Hemoglobinopathies Sub-Committee and the Alliance of Genetics Support Groups. In addition, several individuals were invited because of their expertise in graduate administration, cross-cultural counseling or due to their long-standing interest in genetic counseling education.

Topics and Issues Covered

Participants were assigned to workshops to discuss recommended minimum curriculum and clinical guidelines, post-Master's training and alternative training. The results of each workshop were discussed among all participants and recommendations were made.

Curriculum and Clinical Guidelines

The 1979 Williamsburg curriculum guidelines were updated to include newer topics in genetics, many of which the counselors/nurses had indicated they needed in their positions. In addition, clinical training guidelines were updated to indicate that a student should have a minimum of 50 cases in a broad spectrum of settings. The specific settings and skills to be mastered were outlined. These details, as well as the outlined curriculum guidelines, are endorsed by the NSGC and will be published in the May issue of the *Am J Human Genetics.*

On the Topic of PhD Training

The workshop on post-Master's training challenged the NSGC to explore further the issues of doctoral programs in genetic counseling. First, there is need to assess the demand for such programs. Secondly, the NSGC was asked to create an archive of literature related to genetic counseling questions. Review of this literature may identify institutions and individuals who might support such a degree, as well as possible research topics. These charges are currently being explored by both the Education and Professional Issues Committees.

The Demand for Trained Professionals

The workshop on alternative training discussed three types of genetics services being performed by non-Master's level counselors. The most familiar is sickle cell counselors. Newer professionals, called genetic interpreters or genetic aides, are recruited from non-English speaking populations and are provided training in genetics. The third group is represented by Master's-level professionals in related fields hired to deliver the same service as genetic counselors. A variety of strong reactions was expressed regarding single gene counselors and genetic aides. No consensus was obtained. The latter situation was uniformly found to be objectionable and a need to address the manpower shortage was discussed. Several specific suggestions, including increasing the number of genetic counseling training programs, were outlined. The NSGC was asked to establish a task force to address these issues.

An *ad hoc* committee, chaired by Joan Scott, has been formed to explore the single disease counselor role. The NSGC continues to face the larger challenge of developing strategies to overcome the manpower shortage. One plan is to encourage individual members to recruit undergraduate students into the field.

Follow up Recommended in '92

The NSGC is to be commended for taking a leadership role in addressing these issues. Asilomar participants recommended biannual meetings to further discuss these issues. The Education Committee has already begun work on "Asilomar 1992."

If this project interests you, please contact Beth Conover, Education Committee Chair, University of Nebraska Medical Center, 402-559-5071.

Case No. 20

Patient Confidentiality and the Duty to Avert Harm

by Lorraine Suslak, M.S., New Jersey Medical School, Newark, NJ

Mrs. A., a 33 year old, was referred by her obstetrician for genetic counseling and amniocentesis because of her age. She had one previous pregnancy which ended in spontaneous abortion. The risks, benefits and limitations of amniocentesis were discussed. After our discussion, the patient stated that she thought she would be making an appointment for amniocentesis but first wanted to discuss the counseling session with her husband. However, the patient stated that she had some reservations about testing because she did not technically fit into the advanced maternal age category and she was also worried about miscarrying as a result of the procedure, particularly because she already had one miscarriage.

I then proceeded to take the family history. As the pedigree unfolded, I realized that the patient's cousin, Mrs. B., had been a patient in our genetics unit several years earlier. Mrs. B. had been identified as a 13/14 translocation carrier. My involvement with Mrs. B. began three years after her initial diagnosis. As part of a study of translocation carriers, I was contacting patients to learn whether they apprised family members of their at risk carrier status, and whether they, themselves, had indeed pursued chromosome testing. The informed consent indicated that no information about the study of the subject's chromosome status would be given to relatives without the subject's knowledge. Mrs. B. was one of two patients in the study who had never revealed her carrier information to any other family members and had stated that when her husband learned of her carrier status, he left her. The experience was so painful and devastating that she could never bring herself to reveal the information to anyone; she had not even told her new husband and had no immediate intentions of doing so.

Mrs. A. called back to tell me that she and her husband had decided against having amniocentesis. Their decision was based on their relatively low age-related risk of having an abnormal baby and their concern about miscarriage. As she was, indeed, a translocation carrier, there woud be an increased risk, over her age-related risk. The ethical dilemma was the conflict between one patient's right to confidentiality versus another patient's right to know. In this particular situation, the normal bond of confidentiality with Mrs. B. was strengthened by the fact that she had taken part in a clinical research project in which confidentiality was ensured. Is it ethically appropriate to violate confidentiality in this instance and let the current patient know that her risk for a chromosomally abnormal child may be well above the quoted risk for trisomy at age 33?

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research addressed such questions in their report on "Screening and Counseling for Genetic Conditions."[1] The Commission stated that "a professional's primary obligation (to the patient) is in some circumstances subsumed by the need to prevent harm to others." The Commission suggests that the genetic counselor has a moral obligation to advise relatives of genetic risks (similar to the physician's legal obligation to report communicable diseases) and, further, that the duty of confidentiality can be overridden when several conditions are satisfied, i.e., "there is a high probability both that harm will occur if the information is withheld and that the disclosed information will actually be used to avert harm... ."

This case lends urgency to important questions:

- Should genetic counselors assume responsibility to inform at-risk relatives?
- Should the present norms of medical confidentiality be set aside when translocation carriers fail to inform relatives of their risks?
- Should genetic counselors adopt more rigorous procedures for ensuring that patients inform appropriate at-risk relatives?
- Is there a legal need to document in charts and follow-up letters, specifically which family members should be informed?
- When patients fail to comply with disclosure of information, do we as genetic professionals have a duty to inform family members of their genetic risks? If so, how can this best be accomplished?

As genetic counselors, we need to define further, individually, through our professional literature, and in our organization, those circumstances in which the obligation to inform at-risk relatives appears to override the obligation to maintain confidentiality.

1 Abram, M (Chairman) (1983): Screening and counseling for genetic conditions. Washington, D.C. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research*, pp 41-84.

Ms. Suslak invites readers to respond with their views regarding how this case should have been handled. Responses will be published in the next issue of *Perspectives* along with the manner in which this case was actually managed.

Code of Ethics Update

The *ad hoc* committee on Ethical Codes and Principles' first task for this year was to review the NSGC by-laws and to propose amendments to provide a mechanism for implementation of the Code.

We have proposed to the Board to amend Article I, Section 1.6 and Article III, Section 3.7 and 3.8. The proposed changes to Article I will require compliance to the standards of the Code as a condition of NSGC membership. Proposed changes to Article III will establish a standing Ethics subcommittee under Professional Issues. This subcommittee shall serve as an educational and consultative resource to the Board of Directors and to the membership. Duties will include interpretation, review and revision of the Code as it applies to an individual's practice, as well as to the NSGC's relationship with the membership and Society, at large.

We have also recommended that the Ethics subcommittee consist of five full NSGC members appointed by the Professional Issues Chairperson to serve five year terms. The Ethics subcommittee will be represented on the Board by the Professional Issues chair. The current *ad hoc* Ethics committee will continue to serve through a transition period.

Our next task is to write a Preamble for the Code and to identify ethical principles to be addressed.

We welcome comments or suggestions. Committee members are: Judith Benkendorf, Nancy Callanan, Rose Grobstein, Susan Schmerler and Kevin FitzGerald, S.J., consultant.

craniofacial patients and their families are seen for genetic counseling. A partial listing of these issues would include the following:

Etiology and Inheritance

Many individuals with cleft lip and/or palate do not present with other evidence of altered morphogenesis and the presumed etiology of the disorder in such patients is multifactorial. These patients or their parents often find it frustrating and bewildering that no specific cause can be uncovered. An uneventful pregnancy history may make it difficult for the family to accept a partially environmental etiology for the disorder. Similarly, parents with a negative family history may disbelieve a partially genetic etiology for the cleft. Absence of a positive family history may lead parents of an affected individual to search intensely through the mother's pregnancy history for an environmental cause of the cleft. Such consultands may be unable to believe that non-teratogenic exposures (i.e., diagnostic radiation) during pregnancy did not cause the disorder. Some parents may find it of some psychological benefit to learn that an uneventful pregnancy and family history is common in children with multifactorially determined clefts. Many other parents, however, may *not* find reassurance in such information.

The genetic counselor must be willing to attend to client frustrations regarding the imprecision inherent in the concept of multifactorial etiology. In cases where a syndromic diagnosis is established, the family may continue to flounder in search of a cause. For example, parents of a child with a fresh mutation for Treacher Collins syndrome may query repeatedly to themselves and to the genetic counselor the possible causes of mutational events. In instances where a syndromic diagnosis permits clear assignment of cause, issues may be raised about perceived parental "responsibility" for the occurrence of the disorder. For example, the finding of an unbalanced chromosome complement in a mentally retarded/multiply malformed child may lead to discovery of a balanced translocation in a parent. Such diagnoses may prompt the reactions of guilt, anger, depression and sense of biological defectiveness that genetic counselors see in patients and families with a wide variety of disorders.

In discussing etiology, the genetic counselor occasionally corrects patients and families regarding inappropriate ideas of long standing. For example, an adult with a repaired cleft may have believed for his/her entire life that maternal rubella at six months' gestation was responsible for the disorder. Re-education implies that the patient will need to give up entrenched personal and family beliefs and accept a new, perhaps less comfortable, causal explanation, i.e., that the cleft might have a partially genetic basis, placing the patient at increased risk of having an affected child. Such changes can be unsettling. The genetic counselor must be available to provide support when previously held beliefs are disrupted.

Embryology

Many young adults with orofacial clefts and parents of affected children arrive at clinic without having had a discussion of the nature and timing of lip/palate closure. These patients may incorrectly understand a cleft to represent the result of a traumatic event rather than a failure of migration of embryonic structures. In addition, patients may have not been apprised that formation of the lip and palate is completed before the end of the first trimester. Accurate information can dispel many incorrect concerns about etiology, i.e., that prenatal injury or exposure to medication at five months gestation caused the disorder.

Recurrence Risk

For patients and families with multifactorially determined clefts the quoted empiric recurrence risk (generally between 2- 15%, depending on the family history, severity of cleft, type of cleft, and sex of the affected individual) must be explained as an average figure that has been observed for other kindreds with similar medical diagnoses and family histories. It must be emphasized to consultands that the risk quoted is obtained from studies of many families with possibly different multifactorial etiologies of cleft lip/palate. The individual couple, therefore, may be at greater or lesser risk than average for a recurrence. Careful attention by the genetic counselor to this point can prevent couples from interpreting relatively low recurrence risk figures as zero risk.

With a syndromic diagnosis, recurrence risk for a craniofacial anomaly will depend on the etiology (chromosomal, Mendelian, teratogenic, unknown).

Of note is that patients may perceive risk quite differently. For example, one parent at a 2% likelihood for recurrence of nonsyndromic cleft palate may feel this is an overwhelming risk. In contrast, an individual with a dominantly carried craniofacial anomaly may find a 50% likelihood of having an affected child to be an acceptable chance. The risk that is viewed as low by one individual may appear to be great to another.

Patients and their parents often meet in the clinic waiting room and through the local parent support group. These families tend to compare information received from health professionals. For this reason, it is important for the genetic counselor to explain that different causes exist for craniofacial disorders and that recurrence risks quoted for one family may not apply for another.

Variability of the Disorder

Parents at increased risk for craniofacial anomalies in future children may obtain information from the genetic counselor about the potentially variable presentation of such disorders. For example, parents of a child with a multifactorially determined cleft lip are at increased risk not only for recurrence of cleft lip but also for cleft lip with cleft palate. With a syndromic diagnosis, other potential medical complications must be reviewed, e.g., Stickler syndrome patients are at increased risk to develop ophthalmologic and orthopedic disease.

Information regarding the variable expression of craniofacial anomalies may be disturbing to some individuals. For example, parents of a child with a unilateral cleft lip may react with distress to learning that they are at increased risk for a recurrence of bilateral cleft lip with cleft palate. Stickler syndrome families may describe feelings of "walking along a cliff" in anticipation of the development of retinal detachment or significant arthropathy. Genetic counselors must be willing to acknowledge and address the difficulties that families face coping with a diagnosis involving variable manifestations.

Cohen MM (1978): Syndromes with cleft lip and palate. *Cleft Palate J*: 306-328.

Fraser FC (1970): The genetics of cleft lip and palate. *Am J Human Gen*, 22:336-352.

Rollnick BR and Pruzansky S (1981): Genetic services at a center for craniofacial anomalies. *Cleft Palate J*, 18:304-313.

Shprintzen RT, et al (1985): Anomalies associated with cleft lip, cleft palate, or both. *Am J Med Gen*, 20:585-595.

Point CounterPoint

Should Cystic Fibrosis Testing be Available to the General Population?

Cystic Fibrosis (CF) is the most commonly inherited disease in the Caucasian population. It is estimated that 8 million people in the U.S. are carriers. Because of media attention directed at the discovery of the CF mutation and the availability of testing through commercial and non-commercial laboratories, genetic counselors are fielding an increasing number of requests for CF carrier screening. What follows are the thoughts and comments of two experts in the field of screening.

SUSAN D. FERNBACH, R.N., B.S.N., Genetic Nurse Specialist, Institute for Molecular Genetics, Baylor College of Medicine, Houston, TX

A carrier screening program for CF using F508 mutation would benefit the general community because it would allow over half of carrier couples to have information about their carrier status, thus enabling them to make informed family planning decisions. Potentially, it may lead to a decrease in the incidence of the disease. For couples in which both are carriers, the choices are: prenatal diagnosis, adoption, AID (with a noncarrier donor) or not having children. Carrier couples who choose prenatal diagnosis can then decide to continue or terminate a pregnancy of an affected fetus.

The discovery of the CF mutation that identifies 70-75% of CF carriers has opened the door for active discussions of voluntary population screening. Currently, using the F508 mutation analysis, approximately 75% of carriers and 56% of couples (where *both* are carriers) can be identified. These numbers will probably increase as it is expected that other CF mutations will be identified in the very near future. It should be clear to everyone who undergoes screening that even with the discovery and use of new mutations, a negative result can never *absolutely* rule out the possibility the individual is a carrier. In anticipation that new mutations will be used in the future, a laboratory offering screening should clearly inform potential clients whether it will save the samples of those with negative results or whether the individuals will be recontacted to submit new samples once other mutations are identified.

Couples requiring screening who have little knowledge of CF itself should be made aware that CF has a wide range of severity. Some affected individuals die in infancy, while others are diagnosed in their 20's. The treatment for CF is improving, but there is currently no "cure" and it is not yet possible to predict the level of severity of CF based on current mutation analysis.

Education can begin in doctors' offices, college campuses and through organized community events. Preliminary education can be achieved with videotapes, brochures and group counseling sessions directed at alleviating fears about screening, e.g., that carriers are unhealthy or have "bad" genes, and other common genetic misconceptions.

Because the numbers of people screened may be very high, the physician or clinic requesting the screening will need to assume responsibility for educating couples and conveying their test results. Counseling after test results may be facilitated with the assistance of videotapes. One, specifically for carrier couples, could provide in-depth information about CF and discuss the various options available. Another could focus on information for couples in which only one carrier is identified. Couples who then request or are referred for additional counseling will hopefully be well informed about CF and their options.

The current costs for CF screening of an individual ranges from $125-$225. Since a CF carrier has none of the symptoms of the disease, third party payment may have to be negotiated. Insurers will need to be shown that coverage for CF screening is less expensive than hospitalization and medication fees for patients.

The social, ethical, and economic issues involving CF carrier screening will be addressed as screening efforts begin.

MICHAEL KABACK, M.D., Department of Pediatrics, University of California San Diego Medical Center, Childrens Hospital of San Diego, San Diego, CA

At this time, to offer cystic fibrosis carrier testing to the general public would be more harmful than beneficial. Those couples who test positive would directly benefit. However, the 70 - 75% detection rate will miss too many carriers. If we find that one member of a couple is a carrier, that couple may still be at risk. We may have heightened the anxiety of many couples compared to the scenario of not having had carrier testing at all. Additionally, prenatal diagnosis in such a situation is currently inadequate. Comparing the statistical risk that a couple would conceive a child with CF to the false positive rate of alkaline phosphatase testing, this testing would be of little value.

If we tell a couple, "Well, you're *probably* not a carrier...," what does that mean? Studies have repeatedly shown that it is difficult for people to think in abstract terms. The unknown "maybe" is often worse than a definite "yes" or "no." Studies also show that both professionals and lay people often misinterpret probabilities. We often assume that the message sent is the message received, but people don't necessarily hear or understand what we say. For every at-risk couple that we identify, there would be about 25 couples in "no-man's land." If ten of these couples decide to abort, would that be acceptable?

Widespread testing should only be offered *after* pilot studies are completed and technology is improved. We should take time to study mechanisms for delivery of this testing. Who is going to offer the testing...Obstetricians? Public health workers? There simply are not enough genetic counselors to provide the needed services. Public education tools such as videotapes, computer programs and pamphlets need to be developed. Informed consent has to be studied. Are patients really going to be given the option of refusing testing or is a blood sample just going to be drawn (*a la* MSAFP in many areas).

Cost is another major concern. We may end up screening the wealthy and not the poor, an ethically unacceptable approach. Are labs going to offer retesting for false negatives as technology improves? How are they going to charge?

Another problem is that the general public is not informed about CF. People will be asked to make judgments without ever having seen someone with the disease. This is especially significant with CF because of the wide spectrum of clinical phenotypes.

Quality control of methodology, educational techniques and counseling issues all need to be in place. Perhaps some kind of professional certification is warranted for educators and counselors.

Certainly cystic fibrosis testing can now be offered to those with a positive family history. In the near future, when other improvements, as outlined above, are in place, testing can be offered to the general population. And finally, at that point, it should be offered to everyone, not just Caucasians.

Professional Issues CommitteeReport

1990 Professional Status Survey: The Analysis of Current Salary

by Janice Edwards, M.S., University of South Carolina School of Medicine, Columbia, SC

A total of 603 full members of the NSGC were mailed the 1990 Professional Issues Status Survey in late January. The overall return rate was 65% (391/603). Certain returns (counselors not working, PhDs, late returns) were excluded. The results of the salary information presented reflects 54% (325/603) of the practicing master's-level genetic counselors with full membership status in the Society.

The Committee would like to acknowledge the membership for their prompt response and Frederick Marstellar, Ph.D., for his consultation and statistical analysis.

The complete results of the 1990 Professional Status Survey will be published in the June issue of *Perspectives in Genetic Counseling.*

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Edward M. Kloza, *Editor-in-Chief* • Foundation for Blood Research, P.O. Box 190, Scarborough, ME 04074; 207-883-4131; FAX# 207-883-1527
Vickie Venne, *Assistant Editor; Technology* • Nichols Institute, 26441 Via DeAnza, San Juan Capistrano, CA 92675; 800-642-4657
Karen Copeland, *Professional/Personal Issues* • Baylor College of Medicine, 6550 Fannin, #921, Houston, TX 77030; 713-798-4691
Trish Magyari, *Legislative Issues* • Georgetown University Child Development Center, CG52 Bles Bldg., 3800 Reservoir Road NW, Washington, DC, 20007; 202-687-8635
Seth Marcus, *Point Counterpoint* • Lutheran General Hospital, Perinatal Center #325, 1875 Dempster St., Park Ridge IL 60068; 312-696-7705
Sylvia Mann, *Resources* • Shriners Hospital, 1310 Punahou Street, Honolulu, HI 96826; 808-948-6872
Barbara Bernhardt, *Counseling Approaches* • U Maryland School of Medicine, Div Human Genetics, Bressler Bldg 11-037, 655 W. Baltimore St., Baltimore, MD 21201; 301-328-3815
Susan Jones, Professional Resources • 126 Grandview Ave, Buffalo, NY 14223; 716-878-7545
Bea Leopold, *Executive Director* • 233 Canterbury Drive, Wallingford, PA 19086; 215-872-7608; FAX# 215-872-1192
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1. SALARY DISTRIBUTION OF GENETIC COUNSELORS BY NSGC REGION AND YEARS OF EXPERIENCE

NSGC Region	Percentile	Years of Experience 0-4	5-9	10+
Region I	25th	28,590	30,000	32,160
(CT, MA, ME, NH,	Median	33,400	31,100	36,260
NH, RI, VT)	75th	35,175	35,250	39,000
	N	15	11	7
Region II	25th	28,000	31,000	34,803
(DC, DE, MD, NJ,	Median	30,000	34,000	40,000
NY, PA, VA, WV)	75th	31,925	38,000	45,000
	N	37	32	30
Region III	25th	26,200	28,900	27,500
(AL, FL, GA, KY,	Median	27,400	30,800	31,500
LA, MS, NC, SC,	75th	30,120	32,805	31,900
TN)	N	14	15	4
Region IV	25th	27,800	30,000	31,275
(IA, IL, IN, KS,	Median	29,120	32,630	34,500
MI, MN, MO, NE,	75th	30,800	36,875	40,000
OH, WI)	N	28	21	11
Region V	25th	26,125	30,000	27,570
(AR, AZ, CO, MT,	Median	27,500	32,000	36,000
ND, NM, OK, SD,	75th	30,619	34,906	40,188
TX, UT, WY)	N	9	8	6
Region VI	25th	32,000	32,655	37,234
(AK, CA, HI, ID,	Median	34,000	37,978	40,310
NV, OR, WA)	75th	36,600	40,740	47,875
	N	36	27	17

1. This table demonstrates the 25th percentile, median and 75th percentile salaries for each NSGC region, by years of experience. The mean gross salary without respect to region or experience was $33,879 for full time respondents. The mean salaries for full time v. part time professionals did not differ significantly.

2. MEAN (± STANDARD DEVIATION) SALARIES AND YEARS OF EXPERIENCE OF RESPONDENTS BY REPORTED PRIMARY ACTIVITY

Primary Activity	N	Salary	Years of Experience
Clinical	258	$33,345 ± $5,516	5.6 ± 4.3
Administration	41	$37,527 ± $7,222	9.4 ± 5.1
Education	11	$36,764 ± $5,191	7.9 ± 5.0
Laboratory	1	$44,000 ± ---	17.0 ± ---
Research	7	$34,431 ± $4,024	9.7 ± 4.6
Business	3	$36,533 ± $2,904	9.0 ± 6.5
Other	3	$37,327 ± $3,329	7.3 ± 1.7

2. This table indicates the mean salaries and years of experience for genetic counselors by their primary activity. Eighty percent (258/324) primarily perform clinical work. The mean salaries are slightly higher for those in administration and education. However, those counselors tend to also have more years of experience.
(Tables 1 & 2) An analysis of covariance of salaries controlling for NSGC region, ABMG certification, primary job activity and years of experience was performed. Those with ABMG certification make an average of $1239/yr more than those without certification. For each year of experience, salaries increase an average of $594. The NSGC Region, the counselors certification status and years of experience accounts for 43% of the variation in salary; salary does not differ significantly by primary job activity.

3. ADDITIONAL GENETICS-RELATED INCOME OF RESPONDENTS

Source of Additional Income	N	Mean	Range
Teaching and/or Lecturing Only	29	$808	($150 - $3000)
Consulting or Private Practice	25	$6872	($200 - $20000)
Other Sources of Genetics Income	9	$3205	($200 - $11000)

3: This table reflects 19% (63/328) of the respondents who reported genetics-related income additional to their primary job.

EAST CALLS WEST

To the Editor:

As Chair of the Education Committee of the Council of Regional Networks of Genetics (CORN), I recently received a letter from Professor Mircea Covic of the Medical Institute of Iasi in Romania. The tone of the letter was a mixture of relief — that "... by a genuine revolution Romania has succeeded in getting free from a dictatorial system that... hindered the development of... medical education and research..." — and desperation — "...nothing has been done [in the field of human and medical genetics] in Romania in the last 15 years. We [now] start... a period of reconstructing education and research."

Professor Covic explains the desperate need for materials and information in this area, and specifically cites genetic counseling as one of their activities which sorely needs updating. The NSGC's interest in "genetic counseling in other lands" [Vol. 10, #1], along with its planned participation in the 1991 International Congress of Human Genetics, suggests that it might be willing to assist Professor Covic in his search for knowledge. Specifically, he requests:

- The achievement of a plan and a logistic program for developing a strong center of medical genetics by offering us your opinions and your advice on organization and priorities.
- Scientific documentation: books, monographs and genetics journals (medical and especially human).
- Ways of improving academic education concerning genetics (manuals, video apparatus, video cassettes, film, slides) and ways of formation for young postgraduate researchers and specialists.
- Technologies of genetic exploration at the cell and molecule level, including antenatal diagnosis; the necessary apparatus and reactives (chemicals).
- Computer programs in the field of plurimarformative (sic) syndrome diagnosis.

Perhaps the NSGC, in concert with CORN, could establish with Professor Covic a line of communication that would serve as a conduit of information to a genetics community badly in need of our assistance.

Paula K. Haddow, MAT
Chairperson
CORN Education Committee

In November 1989, I sent a letter to Dr. Larry Shapiro, who was at that time President of the American Board of Medical Genetics, regarding the results of a petition that I circulated at the 1989 NSGC Annual Education Conference in Baltimore. The issue concerned the cost of the ABMG exams for genetic counselors. Below is the text of my letter to Dr. Shapiro, followed by the reply. — Wendy Uhlmann, M.S., Hutzel Hospital, Detroit, MI

Dear Dr. Shapiro:

The enclosed petition was signed by 321 genetic counselors who feel that the fees for the 1990 certification examinations are unduly high. Of the 149 ABMG certified genetic counselors who signed the petition: 38 (25.5%) had examination fees paid by their employers; 107 (71.8%) paid their own examination fees; 2 (1.34%) had fees partially covered; and 2 (1.34%) did not indicate coverage.

Of the 165 board eligible genetic counselors who signed the petition: 31 (18.8%) had examination fees paid by their employers; 84 (50.9%) paid their own examination fees; 5 (3.03%) had fees partially covered; 45 (27.2%) did not indicate coverage. The high proportion of "unknown coverage" can be attributed to the approximately 40 students who signed as board eligible candidates. Seven of the 321 genetic counselors did not indicate whether they were board eligible or board certified and therefore were not included in the above calculations.

Given the salaries and potential earning power of genetic counselors, the examination fees are a significant financial burden. Some genetic counselors have indicated that they are not taking the 1990 certification examinations solely for financial reasons.

We urge the American Board of Medical Genetics to review the examination fees and consider establishing fees for genetic counselor applicants that are more in line with our financial resources. I would appreciate a response regarding the fee structure which I will share with the genetic counselors who signed the petition.

If you have any questions about this petition or the results, please do not hesitate to contact me. Thank you for your consideration on this matter.

Sincerely,
Wendy R. Uhlmann, M.S.

Dr. Shapiro forwarded the letter to incoming president Dr. Charles Epstein. His reply:

Dear Ms. Uhlmann:

Your letter of Nov. 30, 1989, to Dr. Larry J. Shapiro and the petition signed by 321 genetic counselors has very recently been sent to me in my new capacity of president of the American Board of Medical Genetics. The Board is certainly well aware of the concerns of the genetic counselors with regard to the cost of the certification process and discussed this issue extensively when the fees for the 1990 examination were set. It is just for this reason that you indicate in your letter that the fee for the genetic counseling examination was set at $200.00 rather than at $300.00 as is the fee for all of the specialty examinations. However, as a matter of equity, it did not appear appropriate to the Board to maintain a separate fee structure for the application review and general examination.

The fees charged by the Board are determined by the costs incurred in preparing and administering the examination and in reviewing the credentials of the applicants. To a large extent, these costs are, in turn, determined by the fees charged to the Board by the National Board of Medical Examiners which actually administers the examination. Since the Board does not have other major sources of income to underwrite the examinations, it is necessary to make the fees for the examination commensurate with the costs. This notwithstanding, the Board did attempt to ameliorate to some extent the financial burden on genetic counseling applicants by making the fee for the genetic counseling examination less than that charged for any of the other examinations. The current examination cycle is well in progress, and our current fee structure has been determined on the basis of known and expected costs for administering the 1990 examination. To make a significant additional fee reduction for genetic counselors at this time, is unfortunately, no longer possible. As I am sure you realize, genetic counselors represent a large proportion of the persons taking the examinations and reducing their fees would have quite an adverse affect on the financial position of the Board. However, I can assure you that the situation of the genetic counselors will be carefully reviewed and thoroughly discussed when the fees for the next examination cycle are set.

Sincerely,
Charles J. Epstein, M.D.
President
American Board of Medical Genetics

Neurofibromatosis Fdt Annual Conference

The National Neurofibromatosis Foundation will be sponsoring a medical conference, "Psycho/Social Aspects of Neurofibromatosis" on May 16 in New York City. For information, please call NF, 212-460-8980.

Peggy Moss
Director of Administration, NF

Support Group Leadership Expertise Sought

The Iowa Regional Genetic Counseling Service is planning a Spring Conference for parents who have chosen to terminate a pregnancy on the basis of a prenatal diagnosis.

Our largest city population is 200,000 and the state total is 3 million, so we must extend ourselves to both urban and rural populations.

Our goal is to address special bereavement issues and learn more about the grief process and recovery. We are also looking for booklets, articles and resource materials prepared specifically for this group. Ongoing service considerations include monthly meetings and parent-to-parent networking.

We'd like to build on your experiences. If you have offered similar support services in your area, we seek your input and expertise. Contact: Regional Genetic Consultation Service, 1215 Pleasant St, Ste 515A, Des Moines, IA 50309, 515-283-6282, FAX: 515-283-5994

Diane Bierke-Nelson, MS

Dystonia Research Requires Family Data

The breakthrough discovery of a marker for the dystonia gene clearly indicates that dystonia, in Jews and in non-Jews, is inherited as an autosomal dominant disorder. To continue the research, it is important to identify families with two or more living, affected individuals.

Genetic counselors are urged to inform such families of an international registry and urge them to contact: Dystonia Clinical Research Center, Neurological Institute, Box #77, 710 W. 168th Street, New York, NY 10032; 212-305-1303.

Deborah deLeon, MS
Genetics Coordinator

Call for Reviewers

Wanted: NSGC members interested in writing reviews on books, videos, audios and other materials useful to genetic counselors. In addition, individuals who know of materials suitable for review are encouraged to contact me c/o Division of Human Genetics, Children's Hospital, 219 Bryant Street, Buffalo, New York 14222; 716-878-7545.

Susan Jones, MS

MCH Publications Available

Three publications of the Department of Human Services, Bureau of Maternal and Child Health and Resources Development are now available at no charge. These publications are intended to share important program information and to disseminate findings of completed research. They are:

- "Proceedings from the 1988 Tri-Regional Conference on Completed Maternal and Child Health Research: Translating MCH Research Findings into Health Care Applications - A Challenge" and
- "Maternal and Child Health Research Program: I. Active Projects - 1988."
- "Maternal and Child Health Research Program: II. Completed Projects - 1988."

To obtain copies, contact: National MCH Clearing House, 38th and R Streets NW, Washington, DC 20057; 202-625-8410.

Woody Kessel, MD, Director
DMCH Program Coordination and Systems Development

Airfares to Summer Meeting to Benefit Membership

Members planning to attending the March of Dimes Birth Defects Foundation conference in Detroit next July are urged to book airline tickets in one of two ways:

- Book directly through American Airlines, 1-800-433-1790, and receive a 5 - 40% discount on your fare. Please mention Star#S05704H when you call, *or*
- Book through Rhodes Travel, 1-800-877-9494, mention NSGC and receive reduced fares on AA as well as all other carriers. Rhodes will donate to the NSGC 2% of the total amount booked by either option.

Essentials of Pregnancy AFP Screening Course

The Foundation for Blood Research (FBR) will be holding a short course for those interested in acquiring a comprehensive base of knowledge on all aspects of MSAFP screening. For information on this April 30 - May 2 course, contact Dept Education, FBR, PO Box 190, Scarborough, ME 04075; 207-883-4131.

Paula K. Haddow, MAT
Director of Education, FBR

Two Funding Opportunities for NSGC Members

Collaborative Research to Award Grant for CF Materials

President Barbara Bowles Biesecker has announced the availability of a $3000 grant to explore the counseling issues surrounding DNA testing for cystic fibrosis. NSGC members are eligible.

The grantor is particularly interested in the development of a set of counseling materials and professional training protocols. Collaborative Research will not exercise any proprietary interest in the materials, but rather suggests that they be made available to any interested parties. The awardee(s) must be willing and able to work on the project immediately with project completion within several months.

If you are an NSGC member and are interested in working on this project, please contact Barbara Bowles Bieseckler at 313-764-0579 prior to April 15.

Special Projects Fund Application Process Set

A Special Projects Fund Grant Application Instruction Sheet is now available. Members interested in applying for funding for projects with budgets up to $2000 are invited to request information by contacting the Executive Office. (See p. 6 for address.) The deadline for posting applications is Tuesday, May 15.

Last Call for Ts

A limited number of NSGC Commemorative T-shirts are still available at $12 each. Orders are being taken by designer Debra Collins, c/o Division of Endocrinology and Genetics, U Kansas Medical Center, Rainbow at 39th, Kansas City, KS 66103. A check, payable to NSGC, *must* accompany all orders.

BOOK

The Broken Cord

By Michael Dorris, PhD
Publisher: Harper & Row, NY, 1989
Price: $18.95, 279 pp
Reviewed by: Lindsay Eierman, BSN

This insight of fetal alcohol syndrome is written from the author's unique perspective of an academic anthropologist and contemporary novelist. Michael Dorris is also a Native American concerned about the number one public health issue of his culture. But perhaps most significant is his subjective perspective as the adoptive father of Adam, who has FAS.

This book is an autobiographic and chronological account of life with Adam. *The Broken Cord* documents the day-to-day realities of living with a FAS child and highlights some of the frustrations of families who confront the medical, educational and social bureaucracies. It is an excellent account of one parent's experiences with the pediatric health care system. Some of the common assumptions and mistakes of health care providers are described. The didactic information in his book not only adds to the health professional's clinical understanding of this disorder, but what it must be like to have a child with FAS. In a broader context, much of the book explores the historical sociological aspects of FAS in the Native American population.

While this book provides depth of understanding, the information in this book is not easily accessible. A well-categorized index would be appreciated and would allow for better utilization of the significant information contained therein. An extensive bibliography is included.

Divided into 15 untitled chapters, *The Broken Cord* culminates in a moving chapter written by Adam, now 21 years.

This book is an important social document that deserves attention from health and educational professionals, government officials and anyone in the general population who cares about children and the future of our society. This book is a critical companion to the currently available literature on fetal alcohol syndrome and is strongly recommended.

AUDIO-VISUAL

Cocaine's Children

Produced by: March of Dimes and Northwestern Memorial Hospital, 1988
Length: 9:35
Cost: Varies
Reviewed by: Melonie Krebs, MS

Ten years ago when genetic counseling was evolving as a strong voice in the area of birth defects prevention, the major teratology focus was on alcohol. At that time, much of the supplementary counseling and educational tools were lay materials from March of Dimes. These primarily included pamphlets and 16 mm film strips which campaigned strongly against drinking during pregnancy. Today, genetic counselors are faced with a more insidious group of pregnancy complications caused by today's drug of choice: cocaine. March of Dimes is once again helping in the prevention battle with a short, educationally sound videotape entitled, *Cocaine's Children.*

In 1977, the March of Dimes made a strong statement with a pamphlet, "When you drink, your UNBORN BABY does, too!" They used red ink and exclamation points in a kind of "just say no" approach toward prevention of fetal alcohol syndrome. They told the abuser or potential abuser about how alcohol damages the unborn baby and about how big theproblem was but the only solutions offered were to say "no" and seek help. Omitted were any practical and positive suggestions for getting help.

The organization's 1988 campaign for preventing birth defects has come a long way. Solid tenets from adult learning systems have been used in the medium of the 80's, a 9 1/2 minuteVHS videotape. *Cocaine's Children,* geared primarily for lay audiences, begins with an attention-grabbing device which is much stronger than the red words and exclamation points. We see and hear the tiniest victim of cocaine abuse through a neonate's irritable cry. The crying stops and from this point to the end of the video, the viewer is given practical, positive information on what can be done during and after pregnancy. Dr. Ira Chasnoff, who works with cocaine babies and their mothers, explains that the cocaine problem is not only in the inner cities, but it is also in the posher neighborhoods. He also shows a mother how to comfort her jittery baby and reassures her about the improvements which are often seen in the four to six month-old.

The overall message given to abusers is one of hope...hope that the adverse effects of the drug might be reversed, and hope that the pregnant woman at eight months gestation may get help, better late than never.

The most poignant segment comes during an interview with an ex-cocaine user who has a 6-year-old who was exposed to the drug in utero and has had multiple problems since birth. Joanne and her son are observed at play and she remarks at how far both of them have come. She shares, "Babies don't ask to be born with drug sensitive bodies. If you really love them, it changes you; you straighten out your act."

The videotape leaves us with a look back at the cocaine exposed newborn. He is still crying long past the time when most newborns can be comforted. The narrator reminds us that more and more mothers are risking the lives of their young for the sake of a high. It is a frightening message but the more lasting one is the sound of the baby's cry.

Like the field of genetic counseling, March of Dimes has shown significant growth with the production of this videotape. They have replaced the "scared straight" approach with sound adult-learning methods in a 1980s format. They also appear to be getting the word out about drug abuse and pregnancy as they are even beginning to market videotapes similar to "Cocaine's Children" in the meeting place of the 80's — the corner video store.

ORGANIZATION

The Chromosome 18 Registry and Research Society is a newly-formed family support and research organization. The Registry will keep affected patients, families and physicians informed about new developments and issues related to chromosome 18 disorders.

The purpose of this organization is to locate persons with chromosome 18 anomalies; to educate families and the public; to encourage, conduct and publish research; and to link affected families and their physicians to the research community.

For more information or referral, contact: The Chromosome 18 Registry and Research Society, c/o Jannine Cody, 6302 Fox Head, San Antonio, TX 78247; 512-657-4968.

Counseling for Cystic Fibrosis: What do I do today? from p. 1

The ASHG Statement on Cystic Fibrosis Screening clearly states that the Spring of 1990 is not yet the time for routine population screening, but that is *not* the concern that most genetic counselors deal with daily. The ASHG statement also indicates that carrier testing should be offered to couples in which either partner has a close relative affected with CF,[2] an issue which *does* significantly impact many of our professional lives. There are a number of counseling issues to deal with when counseling the extended family members of an individual who has cystic fibrosis.

This article reviews some of the issues and statistics for counseling someone with a family history of CF. The following questions should be resolved as part of the counseling session:

WHAT IS THE A PRIORI *RISK THAT AN INDIVIDUAL IS A CARRIER OF THE CF GENE?*

If the consultand has:

- an affected sibling, the *a priori* risk = 67% (2/3).
- an affected niece or nephew, the *a priori* risk = 50% (1/2).
- an affected aunt or uncle, the *a priori* risk = 33% (1/3).
- an affected first cousin, the *a priori* risk = 25% (1/4).

HOW CAN THAT RISK BE MODIFIED?

1. That risk can be modified by testing for the **△F508** mutation.
   - If a healthy individual is found to be heterozygote positive for the △F508 mutation, that person is a definite carrier of CF.
   - If the consultand who has a positive family is negative for the △F508 mutation, the carrier risk, calculated using Bayesian analysis with a 76% detection rate, will be significantly lower.
   - If the partner who doesn't have a family history of CF has a negative result for the △F508 analysis, the couple may choose to stop testing.
2. *USE OF RESTRICTION FRAGMENT LENGTH POLYMORPHISM (RFLP) MARKERS TO DETERMINE HAPLOTYPE* can further modify the risk if the consultand is negative for the △F508 mutation. RFLPs detected by XV2c and KM-19 may permit construction of haplotypes. By defining the absence of a polymorphic site as the 1 allele and the presence of the site as the 2 allele, the haplotypes with respect to XV2c and KM-19 RFLPs are shown in Table 1. Using the RFLPs and the fact that there is linkage disequilibrium, the risk can be modified in a person with a positive family history who tests negative for the △F508 mutation. Modification will depend on the haplotype: BB haplotypes will calculate to be the highest risk and CC haplotypes will be the lowest risk. Some of the calculations are summarized in Table 2. If the individual has a combination involving an A or a D haplotype, the risk will be adjusted to an intermediate value.

   However, additional DNA studies may not be worthwhile at this time unless the extended family cooperates in a complete linkage analysis. By studying an individual who has a positive family history without the rest of the family, that person may receive a risk calculation which is not significantly different from the *a priori* risk figure. Access to a specimen from the affected individual is essential in these cases.
3. Couples who have a high risk may choose to pursue prenatal diagnosis with *MICROVILLAR INTESTINAL ENZYMES* (MIE).

WILL THE TESTING REQUIRE COOPERATION OF OTHER FAMILY MEMBERS? IF SO, ARE THEY AVAILABLE? ARE THEY COOPERATIVE?

These questions may be important to help the couple decide if they want haplotype analysis. As discussed above, identifying a B haplotype will move a person's risk close to the *a priori* risk, and further clarification will then require family cooperation.

WHAT IMPACT WILL THE VARIOUS RISKS HAVE ON THE COUPLE? IS THE INFORMATION BEING USED FOR FUTURE REPRODUCTIVE DECISIONS OR IMMEDIATE PRENATAL DIAGNOSTIC DECISIONS?

These questions are typical of all counseling sessions, and should be addressed before using the "wonderful, new technology" to identify a risk. For many families, the identification of the major mutation greatly facilitates the analysis, but it is not without limitations in some cases. If reproductive plans are not immediate, the couple may choose to wait one or two years until more information is available. Genetics clinics may want to maintain a file of individuals to be contacted when the scientific community is more comfortable with the informativeness of CF gene analysis.

WHO WILL BE FINANCIALLY RESPONSIBLE?

Although it is usually not the responsibility of the health professional to resolve billing issues, this is an area of concern to counselors because the need for extended family member evaluation, the costs of some of the linkage analyses, and the uncertainty of insurance reimbursement often makes the financial issue a significant part of the decision making process.

The calculations are only one aspect of the content that many couples need to know about testing for CF. A review of the clinical picture as well as the psychosocial aspects of having a child with CF are also important aspects of the session. However, it is the publicity about the new technology which seems to promise definitive answers that is prompting many phones to ring off the wall. Hopefully, this information will provide a guideline when counseling couples who are requesting CF testing.

1. Beaudet AL, *et.al.* Linkage Disequilibrium, Cystic Fibrosis, and Genetic Counseling. *Am J Human Gen.* 44(3):319-326, 1989.
2. Caskey CT, Kaback MM, Beaudet AL. The ASHG Statement on Cystic Fibrosis Screening. *Am J Human Gen.* 46(2):393, 1990.
3. Lemna WK, et.al. Mutation Analysis for Heterozygote Detection and the Prenatal Diagnosis of Cystic Fibrosis. *NEJM.* 322(5):291-6, 1990.

TABLE I

HAPLOTYPE	XV2c ALLELE	KM-19 ALLELE
A	1	1
B	1	2
C	2	1
D	2	2

from reference #1

TABLE 2

RELATIONSHIP OF AFFECTED PERSON	*A PRIORI* RISK	if △ F508 negative: WITHOUT HAPLOTYPE TESTING	if △ F508 negative: IF BB HAPLOTYPE	if △ F508 negative: IF CC HAPLOYTPES
sibling	67%	33%	62%	18%
aunt/uncle	33%	11%	30%	5%
niece/nephew	50%	20%	46%	10%
first cousin	25%	7%	23%	3%
(—) family history	4%	1%	3%	.5%

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.

PHOENIX, AZ: Immediate opening for BC/BE Genetic Associate. Salary Range: $35,000, negotiable with experience.
RESPONSIBILITIES: Wide range of professional opportunity, including general and reproductive genetics, amniocentesis, CVS, teratology, MSAFP screening and high-resolution ultrasound.
CONTACT: Daniel L. Harris, Administrator, United Genetics, 1300 N. 12th St, #316, Phoenix, AZ 85006; 602-254-8337. EOE/AA

MOUNTAIN VIEW, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active prenatal diagnosis specialty practice with 3 genetic counselors and 2 medical geneticists; perform wide range of prenatal, MSAFP and preamnio counseling; travel to satellite sites.
CONTACT: Lee Fallon, MS or William J. Conte, MD, Prenatal Diagnostics, Inc., 1580 W. El Camino Real, #4, Mountain View, CA 94040; 415-966-8597. EOE/AA

PASADENA, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join established team with career growth and financial progression. High-volume, diverse caseload; ongoing professional education in private, for-profit organization.
CONTACT: Debra Cheyovich Tasic, Dr.P.H., Alfigen The Genetics Institute, 11 West Del Mar Blvd, Pasadena, CA 91105; 818-356-3442.

SAN JOSE, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of pediatric and general counseling and case management, including amnio, CVS, teratology, MSAFP and hemoglobinopathy screening.
CONTACT: Karen Wcislo, MS, Kaiser Permanente Medical Center, 260 International Circle, Genetics Dept, San Jose, CA 95119; 408-972-3300. EOE/AA

DOVER, DE: Immediate opening for 2 BC/BE Genetic Counselors. 1) Northern DE, including Wilmington 2) Southern DE.
RESPONSIBILITIES: Prenatal diagnosis, including CVS; coordinate public health pediatrics and general genetic services; MSAFP screening; community education.
CONTACT: Marihelen Barrett, Director Maternal Child Health, Delaware Division of Public Health, P.O. Box 637, Dover, DE 19903; 302-736-478. EOE/AA.

NEW HAVEN, CT: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Varied prenatal counseling; consultation with patients and physicians.
CONTACT: Miriam S. DiMaio, MSW, Yale University School of Medicine, Dept. Human Genetics, PO Box 3333, New Haven, CT 06510; 203-785-2661. EOE/AA

CHICAGO, IL: Immediate opening for parttime BC/BE Genetic Counselor.
RESPONSIBILITIES: General genetic counseling at university-affiliated medical center including: prenatal diagnosis; teratogen counseling; professional education.
CONTACT: Barbara K. Burton, MD, Director, Center for Medical and Reproductive Genetics, Lakeshore Drive at 31st St, Chicago, IL 60616; 312-567-7340. EOE/AA

PALOS HEIGHTS, IL: Immediate opening for motivated, independent, organized, managerial-style BC/BE Genetic Counselor.
RESPONSIBILITIES: MSAFP, CVS, early amnio in high-volume private subsidiary satellite center, affiliated with largest Chicago-based hospital system.
CONTACT: Jerry O'Grady, Administrator, High Tech Medical Park, 11800 Southwest Highway, Palos Heights, IL 60463; 708-361-0220. EOE/AA

ROCKFORD, IL: Immediate opening for BC/BE Genetic Counselor. Full or parttime, negotiable.
RESPONSIBILITIES: Join team to assist in coordination of MSAFP, general genetics and specialty clinics; teratogen and prenatal genetic counseling; professional and community education.
CONTACT: Nancy Williamson, MS, Rockford Memorial Hospital, 2400 N. Rockton Ave, Rockford, IL 61103; 815-968-6861. EOE/AA.

LEXINGTON, KY: July 1 opening for BC/BE Genetic Counselor. Potential for faculty position.
RESPONSIBILITIES: Join active team in expanding program, including: preconceptual and prenatal counseling for MSAFP, amnio, teratology, malformation counseling; outreach to professional community; some teaching.
CONTACT: Anjana Pettigrew, MD, Assistant Professor, Dept Pathology, University of Kentucky Medical School, Lexington, KY 40536-0093; 606-233-4511 x 4504. EOE/AA

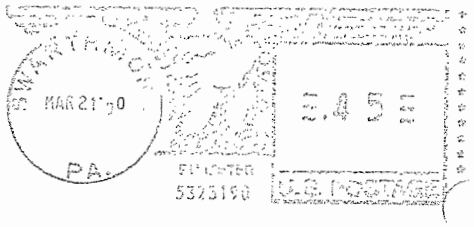
BOSTON MA: Immediate opening for BC/BE Genetic Associate for Statewide Newborn Hemoglobinopathy Screening Project.
RESPONSIBILITIES: Implement and supervise single-gene counseling training program; hemoglobinopathy counseling for RND trait and disease; coordinate multidisciplinary care; develop educational materials and inservice programs. Some travel.
CONTACT: Homer Rahn-Lopez, MSW or Emily Lazar, MS, Boston Sickle Cell Center, 818 Harrison Avenue, FGH2, Boston, MA 02118; 617-424-5727. EOE/AA

BETHESDA, MD: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join well-established private prenatal genetics practice, including pre/post amnio counseling; teratogen, recurrent miscarriage and infertility.
CONTACT: Mark R. Geier, MD, PhD, Genetic Consultants, 5616 Shields Drive, Bethesda, MD 20817; 301-530-6900.

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

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active and growing comprehensive pre/postnatal program, including Tay Sachs, MSAFP, diagnostic ultrasonography, dysmorphology and pediatrics clinics; active psychosocial cross cultural unit, including Hispanic and Chinese communities; opportunity for research and education.
CONTACT: Diana Punales, MS, Beth Israel Medical Center, 16th and First Avenue, Medical Genetics, New York, NY 10003; 212-420-4179. EOE/AA

YORK, PA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: U of PA affiliated program with independent residency program offers MSAFP screening and counseling for abnormal results; general and prenatal counseling for CVS, amnio, PUBS; preconceptual counseling; professional and patient education.
Contact: Alexander Kofinas, MD c/o Nicholas Simon, MD, York Hospital, 1001 S. George Street, York, PA 17405-7198; 717-771-2348. EOE/AA *see next page, col. 3*



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Legislative Briefs

RECENT SUPREME COURT RULING INCREASES ACCESS TO SSI

(adapted from NY Times, 2/21/90)

On February 20, the U.S. Supreme Court ruled that the Supplemental Security Income (SSI) Program has been improperly administered by the Department of Health and Human Services, denying benefits to many children whom Congress intended to help when it set up the program in 1974. SSI is a major Federal benefit program for disabled children from poor families and is important in increasing access to genetic services because recipients are automatically eligible for Medicaid coverage.

The case, Sullivan v. Zebley, was centered around the determination of disability in children. Adults qualify for SSI benefits if they have one of 135 impairments listed in the regulations *or* if, based on an individualized assessment of functional capacity, they are found to be disabled (unable to work). Children, however, have been restricted to specific impairments on the list, which does not include Down syndrome, autism or muscular dystrophy, among others. Children with these conditions have often been denied SSI benefits regardless of the severity of their condition. The Supreme Court, in a 7 to 2 decision, ruled that the Government is required to make determinations based on the individualized "functional capacity" of the child, just as it allows for with adults.

This victory for advocates of children with disabilities has far reaching implications. It is estimated that as many as a million additional children might be ineligible for SSI, which now serves only 290,000 children. The payments average $400/month. SSI eligibility also qualifies a child for other programs, i.e. Medicaid.

How You Can Help

Genetic counselors can play an important role in publicizing this ruling to colleagues, institutions, support groups and families. Encourage families who have been denied benefits to reapply. Encourage others who did not apply because of past experiences to do so. Many needy families will forgo extensive genetic evaluations if they do not have insurance coverage. This ruling should help many more of them appropriately qualify for both SSI and Medicaid.

Trish Magyari, M.S.

• Classified • Classified • Classified

continued from p. 11

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

ROANOKE, VA: September 1990 opening for autonomous, self starter-type, BC/BE Genetic Counselor. Salary range: $32,000 - $36,000, depending on experience. Excellent benefits and strong secretarial support.
RESPONSIBILITIES: Start-up university-affiliated department to focus on prenatal diagnosis, general and pediatric cases on maternal fetal medicine service, including: amnio, transcervical and transabdominal CVS, fetal blood sampling.
CONTACT: (through 9/1/90) C. Lynn Keene, MD, University of Maryland School of Medicine, 149 S. Augusta Avenue, Baltimore, MD 21229; 301-328-5957. EOE/AA