PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 12, No. 2 Summer 1990

EXERCISE YOUR RIGHT: VOTE

Ballots for the election of officers for the 1990/1991 term will be mailed to all Full members of the NSGC on July 16. Elected positions include: President Elect, Secretary and Representatives to Regions II, IV and VI.

Voting is your opportunity to voice your opinions about the direction of your Society and of your profession. Take a moment. Make a difference. Vote!

on the inside

NEXT ISSUE: 1990 Survey of Salary and Benefits for State of California

Point Counterpoint
Is multiple marker screening for Down syndrome useful?

SCREENING PERFORMANCE IMPROVED

by Jacob A. Canick, Ph.D., Women and Infants Hospital, Brown University, Providence, RI and George J. Knight, Ph.D., Foundation for Blood Research, Scarborough, ME

Recently, a new testing procedure designed to significantly enhance prenatal screening for pregnancies affected with fetal Down syndrome has been introduced by a number of clinical laboratories. The new system combines the measurement of maternal serum alpha-fetoprotein (AFP), unconjugated estriol (uE3) and human chorionic gonadotrophin (hCG) levels with maternal age to calculate a new, patient-specific risk, based on the data and methods reported by Wald *et al* in 1988.[1] The unusually short time from publication of the initial reports[1-4] to clinical implemetation of the new test reflects the need for more sensitive Down syndrome screening procedures as well as the reality of competition among clinical laboratories.

CONFIRMATORY STUDIES

The multiple marker test depends on the observation that AFP and uE3 are low and hCG is high in pregnancies affected with fetal Down syndrome. The literature on the association between low AFP and Down syndrome pregnancy is considerable and yields a consensus median AFP value of 0.75 MoM (multiples of the median).

The initial finding of Bogart *et al*[2] that hCG is high in Down syndrome pregnancy was confirmed by Wald *et al*[1] and has been replicated in recently published studies,[5-11] with median values ranging from 1.4 to almost 3 MoM (consensus median - 2.1 MoM).

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TRIPLE TEST PREMATURE, COUNTERPRODUCTIVE

by James N. Macri, Ph.D., NTD Laboratories, Inc., Carle Place, NY

Maternal serum alpha-fetoprotein (MSAFP) prenatal screening to assess the risk of neural tube defect in young apparently healthy families is a procedure introduced by us in 1975[1] and now widely offered in obstetric practice. Lower than expected MSAFP levels are now known to be associated with chromosomal trisomy (in particular Down syndrome).[2] Currently, genetic counselors are being asked to evaluate the risk of trisomy on the basis of a "triple screen" or "triple test" which adds to MSAFP evaluation the assessment of two more analytes, human chorionic gonadotropin (hCG) and unconjugated estriol (uE3). The question we are facing is: *Is the triple test effective and should it replace MSAFP screening for Down syndrome?* Our conclusion is that triple testing should be rejected based on research findings which show that one component (uE3) is not useful.

THE SINGLE TEST

The higher incidence of Down syndrome among patients ≥35 years has traditionally justified offering amniocentesis to all such patients. This practice identifies approximately 20% of affected cases since 80% of Down syndrome occurs in patients under age 35. In 1984, we observed that significantly lower levels of MSAFP in patients under age 35 is an indication of increased risk for Down syndrome. This method is effective in discovering an additional 20-

continued on p. 6

Responses to Case Report #20: Patient Confidentiality and the Duty to Avert Harm

A Reader Responds

Patient confidentiality and the duty to avert harm (*PGC*, Vol 12, No. 1, Spring, 1990), asks us to re-evaluate some basic convictions genetic counselors hold regarding their relationship with patients. The foremost is respect for a patient's autonomy, that is, recognition that an individual has a right to self-determination and dignity. From this conviction follows the need to protect confidentiality and to act non-directively.

A constructive counselor/patient relationship requires mutual respect and trust. The counselor trusts the patient to tell the whole truth; the patient trusts the counselor, among other things, to be honest and to inflict no harm. The obligations of the counselor to the patient are primary and stronger than those to any other parties.

In the specific case presented, there are several alternatives open to the counselor. In developing the pedigree for Mrs. A, she can extend it to include Mrs. B's branch of the family with its multiple pregnancy losses and/or poor pregnancy outcome. Blood chromosome analysis could be offered to Mrs. A to rule out any "familial" chromosome variations. The counselor could also emphasize the relatively low risk of amniocentesis, pointing out that at age 33 it is not uncommon to have the procedure. If Mrs. A refuses, blood chromosomes could be offered as a useful alternative. It is always possible to contact Mrs. B again, asking her to rethink her position.

To answer the specific question raised, i.e. should confidentiality ever be set aside and a counselor circumvent the wishes of a noncompliant patient, I think not. To assume that a patient should be "compliant" in the genetic counseling setting is to suggest that there are correct answers which only the counselor knows. No professional, for example, would force a 40 year old woman (whose risk for Down syndrome is higher than Mrs. A's risk for being a translocation carrier) to have prenatal diagnosis, although we may *think* she should. The duty to avert harm is to the patient first (in this case Mrs. B, whose confidentiality is at stake), and to others *only* if there is a grave danger that is *reasonably* likely to occur. Is Mrs. A reasonably likely to be a translocation carrier? No. She is a third degree relative and may only *possibly* be a translocation carrier. Doing no harm to the patient is a stronger obligation than doing something possibly beneficial for someone else.

I think the only circumstance under which a counselor should breach confidentiality is when the law requires it.

Susan Schmerler, M.S.
St. Joseph's Hospital and Medical Center, Paterson, NJ

The Author's Response

In Case No. 20 (*PGC*, Vol. 12, No. 1, Spring 1990) I reported my professional dilemma regarding breaking the confidence of a previous patient, Mrs. B, a 13/14 translocation carrier, in order to provide potentially beneficial information to my current patient, Mrs. A, a cousin of Mrs. B. Counselors who responded personally to this case uniformly recommended *against* divulging information about Mrs. B and also recommended doing chromosome analysis on Mrs. A to rule out a balanced translocation, the indication being one previous spontaneous abortion.

The case was actually managed by advising Mrs. A that, based upon my own information, the problems apparent in her cousin's baby and her own history of one spontaneous abortion, it would be prudent for her to have a blood chromosome test. She accepted the advice without further questioning. Her chromosome test was normal and amniocentesis was not performed.

I felt relieved that this case was resolved so simply. However, had Mrs. A questioned my motives for recommending chromosome analysis, or if she had turned out to be a translocation carrier, my sentiment was to follow the dictates of the President's Commission Study[1] which states that the genetic counselor's commitment to confidentiality is not absolute and can be overridden under specific conditions, e.g.."...[if] 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; the harm that identifiable individuals would suffer would be serious... ." It was my feeling that this case met the above criteria. I recognize that although many counselors might share my sentiments, there are as many who would feel that confidentiality is professional standard which should never be breached.

It is very possible that the genetic counselor's observations of confidentiality vs. obligation to inform relatives will one day be tested in a court of law. Although we certainly do not want to be practicing legally defensive genetic counseling, we do need to recognize that the issue of confidentiality is a recurrent dilemma in our profession. Perhaps the NSGC should be at the forefront in addressing appropriate counselor behavior and policy involving these issues of confidentiality as well as other ethical dilemmas.

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

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.

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Case No. 21

Double Single Cell Pseudomosaicism

by Denise M. Greene, M.S ., UC Irvine Medical Center, Orange, CA

A 40 year old G4, P2, TAB1 woman, CB, was referred for amniocentesis because of advanced maternal age and a previous child with Down syndrome. Her pregnancy history revealed that she had a healthy 12 year old daughter, a set of premature twins who died shortly after birth and a daughter with Down syndrome who had died at age two years, 16 months before our consultation. CB was still grieving her daughter's death.

CB is Armenian and came to the United States from Iran in 1978. She became pregnant that year and terminated the pregnancy as a result of pressure from her in laws because of limited financial resources.

CB had originally intended to terminate this pregnancy because she and her husband could not face the possibility of having another handicapped child. They were also concerned about finances as they both were currently unemployed. At this point, CB decided she could not go through with an abortion; her husband wanted her to terminate the pregnancy.

After counseling, CB elected to proceed with an early amniocentesis because she wanted test results before she began "showing." She had not told anyone about the pregnancy because "Armenians talk and would tell terrible stories if she had another child with a problem."

The amniocentesis, scheduled twice due to an anterior placenta and a large body habitus leading to poor visualization, was finally performed successfully at 16.6 weeks. No fetal anomalies were noted on ultrasound. The amniotic fluid cell culture revealed the following:

Flask 1: 1/20 cells: Trisomy 21 with a deletion of most of the long arm of chromosome 1; 19/20 cells: 46,XX

Flask 2: 1/20 cells 47,XX + 18; 19/20 cells: 46,XX

Flask 3: 20/20 cells: 46,XX

We termed this result "double single cell pseudomosaicism" and we believed that it was most likely a cultural artifact. But given this patient's history and her desire to terminate an abnormal fetus, we could not ignore the finding.

The couple was told that the findings could be interpreted in three ways:

- Both abnormal cells arose in the culture flasks as an *in vitro* artifact. This was the most likely explanation for these two cells, especially as the one cell with trisomy 21 also showed a 1q- which was almost certainly an *in vitro* event.
- The two aneuploid cells were derived from the placenta and/or fetal membranes and would be unlikely to be present in the fetus.
- The fetus was truly mosaic for trisomy 21 or trisomy 18 or both.

The couple was told that the chance of the two aneuploid cells representing true mosaicism was very small but that no precise occurrence figure for such an event was available. Based on large surveys in the U.S. (Hsu and Perlis, *Prenat Diag* 4:97-130, 1984) and Europe (Bui et al., *Prenat Diag* 4:145-162, 1984), the risk of a fetal abnormality would probably be less than 1%.

We discussed the options to partially resolve the ambiguous findings. We offered to repeat the amniocentesis but warned that even if the second culture showed the absence of trisomy 18 or trisomy 21 cells, the findings in the first cultures could not be ignored. We also discussed PUBS, stating that negative findings could not offer complete reassurance and the risk of miscarriage was about 1%. We offered detailed serial ultrasound examinations to monitor fetal growth and to check for structural abnormalities associated with trisomy 18. We also mentioned the possibility of obtaining cord blood after birth to confirm a normal karyotype.

CB was distraught during this counseling session and had difficulty dealing with the ambiguity of the situation. Her husband seemed to have a better understanding of the factual information presented. Over the next few days, I had a great deal of phone contact with CB. She was in crisis and very unsure about whether to continue or terminate the pregnancy. Her husband wanted her to terminate and told her that it was her decision but that he wasn't sure he could emotionally support her if the child was born with an abnormality. CB was looking for a guarantee of abnormality before she would terminate and her husband was looking for a guarantee of normalcy before he would want her to continue the pregnancy.

CB elected to proceed with a PUBS and simultaneous repeat amniocentesis. At 20.6 weeks gestation, an ultrasound revealed normal interval growth. After a long and difficult attempt at PUBS, only maternal blood was obtained. Amniotic fluid cultures revealed a normal female karyotype in 60 metaphases analyzed from 3 flasks. CB declined a repeat PUBS and elected to continue the pregnancy.

CB developed hypertension and was delivered by C-section. Her daughter was reportedly normal at birth. Due to poor communication, a cord blood sample was not sent for karyotyping. When CB was offered a blood karyotype for her daughter two weeks later, she declined. At two months, her daughter appeared to be developing normally.

This case raises the issue of reporting single cell pseudomosaicism to a patient and whether our motivations are predominantly influenced by ethical and medico-legal concerns.

Genetic Counselors Polled

This case was presented at the April 1990 NSGC Region VI meeting at Asilomar. Of the approximately 100 genetic counselors present, about 60% said they *would* have reported the result to the patient, about 15% said they *would not* have reported the findings and about 25% were undecided. Counselors who would report the result cited the following four reasons:

- if their lab gives them the result, they are obligated at least to inform the referring physician;
- 15% said they discuss the possibility of pseudomosaicism routinely in the preamnio counseling session so they feel they have prepared the patient for such findings;
- they feel obligated to report any finding that could be associated with the delivery of a viable mosaic infant; and
- the finding needs to be reported to the patient because it is included in the file to which the patient may have access.

The only reason cited for *not* reporting single cell mosaicism was because of its very common occurrence and probable artifactual nature.

Our initial finding that uE3 is low in Down syndrome pregnancy (median = 0.79 MoM)[3] was confirmed by us with the Oxford data set (median = 0.73 MoM)[4] and has been replicated in recently published studies[5-8] with median values ranging from 0.5 to 0.74 MoM. In contrast, a recent study by Macri *et al* has failed to find the association.[12] That study reported uE3 results from 41 affected pregnancies and found a median value of 0.99 MoM. Thus, the range of median uE3 MoM values which have been reported is 0.52 to 0.99 (consensus median of published reports is 0.74 MoM) and is similar to the range of MoM values reported for AFP by various centers following the discovery of its association with Down syndrome in 1984. With AFP, one study also failed to find an association. Ultimately, the group consensus was found to be correct. We have no reason to believe it will be different with uE3.

Screening Performance

The article by Wald *et al* provided a statistical method for the calculation of patient-specific risk using AFP, uE3 and hCG values in combination with maternal age[1]. In that article, screening performance using a second trimester risk cut-off of 1 in 190 (which corresponds to a term risk cut-off of 1 in 250) was described. The initial positive rate was predicted to be 5.0% with a detection rate of 61%. If, instead, a second trimester risk cut-off of 1 in 270 (the risk of an unscreened 35 year old) is selected, the initial positive rate is predicted to be 7.2% with a detection rate of 67%.

A recent study from Denmark by Norgaard-Pedersen *et al*[8] largely confirms the findings of Wald *et al*,[1] although they found that an initial positive rate of 5% would result in a lower detection rate (just over 50%). The Danish invetigators questioned that the addition of uE3 enhances detection over that achieved using only AFP and hCG in combination. However, the data in both the Danish and the Wald *et al* studies indicate that for a given detection rate, the initial positive rate is markedly reduced by the inclusion of uE3. In the study of Wald *et al*, at a detection rate of 60%, the initial positive rate decreased from 6.7% to 4.7% (a 30% reduction), and in the study of Norgaard-Pedersen *et al*, at a detection rate of 50%, the initial positive rate decreased from 6.0% to 4.3% (a 28% reduction, derived from data in ref 8) with the inclusion of uE3. A reduction in the initial positive rate translates into a comparable reduction in amniocentesis rate. If, in fact, the inclusion of uE3 results in a 30% reduction in the amniocentesis rate, then the use of uE3 would be cost effective. Prospective studies using much larger numbers of samples are now underway and will soon provide more definitive answers.

Issues in Genetic Counseling

The ability of the new method to enhance prenatal screening for chromosomal defects other than Down syndrome has not yet been demonstrated. However, information regarding the association between the individual markers and other chromosomal defects is becoming available. AFP is low in cases of fetal trisomy 18, with a median of 0.6 MoM.[13] Recently, we reported that uE3 is also low in trisomy 18, with a median of less than 0.5 MoM.[14] Bogart *et al* initially reported very low hCG levels in two cases of fetal trisomy 18;[2] we have found that the median for hCG is less than 0.3 MoM in trisomy 18 pregnancy.[14] Because hCG levels are low rather than high in fetal trisomy 18, these pregnancies would most likely not be identified by a screening protocol designed to detect Down syndrome. A separate risk calculating system would have to be employed to identify individuals at high risk for trisomy 18. Levels of the new markers have not yet been found to be abnormal in any aneuploidies other than trisomy 21 and 18.

With enhanced screening, maternal age becomes just one of four determinants of risk and can no longer be considered the prime screening variable. All women who are currently offered AFP screening should be considered candidates for enhanced screening. Based on current criteria, this includes all women under the age of 35. Patients who are ≥35 years are usually offered amniocentesis and are not routinely offered screening by AFP alone because AFP screening for Down syndrome in older women would fail to detect a substantial number of cases. With the new screening test, the percentage of undetected cases (so-called false negatives) will be much lower. An estimated 85% of all cases of fetal Down syndrome will be found in the screen positive group which will comprise only 20% of all patients who are ≥35. Thus, 80% of all older patients could be reclassified as low risk and could avoid amniocentesis with no more than 15% of the Down syndrome cases in this age group being undetected. However, it must be made very clear that a normal amniocentesis result will rule out Down syndrome and other chromosomal disorders whereas a negative screening result can only reduce the Down syndrome risk below that of a 35 year old. The patient who must be sure that Down syndrome and other chromosomal disorders are ruled out must not be led to believe that a screening test will achieve this.

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14 Canick JA, Stevens LD, Abell KB, Panizza DS, Osathanondh R, Knight GJ, Palomaki GE, Haddow JE. *Second trimester maternal serum unconjugated estriol and human chorionic gonadotropin in pregnancies affected with trisomy 18, anencephaly, and open spina bifida.* Am J Human Genet 1989; 45:A255.

LETTERS TO THE EDITOR

GENERAL CF SCREENING CAUTIONED

To the Editor:

As a genetic counselor employed full time in a Cystic Fibrosis Center, I would like to comment on the recent "PointCounterpoint" (*PGC*, Vol. 12, No. 1, Spring 1990) which addressed the issue of carrier screening for CF.

The CF gene has been identified and one of the responsible mutations defined, ΔF508. This mutation accounts for approximately 70% of the CF chromosomes of Caucasians but for only 40% of CF chromosomes in Italy, 30% in Ashkenazi Jews and 35% of American Blacks. The frequency of this mutation in other ethnic and racial populations at risk for CF is unknown. This point must be emphasized to those who read in the lay press that carrier screening for CF is available to 70% of Americans. CF is *not* a disease which is seen *exclusively* in the Caucasian population; carrier screening will be needed for other populations, as well. The ΔF508 has *wide* applicability for those with a family history of CF with no living proband and for spouses of known carriers. However, the use of this mutation for general population carrier screening must be cautioned.

My concern is for the large number of people at risk who would be missed by the present screening method. Currently, 1 in 15 couples will be identified when one partner has the ΔF508 mutation and the other does not. For this couple, the risk of having a child with CF is now statistically increased to 1:400. Without the benefit of a definitive prenatal test, the ability to offer genetic counseling to ensure an informed reproductive decision and to alleviate anxiety is problematic. Since additional mutations have been identified which do not account for a significant proportion of CF chromosomes, the accuracy of carrier screening has not improved to the degree initially anticipated.

General population screening for CF should begin slowly and only when the accuracy of the test has been greatly improved It is my hope that genetic counseling will be mandatory for any person seeking CF carrier screening.

Kathleen Valverde, M.S.
CF Center, St. Vincent's Hospital and Medical Center of New York

CA 'NICKEL A DRINK' TAX INITIATIVE

To the Editor:

The California "Nickel A Drink" initiative proposes to increase the tax on alcoholic beverages, currently among the lowest in the U.S., earmarking $45M for perinatal substance abuse programs. Over one million signatures were gathered to put the initiative on the November ballot. MCH advocates formed a group to support the campaign and to ensure that programs dealing with perinatal substance abuse are represented when decisions are made about appropriations. Only seven replied to letters sent to every NSGC member in California asking for support.

This lack of involvement will ensure a continuation of poor awareness of our field among policy makers and the public, a consistent loss of direct service money and limited accessibility to services. There are at least 60,000 infants born each year in California with alcohol or drug effects. It is virtually impossible for a poor, pregnant woman to get drug or alcohol treatment. The Alcohol Tax Initiative is one measure that may interrupt the steady stream of troubled children born into our society. The alcohol industry is mounting a $20M campaign to defeat this initiative. Send your donations to: MCH supporters of 'Nickel a Drink,' AC5, 2131 University Ave, Suite 213, Berkeley, CA 94704.

The time is now!

Ilana Mittman, M.S.
Kurt Fenolio, M.S.
San Francisco General Hosptial

LONG TERM SURVIVAL OF TRISOMY 18

To The Editor:

Trisomy 18 in a newborn is a dismal diagnosis to face for both health professionals and parents, alike. Shortly after the baby is born and a diagnosis of trisomy 18 is confirmed by cytogenetic analysis, the parents are often asked to make many frightening decisions. These decisions are often based on published survival data, which indicates that mean survival is 2-3 months for males and 10 months for females.[1] Long term survival is rarely reported. A recent abstract from the 1989 ASHG Annual Meeting reports an individual with Trisomy 18 who, at age 24 years, was still alive.[2]

We have followed a woman with non-mosaic trisomy 18 who died at age 34 years 9 months. The diagnosis was first made when she was 26 years. She had multiple clinical findings consistent with trisomy 18. Cytogenetic analysis confirmed trisomy 18 in all 150 cells from blood culture and 100 cells from fibroblast study. In addition, the patient was a carrier of a Robertsonian translocation between chromosomes 13 and 14 [46,XX,-13,-14,+t(13;14),+18]. This translocation appears to be *de novo* as parental studies were normal and evidenced no translocation.

The potential for long term survival of persons with trisomy 18 needs to be taken into account when providing genetic counseling. Referral to organizations like S.O.F.T. [Support Organization for Trisomy 18/13] provides invaluable additional support to these families.

Gary S. Frohlich, M.S.
Health Services/Prevention Unit
Los Angeles County Regional Center

1 Weber WW. *Survival and the Sex Ratio in Trisomy 18-13*. Am J Hum Genet, 1967; 369-377.

2 Baty B, Carey J, Blackburn B. *The Natural History of Trisomy 18 and Trisomy 13*. Am J Hum Genet, 1989; 45:A71.

CAVEAT RE: CF SCREENING

To the Editor:

One of the purposes of *Perspectives in Genetic Counseling* is to encourage communication within the genetics community. We were pleased that a number of counselors contacted us about the article *Counseling for Cystic Fibrosis*. (Vol. 12, No. 1, Spring 1990) They expressed some concerns regarding whether or not to study extended family members if the consultand does not have the most common of the CF mutations, ΔF508.

We would like to emphasize that it is important to test other family members whenever possible to accurately assess the consultand's carrier risk. Since the ΔF508 mutation is only seen in 70-75% of carriers, a negative result in a person with a positive family history can be significantly modified by knowledge of the mutation status of other family members. In a family in which the person who has the CF diagnosis is living, we *strongly* encourage that DNA testing be conducted on that affected person. If the affected person is no longer alive, testing the affected person's parents will provide additional information.

If the ΔF508 mutation is not seen in the CF family, linkage analysis or linkage disequilibrium can be performed involving the appropriate family members. This will enable the consultand to obtain the most accurate carrier risk assessment possible.

There are many variations of family histories, but the same strategies can be applied given cooperative and available family members.

Susan D. Fernbach, R.N., B.S.N., Baylor College of Medicine and Vickie L. Venne, M.S., Nichols Institute Reference Laboratory

ED NOTES

With this edition of *Perspectives*, I close out my tenure as Editor-in-Chief of the newsletter of the National Society of Genetic Counselors. Three years and twelve issues ago, I accepted responsibility for guiding the development of this publication from Joe McInerney. Joe had taken over the reins from Deborah Eunpu, who began *Perspectives* in her living room.

In relinquishing the editorship of *Perspectives*, I feel both relief and pride: relief from the demands of trimming articles too long to fit space requirements, relief from the discussions with authors regarding what constitutes important and relevant passages in their articles, relief from the quarterly deadlines which seemed to arrive monthly. But I feel pride in what *Perspectives* has become: increased in size, in scope, in interest, a forum for discussion, a place to look for job opportunities, a proving ground for testing one's writing abilities, a classroom for learning how difficult counseling cases are handled.

I am honored to have served as a guide for this publication for the past three years, collecting ideas from the readership, encouraging members and others to submit interesting articles, case reports and reviews. Over the years, I've had the pleasure to work with several Editorial Board members who provided invaluable assistance, energy and creativity. I am grateful to them all. I am especially appreciative of the energy provided by Bea Leopold, whose firm insistence kept me focused and whose prodding made *Perspectives* meet most publication deadlines.

I feel quite comfortable in turning the editorship of *Perspectives* over to Vickie Venne, whose organizational skills, knowledge of the field and enthusiasm are sure to carry *Perspectives* through this upcoming transitional period as we continue to work towards the establishment of a journal. The Board of Directors is expected to vote in July on the issue of a journal and selection of a publisher, so be sure to talk with your Regional Representatives about any interest that you may have.

My thanks to every author, editor, reviewer, letter-writer, supporter, advertiser and reader of *Perspectives*. You've made it what it is today.

Ed Kloza

IS MULTIPLE MARKER SCREENING FOR DOWN SYNDROME USEFUL? *Macri, from p. 1*

25% of Down syndrome cases. Clearly, an improvement in this single test approach to Down syndrome screening would be welcome.

THE DOUBLE TEST

In 1987, Bogart *et al*[3] suggested such an improvement. Their observation of elevated levels of maternal serum hCG (MShCG) in Down syndrome pregnancies promised to improve detection efficiency, perhaps to as much as 60%. Their findings have now been confirmed in a number of laboratories[4,5] and this marker appears to be a promising addition to the MSAFP protocol for Down syndrome screening. However, large scale prospective studies and additional investigations should precede the routine adoption of this screening protocol.

THE TRIPLE TEST

Canick *et al*[6] and Wald *et al*[7] have recently suggested that maternal serum uE3 (MSuE3) levels are lowered in Down syndrome pregnancies and, hence, this analyte should be added to MSAFP and MShCG within a Down syndrome screening protocol. However, there has not as yet been independent confirmation of the effectiveness of MSuE3. In fact, MSuE3 data from our laboratory (employing the same modified assay reagent kit used by Canick *et al*, Wald *et al* and others[8-9]) are in sharp contrast to the reports of these investigators. In addition to having no confirmation of their findings, it is also important to recognize that exogenous factors such as diurnal variation[10] and maternal smoking[6] habits may produce changes in MSuE3 levels sufficient to render it ineffective in screening for Down syndrome. Even if MSuE3 were a marker for Down syndrome, the influence of such exogenous factors would make it an impractical screening tool.

A second report from our laboratory[11] demonstrates that some asssays for MSuE3 actually result in higher than expected values in affected cases. Use of such assays for MSuE3 evaluation will be counterproductive in identifying patients at increased risk for Down syndrome.

Unfortunately, triple screening has been introduced and commercialized prematurely. The interests of the patient and the obstetrical and genetics communities are not well served by urging the introductiaon of such triple screening prior to adequate independent studies and validation. We urge against the prospective use of the so-called "triple test."

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PERSPECTIVES
in Genetic Counseling

Professional Status Survey Results

special supplement to Vol. 12, No. 2 Summer 1990

by Janice Edwards, M.S., University of South Carolina School of Medicine, Columbia, SC, Professional Issues Committee Chairperson

The Professional Issues Committee conducted its first Professional Status Survey in 1980 (*NSGC Professional Status Survey*, Begleiter, Collins, Greendale, *PGC*, Vol. 3, No. 4, Dec. 1981). As the NSGC enters its second decade, the results of the 1990 survey demonstrate tremendous growth in the Society, the profession and among individual genetic counselors.

TABLE 1: PRIMARY WORK SETTING

	%	N
University	52.4	174
Private Hospital	26.2	87
Outreach	0.9	3
Private Practice	4.2	14
HMO	4.2	14
Diagnostic Lab	2.1	7
Government	5.1	17
Voluntary Health	0.0	0
Other	3.7	12
N/A	1.2	4

TABLE 2: CERTIFICATION BENEFITS

	%	N
Raise in salary	10.3	22
Improved job status	2.8	6
New job/promotion	2.3	5
Other	1.4	3
Personal reward	24.4	52
No specific benefit	75.1	160

TABLE 3: PRIMARY ACTIVITY

	%	N
Clinical	79.6	261
Administration	12.8	42
Teaching	3.4	11
Research	2.1	7
Laboratory	0.3	1
Business	0.9	3
Other	0.9	3

The total return rate for the 1990 survey was 66% (396/603). After excluding certain returns (PhDs, counselors not working and late returns), the results reflect 54% (328/603) of those with full membership status as of January 11.

DEMOGRAPHICS

The majority of respondents were female (93.3%) between the ages of 25 and 39 (78.3%) with a master's degree (91.8%) and five or more years of experience (57%). All regions were represented, in the following proportions: I (10.4%), II (30.2%), III (10.1%), IV (17.7%), V (7.0%), VI (24.7%).

Table 1 lists the primary work setting of the counselors. The majority (79.2%) work in a metropolitan or suburban setting. Eighty percent of the respondents work fulltime; most parttime professionals work more than 20 hours per week (71.9%). Most of the genetic counselor positions are funded by the employing institution (38.4%) or state (30.5%). Most positions (66.5%) are not grant dependent. Seventy-five percent of the grant supported counselors felt their institution would support them should grant funding be terminated.

TABLE 4: SPECIFIC AREAS OF RESPONSIBILITY

	%	N
General genetic counseling	82.0	269
Pediatric genetic counseling	62.2	204
Prenatal genetic counseling	83.2	273
Teratogen exposure counseling	75.6	248
Specialty disease counseling	55.8	183
Research	35.7	117
Lectures	71.3	234
Seminars/Workshops	49.4	162
Teaching courses	21.3	70
Clinic coordination	50.9	167
Administration/Management	47.6	156
Marketing	15.2	50
Laboratory work	4.6	15
Outreach/Satellite clinic	33.8	111
AFP screening program	49.1	161
Support/Parent group(s)	28.7	94
Newborn screening	14.3	47
Carrier screening	39.0	128
Patient liaison	36.3	119
Patient education	49.4	162
Reproductive loss counseling	55.2	181
AIDS counseling	3.4	11
Grant writing	18.3	60
Writing for publication	31.1	102
Hotline	7.6	25
Budgeting	16.8	55
Billing	17.1	56
Other	7.3	24

CERTIFICATION

Sixty-four percent of respondents were certified by the American Board of Medical Genetics and 35% were eligible for certification. The majority of those eligible were recent graduates planning to sit for the exam (60%). Some had opted not to take the exam but were planning to to take it at the next sitting (13%); some felt it was not a requirement for employment (5%); and some had other reasons for not taking the exam (10%) or had not passed (11%). Table 2 lists the job benefits of ABMG certification as reported by

TABLE 5: SPECIALTY CLINICS

	%	N
Cardiac	2.4	8
Craniofacial/Cleft Palate	15.2	50
Cystic Fibrosis	14.6	48
Developmental	6.7	22
Down Syndrome	7.3	24
Endocrine/Growth	3.4	11
Hemoglobinopathies	10.7	35
Hemophilia	10.7	35
Huntington's Disease	4.6	15
Infertility	7.6	25
Metabolic Clinic/PKU	10.7	35
Muscular Dystrophy	12.5	41
Neurofibromatosis	11.0	36
Neurology	2.7	9
Orthopedics	1.8	6
Skeletal Dysplasia	4.6	15
Spina Bifida	12.5	41
Tay-Sachs	7.3	24
Teratology	8.8	29
Other	9.8	32

208 certified genetic counselors and six eligible respondents. Thirty-eight percent of employers funded all or part of ABMG certification expenses.

Professional Responsibilities

Table 3 reflects the primary job activity for the 328 respondents. Counselors were also asked to indicate specific areas of responsibility (Table 4) and specialty clinics in which they participate (Table 5). The vast majority of counselors individually provide prenatal genetic services and many provide general genetic services, except diagnostic evaluation, without team members present (Table 6). The average number of patients seen per genetic center per year was 1448 (standard deviation 1452). Genetic counselors saw an average of 416 patients per year (s.d. 255) and an average of 323 were seen independently (s.d. 256). These averages may be underestimates, as some respondents did not appear to answer the survey question accurately. Table 7 demonstrates the method of patient billing for those seen independently, and with a physician. Many counselors have served the profession beyond providing direct patient care, as listed in Table 8.

Faculty Status, Teaching and Research

Thirty-seven percent of respondents work in a setting where a faculty appointment is possible. Seventy-seven individuals reported a current faculty appointment as listed in Table 9. The majority of appointments (80%) were not tenure track positions, 4% were and 16% were not sure. Some counselors received their appointment automatically at the time of hire (30%), others requested appointments (40%), a few were awarded an appointment after a service period (8%) and some sought their appointment in other ways (22%). The majority of faculty appointments were in the medical school (86%).

Seventeen percent of respondents taught an average of 1.38 (max. 4) semester courses per year and 34% coordinated an average of 2.59 (max. 30) conferences yearly. Sixty-three percent supervised students including genetic counseling (41%), medical (23%), residents (23%), undergraduate (10%), nursing (8%) and others. Half of the respondents supervised other employees including administrative personnel (37%), other genetic counselors (23%), nurses (6%), laboratory technologists (3%) and others. Table 10

Table 6: Services Provided Independently

Prenatal	%	N	General Genetics	%	N
Preamnio/CVS counseling	98.2	273	Med history/pedigree	97.9	278
Case management	76.6	213	Case management	59.9	170
Report normal results	86.7	241	Diagnostic eval	11.3	32
Report abnormalresults	83.5	232	Primary counseling	75.7	215
Explain abnorm results	82.0	228	Follow-up counseling	89.4	254
Follow-up counseling	93.5	260	Other	5.6	16
Other	14.0	39	N/A	13.4	44

Table 7: Billing

	Patients Seen Independently		*Patients Seen With Physician*	
	%	N	%	N
Own Name	6.8	20	1.2	3
With Physician	11.8	35	6.9	18
By Physician	47.3	140	61.5	160
Comprehensive Fee	24.7	73	23.1	60
Other	9.5	28	7.3	19
N/A	9.8	32	20.7	68

Table 8: Expanded Professional Roles

	%	N
Written successful grant proposal(s)	26.2	86
Developed video presentation(s)	17.7	58
Personally developed outreach program(s)	24.7	81
Conceived and developed workshop/symposium/meeting(s)	37.8	124
Served on local/county committee(s)	28.0	92
Served on state/national committee(s)	28.0	92
Served on national genetic society board(s)	14.0	46
Served on national genetic society committee(s)	22.9	75
Served on advisory board(s) for voluntary organizations	25.0	82
Developed local screening program(s)	11.6	38
Developed/coordinate support group(s)	30.8	101
Other	7.6	25
Not Applicable	11.3	37

Table 9: Current Faculty Appointment

	%	N
Lecturer	2.6	2
Instructor	33.8	26
Assistant Professor	7.8	6
Associate Professor	1.3	1
Professor	0.0	0
Clinical Instructor	19.5	15
Clinical Assistant Professor	2.6	2
Clinical Associate Professor	1.3	1
Clinical Professor	1.3	1
Other (mostly Clinical Associate)	29.9	23
Non-faculty	77.7	255

reflects additional educational responsibilities indicated by respondents.

Over half (56%) of the respondents were involved in research, most often in the areas of clinical genetics, genetic counseling and prenatal diagnosis. Forty-three percent have made paper, poster or workshop presentations at national genetics meetings and 71% have published. Forty-eight percent of respondents have been first author on their publication(s). Table 11 reflects the type and number of presentations and publications.

Employment Benefits and Salary

Forty percent of respondents received complete or partial reimbursement for job interview expenses. Twenty-one percent received complete or partial moving expenses and 33% received complete or partial payment for professional society memberships. Ninety-five percent received reimbursement for professional meetings, by various methods (Table 12). Forty percent of respondents received compensatory time off in lieu of overtime worked, 35% received no compensation and 4% received additional pay.

The Analysis of Current Salary is summarized in Tables 13, 14 and 15 and was originally published in *PGC*, (Vol 12, No. 1, Spring 1990).

Job Satisfaction

Seventy-three percent of respondents have held one or two genetic counselor positions (max. 6). Fifty-two percent had not changed jobs in the past five years. Those that had, cited various reasons: personal (33.8%), change in job content (26.8%), better salary (8.9%), more autonomy (7.6%) and other reasons (22.9%). The majority of counselors (58.8%) were not planning to leave the field in the near future. Some were considering changes (13.7%) and some were undecided (26.5%). These respondents were considering pursuit of an advanced degree (33%), focusing on family (20%), pursuing a genetics related business (15%), joining a non-genetics related business (12%) or retiring (7%), while some had other plans or were not decided.

The vast majority of respondents were very satisfied or satisfied with the following aspects of their current position: variety of patients, number of patients, administrative responsibilities, autonomy, their director's support, the professional quality of their unit, their

Table 10: Additional Educational Responsibilities

	%	N
Director/Assistant Director of GC training program	1.8	6
Instructor in GC program	7.0	23
Invited speaker for GC graduate students	15.5	51
Director/Assistant Director of other academic program	0.3	1
Instructor in other academic program	6.7	22
Invited speaker in other academic program	34.5	113
Developed genetics curriculum for high school students	3.7	12
Developed genetics curriculum for high school teachers	5.5	18
Developed genetics curriculum for other academic group	6.1	20
Spoken to lay/community group(s)	74.7	245
Spoken to health professional group(s)	76.5	251
Taught in medical school course(s)	26.2	86
Given grand rounds at my institution	27.1	89
Given grand rounds at other institution	14.0	46
Spoken at other regular conferences at my institution	41.8	137
Given conference(s) at other institution(s)	19.8	65
Invited speaker at NSGC or other national meeting(s)	14.3	47
Spoken at my NSGC regional education meeting(s)	22.9	75
Spoken at other NSGC regional education meeting(s)	4.9	16
Quoted/Appeared on television, radio, newspaper, etc	45.1	148
Other	3.4	11
Not Applicable	2.4	8

Table 11: Presentations and Publications

		%	N	
Presentations at ASHG, Birth Defects or NSGC		43.3	142	
	N>0	%	Mean	Max
Platform presentations	69	21.0	1.49	6
Poster presentations	106	32.3	2.33	10
Workshop speaker	44	13.4	1.84	8
	%	N		
Publications		70.7	232	
	N>0	%	Mean	Max
Abstracts on case reports	105	32.0	2.37	15
Abstracts on original research	96	29.3	3.19	20
Articles on case reports	92	28.0	2.57	12
Articles on original research	99	30.2	2.96	15
Books	12	3.7	1.33	5
Chapters in books	54	16.5	1.50	6
Pamphlets	89	27.1	2.45	15
Patient resources	50	15.2	2.08	10
Other	44	13.4	2.14	9
First author	157	47.9	3.21	16

Table 12: Reimbursement for Professional Meetings

	%	N	Mean
Specific amount	24.7	81	$949
Specific number	25.9	85	1.35
No limitations	17.4	57	
Presentation required	8.2	27	
Other	18.9	62	
None	4.9	16	

variety of activity and employee benefits. The majority were also satisfied with other areas, though a portion of respondents felt there was too little of the following: teaching responsibilities, participation in research, institutional support, secretarial support, opportunity for advancement, salary and opportunity for continuing education. Eighty-eight percent of respondents indicated overall satisfaction with their current position.

Respondents were also asked to indicate their satisfaction with the genetic counseling profession. Some concern was reflected in the limitations for professional growth, opportunities to branch out and advance as well as the earning potential. Counselors were highly satisfied with the following aspects of the field: patient contact, scientific content, learning opportunity, the opportunity to provide care and the opportunity for personal growth.

COMMENT

From these results, it becomes obvious that genetic counselors have made great strides in diversifying their clinical responsibilities, increasing their autonomy and developing educational opportunities. The overall satisfaction that counselors feel toward their jobs and the profession is particularly rewarding to see. As director of a genetic counseling training program, my perspective reveals that our ranks continue to be infused with highly motivated, intelligent individuals. With the opportunities that advanced technology creates for our services, there is no doubt the profession will continue to soar.

ACKNOWLEDGEMENTS

I would like to acknowledge the work of Frederick Marsteller, Ph.D., for his consulation and statistical analysis and the members of the Professional Issues Committee: Shari Baldinger, M.S., Beth Balkite, M.S., Michael Begleiter, M.S., Robin Bennett, M.S., Barbara Bernhardt, M.S., Ron Cadle, M.S., Nancy Callanan, M.S., Leslie Ciarleglio, M.S., Debra Han, M.S., Pricilla Harris, M.S., Ph.D., Jacqueline Hecht, Ph.D., Valerie Jansen, M.S., Cindy Malin, M.S., Seth Marcus, M.S., Julie Potter, M.S., Diana Punales-Morjon, M.S., Elsa Reich, M.S., Mimi Rietsch, Robin Schwartz, M.S., Lorraine Suslak, M.S., Helen Temple, M.S. and Wendy Uhlmann, M.S.

TABLE 13: 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

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.

TABLE 14: 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

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 13 & 14) 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.

TABLE 15: 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)

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

Code of Ethics Update

The *ad hoc* committee on Ethical Codes and Principles met in conjunction with the MARHGN/NSGC Region II educational conference in Atlantic City, NJ. The Preamble to the Code of Ethics was written as an introduction to the ethical responsibilities of the NSGC and its members. Acceptance of the guidelines and principles of the Code will be a requirement for Society membership.

We are now ready to begin working on the body of the Code, which will be organized in terms of the following relationships: counselor/patient, counselor/professional, counselor/society, counselor/practitioner. The most important value we found within these relationships is one of care and concern. The guidelines derived from the principles that would support a value of care and concern will form the basis of the Code, and will set a minimum standard for our membership. We plan to have the first draft of the Code distributed to the membership prior to the meeting in Cincinnati, so that any interested members will have the opportunity to comment. To facilitate interaction between the committee and the membership, an open forum will be held in Cincinnati at a time that is free of competing events.

Besides creating a Code of Ethics, we feel that the Ethics subcommittee should also serve as an educational resource. To fulfill this commitment for 1990, we will present a workshop on an ethical issue found in the public health setting at the annual conference.

Committee members are: Judith Benkendorf, Nancy Callanan, Rose Grobstein, Susan Schmerler and Kevin FitzGerald (consultant).

Last Call for '88 Proceedings

The NSGC Eighth Annual Education Conference proceedings, "Strategies in Genetic Counseling: Political Influences from Society to the Workplace," held in New Orleans, October 1988, has been published by the Society. Copies were mailed recently to all registrants of that conference. A limited number of copies is available, as supplies last. Orders *must* be accompanied by a check for $30, payable to NSGC, and mailed to the Executive Office. *(see address, p. 2, 16)*

Networking Opportunity for Genetic Counselors in Non-Traditional Roles

The careers of several members of the NSGC focus less on patient contact and more on education, business, administration or research within the area of human genetics. NSGC members not in the counseling mainstream are invited to an informal gathering at the Annual Education Conference in Cincinnati to meet one another, identify common interests and issues and perhaps begin to develop a sub-network for professional development.

Members interested in receiving further information are encouraged to contact Ed Kloza or Vickie Venne. *(info, p.2)*

Families Needed for Fragile X Research

The Behavioral Genetics Research Center at Johns Hopkins University Hospital and the Kennedy Institute is seeking families with children who have the Fragile X chromosome to participate in NIH-funded clinical research projects. All families will receive free cognitive, social and behavioral evaluations as well as financial compensation.

Free cytogenetic and DNA testing may also be available. Families with affected or unaffected female children are especially needed. All families are encouraged to contact the BGRC to receive updated information about Fragile X syndrome. Information letters for distribution to their clients are available to professionals wishing to make referrals.

For further information, contact Valerie Simon, M.A., project coordinator, or Allan Reiss, M.D. and Lisa Freund, Ph.D., project directors. Call collect or write: The Kennedy Institute, Behavioral Genetics Unit, Room 103, 707 N. Broadway, Baltimore, MD 21205; 301-550-9321 or 9313.

New Genetic Bulletin Published

Probe, a quarterly report on Muscular Dystrophy Association funded genetic research will be published to keep health professionals current on the newest developments related to such inherited disorders as the muscular dystrophies, spinal muscular atrophy, Charcot-Marie-Tooth disease, Friedreich's ataxia and other neuromuscular diseases.

Professionals interested in more information about this publication may contact Donna Hooker, Genetics Research Coordinator, MDA, 810 7th Avenue, New York, NY 10019; 212-586-0808.

Fall Seminar to Focus on Fragile X Syndrome

A two day seminar, *Fragile X Syndrome: Diagnosis and Management in the 90's*, has been scheduled for September 15-16 at the Westin Hotel, Washington, DC. The conference is being jointly sponsored by the Genetics & IVF Institute, Fairfax, VA and the National Fragile X Foundation. For more information, contact Cheryl Richardson, 703-698-3948.

Region III & V to Hold Meetings

Region III will hold a meeting on July 18, at the Sandestin Beach and Resort, Destin, FL. The meeting, "Agenda for the '90s,"will convene prior to the Southern Genetics Group Meeting, and will focus on the Human Genome Project. For information, contact Stephanie Smith, 601-984-1900.

Region V will hold a conference on August 23 at Vail, CO. The one-day meeting will immediately preceed the CORN regional meeting. For information, contact Bonnie Baty, University of Utah Medical Center, Pediatrics 413MREB, Salt Lake City, UT 84132; 608-581-6914.

Genetrix Sponsors Educational Forum

Dr. Robert Logan of Genetrix has offered to host a meeting for 10-12 genetic counselors in January 1991. Genetrix is interested in hearing from genetic counselors who have worked in the commercial sector as well as in a variety of cross-cultural settings. Members will be asked to submit an abstract to Dr. Logan. The selected group will be invited to participate in the meeting at Genetrix's expense. For more information, please contact Barbara Bowles Biesecker at 313-764-0579.

Collaborative Research Awards Educational Grant to Counselors

In April, the NSGC received a grant to develop protocols and resource materials for cystic fibrosis carrier testing from Collaborative Research. Six members-at-large with CF expertise expressed an interest in the project. Becky Anderson, Karen Brook, Amy Lemke, Jannell Sloan, Wendy Uhlmann and Kathy Valverde comprise the committee that will work on the project, which will result in educational materials to be made available to the membership. Our sincere thanks to Collaborative Research for their acknowledgement of the important role genetic counselors serve.

BOOK

The Couple's Guide to Fertility

By: Gary S. Berger, M.D., Marc Goldstein, M.D. and Mark Fuerst
Publisher: Doubleday
Price: $12.95 pbk, 442 pp
Reviewed by: Lisa Butterfield, M.S.

Within the past few years, there has been a virtual explosion in the amount of printed materials devoted to the subject of fertility. By examining the magazines at grocery checkouts, one can usually find a wide variety of articles targeting hopeful parents with information which ranges from solid medical facts to virtual quackery.

The Couple's Guide to Fertility is an outstanding medical sourcebook for any couple undergoing fertility testing or treatment. It is designed to take a couple step-by-step through each phase of the fertility work-up. This book is not intended to be read once and put aside, but to be a constant guide and reference to fertility treatment. From basal body temperature charting to *in vitro* fertilization, the authors clearly and accurately describe the broadest range of current fertility treatments I have seen written for non-professionals.

The team of three authors provides a unique perspective on this subject. Two of the authors are physicians who specialize in the treatment of infertility. They provide critical medical information as well as insight into the patient/physician relationship. I particularly appreciated the attitude of patient empowerment through knowledge, conveyed throughout the book by the medical authors.

The third author looks at the subject from the viewpoint of a patient. This perspective is brought forward through short portions of interviews with fertility patients as well as personal vignettes of his own experience with infertility.

If there is one downside to this work, it has to be the omission of the psychologic impact of infertility and infertility treatments on the couple. The intrusion of timed sex to a healthy sexual relationship, the embarrassment of obtaining a semen sample in a physician's office and the disappointment at the failed insemination, are virtually neglected. There is a small chapter at the very end of the book which attempts to deal with a few of these subjects, but I find it too little and too late. Most infertile couples wish to have a connection with others who understand the emotional toll of infertility. This book does not seem to make that connection.

The Couple's Guide to Fertility is, in general, an informational text which deals with the process and not the psychology of infertility. For professionals unfamiliar with current infertility treatment, this book is a basic guide to understanding this complex and growing field. For patients, this book can help to make sense of the intricate and delicate process of becoming pregnant.

AUDIO-VISUAL

T.A.G. You're It

Produced by: Thalassemia Action Group
Length: 7 min.
Cost: No Charge
Information: TAG, 105 E. 22nd St, New York, NY 10010; 800-221-3571 (outside NY) or 800-522-7222 (within NY)
Reviewed by: Sylvia Mann, MS

The Thalassemia Action Group (TAG) is a patient support group sponsored by the Cooley's Anemia Foundation, Inc. TAG offers support, education and advocacy to all thalassemia patients. This new video has been produced for thalassemia patients wanting more information.

The video emphasizes that TAG was formed by and for thalassemia patients. The patients' personal insight helps show how TAG has helped them change their lives and become more compliant to medical treatment through its support and educational programs. Other information includes a large overview of resources available through TAG, such as scholarships and information about financial assistance.

The video was clearly professionally produced. However, the information is presented at quite a fast pace. Patients who have trouble understanding English may need to view the video more than once to understand and absorb all the information.

ORGANIZATION

BECKWITH-WIEDEMANN SUPPORT NETWORK

A national organization of parents who have children with Beckwith-Wiedemann Syndrome (BWS) has been formed by Roger and Susan Fettes. The network will provide support and facilitate the flow of information between affected individuals, parents and medical professionals.

Affected individuals and parents who do not wish to become involved with the Network can contribute valuable medical information for research. All names used for research will be kept confidential.

Contact the BWSN by writing: Susan Fettes, 3206 Braeburn Circle, Ann Arbor, MI 48108; (313) 973-0263.

DIRECTORY

Ohio's Region 2 Genetics Center in Dayton, Ohio, has just completed a thorough Genetics Resource Directory, containing nearly 400 organizations, foundations, associations and support groups which are indexed by name as well as disorder.

All orders *must* be accompanied by a $4 check, to cover postage and printing, made payable to Children's Medical Center and sent to: Bettsy McFarland, B.S., L.S.W., Department of Genetics, Children's Medical Center, 1 Children's Plaza, Dayton, OH 45404.

CALL FOR PATIENT RESOURCES AND REVIEWERS

Needed desperately: Materials suitable for patient resources, especially educational videos. I would also encourage members who would like to help review any of these materials to contact me c/o Medical Genetic Services, 1310 Punahou Street, Honolulu, HI 96826; 808-948-6834.

Sylvia Mann, M.S.
Resources Editor

Legislative Briefs

NSGC Signs on to Davis Brief

The NSGC recently signed on to an *amicus brief* (friend of the court document) in the Tennessee Court of Appeals case *Davis v. Davis.* This brief, filed by the American Civil Liberties Union, makes several arguments relative to preserving reproductive freedom.

In this highly publicized case regarding the disposition of 4- and 8-celled frozen embryos, a lower court judge mandated that the embryos be given to their mother because "human life begins at conception" and that this was "in the best interests of the children, *in vitro.*"

The ACLU brief does not take a stand on the proper disposition of the embryos; instead, it addresses this lower court's reasoning which, if accepted as legal precedent, could serve to weaken access to both contraception and abortion services.

New Legislation

The following legislation would increase access to genetic services or related research. Please support these bills by contacting your legislators: Senator —, U.S. Senate, Washington, DC 20510; or Rep—, U.S. House of Representatives, Washington, DC 20515. The U.S. Capital Switchboard is 202-244-3121.

Universal Access/ Medicaid Expansion Bills for Pregnant Women & Children

Three bills have been introduced to increase access to prenatal and pediatric services for poor and uninsured women and children. Over nine million women of child bearing age and 12 million children under 18 were completely uninsured in 1986. Clearly, access to insurance is a critical step in accessing genetic services.

Pregnant Women and Infants: Currently, states are required to provide Medicaid coverage to pregnant women and infants to age one with family incomes at or below 133% of the federal poverty level (FPL); and the option of covering those up to 185% FPL (15 states do so). The "Medicaid Infant Amendments of 1990" (HR 3931) would extend coverage to more pregnant women and infants by phasing in mandatory coverage to 185% FPL by July 1, 1993, simplifying and improving the eligibility process for pregnant women and encouraging outreach to newly eligible pregnant women and infants.

Children: Currently, states are required to provide Medicaid to children under 6 at or below 133% FPL; and have the option of covering children ages 6 and 7 to 100% FPL. States do not even have the option to cover poor children over age 7. The "Medicaid Child Health Amendments of 1990" (HR 3932) would increase the number of poor children eligible for Medicaid by phasing in mandatory coverage of children to age 18 at or below 100% FPL; giving states the option to cover children younger than 6 at 185% FPL and optional coverage of poor children in foster care. In addition, this bill would streamline the application process and support hospitals that treat large numbers of Medicaid-eligible children.

Senate Companion Bill: HR3931 and 3932 have been combined into an almost identical companion Bill in the Senate. Please also support the "Medicaid Infant Mortality and Child Health Amendments of 1990" (S2198).

Contraception and Infertility Research Centers

Two bills, S2215 (Sen. Harkin) and HR2956 (Reps Schroeder and Snowe) call for the establishment and operation of three contraceptive research centers and two infertility centers for a five year period. Both types of centers would work toward increasing reproductive options for families affected by genetic conditions and, therefore, deserve our support.

Trish Magyari, M.S.
Legislative Liaison

Video Bag

A Brighter Tomorrow
Produced by: The National Neurofibromatosis Foundation
Length: 15 and 35 min. versions available
Price: $12 and $15, respectively
Reviewed by: Sharon Langshur, M.S.

Neurofibromatosis (NF) is gaining recognition as one of the most common genetic disorders. Referrals are being made to genetics clinics to confirm the diagnosis of this disorder, which is characterized by the presence of several features, including: cafe au lait spots, neurofibromas, skeletal changes and optic gliomas, as well as other less common findings. Given the autosomal dominant mode of inheritance and the extreme intrafamilial variability in expression, there is a need to provide both an accurate diagnosis and sensitive counseling regarding recurrence risk. Therefore, the greater the spread of information about NF, the more likely it is that these needs will be addressed.

To accomplish these goals, the National Neurofibromatosis Foundation (NNF) has been active in disseminating information, generally in the form of written literature. More recently, audiovisual tools have been introduced as well. *A Brighter Tomorrow,* a videotape in both full length and abridged versions, has been produced to educate both the health care provider and the patient about this genetic disorder. These videotapes provide a comprehensive overview of clinical and management aspects of NF as well as an update on the state of research into cloning the genes for NF1 and NF2. In addition, the videotapes provide perspectives on NF unique to people very closely involved with the disorder.

Interviews with affected persons, family members of affected individuals and geneticists involved in the care of NF patients convey several important messages. The first, for individuals with NF, highlights the possibility of developing great inner strength out of adversity. The second message, pertinent to family members, particularly parents, focuses on the need to instill a child with sufficient personal strength to overcome this potential handicap. The third message addresses both the lay and and medical communities and stresses the importance of spreading information about NF to prevent misdiagnosis and to ensure proper treatment. In addition, the role of the NNF as a provider of information as well as a source of support is clear. The overall note of the videotape is a positive one.

A Brighter Tomorrow is a useful educational tool, primarily for health care providers outside the field of genetics, but could conceivably be used to assist in the education of affected individuals and their family members.

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.

LOS ANGELES, CA: Immediate opening for 2 BC/BE Genetic Counselors, 1 fulltime for July 1; 1 parttime for Fall. Minimum 1 year experience required.
RESPONSIBILITIES: Coordinate UCLA's CVS program; counsel prenatal patients; Fulltime counselor to coordinate State MSAFP screening program. Research and teaching opportunities available.
CONTACT: Michelle Fox, MS or Linda Robinson, MS, UCLA Medical Center, Pediatrics/Genetics, 10833 Le Conte Ave, MDCC22-499, Los Angeles, CA 90024-1752; 213-206-6581. EOE/AA.

OAKLAND, CA: Immediate opening for BC/BE Genetic Counselor with Masters in genetic counseling, nursing or related field. Experience in developmental disabilities preferred.
RESPONSIBILITIES: Coordinate and develop existing prenatal diagnosis and new screening programs; participate in counseling and consultations; provide professional and community education and outreach services; serve as liaison with local genetic clinics. Excellent opportunity for expansion of services.
CONTACT: Phyllis Young, Personnel Coordinator, Regional Center of the East Bay (serving Greater Bay area), 2201 Broadway, Oakland, CA 94612; 415-451-7232. EOE/AA.

PANORAMA CITY, CA: Immediate opening for 2 BC/BE Genetic Counselors.
RESPONSIBILITIES: Join large team, of 5 medical geneticists and 10 genetic counselors in comprehensive prenatal diagnosis program, services including amniocentesis, CVS, high-level ultrasound, cytogenetics, teratogen counseling; MSAFP and newborn hemoglobinopathy screening and craniofacial service.
CONTACT: Harold N. Bass, MD, Kaiser Permanente Medical Center, 13652 Cantara St, Genetic Services, Panorama City, CA 91402-5497; 818-375-2073. EOE/AA.

SIGNAL HILL, CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team in well-established, comprehensive genetics program. Services include: pre & early amniocentesis; PUBS, fetal anomalies, teratogen counseling, MSAFP, family history counseling at central and satellite locations. Interface with perinatology, neonatology and ultrasound staff. Opportunity for involvement in pediatric genetics program.
CONTACT: Constance Sandlin, MD or June Peters, MS, Memorial Genetics Center, 750 East 29th Street, Signal Hill, CA 90806; 213-595-3965 or 3424. EOE/AA.

DENVER, CO: Immediate opening for BC/BE Genetic Counselor/Program Coordinator with proficiency expected in counseling issues involving MSAFP screening, advanced maternal age, fetal structural abnormalities, etc.
RESPONSIBILITIES: New position on health care team. Coordinate and administer antenatal testing program for OB/GYN department.
CONTACT: Roger Lenke, MD, Director, Antenatal Testing Unit, University of Colorado Health Sciences Center, Campus Box B198, Dept. OB/GYN, Denver, CO 80262; 303-270-4533. EOE/AA.

TAMPA, FL: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join comprehensive genetics center offering prenatal diagnosis, pediatric genetics, CVS, teratogen service, molecular genetics and satellite clinics.
CONTACT: Boris G. Kousseff, MD, University of South Florida, Dept. Pediatrics, 12901 Bruce B. Downs Blvd, Tampa, FL 33612-4799; 813-974-3310. EOE/AA.

AUGUSTA, GA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coordinate and participate in preconceptional and prenatal genetic counseling. Opportunity to participate in clinical and research activities.
CONTACT: Paul G. McDonough, MD, Medical College of Georgia, Human Genetics Institute, CK159, Augusta, GA 30912-3360; 404-721-3832. EOE/AA.

PEORIA, IL: Immediate opening for BC/BE Genetic Counselor with Master's in medical genetics or related field.
RESPONSIBILITIES: Coordinate on-site and satellite pediatrics clinics for Regional Genetics Program, including CVS, amniocentesis; inpatient consultations at Level II tertiary care hospital; professional and consumer education.
CONTACT: William H. Albers, MD, Professor and Chair, University of Illinois College of Medicine at Peoria, Department of Pediatrics, Box 1649, Peoria, IL 61656. Phone: 309-655-2570. EOE/AA.

SPRINGFIELD, IL: Immediate opening for BC/BE Genetic Counselor with faculty appointment.
RESPONSIBILITIES: Work with medical geneticist in pediatric setting; coordinate and consult in genetics and specialty clinics. Professional and community education.
CONTACT: Ms. Catherine O'Malley, Dept. Pediatrics, Southern Illinois University School of Medicine, P.O. Box 19230, Springfield, IL 62794-9230. Please include letter of interest and CV. EOE/AA.

FRAMINGHAM, MA: Immediate opening for BC/BE Genetic Counselor with minimum one year clinical experience.
RESPONSIBILITIES: Serve as a service and technical liaison between geneticists, genetic counselors and our laboratory, sales and marketing departments. Primary contact and educator of testing technologies as related to DNA-based, cytogenetic and prenatal biochemistry labs. Education and research opportunities.
CONTACT: David Nikka, Director, Human Resources, Integrated Genetics, One Mountain Road, Framingham, MA 01701; 508-872-8400.

BALTIMORE, MD: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Prenatal counseling at established Prenatal Diagnostic Center in large community hospital. Services include: amniocentesis, MSAFP, teratogens, preconceptual and family history counseling.
CONTACT: Theodore Baramki, MD or Sheila Traut, MS, Greater Baltimore Medical Center, Prenatal Diagnosis Center, 6701 N Charles St, Room 1506, Baltimore, MD 21204; 301-828-2753. EOE/AA.

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active team in large, diverse reproductive genetics setting. Service patients from wide range of ethnic and economic backgrounds and include: CVS, amniocentesis, MSAFP screening, diagnostic ultrasound, teratogen counseling, novel fetal therapy. Opportunity for research, publications.
CONTACT: Anne Greb, MS or Mark Evans, MD, Hutzel Hospital, 4707 St. Antoine, Dept OB/GYN, Div Reproductive Genetics, Detroit, MI 48201; 313-745-7067. EOE/AA.

COLUMBIA, MO: Immediate opening for BC/BE Genetic Counselor. Salary Range: $22,816 - $36,505.
RESPONSIBILITIES: Join established team of 3 medical geneticists and 2 genetic counselors. Services include wide range of responsibilities: prenatal and general genetics; outreach and specialty clinics; professional and community education.

— Continued to page 16 —

REGISTER NOW FOR 10TH ANNUAL EDUCATION CONFERENCE

NAME (PLEASE PRINT) _____ DEGREE _____ DAYTIME PHONE ( ) _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

RECEIPT REQUESTED ❑ YES ❑ NO SPECIAL DIETARY RESTRICTIONS (PLEASE SPECIFY) _____

REGISTRATION FEE ENCLOSED ❑ $130 NSGC MEMBERS ❑ $155 NON-MEMBERS ❑ $85 STUDENTS.

❑ EXTRA TICKET(S) FOR SPECIAL EVENT @ $50 PER TICKET

❑ LATE FEE: $20 (IF POSTMARKED AFTER WEDNESDAY, SEPTEMBER 12)

❑ WALK-IN PENALTY: $30 (ON-SITE *OR* IF POSTMARKED AFTER SUNDAY, OCTOBER 7)

❑ DONATION TO SPECIAL PROJECT FUND $ _____

- *Remember, the deadline without penalty is: Wednesday, September 12.*
- Checks or money orders should be made payable, in U.S. currency only, to NSGC. Send this form or a duplicate to: Betsy Gettig, Treasurer, 132 LeGrande, Pittsburgh, PA 15221.
- Payment must be received prior to the conference. If your institution pays your registration fee, and you anticipate a delay, please write a personal check and request reimbursement. Indicate "Receipt Requested" above.
- All cancellations are subject to a $25 administrative fee. After Sunday, October 7, refunds will not be granted.

THE INTERFACE BETWEEN PUBLIC HEALTH AND CLINICAL GENETICS

THIS CONFERENCE will cover areas of interest to genetic counselors and other health care professionals working in clinical genetics and public health settings and will focus on screening new populations; needs assessment and quality assurance; access to services; and legislative and regulatory issues related to funding at state, regional and federal levels.

➤ *HOTEL ACCOMMODATIONS:*
Hyatt Regency, 151 W. Fifth Street, Cincinnati, OH. Rates: $94 single; $114 double; $15 per additional person in room.

The NSGC block of rooms will be held through Wednesday, September 12. Reserve as soon as possible to ensure room availability. Call 513-579-1234. If rooms are filled, several hotels are nearby and within easy walking distance. Inquire when you call or check the ASHG information brochure. If you are continuing your stay at the Hyatt for the ASHG conference, you must register separately. To ensure an uninterrupted stay in your room, please confirm the length of your reservation when you check in.

➤ *AIR TRAVEL:*
A 5 - 40% discount is available on all American Airline airfares. Call 1-800-433-1790 and refer to account Star #S84008.

RHODES TRAVEL will assist with obtaining the lowest fares with American Airlines or other air carriers *and* will donate 2% to NSGC for all conference travel plans booked through their agency or directly through American Airlines. Call Rhodes at 1-800-877-9494.

➤ *PROGRAM ADDITIONS:*
Two workshops have been added to the five listed in the program brochure. Each will be given once during scheduled workshop blocks. They are:

Ethics: *Use of Coercion: Prenatal Substance Abuse in the Genetic Counseling Setting*
Licensure: *Licensing: Benefit or Burden?*

➤ *INFORMATION:*
KAREN GREENDALE, M.A., Conference Chair, Wadsworth Center for Labs and Research, NY State Department of Health, Empire State Plaza, E275 - Box 509, Albany, NY 12201; 518-473-9830

NSGC EXECUTIVE OFFICE, c/o Bea Leopold, 233 Canterbury Drive, Wallingford, PA 19086; 215-872-7608.

A complete program and the tentative agenda will be sent by calling or writing the Executive Office.

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EXECUTIVE OFFICE
233 CANTERBURY DRIVE
WALLINGFORD, PA 19086

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CONTACT: Elizabeth Otto, MS, University Hospitals & Clinics, DCO58.00, Dept Child Health, Div Medical Genetics, One Hospital Drive, Columbia, MO 65212; 314-882-6991. EOE/AA.

KANSAS CITY, MO: Immediate opening for independent, BC/BE Genetic Counselor. Experience preferred. Salary Range: Starting in low $30s, negotiable with experience.
RESPONSIBILITIES: Prenatal counseling and consultation with patients and physicians; assist perinatologists with prenatal diagnosis and specialized disease counseling; coordinate MSAFP program.
CONTACT: David Galle, Coordinator, St. Lukes Hospital of Kansas City, 4400 Wornall, Dept. Maternal Fetal Medicine, Outpatient Center, Kansas City, MO 64111; 816-932-2009. EOE/AA.

CAMDEN, NJ: Immediate opening for BC/BE genetic counselor. Experience preferred. Faculty appointment available.
RESPONSIBILITIES: Comprehensive center includes: prenatal diagnosis; pediatrics; AFP screening; teratology; FAS; research; professional and community education.
CONTACT: Alice Lazzarini, MS, University of Medicine and Dentistry New Jersey/SOM, 401 Haddon Ave, Camden, NJ 08103; 609-757-7812. EOE/AA.

STATEN ISLAND, NY: Immediate opening for BC/BE genetic counselor. Fulltime or parttime negotiable.
RESPONSIBILITIES: Join active multidisciplinary genetics dept with cytogenetic, biochemical genetic and DNA laboratories. Prenatal, pediatric, developmental disability and research program; professional and lay education.
CONTACT: Susan Sklower Brooks, MD, NY State Institute for Basic Research in Developmental Disabilities, 1050 Forest Hill Rd, Staten Island, NY 10314; 718-494-5240. EOE/AA.

COLUMBUS, OH: Immediate opening for BC/BE Genetic Counselor. Minimum of 2 years experience and BC status preferred, but not required.
RESPONSIBILITIES: Join interdisciplinary team providing counseling for pediatrics, high-risk OB and families with known genetic disorders; professional and community education. Travel to SE Ohio clinics.
CONTACT: Laurel Masimore, Personnel Recruiter, Children's Hospital, 700 Children's Drive, Columbus, OH 43205; 614-461-2180. EOE/AA.

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

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Wide range of responsibilities, including: assisting in coordination of MSAFP screening birth defects and dysmorphology programs; teratogen, pre and post amniocentesis counseling; professional and community education.
CONTACT: Krista Sauvageau, Employment Manager, Womens & Infants, 101 Dudley, 45 Willard Ave Office, Providence, RI 02905-2499; 401-274-1100 x 8282. EOE/AA.

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

CHARLOTTESVILLE, VA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join team of 4 genetic counselors and 3 MDs. General genetic counseling includes: prenatal, pediatrics and specialty clinics; MSAFP; teratology.
CONTACT: Patricia Schnatterly, MS, UVA Medical Center, Box 386, Dept. Genetics, Charlottesville, VA 22908; 804-924-2665. EOE/AA.

SEATTLE, WA: Immediate opening for nonsmoking, BC/BE Genetic Counselor.
RESPONSIBILITIES: Join large multidisciplinary team in busy, expanding prenatal diagnosis clinic: full range of prenatal services; community and professional education; consultation for IVF/GIFT program. Opportunities exist for developing computer skills, publishing and clinical research.
CONTACT: Robert Resta, MS, Director, Genetic Counseling Service, Swedish Hospital Medical Center, 747 Summit Ave, Div Perinatal Medicine, Seattle, WA 9810[illegible] 206-386-2101. 3 letters of recommendat[illegible] must accompany CV. EOE/AA.