PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 13, No. 2 Summer 1991

Member Input

CASTING THE FUTURE

This summer, full members will be given two opportunities to determine the future of the NSGC. Board elections will be held and the final document for the Code of Ethics, if approved by the Board in July, will be called to vote. Also, the entire membership may respond to a networking opportunity, an opinion poll and an informational request (see p. 9) via three color coded postcards enclosed in this issue. Please take advantage of these opportunities to voice your opinions.

Erratum

One of the laboratories listed in the Supplement in *PGC* 13(1):10 was incorrect. Please note:

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APK, B, BANK, BCR, CF, CPS, HEMA, SC, T, Y, OTHER

Please correct your reference guide.

on the inside...

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

Committed to providing highest quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

THE DILEMMA OF SEX SELECTION...

Sex selection in prenatal diagnosis presents unique dilemmas by forcing the genetic counselor to assume uncomfortable and ill-defined roles. Many centers have long term policies of denying prenatal diagnosis solely for sex selection, which may place the counselor in an adversarial position with the patient. Among the many aspects of this topic that need to be considered are:

- **patient freedom of choice, confidentiality and access to information**
- **conflict between females being the sex most commonly selected against and females being the gender of most genetic counselors**
- **possible entrapment if only couples with "suspicious" backgrounds are queried**
- **cultural centrism if we impose our biases on patients.**

In an international spirit, coincident with this year's International Congress, we present two opinion articles about this subject. Perhaps it is time for genetic counselors to re-evaluate this issue.

— Karen Copeland, M.S.

...the issue in India

by Suha Patel, M.S., Private Practice, Bombay, India

In India, as in many developing countries, basic medical care is unavailable to many and genetic counseling is unknown to most. Knowledge about one aspect of genetics, however, is used in a manner that has been declared illegal, but remains pervasive throughout the country.

The sex ratio in India has been declining at an alarming rate throughout this century. In 1901, the ratio was 972 females to 1000 males, while in 1951, it was 946, and in 1981, 933. Every year, 12 million females are born in India and only 9 million will be alive at age 15. This has created a situation in which there are 23 million more males in the country at this time. Kerala, the only state to have a predominantly matriarchal society, is an exception, with a sex ratio of 1032 to 1000 in favor of females.

GENDER DISCRIMINATION PERVASIVE

This inequity is not a gift of nature, but rather a gift of man.

In both rural and urban India,

• continued on p. 6, col. 1 •

...the issue in the U.S.

by Lavanya Marfatia Misra, M.S., University of Florida, Gainesville

In many developing countries, amniocentesis is often used to determine fetal sex so that female fetuses can be aborted. The manner in which couples use information gained from new reproductive technologies, and the facets that are incorporated in their decision making process are important issues to consider in cross-cultural genetic counseling sessions.

Amniocentesis for the purpose of sex selection evokes strong reactions from many individuals who deem it a cold-blooded, callous practice. But the issue is far from simple.

THE RULES ARE DIFFERENT

The Third World is a different place in ways that are not easy for Westerners to understand. The rules are based on "survival of the fittest." The female is the disadvantaged sex, and the social fabric is biased against her. Economic factors, very different from the U.S., are the primary cause of sex determination tests. Males have far more opportunities in the job market and

• continued on p. 6, col 2 •

Legislative Briefs

Human Genome Privacy Act Introduced

The first piece of Federal legislation designed to protect an individual's genetic information from misuse and disclosure was introduced as the Human Genome Privacy Act by Rep. John Conyers (D-MI) on May 3. This bill centers on the right to privacy and the right to protect the disclosure of one's personal genetic information as an extension of one's basic civil rights.

Conyers cites reports from the Office of Technology Assessment and other agencies of broad based genetic discrimination, saying "people have been turned down for life, health, disability and auto insurance, denied government benefits and employment, and turned away from adoption agencies based on personal or family genetic predispositions."

The bill aims to safeguard the abuse and unauthorized disclosure of genetic information. It would:

- allow an individual to determine what genetic records are collected, maintained, used or disseminated by government or private sector agencies.
- prevent disclosure of genetic records without an individual's personal written consent.
- guarantee everyone the ability to correct or amend records containing genetic information.

The bill also contains sections relative to disclosure of genetic information to health professionals and adoption agencies. These sections address disclosure of information regarding minors, persons deemed mentally incompetent and persons who are deceased. These sections, in particular, may have a significant impact on genetic counseling situations.

Clearly, the intent of this bill is to protect against discrimination of the individuals that we serve. It is important, however, to implement the safeguards in a way that does not severely limit the way that we practice our profession. For this reason, the NSGC Subcommittee on the Human Genome Project will be conducting an analysis of the bill to determine its impact on the genetic counseling profession.

Express your support or concerns regarding this bill by contacting Rep. Conyers c/o House Committee on Government Operations, Washington, D.C. 20515.

Supreme Court Decision to Uphold "Gag Rules"

In a 5-4 decision on May 23, the Supreme Court upheld regulations prohibiting physicians and counselors who receive federal Title X (family planning) funds from providing information about, and making referrals for, abortion services. The regs also require that clinics physically and financially separate their Title X programs from the provision of abortion services and any services that provide abortion counseling or referral.

This decision has broad implications for the provision of genetic counseling services in federally funded programs. To uphold the NSGC pro-choice policy, the NSGC has joined the "Emergency Campaign to Overturn the Gag Rules," a coalition of organizations advocating a Congressional statute to nullify the rules before they take effect. To do this, the bills will need a 2/3 majority to override the expected Presidential veto.

Sen. Kennedy introduced S.323, and Rep. Wyden introduced H.R.393. Action is expected before July 4. Please contact your senator or congressman to express your concerns and views.

Trish Magyari, M.S.

News From the Regions...

Utah once again gained national prominence in February with the passage of one of the nation's strictest abortion laws. The only exceptions to the ban on abortion were to be certain incest cases ...only involving minors reporting the case themselves when the perpetrator was a father, stepfather, adoptive parent or guardian...certain rape cases involving minors, grave risk to maternal health or grave fetal abnormalities. This law was introduced without much fanfare, with very little time allowed for debate or expert testimony, and was signed into law three days later. A previous law coupled with this law also allowed for prosecution of women obtaining abortions and professionals aiding in the attainment of an abortion for criminal homicide.

The ACLU brought a lawsuit against the State of Utah challenging the law, and there is currently a temporary restraining order in place while the case is argued in the courts. I am one of the plaintiffs on this landmark reproductive freedoms case.

The legislature amended a few of the provisions of the law in a recent special session, which broadened the definition of incest and exempted women (but not professionals) from any penalties for seeking or obtaining an abortion prohibited under the statute. The criminal homicide act was amended so that it no longer applies to abortion. In one further "clarification," the Act no longer threatens professionals with third degree felony, although Utah's general "criminal responsibility" laws may still threaten prosecution. Clearly, some of the worst provisions of the law are being corrected, but the law continues to represent an infringement of reproductive choices.

Probably the part of the law most pertinent to the bread and butter trade of genetic counseling is the provision exempting "grave" fetal abnormalities. Since there is absolutely no attempt to define "grave," it leaves practitioners to guess when they are violating the law and when they are not. It already has had a chilling effect on the ability to offer pregnancy terminations in over 20 week pregnancies with any fetal abnormality that is not lethal.

I am compelled to pursue this action for obvious professional reasons as well as for my personal feelings of responsibility to my patients.

Bonnie Jeanne Baty, M.S.,
Region V Representative

Note: The NSGC will sign onto an amicus brief in support of repealing this law.

Ask A Colleague

How do you counsel families with a vague family history of respiratory illness or emphysema?

One of the more common differential diagnoses in these cases is the genetic condition alpha-1-antitrypsin deficiency. It is associated with development of emphysema in young adults and liver cirrhosis in children who may have had prolonged jaundice at birth. With a documented family history of A-1-A, family members can be tested, including the analysis of the concentration as well as the phenotype of alpha-1-antitrypsin in serum of patient and family members. Since the range of clinical manifestation is broad, and clinical outcome cannot be precisely predicted, prenatal diagnosis for A-1-A becomes a difficult decision for most families.

Since the most challenging cases are those with vague clinical symptoms or history, concentration and phenotype of alpha-1-antitrypsin are useful to obtain. The gene frequency for the Z allele is close to 2%. Although there is no formal consensus in the medical community, an individual with a Z haplotype may be at an increased risk if exposed to air pollutants. Using the unique opportunity offered by genetic counseling to focus on prevention, one can educate the family to consider lifestyle modifications such as not smoking, living in a community with clean air and working in an environment which would not further jeopardize a compromised respiratory system. There is evidence that smoking is especially dangerous to the lungs of individuals with A-1-A.

Treatment can now be considered by intravenous administration of purified alpha-1-antitrypsin, but patient selection and dose schedule for this therapy are not routine matters.

Crystal RG. (1991). Alpha-1-antitrypsin deficiency: pathogenesis and treatment. *Hospital Practice* 26:81.

George Hug, M.D., is Director, Division Enzymology, Children's Hospital Medical Center, Cincinnati, Ohio.

Literature Search...

The genetics of fragile X is complex. Three recent publications may improve the ability to diagnose, help resolve the carrier status of family members at risk and aid genetic counselors as they work with fragile X families.

Oberle I, *et. al.* (24 May 1991). Instability of a 550-base pair DNA segment and abnormal methylation in fragile X syndrome. *Science 252(5009):*1097.

Normal transmitting males (NTMs) with the fragile X gene had a 150 to 400 base pair insertion, which was inherited with little change by their daughters. Fragile X-positive individuals had fragments with a larger and variable insertion. The mutation was unmethylated in NTMs, methylated only on the inactive X in their daughters and totally methylated in most fragile X males. This could be explained by a two step mutation. These observations can identify male or female carriers of the fragile X mutation with high reliability and specificity, while the size of the insertion and the degree of methylation may predict the clinical outcome.

Yu S. *et, al.* (24 May 1991). Fragile X genotype characterized by an unstable region of DNA. *Science 252(5009):*1179.

DNA sequences at the fragile X site of affected individuals were found to be larger. Variations were found in families, indicating an unstable region. This might be a diagnostic tool to predict fragile X genotype.

Warren, ST *et.al.* (1991). Identification of a gene (FMR-1) containing a CGG repeat coincident with a breakpoint cluster region exhibiting length variation in fragile X syndrome. *Cell* 65(5).

A gene which expresses a 4.8 kb message in human brain has been identified and sequenced. This gene is located distal to a CpG island previously shown to be hypermethylated in fragile X patients and within a 7.4 kb fragment that exhibits length variation in fragile X chromosomes.

• • • • •

Labs are already offering this test. DNA-based testing is not ready to be used independently for clinical diagnosis since DNA would miss other cytogenetic abnormalities often found in individuals screened for fragile X. However, highly reliable carrier and prenatal testing is now available for families positive for fragile X. The genetic counselor must evaluate the strategy behind each test and what actual information will be obtained.

— Andrew Faucett, M.S.

NSGC...What's In It For Me

"The NSGC is useful to me as a Genetic Counselor/Technical Support Specialist at my commercial DNA reference laboratory. My previous experience as a genetic counselor in private practice and in a university genetics program helped me understand the influence that genetic counselors have in directing where reference specimens are sent. I encourage my company to focus their marketing efforts toward this well-defined professional group. Since I regularly use the NSGC mailing list, genetic counselors who are members of NSGC benefit by learning about our newest offerings that are available to them and their patients. I enjoy helping genetic counselors realize their impact on how companies choose to market genetic and paternity tests.

Since my previous positions were in Florida, I now really enjoy the opportunity to develop professional contacts with my colleagues throughout the country by phone and at national meetings. However, sometimes I am at a loss when trying to make a genetics referral in a community where I know there are genetic services, but do not know of genetic counselors because they are not NSGC members. I would encourage all genetic counselors to become members of NSGC and use the authority of the organization to create a voice in the medical community."

— Jill Cortada, R.N., M.S.N.
GeneScreen

POINT COUNTERPOINT

Elevated MSAFP:

The quality of the ultrasound exam continues to improve the ability to assess fetal abnormalities. Simultaneously, the clinical correlation of laboratory data has provided greater sophistication for prenatal screening. These data points are usually incorporated as part of a genetic counseling session with families who are hearing that there may be a problem with their fetus. Historically standard technologies (amnio) may be replaced by others that are improving but may not provide the highest level of assurance (ultrasound). Dr. Nadel's article in the *New England Journal of Medicine* generated many letters and much discussion in the obstetric community. In this issue of *PGC,* we present Dr. Nadel's review of the information as it relates to the genetic counseling session, and Dr. Peilet's response to the article. Related to this topic, Kathleen O'Connor (Letters, p. 10) asks us to address some insurance issues impacting patients who seek genetic services. If the medical community is able to read and interpret the information presented on these two pages, then surely policy makers at the insurance companies are also considering it. In an era of cost containment, the concept of screening and providing multiple levels of testing provides an attractive method of saving money.

WHEN IS AMNIOCENTESIS NECESSARY?

by Bruce Pielet, M.D., Perinatologist, Lutheran General Perinatal Center, Park Ridge, IL

In the past, an elevated MSAFP has been a routine indication for amniocentesis to diagnose neural tube and ventral wall defects. Recent improvements in the accuracy of ultrasound diagnosis of these anomalies have raised a question about the necessity of performing amniocentesis when a patient has an elevated MSAFP. It has now been suggested by some that ultrasound be used without amniocentesis in the evaluation of elevated MSAFP.[1]

Various investigators have used ultrasound to successfully diagnose from 75 - 100% of fetuses with spina bifidas.[1-4] The likelihood of missing spina bifida with a given MSAFP value has also been calculated.[1] Using these calculated odds ratios, centers that counsel couples with elevated MSAFP values might be able to give specific risks of obtaining a false negative diagnosis with ultrasound. However, when using ultrasound to evaluate high MSAFP values, it is assumed that sonography is performed with high resolution equipment and appropriately trained personnel (Level 2/Targeted imaging). If this type of evaluation is unavailable or uncertain, ultrasound can not be relied upon to the same degree. Amniocentesis must then be considered.

> …it is assumed that high resolution equipment and appropriately trained personnel are available…

Calculating the Risk

Centers that counsel patients with abnormal MSAFP values should be able to calculate the probability of a fetal defect based on the MSAFP values. Knowing the approximate sensitivity of ultrasound in detecting spina bifida, a couple should be informed regarding the possibility of missing a neural tube defect. Although ultrasound is an excellent modality for diagnosing spina bifidas, there are instances of its failure. On occasion, a spina bifida might be small enough and located in a difficult to image region such that it might escape ultrasound detection. That same spina bifida will be diagnosed by testing amniotic fluid alpha fetoprotein and acetylcholinesterase obtained by performing an amniocentesis.

In the workup of a pregnant woman with an elevated MSAFP, once the ultrasound examination has been performed, a couple can then make an informed decision regarding whether to proceed with amniocentesis for prenatal diagnosis. Other factors, such as the age specific risk of a chromosome abnormality, should be factored into the decision making process of a couple at this stage of the process. Only then can all factors for a specific couple be considered appropriately. An informed decision will, at a minimum, involve counseling and knowledge regarding all of the previously discussed considerations.

AMNIOCENTESIS IS NOT *ALWAYS* NECESSARY

by Allan S. Nadel, M.D., High Risk Obstetrics, Brigham and Women's Hospital, Boston, MA

Routine obstetrical care now includes offering maternal serum alpha fetoprotein (MSAFP) screening early in the second trimester. Women with elevated values are evaluated by ultrasound. If the elevated MSAFP value cannot be attributed to fetal demise, multiple gestation, incorrect dates or definite congenital anomaly, amniocentesis is advised. If amnio reveals elevated amniotic fluid AFP and/or elevated acetylcholinesterase, current guidelines indicate that a repeat, detailed ultrasound evaluation is indicated.[1] In some centers, such a detailed ultrasound examination can be offered to *all* patients with an elevated MSAFP value, thereby obviating the need for amniocentesis.

Retrospective Evaluation

To support this view, we retrospectively evaluated our ability to diagnose spina bifida, encephalocale, gastroschisim and omphalocele by ultrasound between 16 and 24 menstrual weeks. (The diagnosis of anencephaly by ultrasound is obvious.) We identified 51 fetuses with these anomalies that delivered or were aborted at Brigham and Women's Hospital between 1984 and 1990. The correct diagnosis was made in all 51, yielding a sensitivity of 100% (95% confidence interval 94%-100%). We used the lower limit of this confidence interval to calculate the likelihood that an

anomaly was present in a woman with a given MSAFP value and a negative ultrasound examination. We found that the probability of an affected fetus for MSAFP values of 2.0. 2.5, 3.0, 3.5, and 4.0 MoM are 0.01%, 0.03%, 0.07%, 0.15% and 0.31%, respectively.[2]

These numbers are small and may lead some women to conclude that the likelihood that an anomaly is present, but missed on ultrasound, is low enough to not warrant an amniocentesis. Therefore, we offer such patients the option of stopping the diagnostic evaluation at that point. However, women

- who desire maximal reassurance
- with MSAFP values greater than 4.0 MoM
- with elevated MSAFP in addition to other risk factors such as a positive family history, and
- in whom normal fetal anatomy cannot be demonstrated by ultrasound

should continue to be offered amnio.

Landmarks Identified

The last point is probably the most important. To confidently exclude spina bifida, it is necessary to demonstrate a normally shaped calvarium and normal anatomy in the posterior fossa in addition to demonstrating a normal appearing spine in both longitudinal and transverse views. Since virtually 100% of fetuses with open spina bifida have abnormalities in the calvarium shape, the posterior fossa, or (most often) both,[3] demonstration of the normal anatomy in the fetal head is necessary to confidently exclude a diagnosis of spina bifida. Indeed, there were several cases in our series in which the head signs were the only ulltrasound clue of an abnormality. Since most encephalocales are occupital in location, ultrasound of the fetal head should disclose most of these. Finally, it is necessary to demonstrate a normal umbilical cord insertion site to rule out gastroschisis and omphalocele. If, due to maternal obesity, fetal position, lack of availability of high resolution sonography equipment, lack of availability of experienced ultrasound personnel, or for any other reason the normal anatomy cannot be demonstrated, amniocentesis should be offered.

Other Abnormalities Identified

Women who choose not to proceed with anmiocentesis should be informed that, in addition to the small chance that spina bifida, encephalocele or ventral wall defect were missed, other anomalies may be associated with elevated MSAFP. Some of these, such as sacrococcygeal teratoma, extrophy of the bladder or cloaca, cystic hygroma, renal agenasis and upper gastrointestinal obstruction, should usually be identified in the course of a thorough ultrasound examination. Skin abnormalities are seldom diagnosed by ultrasound, but only rarely would result in a decision to terminate the pregnancy. On the other hand, congenital (Finnish) nephrosis is a lethal disorder that has no sonographic signs whatsoever. Fortunately, it is extremely rare in North America, and seems to be associated with very high (greater than 4.0 MoM) elevations in MSAFP.

…some such women can be offered the choice of stopping the evaluation after a carefully performed ultrasound.

Include Chromosomes

Finally, several recent papers have indicated a relation between elevated MSAFP and aneuploidy. A review of five papers reporting a total of 4,149 fetus indicated 35, or 0.8%, had an aneuploidy.[4] Some of these, such as trisomy 18, are likely to be identified by sonography, particularly if there is a defect such as omphalocele or spina bifida as part of the syndrome. Nine of the 35 cases of aneuploidy were 47,XXX or 47,XYY - situations in which many women might not choose to terminate the pregnancy and perhaps would be better off not knowing about the aneuploidy. Nonetheless, in some cases of elevated MSAFP, the decision not to have an amniocentesis could result in the delivery of a child with a serious chromosomal disorder.

With these considerations in mind, we emphatically *do not* advocate abandonment of amniocentesis in women with elevated MSAFP. Instead, we suggest that some such women can be offered the choice of stopping the evaluation after a carefully performed ultrasound. Their decision will, in large part, depend on their valuation of the relative disutility of iatrogenic miscarriage versus raising a disabled child.

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Nadel

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The Dilemma of Sex Selection

Patel, from p. 1, col. 2.

males are *consciously* treated better than females. Gender discrimination occurs because women are seen only as childbearers. They are not considered important in terms of their earning capacity or in terms of their ability to carry forward the family name or its property.

No Karyotype

Modern science has also contributed to the oppression of women in this country. "Sex determination centers" can be found in every major city in the country. *Any* physician in *any* medical field can initiate and operate a center. These centers perform amniocentesis to determine the sex of a fetus for the purpose of aborting female fetuses. Commonly, *only* the sex chromosomes are identified by microscope to provide an answer to the patient's question. Some of the centers are beginning to offer ultrasound as an alternative.

A recent doctoral thesis focused on the practice of prenatal sex determination in India. The researcher interviewed seven doctors directing sex determination clinics and 100 women from diverse economic backgrounds who were undergoing this testing. Neither were the women >35 years of age, nor did they have any medical indication for the test. Most of the women and their husbands were highly educated; several knew that abortion based only on sex selection was illegal. Most of the women were not aware of the names of the specific procedures or the risks involved. For them, it was simply a gender identification test.

Yellow Page Listings

Both male and female doctors perform these tests. The bias of the doctors is visible in the prices they charge. If the fetus is male, the charge is Rs 1000 (about $50), while the same test commands Rs 800 ($40) for a female fetus. Some clinics even offer sex determination tests followed by an abortion as a package deal. Consent forms are a legal requirement, but only three of the 11 clinics had these forms available. None of the clinics prepared written reports or issued receipts.

The fact that this is an offense punishable by up to seven years of imprisonment does not deter doctors, since to date, not one case has ever been litigated. In fact, business is booming, aided by blatant advertisements in phone books. One reads: "Pay Rs 500 now (for the tests) or Rs 500,000 later (as dowry.)"

Role of Education

As a recently graduated genetic counselor, I returned to my homeland with great expectations. However, the use of "genetic services" is skewed such that the sex determination clinics see at least 20 women daily while the few genetic centers at major hospitals see only one or two patients daily. Since working at a sex determination center is an unacceptable option, I practice independently. Public education and screening for thalassemia are two of my major responsibilities. Slowly, the future is changing. Clearly, one aspect of genetic counseling, education, will need to play a major role before current practices alter.

Marfatia Misra, from p. 1, col. 3

can more easily become an added source of income, whereas a woman's professional choices remain restricted. Males are better providers for parents in their old age and will perpetuate the family name, while women live with their husbands' families and require dowries.

The individuality of women has been submerged in preference to the overall good of the patriarchal family. One crucial way women improve their place in this hierarchy is to give birth to males. A woman bearing two or more males has a high status in her family. Women are often trapped into utilizing amniocentesis and aborting female fetuses for that advantage. Many also feel that they are saving these daughters from a future of abuse and suffering. Therefore, in reality, certain segments of the population utilize these tests—illegally or otherwise.

Cultural Centrism

Today, in the United States, amniocentesis is sometimes used by certain ethnic groups solely to determine fetal sex. Most often, it is used by immigrant families who are incorrectly presumed to have been absorbed within mainstream American culture. Currently, our society encourages individuals to maintain part of their ethnic and cultural heritage. However, when those same individuals request testing for sex determination, health professionals are outraged and shocked. The counselor must understand that this preference comes from a tradition of cultural and economic necessity. Although this is primarily used by immigrants, other Americans use sex determination as well.

Explore the Situation

Instead of automatically rejecting a couple seeking sex selection, the counselor's duty is best served by working with the couple to understand the reasons behind the couple's desire. Many couples realize genetic counselors are not comfortable with sex selection, so they find another "acceptable" reason for prenatal testing. This hidden agenda created by American society's feelings makes it difficult for the counselor to effectively work with a couple. Since each situation is unique, it is impossible to prescribe one single solution. It may be possible to explore the situation with the couple, or if necessary, have individual discussions with each partner. The best way to begin may be to state that even though this practice is not generally acceptable in American culture, the counselor would like to understand it from the patient's perspective.

It is important to educate people who perpetuate this custom, not condemn them. In this way, the powerful hewing to blind tradition may be weakened or broken, and the couple can make a genuinely informed decision.

Continuing Words

Change happens. That inevitability rings true in our profession and is reflected in this publication. As the NSGC makes room for a monumental change and accomplishment, the inaugural issue of the *Journal of Genetic Counseling,* the *PGC* Editorial Board continues to examine the face of our newsletter.

Perspectives is here to stay! The newsletter format allows for a quick response time for important issues, alerts you to legislative topics, delivers job openings to your doorstep, alerts you to upcoming meetings and provides an invaluable networking opportunity. We are moving toward a more reader-friendly format, but plan to maintain a high level of professionalism.

The "Case Report" section has been replaced with "The Art of Genetic Counseling," in part because we have not been receiving unsolicited case reports. "Art" will include counseling and education tips, a Q&A column, important literature highlights and, of course, case reports.

As a foil to "Art," the Editorial Board discussed the possibility of "The Science of GC." Since the *Journal* will be more appropriate for that counterpart, "Practical Applications of Genetic Counseling" will include lead articles and news.

Look for lead topics such as billing, reimbursement, paternity, non-paternity, teratogen counseling and non-traditional roles. We will include news from the regions, and "Celebrate Ourselves" will announce grant awards and major professional accomplishments.

We continue to rely on your articles, cases, letters, reviews, tips and various ideas of general interest. Feel free to contact board members directly with specific ideas. We welcome your feedback and input. And, as always, thank you for your continued support as readers.

Vickie Venne, M.S.

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The opinions expressed herein are those of the authors and do not necessarily reflect those of the Editorial Staff or the NSGC.

Celebrate Ourselves!

Members Awarded National Grants

• **Beth Fine, M.S., of** Northwestern University School of Medicine in Chicago, [NSGC President, '86-'87] was awarded a three-year grant from the NIH/National Center for Human Genome Research under the Ethical, Legal, and Social Issues Program. Genetic counselors with specialized expertise in the areas of DNA testing, counseling families with DNA-based genetic concerns and training of non-genetic health care professionals will develop a train-the-trainer program.

• **Joseph McInerney, M.S.,** director and president of Biological Sciences Curriculum Study (BSCS) in Colorado Springs [PGC Editor, '83-'87] was awarded a 16-month grant from the U.S. Department of Energy to create an instructional module for the high school biology classroom titled "Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy." The materials will be reviewed by education committees of NSGC, ASHG and CORN. Under the terms of the grant, BSCS will send a copy of the final program free of charge to each of the 50,000 biology teachers in the U.S.

It is exciting to watch members of our organization receive national recognition in such dynamic arenas. Please let us know about your accomplishments for publication in this new column.

Guidelines for Submissions

- Contributors should strive for professionalism by adhering to accepted English grammar and usage, avoiding the use of slang, colloquial and casual language. When possible, avoid use of the first person.
- Articles are subject to editing for reasons of space or grammar. Suggested editorial changes will be cleared with the contributor before publication.
- Letters to the Editor are welcome and encouraged. All letters must be signed, include a professional affiliation and daytime telephone number. The decision to publish letters will depend on the availability of space, the timeliness of the issue, and the relevance to the readership as determined by the Editor. The author may request to have his or her name withheld.
- All data or facts must be referenced. Number all references for footnoting.
  Reference style from a journal: Author name(s) (year) Title of article. Journal Vol(issue): pages.
  Reference style from a book: Author name(s) (year) Title of book. Editor, Location, pages.

Bulletin Board

International Congress... Focus on NSGC Activities

October 6 - 11

- NSGC Administrative Office, Room 17, Convention Center

Sunday, October 6

- 9:00am - 3:00pm, Board Meeting, Conference Room 16, Ramada Renaissance Techworld.
- 3:00pm - 5:00pm, Open committee meetings, Ramada Renaissance Techworld.
  From social and professional issues to finance to the education conference in 1992...become involved. Meeting locations will be posted on the electronic message bulletin board, Ramada lobby and in the NSGC Administrative Office, Convention Center.

Monday, October 7

- 5:00pm - 7:30pm, Annual Business Meeting and Presidential Address. Members are invited to attend this gala dinner meeting and address. Cost of tickets: $10 for members, $30 for non-members. Registration available through the ICHG.
  Live Your Fantasy...*Have you ever dreamed of taking a year off to pursue a professional interest? An exciting new opportunity exclusively for genetic counselors will be anounced at the NSGC business meeting. Don't miss it!*

Daily at Noon

- 12:00 - 2:00pm, Shaping the Future of the NSGC.
  Do you have a vision for our future? The ad hoc Long Range Planning Committee will be hosting focus groups throughout the Congress, inviting members to share their ideas, suggesions and "visions" of where they want the NSGC to be...in 2 years, in 5 years, in 10 years. These focus groups will be limited to 12-15 members and will held during the lunch hour in the NSGC Administrative Office (Room 17), Convention Center. Members of the committee will facilitate brainstorming sessions to assist each group with visioning and setting priorities. Preparatory materials and sign up sheets will be available in the office. ***Box lunches will be provided, courtesy of Vivigen.***

Special Membership Bonus: The $15 Membership Application Fee will be waived for professionals attending the Congress who purchase guest tickets to the NSGC Membership Dinner *and* who join the NSGC during the Congress. Do you work with colleagues who have expressed interest in becoming a member but just haven't taken the time to join? Encourage them to take advantage of this bonus membership offer.

Oxford Press Ad Here

Resources

• Brochures •

Genetics and Deafness

The Genetics Unit of The Brooklyn Hospital Center has published a brochure, "What You Should Know About Genetics and Deafness." This 8-page Q&A format covers causes, the difference between environmental and genetic deafness and genetic counseling.

For more information, contact: Karen L. David, M.D., Genetics Unit, The Brooklyn Hospital Center, 121 DeKalb Ave, Brooklyn, NY 11201; 718-403-8032.

Genetic Counseling: Valuable Information for You and Your Family

The NSGC has published two versions of a general information brochure. The contents include the following headings: "What is Genetic Counseling?", "Is Genetic Counseling Indicated in Your Family?", "Facts and Myths about Genetic Counseling", and "When You Visit a Genetic Counselor."

The contents are identical except that Version #1 provides space for your institution's stamp and Version #2 provides general information for persons seeking genetic counseling services.

This brochure is priced as follows: quantities of <100 copies, 25¢ each + $3.00 P&H; quantities of 100 copies, 15¢ each + $4.50 P&H. For samples and an order form, please call the NSGC Executive Office.

• Organization •

Support Group for Multiple Birth Loss

In 1987, Jean Kollantai founded a support network for parents who have experienced the death of one or more in a twin/multiple birth pregnancy. A newsletter, resources and support are some of the available services.

For additional information or to be added as a patient referral source, contact Jean Kollantai, P.O. Box 1064, Palmer, AK 99645; 907-745-2706.

Members' Input

Do You Define Yourself as a Psychotherapist?

We who practice as psychotherapists and who are trained as genetic counselors are eager to identify genetic counselors with this interest and/or professional focus. It is our hope that we can establish a special interest group within NSGC.

Our goal is to facilitate discussion of styles of practice, training backgrounds, continuing education and supervision. Further, our work as psychotherapeutically-oriented genetic counselors provides us with a particular perspective of our patients and the genetic counseling process. It is our hope that this group can support and encourage future contributions to the genetic counseling literature, enhancing all genetic counselors' understanding of the psychosocial dynamics of our patients and their families.

If you are interested in forming a network of members with this focus, please return the enclosed *blue* postcard, enclosed within this issue of *Perpectives*.

June Peters, M.S.
Luba Djurdjinovic, M.S.

Meeting Logistics Examined

Since 1985, the NSGC annual education conference has been held prior to the annual American Society of Human Genetics meeting. The NSGC had previously met in conjunction with the March of Dimes annual professional conference.

The Annual Education Conference (AEC) subcommittee wishes to determine if this continues to be the preference of the membership. Our options are to conduct our meeting in conjunction with ASHG, MOD, or to stand alone.

Factors to consider if the AEC is held with MOD:

- opportunity for increased genetic counseling input into planning
- possible funding from the MOD
- easier logistics and less tendency to get lost in the crowd
- shorter time out-of-office than current linkage to ASHG
- the single topic format is more clinical with more opportunities for discussion of genetic counseling aspects.

Factors to consider if the AEC is held with ASHG:

- opportunity for interviewing
- ancillary meetings scheduled in conjunction with ASHG (ASHG business meeting, CORN, ABMG)
- broader scientific applications
- NSGC members are more visible to ASHG members

Factors to consider if the AEC stands alone:

- autonomy
- budget savings, if we choose "second city" locations
- ability to rotate, providing network opportunity with other organizations

We would appreciate a response via the enclosed *yellow* postcard included within this issue of *PGC.*

Susie Ball, M.S., Chair
AEC Subcommittee

Let's Get It Right

Please be sure to return the *green* Let's Get it Right form, included in this newsletter. The information is vital to the accuracy of the membership directory as well as to your ability to network with colleagues.

Bea Leopold, M.A.

Research Network

Enhance clinical research in genetics and genetic counseling by sharing your interesting and valuable patient contacts. Likewise, if your clinical research project has a specific patient need, *PGC* is the place to network.

• • • • •

Baylor College of Medicine in Houston is seeking samples on 50 mother-son pairs to further establish the genotypic predictability of the new fragile X DNA sequence. The mother must be an obligate carrier by pedigree and the son must have cytogenetic confirmation. Your patients can participate at no charge. For further information, contact Pat Ward, M.S., 713-798-6534.

Letters to the Editor

Insurance Companies — Concerning Denials

To the Editor:

Recently, some of my patients in Denver have been told by their insurance companies that maternal age alone is not an indication for prenatal diagnosis. Other insurance companies have been requesting *results* of the amniocentesis before they will consider the claim. One of our patients was referred for amniocentesis because of a low maternal serum alpha fetoprotein, and the claim was denied because the woman had a previous child with Marfan syndrome.

I find these incidents disturbing. At the very least, they raise questions about patient privacy and confidentiality. Could or would an insurance company use amniocentesis or CVS results to establish a pre-existing condition?

Whenever one files an insurance claim, a blanket authorization to obtain medical records is part of the form, and often a claim will not be processed without authorization.

I am interested in collecting detailed accounts of insurance claim denials where genetic consultation or testing was appropriately offered. It would be helpful to know the name of the insurance company and reason for denial as well as the reason for the genetic referral. Both prenatal and pediatric cases are of interest. Please use only patient initials or some internal code on these accounts.

I can be reached at Reproductive Genetics Center, 455 S Hudson St, Level 3, Denver, CO 80222; 303-399-5393.

Kathleen O'Connor, M.P.S.

Genetic Counselor as Lab Liaisons

To the Editor:

I read with interest the articles by Andrew Faucett which were published in the last two issues of *Perspectives in Genetic Counseling* [12:4 and 13:1]. He describes what he feels is a valid approach for genetic counselors to use in selecting a reference laboratory. I have at least two issues to raise with his recommendations.

The first is that his review of laboratories presents an interesting list of questions but, unfortunately, there is no indication of what the appropriate response should be. Mr. Faucett does us all a disservice by raising the questions without offering some measure or standard by which responses can be judged. The assumption, I presume, is that all genetic counselors are experts in clinical laboratory science and are knowledgeable about all standards of good laboratory practice.

If laboratory standards in the various disciplines involved in clinical genetics are so well established, then those of us from around the country who are devoting much effort to developing and promoting acceptable standards have somehow missed the boat.

The second issue that I raise with Mr. Faucett's approach is that he is essentially suggesting that the genetic counselor become a laboratory inspector. Interestingly, many of the questions he proposes are similar to those found in the checklists that inspectors use as part of laboratory accreditation and licensure reviews.

What would *I* suggest? Get to know your laboratory scientists as colleagues whose interests in patients and quality service are just as strong as your own. Select your reference laboratories on the basis of nurtured trust. Leave the boots, whips and clipboards back at the office. I keep my own handy for motivational meetings with my staff.

Laurent J. Beauregard, Ph.D.
Director, Genetics Program,
Eastern Maine Medical Center
Bangor, ME

Author's response.....

Laboratory standards in clinical genetics are *not* well established, and that is the problem. By asking the published questions of several laboratories, a counselor should be able to *compare* their responses. Some laboratories will accommodate to meet a specific goal (rapid turnaround, cost, etc.) and counselors can learn that by asking the questions. Genetic counselors have a commitment to protect the patients' best interest. And they should feel free to "inspect" laboratories until an adequate national system is in place.

The intent of the articles was to provide a basis for counselors to begin a process in the face of confusing and often seemingly divergent information, not to encourage confrontation. I agree, "boots" and "whips" are best left behind. But sound planning and serious forethought regarding choice of laboratories can save valuable time in the long run.

Andrew Faucett, M.S.

OTA to Request Opinions re: CF Screening

To the Editor:

The Congressional Office of Technology Assessment is currently conducting a study of "Implications of Population Screening for Cystic Fibrosis." As part of the study, a survey will be distributed to members of the NSGC to assess attitudes and practices regarding screening and testing for the CF mutations. The survey will arrive in your mail in late June. Please participate, as the results will help focus the debates on the adequacy and sufficiency of personnel, the need for research and appropriate policies for public health.

Kathi Hanna, Ph.D.
Office of Technology Assessment

Positive Response Appreciated

To the NSGC Membership:

Thank you for your help! More than 200 of you responded to my lab survey. Of those, 87% responded positively and the project is on! Special thanks to all of you who listed names and addresses. Your response is helping me locate some of the smaller labs I might otherwise have missed.

Kathleen C. Rossello
Genetic Support Service

• CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED •

LITTLE ROCK, AR: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join multidisc team svg ped & adult genetic pop'ltns; coun & case mngmt in genrl genetics; wide range of spec clinics; oppty for rsrch, tchg, commun svc.
Contact: Chris Cunniff, MD, Section Chief Genetics, Arkansas Childrens Hospital, 800 Marshall St, Little Rock, AR 72202; 501-320-2966. EOE/AA.

LA JOLLA, CA: Immediate opening for BC/BE Genetic Associate.
Responsibilities: Rapid-growing academic ctr w/wide range clin & lab svcs & GC oppty: gen & repro gen, amnio, CVS, terat, MSAFP scrng.
Contact: Marilyn Quinnell, Personnel Manager, Univ California San Diego 10280 N. Torrey Pines Rd, Ste 265, La Jolla, CA 92093; 619-597-2615. Refer to job #28329-L. EOE/AA.

PANORAMA CITY, CA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join lrg, comphnsv clin & PNDx prog: amnio, CVS, hi-level ultra-snd, cytogen, teratogen coun; MSAFP, newborn hemoglob scrng, craniofac svc.
Contact: Harold N. Bass, MD, Kaiser Permanente Med Ctr, 13652 Cantara St, Genetics Svc, Panorama City, CA 91402-5497; 818-375-2073. EOE/AA.

SACRAMENTO, CA: July 1 opening for BC/BE Genetic Counselor.
Responsibilities: Join multidisc team incl 5 GCs in active PN prog: CVS, PUBS, early amnio, reg'l hi-vol MSAFP scrng prog; prof & commun ed.
Contact: Frances Tennant, PhD, Univ Calif Davis Med Ctr, Dept OB/Gyn, 1621 Alhambra Plaza, Sacramento, CA 95816; 916-734-6502. EOE/AA.

SAN JOSE, CA: Two immediate openings: A) Genetic Counselor B) CF Proj Coord. BC/BE req.
Responsibilities: A) All aspects of coun/case mngmt for peds & genrl genetics. B) One-yr position to coord CF PN scrng rsrch proj w/ oppty for genrl GC position upon proj completion.
Contact: Karen Wcislo, MS, Kaiser Permanente Medical Care Program, Genetics, 260 International Circle, San Jose, CA 95119; 408-972-3306. EOE/AA.

DENVER, CO: August 1991 opening for BC/BE genetic counselor. Exp in genrl genetics preferred.
Responsibilities: Coord outpt Denver Gen Clinic incl: assesmt & coun; clin rsrch; educ activ in newly merged units of Med School/Childrens Hosp; ABMG approved trng site. *Note: this program is separate from PNDx program.*
Contact: Eva Sujansky, MD or Rebecca Berry, MS, The Children's Hosp, Genetic Svc B-300, 1056 E 19th Ave, Denver, CO 80218; 303-861-6395. EOE/AA.

DENVER, CO: Immediate opening for BC/BE Genetic Counselor w/ desire to integrate GC w/ NIMH Fragile X rsrch study. Parttime w/ potential for fulltime.
Responsibilities: Wide range of resp & chall w/ oppty for indepen on interdisc fragile X team: iden & coun fam, coord PN & cytogen/DNA linkage tests; coord gen cmpnt of 5-yr grant.
Contact: Amy Cronister, MS or Randi Hagerman, MD, Child Development Unit, The Children's Hospital, 1056 E. 19th Ave, Denver, CO 80218; 303-861-6630. EOE/AA.

CHICAGO IL: Immediate opening for BC/BE Genetic Counselor. Exp pref.
Responsibilities: Join busy PNDx Univ-based Ctr: PN & genrl GC; coord genetic activ at CF clin & NIH early amnio study; s'vise GC grad studnts; oppty for rsrch.
Contact: Eugene Pergament, MD, PhD, Northwestern Univ Medical School, Dept Pediatrics, Sectn Reproductive Genetics, 333 E. Superior, Ste 1564, Chicago, IL 60611; 312-908-7441. EOE/AA.

LEXINGTON, KY: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Promote/org 35-40 state reg'l genetics clinics/yr, prov genetic educ svcs to local hlth progs & suptg agncies; part in clin genetics team in reg'l & univ-based clin; hosp consults.
Contact: Ron Cadle, MS or Bryan D. Hall, MD, Univ Kentucky Col Medicine, Dept Pediatrics, Lexington, KY 40536-0084; 606-233-5558. EOE/AA.

LEXINGTON, MA: Immediate opening for BC/BE Genetic Associate.
Responsibilities: Assume signif pt coun & case mngmt respon in clin-oriented svc: amnio, MSAFP, cytogen lab svcs.
Contact: Barbara Thayer, MS or Christine Ford, Prenatal Diagnostic Center, Inc., 80 Hayden Avenue, Suite 200, Lexington, MA 02173; 617-862-1171. EOE/AA.

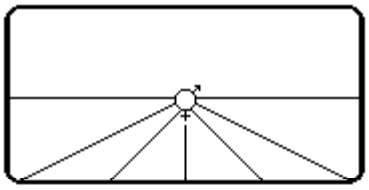
ANN ARBOR, MI: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Comphnsv prog in estab academ stg: coun & coord ped gen prog; s'vise state-funded Nwbrn Scrng & Outrch Clin Prog; s'vise GC students; interact w/ PN, tera & med gen svcs & Human Genome Ctr.
Contact: Jerome Gorski, MD, Univ Michigan, Dept. Pediatrics, 3570 MSRB II, Box 0688, Ann Arbor, MI 48109-0688; 313-764-0579. EOE/AA.

CHAPEL HILL, NC: Immediate opening for BC/BE Genetic Counselor w/ Faculty Position.
Responsibilities: Join well-estab PNDx prog: CVS, PUBS, hi-vol MS-hCG/AFP lab; database mngmt; commun educ.
Contact: Beth Boyea, MS, Univ North Carolina, Dept. OB/GYN, CB#7570, Chapel Hill, NC 27599-7570; 919-966-2229. EOE/AA.

BROOKLYN, NY: Immediate opening for BC/BE Genetic Counselor - 4 or 5 days, negotiable.
Responsibilities: General GC in OB & peds setting at major med school-affil tchg hospital.
Contact: Eve Beller, MS, SUNY/Health Science Ctr at Brooklyn, Box 24, 450 Clarkson Ave, Brooklyn, NY 11203; 718-270-2072. EOE/AA.

• see next page •

GeneCare
Medical Genetics Ctr
(Buchanan)
ad here



National Society of
Genetic Counselors, Inc.
Executive Office
233 Canterbury Drive
Wallingford, PA 19086

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NEW YORK, NY: July 1 opening for BC/BE Genetic Counselor. Bilingual, Spanish preferred.
Responsibilities: Oppty for indepnd in i'disc setting; comphnsv prog w/ full range of PN & ped svcs; coord prof/ commun outreach.
Contact: Doris Wethers, MD, St. Luke's Hosp 411 W. 114th St, 2nd Floor, #2C, New York, NY 10025; 212-523-3103. EOE/AA.

NEW YORK, NY: Immediate opening for BC/BE Genetic Counselor. Experience req; Spanish pref.
Responsibilities: Join expndg academ prog: PN coun, ped spec clinics; ward consults, tchng, indep rsrch.
Contact: Harry Ostrer, MD, New York Univ School of Medicine, 550 First Ave, Human Genetics Program, New York, NY 10016; 212-263-5746. EOE/AA.

QUEENS, NY: Challenging position at our Queens Hospital affiliation for Genetic Counselor w/ min 1 yr related exp, famil w/ genetic abnorm & Master's in genetics or closely related disc req.
Responsibilities: Divers genetic coun activ for PN & ped pts.
Contact: Employment Representative, PO Box 3999HR, New Hyde Park, NY 11042. Long Island Jewish Med Ctr, the LI Campus for the Albert Einstein Col Med. EOE/AA.

TOLEDO, OH: July 1 opening for BC/BE Genetic Counselor.
Responsibilities: Coord MSAFP prog for prof & pts: tstg, coun, follow-up; data collectn; potentl for rsrch. Prog soon to expnd to incl HCG & estriol scrng.
Contact: Thaddeus Kurczynski, MD, PhD, Medical College of Ohio, Dept. Pediatrics, PO Box 10008, Toledo, OH 43699-0008; 419-381-4435. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Peds & adult genrl genetics; coord spec clinics: NF, myelomen'g'cle; ophthal & neuro genetics; rsrch; tchng; affil w/ PNDx ctr at Hosp Univ Penna.
Contact: Donna McDonald-McGinn, MS or Elaine Zackai, MD, Clin Genetics Ctr, Childrens Hospital of Phila, 34th & Civic Center Blvd, Philadelphia, PA 19104; 215-590-2920. EOE/AA.

JOHNSON CITY, TN: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join multidisc team serving PN & peds pop'ltns: evals, coun & clin rsrch in Univ Phys Prac Grp affil w/ James H. Quillen Col Med.
Contact: Barbara Love, Human Resource Coordinator, East Tennesee State Univ, P.O. Box 5310, Johnson City, TN 37603-5310; 615-926-3188 or 615-245-1203. EOE/AA.

DALLAS, TX: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Oppty for indep in upscale priv prac spec in PNDx procedures (amnio, CVS, PUBS, Lev II U/S).
Contact: Walter W. Taylor, MD, 9330 Amberton Parkway, Suite 145, Dallas TX 75243; 214-437-9393.

BURLINGTON, VT: July 1 opening for BC/BE Genetic Counselor. 75% time w/ potential for expansion.
Responsibilities: Teratogen coun in reg'l ctr; some peds & PN coun.
Contact: Barbara West, MS, Vermont Regional Genetics Center, Dept. Pediatrics, Univ Vermont, Burlington, VT 05405; 802-685-4310. EOE/AA.

SEATTLE, WA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join comphnsv hosp-based ped genetic coun team w/ major tchg & rsrch prog; func indpndtly in CF & MD clins; srv as liaison to reg'l DNA bank & DNA dx svcs.
Contact: Bonnie Pagon, MD or Linda Ramsdell, MS, Childrens Hosp & Med Ctr, Med Genetics, 4800 Sand Point Way NE, Seattle, WA 98105; 206-526-2056. EOE/AA.

SEATTLE, WA: Immediate opening for BC/BE Genetic Counselor w/ min. 2 yrs. exp in pt care, clin coord & educ.
Responsibilities: Statewd activ incl: devlp & monitor contracts for reg'l genetics clins, eval genetics educ & other svc needs, montr PNDx svcs.
Contact: Robert Fineman, MD, Office of Maternal/Infant Health & Genetics, 1704 N.E. 150th St, Seattle, WA 98155; 206-545-6724. EOE/AA.

GREEN BAY, WI: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Work independently in reg'l refrl ctr svg NE Wisc & Upper Peninsula Mich: coun in genrl genetics clinics; pub & prof educ.
Contact: Sue Edminster, St. Vincent Hosp, Box 13508, Green Bay, WI 54307-3508; 800-236-3030x8139. E O E / A A .

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