PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 11, No.1 Spring 1989

Anniversary Report

Special Fund and Celebration to Mark Society's 10th Year

As announced in the last issue of *Perspectives*, NSGC will mark the 10th anniversary of its incorporation this year. The milestone will be marked with two special activities: a retrospective highlighting the major accomplishments of our Society and a prospective, looking at our profession's legacy to the future.

The showcase for the retrospective will

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on the inside

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

Theme: Counseling for Adult Disorders

Reproductive Counseling for Individuals with Mild Mental Retardation

by Barbara Dixson, R.N., M.N., San Diego-Imperial Counties Developmental Services, Inc., San Diego, CA

Reproductive counseling for mildly mentally retarded individuals is extremely complex. Each situation is unique; there is no set of rules or formulas that apply to these situations.

The percentage of the general population classified as mildly mentally retarded (I.Q. 50-70) is probably not increasing, but the number of these individuals who are getting married and/or having children is clearly increasing. There are several reasons for this increase, but two of the most important are educational mainstreaming and the current emphasis on normalization for the developmentally disabled. As a result, mildly mentally retarded individuals are being taught independent

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Identifying Individuals At Risk for Familial Lipid Disorders

by Dale Lea, R.N., Southern Maine Genetics Service, Foundation for Blood Research, Scarborough, ME

Genetic counselors, because of their in-depth training and skill in pedigree analysis, are in an excellent position to identify families at high risk for premature coronary artery disease (CAD) and thereby to contribute to CAD risk reduction.

Now recognized as a complex, chronic condition, coronary artery disease results from atherosclerosis, a process which begins in early childhood and results in the progressive narrowing of the coronary arteries.[1] It is a significant cause of morbidity and mortality in the United States, accounting for more deaths annually than any other disease, including all forms of cancer combined.[2] Because of its high frequency in the

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Counseling in Deaf/Hearing Impaired Adult Populations

by Jamie Israel, M.S.,
Genetic Services Center, Gallaudet University, Washington, DC

The incidence of congenital or early onset hearing impairment in the United States is estimated to be 1/1000, with at least 50% of these cases having a genetic etiology. Genetic deafness is heterogeneous. There are approximately 150-200 distinct genetic types of hearing impairment; 1/3 of these are felt to be syndromic. Approximately 80% of genetic hearing impairment is autosomal recessive, 20% autosomal dominant and 1-2 % X-linked. The majority of deaf individuals come from hearing families.

Traditionally, deaf individuals are a medically underserved population due in part to language and cultural barriers. Genetic services have also been underutilized. In 1984, Gallaudet University, in Washington, D.C., received grant funding from the United States Department of Health and Human Services to develop the Genetic Services Center (GSC), a "model program for the provision of genetic counseling services to the

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EdNotes

At last year's education meeting, *PGC* was asked to devote some space to non-prenatal issues. Since the theme of the 1989 education conference (and summer issue of *PGC*) will be devoted to "Reproductive Technologies," and since a significant proportion of the NSGC membership deals with non-prenatal counseling, we decided to devote this first issue of 1989 to counseling adults with genetic disorders.

Our feature articles look at three interesting adult populations:

- Barbara Dixson shares her experience with counseling the mildly mentally retarded adult population and in her cover letter to *PGC* suggested that genetic counselors initiate a long term follow up of the offspring of these individuals;
- Dale Lea calls attention to the high frequency of individuals at risk for coronary artery disease who may be found in prenatal or general genetics clinics; and
- Jamie Israel provides practical advice for dealing with the Deaf culture, where deafness may be considered a "difference," not a "disorder."

Judith Benkendorf's case report deals with identifying and managing FAS when it's diagnosed in pregnant women.

The theme is developed further by Joan Weiss, whose interview inaugurates a new *PGC* feature which replaces *Corner Thoughts*. Under the guidance of Seth Marcus, these interviews will provide more meaningful dialogue between *PGC* and the movers and shakers in the field of genetic counseling. Let *PGC* know who you'd like to have interviewed for the upcoming issues.

While you're thinking of that, what themes would you like to see covered in 1990? In a few months you'll be receiving a questionnaire asking your opinion on features and themes for future volumes of *PGC*. The editorial board will make its selections from among your ideas. Take the opportunity to help make *PGC* the newsletter that you want it to be.

Ed Kloza
Editor-in-Chief

Visions, Viewpoints &...

Counseling Adults with Genetic Diseases

An Interview with Joan Weiss, M.S.W., A.C.S.W.

Joan Weiss is Coordinator of the Alliance of Genetic Support Groups and Consultant in Social Work to the Johns Hopkins Center for Medical Genetics.

WHAT ISSUES ARE PARTICULAR TO ADULTS WITH GENETIC DISEASES AS CONTRASTED WITH CHILDREN WITH SUCH CONDITIONS?

The chief concerns of a genetically affected child are first and foremost, acceptance by his parents, and then, as the child reaches school age, acceptance by his peers. Genetically affected adults, in addition to the problem of acceptance and self acceptance, must cope with an array of issues: career choice, marriage, children and the means by which to have children, if that is indeed their decision. Those individuals who are able to realize their full potential are the adults who as children were in a supportive social milieu.

HOW WOULD YOU DISCUSS LONG TERM PLANNING, MARRIAGE AND CHILDBEARING WITH AN INDIVIDUAL WHO HAS A DISORDER WHICH MAY INVOLVE A SHORTENED LIFE EXPECTANCY OR MANY PHYSICAL PROBLEMS?

If a patient seems aware of a threatened life expectancy and is depressed about not being able to fulfill personal life goals, I have found it helpful to sort out short term objectives that are potentially reachable for that patient. If someone with a genetic disorder involving either an abbreviated life span or chronic physical problems expresses anxiety about whether or not to marry, I encourage the patient to be as truthful as possible with the prospective spouse regarding the diagnosis, prognosis and future disability.

I have sometimes been surprised by the reactions of those involved. In one situation, a woman had ectodermal dysplasia. Her fiance was able to accept the seriousness of her condition but could not cope with the possibility that she would lose her hair and have to wear a wig or that if they had a daughter, she might be without hair, as well.

When I counsel couples with life threatening genetic disorders regarding the dilemma of whether or not to have children, it has been helpful for me to raise the following questions:

- What is your understanding of pregnancy risks?
- Have you considered alternatives to parenthood, i.e. working as a nursery school teacher or with developmentally delayed young children?
- Have you considered adopting a child (if pregnancy is a risk to the mother)?
- How might your genetic condition impact on your ideas about being a parent?
- How would you feel about having a child with the same genetic condition?

I try to find out the ethnic, religious and social background of each partner, as well as the status of their marriage and their support network. Are they feeling pressured by family or friends to have a child? Is it important for them to have a child in order to improve their self image? Have they communicated to each other their hopes, fears and expectations in having children?

My primary role in this situation is to help the couple sort out the pros and cons of having a child, knowing in many instances that the woman might be at risk during pregnancy (i.e., Marfan syndrome) or that one of the parents might not be there for the child during adolescence. There is no set formula except to individualize each situation and help couples face realities before making these decisions.

ARE WE RESPONSIBLE FOR RAISING MORAL QUESTIONS ABOUT PASSING ON "DEFECTIVE" GENES?

If there are moral questions to be raised, they certainly should not be raised by the social worker or any other health professional. The patient, along with the partner, if there is one, has occasionally asked me if I would have a child if I were in their position. I usually explain that even if I were in the same position, it would not help if I said what I would do since this is such a personal decision.

I find it helpful to assess the individual's own concept of the "burden" of his or her genetic disorder, what support network has been available and what support can be counted on in the future if an affected child is born.

A couple's perception of the burden attached to a genetic disorder is quite unpredictable. Feelings of defectiveness and a poor sense of self are common in individuals who have a genetic disorder, regardless of how few the outward signs. Many will continue to feel blemished, no matter how mildly affected. These are the patients who often do not want to have children. In contrast, there are others who are severely affected by genetic disorders who have had what they consider to be

...Valued Opinions

successful lives and who are willing to risk having children who will be affected like themselves.

IF THE CONDITION IS PHYSICALLY DISABLING TO THE PARENT, HOW DO YOU RAISE THE ISSUE OF CARING FOR THE AFFECTED CHILD?

I recall working with a couple, both of whom were rather severely affected by osteogenesis imperfecta, who had decided to adopt a child.

In this situation, I raised the question of who would take care of the child, since one was in a wheelchair and the other needed two canes. In addition, they were subject to future fractures and possible hospitalizations. They were able to convince their adoption social worker and me that not only would they be able to care for a youngster, but that they would indeed make superior parents to a child with a similar handicap, based on the love they could offer and on the experiences they had had themselves.

This couple very successfully parented two adopted dwarfed children. It is important, I learned, that we ask the right questions to help individuals and couples who are physically disabled face the realities of caring for others or of having significant people around them take care of their children when necessary.

WHAT RESOURCES OR SUPPORT GROUPS WOULD YOU RECOMMEND FOR THESE ADULTS AND/OR THEIR FAMILY MEMBERS?

Appropriate referrals are often made to family service agencies, mental health clinics, pastoral counselors, respite care facilities, vocational rehabilitation counselors and the Department of Social Services, including local social security offices for financial and disability claims.

Support groups can be extremely helpful, both to affected adults and to family members, providing opportunities to share experiences and feelings with others in similar situations. For some, the most effective resource is another individual who has "been there," a peer counselor who is available at various times of crisis.

For information about the availability and location of particular genetic support organizations, I suggest that counselors contact the Alliance of Genetic Support Groups, 38th and R Streets, N.W., Washington, D.C. 20057; 202-625-7853.

Case Report

Case No. 15

Maternal FAS: Diagnosis & Management in a Prenatal Clinic

by Judith L. Benkendorf, M.S., Department of Obstetrics & Gynecology, Georgetown University Medical Center, Washington, D.C.

Fetal Alcohol Syndrome (FAS) is one of the most common birth defects with an incidence of 1 to 3 per 1000 births[1] and represents the most common form of preventable mental retardation. It is not unusual for offspring born to alcoholic women prior to the 1970s to have undiagnosed FAS because this syndrome has been clinically delineated only since 1973.[2] Two recent cases of adult cases with undiagnosed FAS recently presented at our clinic.

Patient 1 is a 23-year-old black prima gravida single parent referred for genetic counseling at 20 weeks gestation because of hydantoin and phenobarbital intake during pregnancy for seizure management. Physical stigmata, a history of developmental deficits, significant psychiatric history and maternal admission of alcohol consumption during pregnancy suggested FAS, which was later confirmed by a clinical geneticist. This patient was transferred to the high risk pregnancy clinic where she was followed with serial ultrasonography in conjunction with frequent prenatal visits. She delivered at term an approximately 5 1/2 pound SGA male infant. At 17 months, he is developmentally normal and not dysmorphic, although he continues to be small for his age. Social work intervention was arranged when the FAS diagnosis was established and mothering problems were detected early. Patient 1 has recently decided to place her son for adoption.

Patient 2, a 21-year-old black female G2P2 single parent, was first identified at 32 weeks gestation in the prenatal substance abuse clinic because of PCP and cocaine use in pregnancy. Physical stigmata as well as a history that included growth retardation present from birth, learning problems, history of psychiatric treatment, difficulties with the law as well as a mother who "used to drink heavily" resulted in referral to a clinical geneticist who again diagnosed FAS. At 36 weeks, Patient 2 delivered a 7 pound female infant who at six months is developmentally normal and not dysmorphic.

These patients are at risk for skeletal, renal and vision problems.[3] Early identification during pregnancy may help not only to control risk for problems such as low birth weight, but may also help to effectively manage related medical problems. Also, this may provide the first explanation to the patient and family which can account for the totality of the patient's medical, developmental and behavioral problems. (Both patients were counseled that their own mothers' drinking during pregnancy might explain many of their problems and concerns.)

Follow up studies on affected individuals reported by Streissguth[4] and others have demonstrated learning disabilities, poor mothering skills, short attention span, impulsive behavior, poor social judgment and lack of attention to social cues in many adolescents with FAS. Establishing the FAS diagnosis may help qualify these high risk mothers for financial subsidy and mobilize community resources. Referral to social work, protective services as well as periodic developmental and genetics follow up will allow their children to be watched closely.

FAS is more likely to be discovered in busy urban public hospital prenatal clinic populations and in rural areas surrounding native American populations, due to a higher rate of alcohol abuse in these groups. The impact of recognizing these patients cannot be understated.

Follow up studies on the newborns of FAS women may lead to better understanding of whether alcohol is simply a teratogen or it is also a mutagen. Referral for diagnosis, care and follow up will enhance pregnancy outcome by providing better pregnancy management and reentering these mothers into the health care system.

1 National Institute on Alcohol Abuse and Alcoholism. *Alcohol and Birth Defects: The Fetal Alcohol Syndrome.* (DHS Publication No. ADM 87-1531), 1987, p. 11.

2 Jones, K., et al. *Pattern of malformation in offspring of chronic alcoholic mothers.* Lancet 1; 1973, pp. 1267-1271.

3 Jones, K.L. "Fetal Alcohol Effects/Fetal Alcohol Syndrome" in *Smith's Recognizable Patterns of Human Malformations.* 4th ed. Philadelphia: WB Sanders, Co., 1988, pp. 419-499.

4 Streissguth, A.P. and R.A. LaDue. "Fetal Alcohol-Teratogenic Causes of Developmental Disabilities" in S. Schroeder (Ed), *Toxic Substances and Mental Retardation* Washington, D.C.: American Assoc. on Mental Deficiency, 1987., pp. 1-32.

deaf population."

Gallaudet University is the world's only accredited liberal arts university for deaf students. The majority of GSC clients are self referrals who have learned about the services from friends or colleagues through "word of hand." Through the GSC program, we have found that deaf individuals are interested and curious to learn more about the cause of their hearing loss and the possibilities to have deaf or hearing children. GSC staff members are fluent in sign language; therefore, communication can occur directly with the client in his/her native language.

For many Deaf individuals, there is a great sense of pride in being Deaf and being part of the Deaf culture.

Effective communication is essential to genetic counseling. When working with hearing impaired adults, it is important to use the language with which the client is most comfortable. American Sign Language (Ameslan or ASL) is the native sign language of many deaf individuals. ASL is linguistically a recognized language with its own grammar and syntax and differs from the English language. Other hearing impaired individuals may prefer to use a form of signed English, which uses some of the signs of ASL, but puts them in English word order. Individuals who use one of these forms will generally say or mouth the English words that they are signing. Some hearing impaired individuals may rely more on finger spelling and lipreading skills.

Section 504 of the Rehabilitation Act of 1973 requires that any agency that receives federal funding is required to provide "effective communication for hearing impaired persons." A range of communication options must be offered to the hearing impaired person at no additional charge, including qualified sign language interpreters, written communications and telecommunication devices for the deaf (TDD).

An understanding of Deaf culture is *critical* in genetic counseling for the deaf/hearing impaired client. The Deaf population in the United States is a closely knit group that is bound together by common values, experiences, language and history. For many Deaf individuals, there is a great sense of pride in being Deaf and being part of the Deaf culture.

Although by the audiologic definition, deaf refers to any person with severe to profound hearing loss, *Deaf* refers to an individual who is part of the Deaf culture. Therefore, many deaf adults do not feel that their deafness is a "handicapping condition" or a "disorder." Most deaf persons will marry another deaf individual and in many instances *prefer* to have deaf children.

Through our genetic counseling training, we develop nondirective skills, but we are also trained to use traditional medical terms such as "risk," "affected," and "disease." These terms become ineffective for the deaf adult who does not see him/herself as handicapped and who feels pride in being deaf. The use of these medical terms may portray a poor understanding and acceptance of the Deaf culture and has created barriers to genetic services in the past.

To work toward acceptance within the deaf community, the GSC staff made some changes to the traditional model of genetic counseling. Counseling tools which are sensitive to the deaf individual's sense of self were developed. For example, the terms "hearing" or "deaf/hearing impaired" were substituted for the terms "normal," and "affected," in commonly used charts which illustrate the patterns of inheritance. The "chance" for having a deaf child is used in place of the word "risk." (Some deaf individuals and couples may be concerned about their "risk" of having a hearing child.)

Genetic counseling for the deaf/hearing impaired adult offers many challenges for the genetics team. An understanding of the linguistic and cultural issues in the deaf population is essential to effective genetic counseling.

Konigsmark, B.W., and Gorlin, R. *Genetic and Metabolic Deafness*. Philadelphia: W.B. Saunders Company, 1976.

National Center for Law and the Deaf. *Guidelines for Hospital Policy and Hearing Impaired Patients*. Washington, D.C.: Gallaudet University, 1988

National Information Center on Deafness. *Educating Deaf Children, An Introduction*. Washington, D.C.: Gallaudet University, 1987

Padden, C. *The Deaf Community and the Culture of Deaf People*. In Baker, C. and Battison, R. (eds), Sign Language and the deaf community: essays in honor of William C. Stokoe. National Association of the Deaf, 1980.

Rose, S.P., Conneally, PM, Nance, WE. *Genetic Analysis of Childhood Deafness*. In Bess, FH (ed), *Childhood Deafness*. N.Y. Grune and Stratton, 1977.

Shaver, K.A. *Genetic Causes of Childhood Deafness*. In Bess, F.H. (ed), *Hearing Impairment in Children*. York Press, Inc., 1988.

Tips for Counseling Deaf/Hearing Impaired Adults

- **Determine, at the time the appointment is made, whether an interpreter is needed. It is essential that you have a qualified interpreter.**
- **Set aside adequate time for the appointment. Introductions, getting comfortable with using an interpreter, defining each person's role during the session and making sure that the information is clear to the client requires more time in this setting.**
- **Determine what the deaf/hearing impaired client's questions or concerns are in genetic counseling. Is the client coming for genetic counseling solely for more information about the cause of hearing loss, or does the primary concern involve counseling for an unrelated genetic condition/chromosome abnormality? Failure to identify the client's agenda may prevent the establishment of the trustful relationship necessary for clear communication.**
- **Ask how the client views his/her deafness. Listen how the client refers to him/herself; is it as "deaf," "Deaf," "hearing impaired" or "hard of hearing"? This will reveal important information about the individual. Also ask if the client prefers deaf or hearing children.**
- **For more information about qualified sign language interpreters, contact the Registry of Interpreters for the Deaf, Inc. at 301-588-2406 (V/TDD).**

Pre- and Perinatal Psychology: An Introduction

Edited by: Thomas R. Verny
Publisher: Human Sciences Press, New York 10011-8004, 1987, 296 pp.
Price: $36.95 hardback
Reviewed by: Gloria W. McNally, Ph.D., L.C.S.W., Consulting &, Counseling Center, Washington, D.C.

The material in this book was originally presented at the First International Congress on Pre- and Perinatal Psychology held in Toronto in 1983. Although some of the articles are *by* specialists in their fields, such as Professor A.A. Tomatis of Paris who writes on the psychological dimensions of listening perception in fetal life, many are written *about* experts and their theories on what takes place prenatally and at time of birth.

What is badly needed in this volume is some chronological editorial sense-making that would bring the reader into a readiness for concepts by detailing the precedents to these ideas and theories. In addition, the scientific quality of the material is jarringly uneven: articles on subjects such as maternal-fetal bonding, underwater birth and empathetic birthing have immediate intuitive appeal, whereas those on subjects such as how the original birth trauma repeats itself throughout life and how parental life events can be transmitted through DNA to the unborn require some scientific grounding. For example, the presentation on "Perinatal Imagery in UFO Abduction Reports" attempts to provide correlations between persons reported to have been abducted by unidentified flying objects on the basis of whether they had normal or cesarean births. Fortunately this adventure into sci-fi was the only off-tone article.

While readers may feel, as I did, a certain uneasiness with the futuristic quality of some of these articles, the linking of prenatal psychological life and later life events for the most part is convincing, validating as it does what is already known or suspected about fetal life. Surely, new revelations about how newborns feel pain (not treated in this collection) is one such item.

Arnold Buchheimer's article on preverbal memory, proposing that memory storage exists throughout the body, not only in the mind, (ask any pianist if this is true) is exciting to contemplate since this capacity would make it possible for human beings to remember accurately and verifiably what occurred during their own birth. The therapeutic possibilities alone of such a revelation are immense.

In Judith S. Kestenberg's article on fetal movement and dreams, a method is detailed which uses the dreams of pregnant women and "tension-flow charting" to provide natural gentleness during pregnancy and birthing.

Considering Freud's interest in infantile amnesia and his initial (though not later) approval of Otto Rank's 1929 book "The Trauma of Birth," scientific interest in the psychological and emotional well being of the fetus and newborn seems long overdue. Dr. Verny, also the editor of *Pre- and Perinatal Psychology Journal*, has laid a strong foundation for continued study of the psychological dimensions of human reproduction and the mental and emotional development of the unborn and newborn. His views have a religious, pro-peace flavor, and his emphasis on the personal consciousness of the unborn puts him squarely on the pro life side of the issue. Be that as it may, readers will find this book, despite many typos and sparce indexing, a fascinating addition to their library. The future is now, and here is a book that will help get a grasp on it.

Prenatal Diagnosis of Congenital Abnormalities

Authors: Roberto Romero, Gianluigi Pilu, Philippe Jeanty, Alessandro Ghididni and John C. Hobbins
Publisher: Appleton & Lange, Norwalk, CT and San Mateo, CA, 1988, 466p.
Price: $79.95
Reviewed by: Maria J. Mascari, M.S., The Milton S. Hershey Medical Center, Hershey, PA

Advances in reproductive technology are always accompanied by new and challenging questions, concerns and ethical issues.

The authors wrote this book to provide the practicing sonographer, geneticist, obstetrician and counselor with a source of information to which they could refer when faced with the diagnosis of a fetal abnormality on ultrasound. As genetic counselors, our role is to provide couples with information regarding the prognosis for the fetus and the risk of recurrence in future pregnancies so they may make informed decisions.

The book is organized by organ systems, with chapters devoted to the central nervous system, face, neck, heart, lungs and abdominal wall. In addition, the gastrointestinal, urinary and genital tracts are covered in great detail. The chapter on skeletal dysplasias is excellent. Various abnormalities of the umbilical cord and other anomalies such as amniotic band syndrome and non-immune hydrops fetalis are also addressed.

When available, the authors have provided information about the frequency, etiology, genetic basis, pathology, associated anomalies, diagnosis, prognosis and obstetrical management for each anomaly. I found the tables listing associated abnormalities to be extremely useful and I support the authors' advocating cytogenetic evaluation of fetuses with congenital anomalies. I also commend the authors for addressing the controversial issues which surround obstetrical management.

The tables and figures succeed in supplementing information contained in the text; the ultrasound images are impressive. Detailed labeling of the ultrasound images enable the nonspecialist to differentiate variations from normality. Fetal biometry is addressed throughout the text and appendices since it is an important part of the diagnosis of congenital anomalies.

The only limitation of the book is clearly stated by the authors in the preface. In their attempt to provide prognostic information about the various disorders, the authors are limited by the scarce amount of data which exist for cases identified in utero. To compensate, they utilize information available in the pediatric literature regarding newborns with anomalies, acknowledging the differences between fetuses and newborns and the limitations of extrapolating data from pediatric and autopsy studies.

Prenatal Diagnosis of Congenital Anomalies is a welcome addition to our expanding library of references. Its use can only serve to improve the supportive care of couples who must confront difficult situations.

population, CAD is often coincidentally encountered when family histories are taken for unrelated circumstances, i.e., pre-amniocentesis counseling for maternal age. Approximately 25% of families seen for genetic counseling at the Foundation for Blood Research have one or more members affected with CAD.[3]

Approximately 25% of families seen for genetic counseling at the Foundation for Blood Research have one or more members affected with CAD.

Early Identification of CAD Risk via Family History

Family history of premature CAD is defined as definite myocardial infarction or sudden death before age 55 in two or more first degree relatives[4] and has been found to be a strong predictor of CAD risk. First degree relatives of early coronary disease patients have a three- to ten-fold increased risk of developing early coronary events.[5] Family history evaluation is a potentially cost effective and accurate screening method that can function as a biological marker for identifying and referring families at increased genetic risk for CAD.

If a routine family history is suspicious, or if an extensive genetic evaluation is planned, a detailed family history should be obtained. This should include sex of the affected relative, manifestations of heart disease (e.g., angina, heart attack, cholesterol abnormality), age of onset and treatment (e.g., bypass surgery) and degree of relation to the patient. The presence of other CAD risk factors such as diabetes, obesity, smoking and hypertension should also be documented. Complete information on spouses and children should also be collected.[6] Non-CAD heart disease (rheumatic or congenital) should be identified.

The presence of other anxiety-producing counseling issues may enhance the denial of potential CAD risk and may interfere with compliance, additional evaluation and treatment.

A positive family history for early CAD may be associated with familial hypertension or coagulation abnormalities or with genetically determined lipid abnormalities, several of which have been classified.[7]

Referral

When a familial lipid disorder is suspected, the family should be referred for additional counseling and evaluation starting with a conventional measurement of total blood cholesterol. If cholesterol is elevated (>200 mg/dl in adults), then secondary causes such as thyroid or kidney disease, diabetes or medications such as hormones or beta blockers must be ruled out. Detailed lipid studies of first degree relatives may also be ordered to help classify a familial lipid disorder.[2]

Treatment

Individuals with a lipid disorder are candidates for dietary modification and drug therapy, accompanied by weight loss, smoking cessation and exercise regimens as indicated.

Medications used in treatment of lipid abnormalities lower lipid levels by binding with cholesterol in the digestive tract and facilitating its excretion, interfering with the synthesis or metabolism of triglycerides or inhibiting enzymes involved in cholesterol synthesis.

Potential Pitfalls

A number of factors may interfere with evaluation and management of CAD. Patients referred for genetic counseling for risk of one condition may not be receptive to the identification of risk for an unrelated condition. Discovery of a positive family history for CAD may add stress to an already anxious situation.

Individuals may be aware of their family history but, because they are asymptomatic, decide that there is no urgency for follow up. The presence of other anxiety-producing counseling issues may enhance the denial of potential CAD risk and may interfere with compliance, additional evaluation and treatment.

If an individual denies his/her risk of CAD, it is important to explore with the family possible causes for initial refusal. If this approach is ineffective, the counselor should determine how aggressively to pursue the situation. If CAD risk is identified during prenatal counseling, this CAD risk may have direct bearing on the future health and well-being of the developing fetus. Circumstances would dictate whether the counselor should provide this information to the expectant couple or wait until the anxiety of pregnancy and the newborn period has passed.

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As in many other genetic counseling situations, laws and policies protecting the privacy and confidentiality of medical information may prevent early classification of CAD or of informing at-risk relatives of potential danger. Counselors who feel thwarted in their efforts to assess and counsel for risk should refer to the interviews with Philip Reilly and Ruth Mickelsen in previous issues of *Perspectives*.[8]

Family members may be aware of a familial tendency toward CAD but not of the availability of risk management. Williams' experience with coronary-prone family members has shown that few are receiving maximal medical support and help in screening and prevention.[6]

SUMMARY

Identification of families at high risk for premature CAD is the first and foremost step towards early intervention and prevention. Once a high-risk family is identified by the genetic counselor, initiation of screening and management, particularly in children and young adults, should assist in prevention or delay of coronary disease symptoms and ultimately of excessive CAD morbidity and mortality.

1 National Institutes of Health, Consensus Development Conference Statement, Lowering Blood Cholesterol, December 10, 1984, pp.1-28.

2 Report of the National Cholesterol Education Program Expert Panel on Detection, Evaluation and Treatment of High Blood Cholesterol in Adults, *Arch. Intern. Med.* Vol. 148, pp. 36-69, January, 1988.

3 Lea, D.H. (Unpublished) 1988.

4 Williams, RR. Editorial. Nature, Nurture, and Family Predisposition, *N Engl J Med.*, 318 (12): 769, March 24, 1988.

5 Willams, R.R, et, al. Health Family Trees: A Tool for Finding and Helping Young Family Members of Coronary and Cancer Prone Pedigrees in Texas and Utah, *AJPH*, 78 (10):1283, October, 1988.

6 Williams, RR. Understanding Genetic and Enviromental Risk Factors in Susceptible Persons, *The Western Journal of Medicine*, 141(6):799, December 1984.

7 Gotto, A.M. Jr., Cholesterol: New Approaches to Screening and Management, *Contemp OB/GYN*, 56-70, July, 1988.

8 *Perspectives in Genetic Counseling*, Counselor Liability in Risk Communications: An Interview with Philip Reilly, J.D. M.D. and Ruth Mickelsen, M.P.H., J.D., Vol. 10 (Nos. 3 and 4): p. 1, Winter and Fall, 1988.

Counseling Mildly Retarded Adults, from p. 1

living skills and are given social and work opportunities in the community rather than being segregated from the mainstream of society. Adult relationships, including marriage and parenthood, are more likely to occur with increased independence and social acceptance.

...when conducting reproductive counseling for the mildly mentally retarded...the genetic component plays a minor role to the many psychosocial factors of parenting.

Multiple reproductive counseling issues arise with this population. In addition to genetic factors, there are a number of psychosocial issues to consider, such as parenting skills. Other complicating factors include: a lack of knowledge about pregnancy, a lack of planning for pregnancy, difficulty obtaining prenatal care, use of prescribed drugs (primarily psychotropic and anticonvulsant medications) and sometimes abuse of alcohol or drugs.

Genetic factors are often of less significance than psychosocial issues. The etiology of mild mental retardation is usually unknown, but is frequently believed to be multifactorial in origin. An accurate family history and a thorough medical/genetic diagnostic evaluation are essential for providing genetic counseling. This may be easier to obtain when both partners have been diagnosed mentally retarded. Frequently, however, only one partner, usually the female, has been diagnosed as being mentally retarded. Often their partners are learning disabled, sometimes mentally ill and sometimes abuse alcohol or other drugs.

The majority of clients who are mildly mentally retarded have few parenting skills. The quality of parenting that they experienced as children greatly impacts their abilities. Those who are motivated and have some appreciation of the responsibilities of parenthood can often be taught basic parenting skills. Some mildly mentally retarded adults are compliant; others have underlying emotional or psychiatric disorders manifested by acting out behaviors such as promiscuity, lying, refusal to keep appointments or refusal to take prescribed medication.

Individuals who are mentally retarded tend to be very concrete and literal in their thinking. They have difficulty transferring learning from one situation to another. This cognitive trait needs to be taken into consider-ation in any teaching or counseling situation. Most mildly retarded indivi-duals are competent to give informed consent for various procedures such as amniocentesis, ultrasound and even sterilization and abortion. However, they may be easily influenced, making it critical to ensure that any consent obtained is without undue influence from the family or from others working with the client.

Most women who are mildly mentally retarded do not appear to be abnormal. Health care professionals may sense that a patient is "slow," but unless a woman is clearly psychotic or otherwise obviously incompetent, her newborn infant probably will be sent home with her. Child protective services may or may not be consulted in these instances. Usually the mother is given every opportunity to demonstrate her ability to parent adequately. Only in exceptional cases is the child separated from the mother at birth and sent to a foster home.

A primary concern is the quality of life of the child. Children of mentally retarded parent(s) have a significant risk for environmental deprivation, neglect and abuse. Even though the majority of these children are born structurally normal, many show developmental delay by age three, especially in the area of speech and language. Parent training and infant stimulation programs can maximize the potential of these children. Nonetheless, they remain at high risk for future problems with learning.

In summary, when conducting reproductive counseling for the mildly mentally retarded, the genetic counselor often finds that the genetic component plays a minor role to the many psychosocial factors of parenting.

1988 Proceedings to be Available this Fall

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

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

Orders will not be processed without prepayment.

LuAnn Weik, M.S.
Conference Chairperson

Survey to Address Education, Training Concerns

The NSGC Education Committee has organized a meeting of graduate training programs and other related groups to consider future curriculum. This meeting is scheduled for September 1989 at Asilomar Conference Center in California.

Within the next several weeks, members of the NSGC will be receiving a questionnaire addressing training and education needs of genetic counselors.

Please take a few minutes to complete the questionnaires and encourage your employer to complete the second questionnaire, which will be directed to his/her expectations for the training of genetic counselors.

NSGC Education Committee

Molecular Genetics to be Focus of March of Dimes Conference

Boston has been chosen to be the site of the 1989 Clinical Genetics Conference, sponsored by the March of Dimes Birth Defects Foundation. "Clinical Applications of Molecular Genetics" has been scheduled for July 9 - 12. The meeting will focus on recombinant DNA approaches as they are currently being successfully applied. Abstracts are being accepted through April 15.

Sue Greene
Professional Services Department
March of Dimes Birth Defects Fdt.

Region IV Holds Conference

The Campus Inn in Ann Arbor has been selected to be the site of the Region IV education conference, April 10 - 11. The topic, "Difficult Counseling Situations," will focus on skills and techniques for handling both prenatal and pediatric diagnoses. Region IV gratefully acknowledges Integrated Genetics and Genentech for funding support for the conference.

For information and registration materials, contact Conference Coordinator, Robin Belsky Gold, M.S., 313-493-6060.

Kathy Morris, M.S.S.W.
Region IV Representative

Ethics Focus of MARHGN Meeting

The Mid-Atlantic Regional Human Genetics Network will sponsor a conference entitled "Ethical Dilemmas in Medical Genetics," April 2-3 at the Boar's Head Inn, Charlottesville, VA.

For more information, contact the MARHGN office, 804-924-9477.

Suzanne Holowinsky, M.S.
MARGHN Cooridinator

Members Invited to Annual Conferences for Voluntary Organizations

"Advances in Craniofacial Developmental Biology and Clinical Implications," sponsored by the American Cleft Palate Craniofacial Association, has been scheduled in San Francisco, on April 23 - 24. This professional conference immediately precedes the organization's 46th annual meeting. For more information, contact ACPCA, 412-481-1376.

Nancy C. Smythe
CPCA Executive Director

"Generation to Generation: Help, Healing, Hope" is the topic of the Annual National Tay Sachs and Allied Diseases Association, May 5 - 7 in Chicago, IL. The theme will focus on loss, grief, healing and coping. For more information, contact NTSADA, 617-964-5508.

Marjorie Epstein
NTSADA Executive Director

Special Project Fund, Special Event to Mark 10th Year from p. 1

be a special event at our Annual Education Conference in Baltimore this November. The traditional annual banquet will include an historical presentation, exhibits of photographs and other memorabilia. The presentation promises to be nostalgic, enlightening and entertaining.

The purpose of the newly-created Special Projects Fund is to support innovative projects presented by members based on their strength, merit and relevance to the mission of the NSGC and future of the profession. The goal is to raise $20,000, with the annual interest on this sum to be awarded annually for the proposal or proposals submitted by genetic counseling professionals that meet the stated goals. The first award is slated to be granted at the 1990 Annual Education Conference in Cincinnatti.

Your membership dues are used entirely for operating expenses and to subsidize the Annual Education Conference. This Special Projects Fund will enable the Society to undertake new projects each year that otherwise could not be funded.

Members, corporate friends, voluntary organizations and related professionals interested in the future growth of the genetic counseling profession are being asked to contribute to this fund. In several weeks, you will receive a letter requesting your contribution. The support of our membership is essential to the success of this project. We hope you will join us by taking an active role in the future of your profession by participating at a level that is personally comfortable to you. We hope you will also want to help celebrate by joining us in Baltimore in November.

Members who have photos and other memorabilia that might contribute to the Special Event Retrospective are invited to send the information to: Luba Djurdjinovic, Genetic Counseling Program, 16 Leroy St, Binghamton, NY 13905; 607-724-4308.

Correction

The Social Issues Committee reported at the Annual Meeting and in the Winter 1988 (Vol. 10, No. 4) issue of *PGC* that 95% of our membership was motivated to enter the field of genetic counseling because they, a relative or close friend had a genetic disease or birth defect.

In fact, these reports should have stated that only 5% (12) of the respondents entered for this reason and 95% (226) did not.

Letter to the Editor

Response to Ethical Dilemma Surrounding False Paternity

To the Editor:

Case Report No. 14 in the last issue of *Perspectives* (Vol. 10, No. 4) regarding a family that underwent DNA-based diagnostic analysis that revealed potential false paternity raised an interesting ethical issue as to the rights of that family member to this information about his genetic heritage. I would like to propose several arguments in favor of disclosing such information to clients.

First, when blood samples are taken from an individual for DNA studies, the laboratory records can not legally be withheld. It is, therefore, illegal to withhold even potentially sensitive or controversial information. It is difficult to imagine how a medical facility could have such information in its files or records, but choose to withhold some or all information from the client.

Second, while it is true that many families have maintained secrecy regarding sensitive life circumstances, including the situations surrounding the birth of a child, it is not the counselor's role to determine that disclosure of false paternity would be psychologically damaging. The trend in our society is to defend childrens' right to knowledge of their biological background. More and more adoptions are classified as "open," and adopted children are obtaining much more information about their biological parents. It has been my experience that, even if the intent is to protect children, the perpetuation of secrets or lies in a family is more likely to result in dysfunction and damage.

Finally, there appear to be solutions to some of the potential conflicts caused by the new genetics technology. If potential clients are to give "informed consent" to DNA-based family studies, then they must know what other information may be revealed by such analysis. It has become increasingly essential that to be an educated consumer of medical care and to take advantage of new technology, one must be fully informed of the possible implications. Therefore, a consent form or informative brochure which mentions the possibility of false paternity being discovered should precede any DNA-based family study undertaken.

Elaine Fleming, A.C.S.W.
Clinical Social Worker
Lutheran General Hospital

Resources

Book

A Neurologist Speaks About Huntington's Disease

Publisher: Huntington's Disease Society of America, Inc., New York, NY: 1986 22 pp.

Price: $.50 ea.

Reviewed by: Melonie Krebs, M.A., Akron, Ohio

This multi-purpose booklet is a valuable resource for families and individuals who have been diagnosed with or undergoing testing for Huntington Disease. It features highlights from a speech delivered by Dr. Anne B. Young to the Huntington Society of Canada in October, 1986. Dr. Young, coordinator of the Movement Disorder Clinic at the University of Michigan, is a member of the Huntington's Disease Venezuela Research Team.

This booklet is the conversation many families wish they could have with a specialist when the effects of this condition seem overwhelming. It is informative regarding neurological signs of onset, diagnosis, staging and therapies for the disease. It also addresses the search for the Huntington gene. It is personal and has a caring tone, sensitively clarifying the confusion surrounding the perceived association between Alzheimer's Disease and Huntington Disease.

Dr. Young's experience with supporting many families experiencing this disease is evident. Her description of the quest for the Huntington gene in a remote Venezuelan village successfully personalizes the often overly-clinical approach to disease research.

Audiovisual

And Then Came John

Produced by: Telesis Productions, 1988

Format: 1/2" VHS

Price: Sliding fee scale for parent and regional organizations

Orders: Telesis Productions, Attention: Scott Andrews, P.O. Box 948, Mendocino, CA 95460, (707) 937-3048

Reviewed by: Stefanie Uhrich, M.S., University of Washington, Seattle, Washington (Reprinted by permission of Genetics Northwest)

This film chronicles the life of John McGough, a 30 year old man who was born with Down syndrome. It begins at his 26th birthday party and describes the frustrations and triumphs in John's life through pictures and interviews with his family and friends.

Despite the rejections and prejudice he faced for much of his life, he made his own personal contribution to the world with his art, his music and his philosophy of life. He was able to do this only after he found a place in the world where people accepted him and encouraged him to grow. The message is not just one of how an individual triumphs over his handicap, but that we should not be judged and limited by our appearances.

The story of John's life is somewhat one sided in that John McGough is a gifted individual with Down syndrome. Therefore this film would not be appropriate for couples who are deciding whether to keep a baby with Down syndrome. However, it would be of great benefit to parent support groups or families who are raising children with Down syndrome or with other handicaps as it provides hope and encouragement.

And The Came John is more than a story about Down syndrome. It is a lesson for children of all ages and for adults on acceptance and the importance of encouraging all individuals to be who they are and achieve their greatest potential. Therefore, it would be a valuable resource for primary and secondary education classes as well as churches and community groups.

Organization

Turner's Syndrome Society of the United States

A new organization for families and professionals in support of Turner's Syndrome has been recently formed. The group desires to assist those women and girls with Turner's Syndrome and their families by providing informational support with the varied problems associated with Turner's Syndrome which appear at different stages of life.

It also wishes to promote public and professional awareness of Turner's Syndrome and the problems associated with the disorder. They hope to accomplish these goals through support networks, publication of a newsletter, annual conferences and other promotional activities.

To join the organization and receive the Turner Syndrome Society newsletter, contact: TSSUS, 3539 Tonkawood Rd., Minnetonka, MN 55345,(612) 938-3118.

Classified • Classified • Classified

The classified listings printed in this issue represent the most recent additions to the NSGC's Job Connection service. Members and students interested in complete or regional information may receive a computerized printout by contacting the Executive Office.

MOBILE, AL: Immediate opening for BC Genetic Counselor. Writing ability essential; computer experience helpful.
Responsibilities: Coordinate special project concerned with microcomputer databases and genetic information. Parttime participation in all areas of clinical services available.
Contact: Wladimir Wertelecki, M.D., Professor and Chairman, Department of Medical Genetics, University of South Alabama, CCCB214, Mobile AL 36688; 205-460-7500. EOE/AA.

FRESNO, CA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Wide variety of general genetics, including prenatal diagnosis, specialty clinics and education.
Contact: Susan Snyder, Preventive Services Coordinator, Central Valley Regional Center, 4747 N. First Street, Suite 195, Fresno, CA 93726; 209-228-3061. EOE/AA.

SACRAMENTO, CA: Immediate opening for BC/BE Genetic Counselor. Parttime/fulltime negotiable.
Responsibilities: Start-up prenatal diagnosis and counseling position. Some administrative work; opportunity for collaboration in clinical research project.
Contact: Douglas Hershey, M.D., Sutter Perinatal Center, 5275 F Street, Sacramento, CA 95819; 916-733-1750. EOE/AA.

SAN DIEGO, CA: Spring 1989 opening for BC/BE Genetic Counselor with Masters or Nursing Degree. (If BE, successful candidate will be expected to sit for and pass next ABMG exam.) Salary: $30,944-$43,322 depending on qualifications and experience.
Responsibilities: Prenatal counseling and consultation with patients and physicians; utilize hospital subspecialty programs.
Contact: Carol Heylman, Human Resources Dept., Children's Hospital & Health Center, 8001 Frost Street, San Diego, CA 92123; 619-576-5809. A CHHC application and 2 or more references are required. Call 619-576-5827 (CA) or 800-634-4441 (outside CA) for application form. EOE/AA.

NEW HAVEN, CT: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Varied, including prenatal diagnosis.
Contact: Katherine A. Schneider, M.P.H., Yale University School of Medicine, Human Genetics, P.O. Box 3333, New Haven, CT 06510; 203-785-2661. EOE/AA.

TAMPA, FL: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Faculty position with wide variety of cases, autonomy and high degree of responsibility in active, multidisciplinary clinical service. New, on-site molecular genetics laboratory.
Contact: Boris Kousseff, M.D., University of South Florida, College of Medicine, 12901 Bruce Downs Blvd, Tampa, FL 33612; 813-974-3310. EOE/AA.

WEST PALM BEACH, FL: Immediate opening for BC/BE genetic counselor. Salary range: $28,000 - $34,000, based on experience and credentials.
Responsibilities: Focus on first semester prenatal diagnosis at this rapidly-growing, free standing center associated with a national network of leading medical geneticists.
Contact: Gene Manko, M.D. or Jay Trabin, M.D., The Genetics Institute of Florida, 1401 Forum Way, #210, West Palm Beach, FL 33401; 407-697-4200. EOE/AA.

SAVANNAH, GA: Immediate opening for BE/BE Genetic Associate.
Responsibilities: Start-up position in regional medical center on perinatal team. Act as liaison with neonatology department to coordinate and identify cases; conduct community outreach, medical and resident education.
Contact: Roger Munderloh, Recruiter, Memorial Medical Center, P.O. Box 23089, Savannah, GA 31403; 912-356-5198. EOE/AA.

CHICAGO, IL: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Coordinate successful CVS program; provide prenatal & general genetic counseling; professional education.
Contact: Ralph K. Tamura, M.D., Northwestern Memorial Hospital, 333 E. Superior Street, Suite 1176, Chicago, IL 60611; 312-908-7441. EOE/AA.

PALOS HEIGHTS, IL: Immediate opening for highly motivated, independent, organized, managerial-style, BC/BE Genetic Counselor.
Responsibilities: Start-up position in large Chicago hospital system, including MSAFP, CVS, early amniocentesis and genetic amniocentesis.
Contact: Debra Han, M.S., High Tech Medical Park, 11800 Southwest Highway, Palos Heights, IL 60463; 312-957-4363. EOE/AA.

INDIANAPOLIS, IN: Spring 1989 opening for BC/BE Genetic Associate.
Responsibilities: Evaluate and counsel in genetics clinics affililated with Indiana University School of Medicine. Outreach clinics; help establish and operate teratogen information service.
Contact: David D. Weaver, M.D., Riley Children's Hospital, Medical Genetics, RR 129, 702 Barnhill Drive, Indianapolis IN 46223; 317-274-5740. EOE/AA.

BOSTON, MA: Immediate opening for BC/BE Genetic Counselor. Minimum 2 years experience preferred.
Responsibilities: Join 1 genetic counselor, 2 M.D. geneticists in large successful HMO. Broad range of counseling issues; strong prenatal diagnosis program; professional education.
Contact: Juli Horwitz, M.S., Harvard Community Health Plan, 147 Milk Street, Genetics Dept., Boston, MA 02109; 617-654-7330. EOE/AA.

LANSING, MI: BC/BE Genetic Counselor or related professional with minimum of 2 years genetic counseling experience. Salary Range: $29,000-$42,000, depending on experience.
Responsibilities: Administer state genetics program; develop policy and procedure systems, education and training programs; assist with newborn screening program.
Contact: William Young, Ph.D., Michigan Dept. of Public Health, BCS-ERD, 3423 N. Logan, Lansing, MI 48909; 517-335-8938. EOE/AA.

COLUMBIA, MO: Immediate opening for BC/BE Genetic Counselor. Experience not required.
Responsibilities: Join 3 medical geneticists, 1 Ph.D. geneticist and 2 genetic counselors to coordinate prenatal diagnosis program. Some general genetics.
Contact: Judith H. Miles, M.D., Ph.D., University of Missouri at Columbia Hospital Clinics, 1 Hospital Drive, Columbia, MO, 65212. EOE/AA.

WINSTON-SALEM, NC: Immediate opening for BC/BE Genetic Counselor. Experience not required.
Responsibilities: 50% MSAFP, 50% high risk OB/GYN; education opportunities.
Contact: Jeannette Bensen, M.S., Bowman Gray School of Medicine, 300 S. Hawthorne Rd., Dept. of Pediatrics, Winston-Salem, NC 27103; 919-748-4321. EOE/AA.

HANOVER, NH: Immediate opening for BC/BE Genetic Counselor or Nurse with experience in genetics. Salary Range: $23,760-$36,600, depending on experience.

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Responsibilities: Coordinate outpatient clinical genetics and dysmorphology programs; inpatient consultation; prenatal diagnosis; MSAFP; professional education.
Contact: Susan Berg, M.S., Dartmouth Hitchcock Medical Center, Butler Building, Hanover, NH 03756; 603-646-8453. EOE/AA.

RENO, NV: May 1 opening for Nevada State Coordinator position for Pacific Southwest Regional Genetics Network. Background in public health desirable. Salary Range: Low $30,000s.
Responsibilities: Coordinate statewide genetics services.
Contact: Tamara Lieberman, March of Dimes, 3100 Mill Street, Suite 117, Reno, NV 89502; 702-323-4107. EOE/AA.

ALBANY, NY: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Collaborative program between OB/Peds departments, including counseling, diagnosis, prognosis, recurrence risk and follow-up; specialty clinics in hemophilia, myelo & other satellite clinics; professional and public education.
Contact: Bernard Pollara, Ph.D., Albany Medical Center, Dept. of Pediatrics, New Scotland Avenue, Albany, NY 12208; 518-445-5120. EOE/AA.

NEW YORK, NY: Two immediate openings for BC/BE Genetic Counselors in active medical genetics units located at Booth Memorial Hospital in Queens and Lenox Hill Hospital in Manhattan. Experience required.
Responsibilities: Coordinate genetic counseling service for prenatal and pediatric referrals.
Contact: Gloria Harris, M.S., Suite 308, 146-01 45th Avenue, Flushing, NY 11355; 718-670-5936. EOE/AA.

SYRACUSE, NY: Immediate opening for BC/BE Genetic Associate. Computer literacy helpful.
Responsibilities: Join genetic counseling team in comprehensive genetics program at SUNY Health Science Center, a NY State Dept of Health program. Perinatal and general genetic counseling; opportunity for education, research projects.
Contact: Barbara Silverstone, Central New York Regional Genetic Program, SUNY Health Science Center, WSK750 E. Adams Street, Room 3109, Syracuse, NY 13210; 315-473-5884. EOE/AA.

COLUMBUS, OH: Immediate Opening for BC/BE Genetic Counselor or Nurse with Masters degree.
Responsibilities: Genetic, preconceptual and high risk pregnancy counseling in newly-developed perinatal service at Elizabeth Blackwell Hospital, Riverside Hospital. Some scheduling flexibility available.
Contact: Dixie Biehl, Recruiter, Riverside Methodist Hospitals, 3535 Olentangy River Rd., Columbus, OH 43214; 614-261-5165. EOE/AA.

PORTLAND, OR: Immediate opening for 1/2 time, BC/BE Genetic Counselor. Experience preferred.
Responsibilities: Prenatal diagnosis; amniocentesis counseling; CVS; MSAFP; teratogen hotline.
Contact: Wendy Busch, M.S., Emanuel Hospital, 2801 N. Gantenbein, Portland, OR 97227; 503-280-4726. EOE/AA.

PHILADELPHIA, PA: Immediate opening for 2 BC/BE Genetic Counselors.
Responsibilities: General counseling; teratogen counseling; MSAFP; PUBS; CVS; early and routine amniocentesis; intrauterine surgery. Travel to satellite clinics required.
Contact: Lynn Godmilow, M.S.W., Director, Genetic Counseling Services, Genetiks, Ltd., 301 S. 8th St, Suite 3C, Philadelphia, PA 19106; 1-800-336-5633. EOE/AA.

PHILADELPHIA, PA: Immediate opening for BC/BE Genetic Associate with special interest in case management and single gene disorder counseling.
Responsibilities: General and specialty clinics; service for deaf, hearing impaired, foster care and adoptees.
Contact: Kathleen E. Toomey, M.D., J.D., St. Christopher's Hospital for Children, 5th & Lehigh Ave, Philadelphia, PA 19133; 215-427-5000. EOE/AA.

PITTSBURGH, PA: Immediate opening for BC/BE Genetic Associate. Some experience preferred.
Responsibilities: Comprehensive counseling in large tri-state referral center for high risk pregnancy; professional and public education; lectures and seminars; research.
Contact: Diana Long, Human Resources Dept., Magee Women's Hospital, Forbes & Halket Sts, Pittsburgh, PA 15213. EOE/AA.

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor as member of existing team of 2 genetic counselors and 2 M.D. geneticists. Some MSAFP testing and counseling experience preferred.
Responsibilities: Assist with statewide MSAFP program; preamniocentesis, teratogen exposure and general genetic counseling; participation in specialty clinics; birth defects and dysmorphology consultation; lecturing; participate in research and manuscript preparation.
Contact: Marshall W. Carpenter, M.D., Womens & Infants Hospital, 101 Dudley St., Providence, RI 02905; 401-274-1100. EOE/AA.

FAIRFAX, VA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Counsel pediatric and adult patients including CVS, amniocentesis, MSAFP, follow-up for large prenatal research project.
Contact: Shirley L. Jones, R.N.,M.S., Genetics & IVF Institute, 3020 Javier Rd., Fairfax, VA 22031; 703-698-7355. EOE/AA.

The Bush Health Agenda

Prior to election, the Bush-Quayle ticket committed to a four point health care plan consisting of: 1) expanding Medicaid coverage of pregnant women and infants (currently at 100% of the poverty level); 2) incentives to cover children of poor families (currently an option for states to cover children up to age 8 at 100% of poverty); 3) Medicaid buy-in for low-income adults; and 4) developing a state insurance "risk pool" for individuals with pre-existing conditions.

If passed, all four components could serve to increase access to genetic services.

Infant Mortality and Children's Health Act of 1989

Building on last year's passage of mandated state Medicaid coverage of pregnant women and infants up to 100% of the Federal poverty level, and encouraged by the above Bush agenda, Senator Bradley (D-NJ) recently introduced S.339, the Infant Mortality and Children's Health Act of 1989. This bill would phase in coverage for pregnant women and infants up to 185% of the poverty level, would require phase in coverage of children up to 18 years at 100% of the poverty level, would increase provider participation in the Medicaid program, would streamline eligibility and would increase access to the WIC program. This bill is a giant step toward improving access to genetic services.

To support this bill, please contact your senator at the U.S. Senate,Washington, D.C. 20510.

Right To Choose in Jeopardy

The National Abortion Rights Action League (NARAL) considers a woman's constitutional right to abortion to be in greater jeopardy in 1989 than anytime since Roe v. Wade was decided in 1973. The Supreme Court announced January 9 that it will hear Webster v. Reproductive Health Services in which it may reexamine Roe v. Wade and decide the extent to which women possess a constitutionally-protected right to choose abortion. The U.S. Justice Department has asked the Supreme Court to use this case to overturn Roe v. Wade.

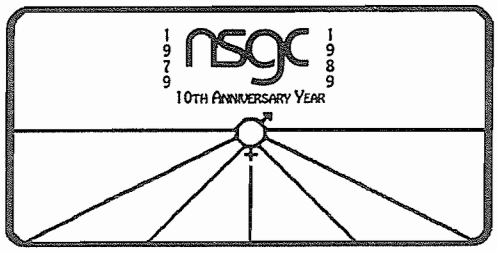
Keeping with its pro choice policy, the NSGC supports your participation in the following:

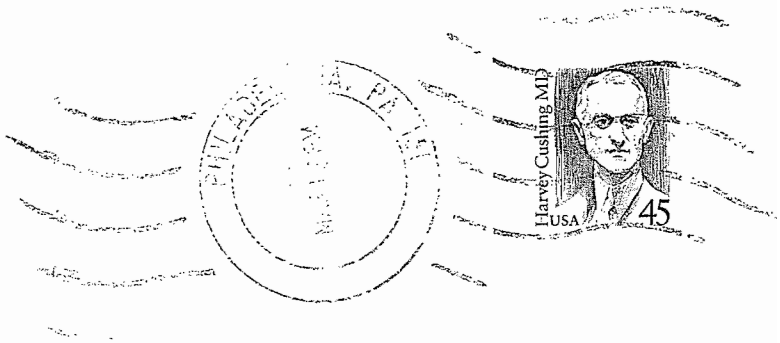
Signature Drive: NARAL is collecting signatures in support of reproductive choice to demonstrate public opposition and to organize a pro choice network. NSGC regional representatives have copies of these petitions; please contact them if you wish to sign or help collect signatures. For more details, contact your local NARAL or their national legislative staff at (202) 371-0779.

March on Washington: The National Organization for Women (NOW) is coordinating the "March for Women's Equality, Women's Lives" in Washington D.C. on Sunday, April 9. This rally calls for support of reproductive freedom and is timed to correspond with the Supreme Court case (above).

The NSGC has been asked, along with many other organizations, to co-sponsor this march. Contact NOW at 1401 New York Avenue, N.W., Washington D.C. 20005, (202) 347-2279 or Joanne Malin, NSGC Social Issues Chairperson, if you wish to participate.

Trish Magyari, M.S.
Legislative Issues





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