PERSPECTIVES IN GENETIC COUNSELING

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.

Volume 4, Number 1, March, 1982

AN UPDATE ON SPECIAL PROJECTS AT THE OFFICE OF MATERNAL AND CHILD HEALTH

Edward M. Kloza

The Office of Maternal and Child Health (OMCH) has recently announced its interim priorities for Special Projects of Regional and National Significance (SPRANS) for FY 1982. The SPRANS program is to be funded by the 15 percent federal set-aside in the Maternal and Child Health (MCH) block grant.

A December 11 memo from Dr. Vincent L. Hutchins, Associate Bureau Director, explained that while the intention of the block grant mechanism is to give individual states more authority in the disbursement of federally allocated funds, Congress has "recognized the importance of providing a national focus and support for a program of special projects of regional and national significance" and has authorized an expenditure equal to 15 percent of all appropriated funds. Among programs considered for SPRANS funding are those which 1) develop new and improved services or which meet special needs, 2) are regional or multi-state in scope, 3) contain needs assessment and satisfaction components, 4) deal with the development and transfer of technologies, 5) develop or disseminate information as part of limited purposes programs, 6) provide training, and 7) conduct research.

Genetics, in general (and hemophilia, specifically), along with biochemical cytogenetics and improved pregnancy outcome, are among 15 categories of projects currently funded by Title V, and eligible for SPRANS funding. Because of general funding reductions, it is anticipated that funds will not be available for new applications, but will be limited to current grantees.

Forty-five projects received a share of $13.1 million in FY 1981 for Areawide Genetic Service Systems. This category faces a substantial reduction, to a proposed level of $6.9 million in FY 1982. Many of these projects are expected to be funded under the MCH block grant program up to the project's fourth year of operation. The proposed SPRANS projects related to genetics will focus on regionalization efforts, research, training, and demonstration service projects in genetics which have received fewer than four years of support.

The amendment of Title V of the Social Security Act, by providing for a maternal and child health block grant (under P.L. 97-35), is meant to provide each state with the ability to maintain and strengthen its leadership in planning, promoting, coordinating, and evaluating health care for mothers and children. In accordance with that philosophy, the SPRANS priorities are presented as "interim." The OMCH is soliciting feedback "from state MCH leaders, professional and voluntary organizations, the private sector, educational institutions, the public, advocacy groups, and many others to express their views about current and emerging changes, trends, and needs which should be responded to through research, training, and other such activities." This input will be used to establish new priorities for coming years.

Edward M. Kloza is Director, AFP Prenatal Screening Project, Foundation for Blood Research, Scarborough, Maine 04074.

THE GENETIC COUNSELOR AND THE HIGH SCHOOL BIOLOGY TEACHER: Team Teaching

Paula K. Haddow

It has been recognized for some time that an ideal place for the teaching of human genetics is the high school biology class. According to data from the Biological Sciences Curriculum Study (BSCS), Boulder, Colorado, more than 80 percent of all students in high school will have taken a course in biology before they graduate.[1] Although about 20 percent of high school students would be missed, there are definite advantages to introducing the study of human genetics in high school biology classes. One advantage is that biology teachers already have a knowledge of Mendelian genetics, another is that human genetics can be added easily to an already existing biology curriculum in genetics.

The major considerations in introducing human genetics into the high school genetics curriculum are curriculum materials and teacher education. Although curriculum materials in human genetics have been very scarce, there are several choices available now, and more will be appearing on the market, most notably, the BSCS materials. Even now, there is a variety available to suit the approach and educational needs of most high school biology teachers.

Teacher training in human genetics should precede choice and distribution of materials. There are several options for accomplishing teacher education, including formal, graduate-level university courses, continuing education courses, in-service sessions, and workshop-seminars. At present, there are very few graduate-level or continuing education courses in human genetics. Most education in this field is being done via in-service and workshop sessions. Those are perfect settings for a team approach to planning and teaching courses in human genetics for high school biology teachers.

We have had great success in Maine with a pilot project consisting of two days of human genetics education for high school biology teachers. The planning has been done by a team consisting of a genetic counselor and a former high school teacher and principal, bringing together expertise in genetics and in educational methodology. Each workshop has been taught by a group of five to eight faculty, consisting of a genetic counselor, a pediatric geneticist, a cytogeneticist, a specialist in newborn screening, an obstetrician/geneticist, a population geneticist, a parent, and the director of the state genetics program. Workshops are limited to 30 participants. All teachers are given packets of informational material relating to each lecture. In addition, a bimonthly newsletter is sent to all participants to keep them apprised of the current literature in human genetics and to inform them of new curriculum and other educational materials.

The genetic counselor is crucial to smooth operation of such a program. His or her expertise is needed in the selection of speakers, presentation of some of the lectures (in Maine, the genetic counselor gives one lecture on counseling and one on ethical issues), help in selection of materials for packets, review of newsletter items, and assistance with requests for information from teachers and students following workshops. Whether the educational session is a two-day workshop during the school year or a longer one offered in the summer, our experience in Maine has been that the combined expertise of an educator and a genetic associate is critical to the successful outcome of the program.[2]

1. Hickman FM, Kennedy, MH, and McInerney, JD: Human genetics education: Results of BSCS needs assessment survey. *Am Biol Teacher* 40(5):285, 1978

2. For a detailed description of Maine's program, see *Am Biol Teacher*, February, 1982

Paula K. Haddow is Director, Genetics Education, Foundation for Blood Research, Scarborough, Maine 04074.

REGIONAL REPORT

The third annual Region V conference was held March 26-27, 1982 in Salt Lake City, Utah. The meeting was held in conjunction with Utah's annual Birth Defects symposium, held March 24-25, 1982.

The theme of this year's birth defects symposium was "The Impact of Genetic Disorders on the Family." Guest speakers from around the country were invited to discuss a variety of psychosocial issues encountered in genetic counseling. Visiting faculty included Bruce Blumberg, M.D., an obstetrician-geneticist; Seymour Kessler, Ph.D., director of the genetic counseling training program at UC Berkeley; Tempa Weir, M.S., child development specialist; and Joan Westphal, M.S., genetic counselor.

The Region V conference emphasized workshops and the free exchange of ideas and strategies, as reflected in our title, "It's a Working Conference." In addition to workshops and case presentations, Tempa Weir discussed the impact of the handicapped child on the family and co-moderated a panel composed of siblings and non-parent family members.

Liz Stierman
Region V Reporter
Medical Genetics Program
University of Utah Medical Center
Salt Lake City, Utah 84132

"THE SERMON ON THE AMOUNT:" The Status of NSGC Finances

Ann C.M. Smith, President, NSGC

In these times of tightened economic circumstances, it will come as no surprise to the membership that NSGC is feeling the pressures of rapidly escalating costs for its programs. Routine expenses for NSGC include general operating costs, *Perspectives*, educational conferences, board of directors meetings, and special projects.

Detailed analysis of our revenues and expenditures indicates that continued spending at current levels on projects already approved by the board will result in a deficit of approximately $2,000 by the end of 1983. This deficit assumes expenditures of all savings accumulated since the incorporation of NSGC, leaving no funds for emergencies. It also assumes 100 percent payment of dues, an unrealistic expectation, given the 22 percent nonpayment rate for 1981-82. In addition, acquisition of grant monies, which helped fund society activities in the past, is becoming increasingly difficult.

According to a survey conducted by the professional issues committee of NSGC, average annual dues for professional societies offering similar services to their memberships (e.g., journal subscriptions) are approximately $80, with a range of $40-$140. That is compared to the NSGC dues structure of $20 for full members, $15 for associate members, and $5 for student members.

As president, I have strongly recommended that the board of directors address the inadequacies of our dues structure, and develop a mechanism for long-range financial planning. To that end, I have recommended the establishment of a four-person budget committee to advise the board on fiscal matters. The board will consider the constitution and functions of that committee at its next meeting. While it is evident that a dues increase will be necessary for 1983, we will do everything in our power to hold that increase to a minimum.

The society has made great progress in its brief existence. The future of NSGC is predicated on continued fiscal solvency, which in turn requires support from the membership. NSGC provides us with a mechanism to contribute to our individual and collective professional growth, and equally important, to the continued growth of genetic counseling as a profession. None of that is possible if we are crippled by economic problems. The important work we have yet to do will require everyone's cooperation and understanding. Your comments and suggestions are welcome.

On a happier note, you should by now have received your copy of the first edition of the NSGC Membership Directory; copies have been sent to all members in good standing. Additional, limited copies of the directory are available for $5.00 from Ann C.M. Smith, Clinical Director, Genetic Services, The Children's Hospital, 1056 East 19th Avenue, Denver, CO 80218.

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RESOURCES, Beth A. Fine

Families seeking genetic services often are in one of the stages of the grieving process when they receive genetic counseling. Genetic counselors often are in a position to inform parents that their child is or will be physically or mentally handicapped. After this initial crisis, genetic counselors assist parents in grieving for the normal child they expected while helping them to cope with the special needs of their infant. In many cases, the child dies in the newborn period. Since more physicians are becoming aware of the need to investigate the etiology of multiple miscarriages and stillbirths, genetic counselors are seeing more families who have suffered fetal loss and infant death. The psychological responses of families—and especially mothers—to spontaneous abortion, stillbirth, and neonatal death are just being studied. A dire need for understanding how to work with these families is becoming apparent. Women who have been through these ordeals are demanding that professionals and others be sensitive to their feelings and needs. Perhaps through education, genetic counselors and other professionals can alleviate some of the pain these people suffer.

In 1981, Susan Borg and Judith Lasker published *When Pregnancy Fails: Families Coping with Miscarriage, Stillbirth, and Infant Death*. One of the authors had a child born with multiple malformations and who died in the neonatal period; the other delivered a stillborn infant. As they shared their experiences with others, they realized that women who had miscarriages, stillbirths, or babies who died neonatally, as well as women who chose to abort an abnormal fetus, had very similar feelings and reactions to those losses. The purpose of their book is to help professionals and lay people spare families needless suffering by developing an appreciation of their emotional needs.

Borg and Lasker emphasize the importance of professionals in assisting parents to begin the grieving process. This is accomplished by encouraging parents to express their anger and sorrow, while helping to "create concrete memories for the parents to hold on to." The book opens with various discussions, including personal statements concerning miscarriage, prenatal diagnosis and the unwanted abortion, stillbirth, and infant death. The authors explain that the sense of failure and disappointment these parents experienced is often overlooked; self-esteem, confidence and a sense of identity are often destroyed. Friends, families, and professionals try to ease despair by encouraging and expecting such parents to recover quickly, forget about the normal child, and try again. While these losses are not treated like deaths of older people by families, friends, or society, the parents need to work through this death like any other loss. The authors delve into the impact of failed pregnancies on the couple, other children, grandparents, friends and relatives. The unique needs of teenage and adult single women are also reviewed. The importance of open, interpersonal communication and of encouraging people to express their grief, guilt, and other feelings is reiterated throughout the book.

The chapter dealing with prenatal diagnosis describes the indications for amniocentesis and the genetic counseling process adequately. Included are positive and negative experiences of couples who receive genetic counseling. In general, the issues surrounding genetic counseling and prenatal diagnosis are presented well.

Dissatisfaction of bereaved families with the coldness and inaccessibility of physicians is described with many direct quotations. The need for hospitals to restructure policies to decrease the suffering of these families is crucial. Women who miscarry or lose a child should not be in rooms on the maternity floor, where busy health professionals might greet the bereaved mother with questions about the new baby. Many women testified to the pain and anger this carelessness causes. They also feel that spouses should be able to spend the night at the hospital; parents desperately need each other's support at the time of the loss.

Funerals, baptism, and the role of the clergy are discussed in a section on public issues. The need for funerals to help parents face the loss is discussed. Each case is unique, but there is consensus that holding the baby, as well as burying the child, are important to the grieving process. Another public issue, law and malpractice suits, is considered. Also included is a brief discussion of environmental influences on the developing fetus.

The book closes with an argument in favor of support groups and their role in recovery. Plans and options for another pregnancy are also described. Most genetic counselors are aware of the benefits of support groups for many families. *When Pregnancy Fails* has two useful appendices. The first lists national, state, and local support organizations, the second highlights organizations and resources for adoption, childbirth, counseling services, environmental and occupational health, infertility, genetics, and abortion. One address that will be especially helpful to genetic counselors is that of The Compassionate Friends, Inc., National Headquarters, P.O. Box 1347, Oak Brook, Illinois 60521, (313) 323-5010.

This book is highly recommended for all genetic counselors working in prenatal diagnosis or general genetics clinics, as well as for any other health care professional in obstetrics or pediatrics. *When Pregnancy Fails* is available in paperback from Beacon Press, 25 Beacon Street, Boston, Massachusetts 02108 ($6.95).

Nothing To Cry About, by Barbara Berg (Seaview Books, New York, 1981) details the experiences of one woman who had two miscarriages. This is a personal story that verifies the points elucidated in *When Pregnancy Fails*. Ms. Berg's statement offers the health professional insights into the needs of families whose pregnancies have failed. Clients might benefit from reading a book such as *Nothing To Cry About* when a local support group is not available. The therapeutic benefits to be derived from hearing about others in similar situations and their coping mechanisms are evident in this book and in the proliferation of support groups. *When Pregnancy Fails* and *Nothing To Cry About* corroborate those ideas.

All genetic counselors can benefit from the writing of Borg, Lasker, and Berg. As the psychosocial aspects of genetic counseling become better understood and are incorporated into practice, books such as these offer the genetic counseling profession a great deal of useful information.

Beth A. Fine is a genetic counselor at the Clinical Genetics Center, Children's Memorial Hospital, Omaha, Nebraska 68114.

ANNOUNCEMENTS

Announcement of Conference and Call for Abstracts

The Second Annual Professional Education Meeting of the NSGC, Inc. will be held on June 11-12, 1982 at the Downtown Medical Center Holiday Inn in Birmingham, Alabama. The theme of the conference is "Strategies in Genetic counseling: The Community Around Us." The goal of this conference is to assist genetic counselors in identifying, utilizing, and working with community resources to provide families with optimal and comprehensive services. Abstracts dealing with any subject related to genetic counseling are being accepted from members, students, and non-members with member sponsors. An abstract form was included in the introductory and registration flyer mailed in March. All abstracts should be sent to Anne Matthews, Genetics Unit B-160, University of Colorado Health Sciences Center, 4200 East Ninth Avenue, Denver, Colorado 80262.

Nominating Committee

Due to circumstances beyond the control of the members of th 1982 nominating committee, the December, 1981 edition of *Perspectives in Genetic Counseling* was delayed in press and at the post office. As a result, the call to the membership for suggestions for the 1982 slate of candidates for office in the NSGC, included in that edition of *PGC*, was outdated *prior* to mailing and receipt by the membership. Financial considerations precluded a separate mailing.

In an attempt to rectify this situation, the nominating committee extended its deadline for receipt of recommendations from the membership. The regional representatives were notified accordingly.

The nominating committee has made every effort to include the membership in the nominating process. We regret any inconvenience caused by production delays.

Beverly R. Rollnick
Chair
1982 Nominating Committee

POSITIONS AVAILABLE

Genetic Counselor: Position available May 1, 1982 for a genetic counselor to develop a regional genetic counseling program in counties surrounding the chicago, Illinois area. Counselor will work under the supervision of two medical geneticists in a large tertiary care suburban hospital with fully developed genetic, diagnostic, and counseling services. Experience in program development is helpful. Competitive salary depending on experience; full range of benefits.

CONTACT: Celia Kaye, MD, PhD or Carol Booth, MD
Lutheran General Hospital
1775 Dempster
Park Ridge, IL 60068
(312) 696-7705

Genetic Counselor: A full-time position with the Genetic counseling Program at The University of North Carolina-Chapel Hill is available July 15, 1982. Responsibilities include clinic coordination, initial and follow-up counseling, and educational programs. Applicants must have master's degree; prefer ABMG eligible/certified and at least one year's experience. We are particularly interested in attracting outstanding minority candidates to this program. Send resume and two references to Arthur S. Aylesworth, MD, Director, Genetic Counseling Program, Department of Pediatrics, University of North Carolina at Chapel Hill, 306 BSRC 220H, Chapel Hill, NC 27514. Equal Opportunity/Affirmative Action Employer.

INSTRUCTIONS FOR CONTRIBUTORS TO *PERSPECTIVES IN GENETIC COUNSELING*

Types of Contributions Accepted

Authors may submit for consideration for publication articles dealing with the varied professional roles of the genetic counselor; single case reports, with discussion of difficult aspects of management and proposed means to improve the provision of genetic services; or letters to the editor that deal with issues relevant to the profession of genetic counseling or to the society.

Instructions

All contributions must be typed and double-spaced. Three copies of each article should be submitted. The author's name, preferred title, and address must be included with all contributions.

Send all contributions to

Deborah L. Eunpu, Editor
Perspectives in Genetic Counseling
Clinical Genetics Center
Children's Hospital of Philadelphia
Philadelphia, PA 19104

Deborah L. Eunpu, NSGC
Clinical Genetics Center
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, Pennsylvania 19104

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