PERSPECTIVES IN GENETIC COUNSELING
NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.
Volume 4, Number 2, June, 1982

NEW ROLES FOR GENETIC COUNSELORS

Edward M. Kloza

The impact of the current state of the economy on the genetic counseling profession may lead to a search for non-traditional roles that might be suited for those with specialized skills in interpreting and communicating genetic information.

This issue was addressed at the first national education meeting sponsored by the NSGC, in a workshop focusing on professional roles and issues. The panelists discussed the role of the genetic counselor in education, administration, public health, and risk screening. Whether by choice or necessity, it is likely that an increasing number of genetic counselors will extend their roles into these and other areas. The following examples indicate the possible range of those new roles.

Paternity testing—Immunological tests used as evidence in cases of disputed paternity have their basis in the well-defined laws of Mendelian inheritance. It follows, therefore, that institutions providing such services should have, at least on their consulting staff, individuals qualified to explain in detail the results of those tests. While laboratory licensing requirements may demand that test results be *interpreted* by an MD or PhD, it would not be inappropriate for a genetic counselor to be involved in the education of attorneys, legislators, judges, and consumers, or to appear as an expert witness in court trials or hearings.

Paternity testing is often performed by laboratories that provide histocompatibility testing for organ transplant programs. The immunological test systems will vary from lab to lab, and the extent to which this type of evidence can be presented in a court of law will vary from state to state. In states allowing nonexclusionary evidence, Bayesian probability is generally used to compute the likelihood that the tested male is actually the father. Knowledgeable prosecutors or defense attorneys might require that an explanation of Mendelian inheritance and probability be provided to the court.

Genetic counselors wishing to investigate the possibility of offering their services to paternity testing facilities should familiarize themselves with the American Association of Blood Banks guidelines for paternity testing.[1] A national listing of facilities that offer paternity testing is also available.[2]

Adoption—In an article published in the *Journal of Pediatric Ophthalmology and Strabismus*,[3] Kenneth Hansen and Gilbert Omenn describe an administrative mechanism that has been established in the State of Washington for contacting adoptees at risk for genetic disease and for providing appropriate counseling. This mechanism was established to facilitate movement through state judicial and bureaucratic structures designed to maintain strict confidentiality in adoption cases. Individual clinicians generally must file suit to gain access to sealed adoption records, or to convince adoption agencies that adoptive parents should be made aware of newly uncovered genetic information. Even then, information might be presented by unqualified personnel, with less than satisfactory results.[4]

A brief survey of the state adoption bureaus of four New England states suggests that family history information is collected by a social worker and not reviewed by anyone with genetic expertise. Genetic consultation is used as required, but no hint is provided as to how need was determined in the 1690 adoptions that occurred in those states in 1981. Genetic counselors could play a central role in facilitating the identification and communication of vital genetic information to interested parties in an adoption situation by 1) working with adoption agencies in developing useful family history questionnaires, 2) screening completed questionnaires for indications of risk, 3) providing workshops for adoption agency staff on proper methods of obtaining a genetic family history, and 4) providing the necessary counseling in situations that will demand extreme sensitivity to requirements for confidentiality. State statutes may make this last recommendation difficult to accomplish.

Artificial Insemination by Donor—With the infertility rate in the United States reportedly at 12-15%, artificial insemination by donor (AID) is an increasingly popular method of achieving pregnancy in the 40-50% of cases attributable to infertility factors occurring in the male partner. Additionally, AID is utilized where a mating might be at risk for a genetic disorder, and donor's sperm is utilized to achieve pregnancy. Results of a nationwide survey of physicians performing AID revealed that screening for genetic risk in donors was inadequate. The authors of the survey suggest that a list of traits be developed for use in routine screening of donors, and further suggest that this screening be conducted by people trained in recognizing and evaluating genetic traits.[5]

Screening donors for AID is another opportunity for genetic counselors to apply their specialized skills in a somewhat unconventional setting, but one that could benefit from the counselor's recognized expertise. While donor screening will not eliminate the possibility of the manifestation of rare disorders such as familial histiocytosis,[6] disorders for which carrier identification is available, such as Tay-Sachs disease, should be avoidable in AID situations.[7]

Expansion of the genetic counselor's role is limited only by the individual's ingenuity and local opportunity. The challenge for the profession in the years ahead will be to identify new areas where these skills are needed, and to share this information effectively with colleagues. NSGC members who have extended their professional network are urged to contact *Perspectives* with their experiences.

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USE OF NSGC BULK MAILING PERMIT

NSGC has recently acquired a bulk mailing permit through the U.S. Post Office in Louisville, Colorado. This permit allows us to mail in bulk (200 piece minimum) for 10.9¢ per piece, a considerable savings over first class postage. There is, of course, a trade-off; the normal, ponderously slow handling of mail slows even further, to near glacial speed. The post office simply will not guarantee anything under 10-14 days delivery time with bulk mail, and the first two experiences with our permit have indicated that it can be much longer.

Some of the problem has been my own inexperience in preparing material for bulk mailing, and my apologies are due Beverly Rollnick and Beth Fine for any problems caused with the nominating committee and the June, 1982 professional education meeting. Even if we get all the kinks straightened, however, we still need to plan on a *minimum* of two weeks delivery from the time it leaves the post office. I would suggest, therefore, that anyone wishing to use the bulk mail permit have her or his materials to me well in advance of the time she or he wishes to have them in the hands of the membership. It would be quite helpful if you could give me at least ten days to do the stamping, sorting, and bagging required by the postal regulations. Materials should be sent to me at BSCS, 833 W. South Boulder Road, Louisville, CO 80027. Thank you for your patience and cooperation.

Joseph D. McInerney
Assistant Editor
Perspectives

BOOK REVIEWS

Linda T. Nicholson

Children with Handicaps: A Medical Primer by Mark L. Batshaw, MD and Yvonne M. Perret. Baltimore: Brooks Publishing Company, 1981. 464 pages, $18.95.

Physically Handicapped Children: A Medical Atlas for Teachers. Second Edition. Edited by Eugene E. Bleck, MD, and Donald a. Nagel, MD. New York: Grune & Stratton, Inc., 1981. 530 pages, $21.75.

These two books will be very helpful for counselors in need of a nontechnical article for parents, teachers, extended family members, and others about a specific disorder or about aspects of various handicapping conditions. Both are clearly written in easily understood language and liberally and clearly illustrated. Both also have extensive glossaries and lists of additional resources.

Children with Handicaps begins with two chapters reviewing elementary genetics. Abnormalities and problems caused by unfavorable environments in utero, prematurity and poor nutrition are also covered. This book deals with disorders that are common to many handicapped children regardless of the cause of their problem. The chapters on development, the central nervous system, epilepsy, hyperactivity, learning disabilities, hearing, vision, and speech and language define and explain simply but thoroughly what is normal and what can go wrong at varying stages of development. Some attention is given to specific disorders such as cerebral palsy and some of the inborn errors of metabolism. The strong point of this book is its clear explanations of areas common to a wide variety of handicapping disorders. Words appearing in the glossary are indicated in bold type in the narrative and case histories illustrate specific disorders.

Editors Bleck and Nagel have greatly expanded the second edition of *Physically Handicapped Children.* As the title implies, the atlas is intended primarily for use by teachers, but should not be reserved for them alone. I use it to provide parents with a short, simple first article about their child's disorder. This provides basic information that can be elaborated on in subsequent sessions. Parents in turn can give this article to others who are interested in knowing more about their child. This book has the only articles I have found in lay terminology on disorders such as arthrogryposis, Duchenne muscular dystrophy, Friedreich ataxia, and osteogenesis imperfecta. Most of the chapters are very brief, but more extensive chapters detail cerebral palsy, myelomeningocele, scoliosis, cystic fibrosis, and short stature. Also of interest are some first-hand accounts from a mother with a daughter affected by Cornelia de Lange syndrome and from a teenager with Friedreich ataxia.

Counseling the family with a disabled child is addressed by both sets of authors. Each covers the stages of coping and reviews developmental periods in the child's life that may present particular problems to parents. Each of these books will be a valuable addition to your departmental library and will be especially helpful as resources for parents.

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CAREER SATISFACTION: A LOOK TO THE FUTURE

Deborah L. Eunpu

Are you satisfied with your current position? ipressively, most of you are, according to the recent NSGC professional status survey (*Perspectives*, Vol. 3, No. 4). The art of achieving and maintaining career satisfaction is a process that demands continued attention to goals and personal needs.

It is good to know that so many NSGC members are content with their current positions. It is probably also good that in describing their ideal job respnsibilities and titles ten years from now, most members stated that they envision changes involving advancement. However, it is troublesome to note that most members see no opportunities for the advancement that would enable the desired changes to occur. This area deserves consideration if genetic counselors are to continue being satisfied with their careers.

Career satisfaction is important; one selects a career based on personal interests and abilities, but the decision to continue in a profession depends on having an ongoing sense of satisfaction with what one does. I think it is important to consider the factors that determine career satisfaction and the strategies we, as individuals and as a professional group, can devise to foster continued career satisfaction.

Obviously, no two individuals have the same requirements. However, one might surmise that career satisfaction results from some combination of input from each of three major categories: 1) concrete benefits; 2) intellectual challenge; and 3) emotional support. Concrete benefits might include such things as monetary compensation or a mechanism for advancement that permits one to assume new responsibilities and gain tangible recognition for such changes. Opportunities to explore new interests and hence to tinue to grow within one's career are essential to provide tinued intellectual challenge. The respect of one's colleagues is an example of emotional support every professional needs. Other elements that might contribute to career satisfaction include pride in having done one's job well, some measure of independence in determining one's activities, and sufficient time and staff support to enable one to pursue new interests.

Although the elements that determine career satisfaction apply in general to any profession, there are some circumstances unique to genetic counselors. One important example is the team approach to genetic counseling. This style of providing genetic services has definite benefits for patients, but the benefits to the genetic counselor are not always so clear. As a member of the team, the genetic counselor must be sure of his or her identity and must not regard himself or herself merely as a subordinate or appendage. This is not to advocate independent functioning, but rather an increased self-awareness of the positive professional contributions made by the genetic counselor to the services provided. What must then follow is recognition by other members of the team. The end result should be that as one acquires increased skills and experience, one assumes increased responsibilities and gains recognition for them.

An example of one possible strategy to provide recognition within the team-care concept comes from the nursing profession. Some institutions have established a ladder of advancement that is predicated on experience, seniority, and skill. Specific titles that permit increasing levels of responsibility and salary differentials facilitate recognition of progress. This strategy might not be as feasible genetic counselors, since there are often only one or two genetic counselors at a given institution. However, as a professional organization we can, if we so choose, formulate and endorse a similar type of system.

Diversification and expansion of activities can be important ways to keep one's perspective fresh. Certainly, as one becomes more experienced, such change is a natural result of growth. Unfortunately, many colleagues have related that while they welcome these changes, they do not receive additional staff support to cover prior responsibilities. Unless one realistically assesses how responsibilities can be handled and who on the existing staff can provide assistance, the result can only be frustration. One wants to undertake new projects, but without support cannot responsibly do so. The solutions for this type of problem are specific to each center; individuals must find creative solutions suited to their particular circumstances.

This discussion has focused on the place of employment as the source of career satisfaction. However, there are also sources outside one's office. One might consider applying one's expertise to any of a number of community based organizations, or to providing training to professionals in related fields. Alternatively, one might participate in scientific or professional societies and thereby gain substantial benefits one might not be able to obtain from one's employment.

As a professional society, we need to consider our future goals, both individually and collectively. We must begin to formulate ways to achieve the changes and advancement we as individuals have stated we desire. We have, as a group, a tremendous capacity to shape the future of our profession. It is up to each of us to consider where we want to be in the future and to determine the strategies to meet those goals. Ours is a young profession, and that is a factor in our favor. We have the time and resources to make plans that will enable us to meet our individual and common goals. We only need to decide to act and begin the work.

I would be interested in receiving letters from the membership describing the problems they have faced in career development and the strategies they have found helpful in overcoming these obstacles. Responses will be published in a future issue of *Perspectives in Genetic Counseling*.

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1983 Professional Education Conference

Plans are underway for the 1983 Professional Education Conference to be held in conjunction with the March of Dimes Birth Defects Conference. The location of the conference has not yet been selected. The theme of the meeting is "Strategies in Genetic Counseling: Clinical Investigation Studies." The goal is to focus on practical skills genetic counselors require for clinical research and professional communication. Prospective conference participants are encouraged to undertake clinical investigations regarding the efficacy of the genetic counseling process and observations concerning various genetic conditions and prenatal diagnosis. Collaborative studies, grant writing and writing for publication, as well as research design will be included in the program. Genetic counselors involved in studies regarding specific disorders or assessment of genetic counseling in prenatal diagnostic services are urged to submit abstracts of their work. Those not involved in clinical investigation may want to begin thinking about a project.

The membership will be informed about this conference as planning progresses. This conference promises a new focus for the profession. The quality of the meeting depends on the participation of the membership. We anticipate an exciting and educational meeting.

Beth A. Fine
Conference Chairperson

Ann C.M. Smith
President, NSGC

LETTERS

To the Editor:

A recent unfortunate experience with a genetics unit in a neighboring city has prompted me to share some thoughts. In a metropolitan area as large as ours, the same patient is sometimes seen by more than one unit over a period of time. This requires sharing of information, occasionally through the patient. Comments made, off-handedly or directly, can easily cause confusion in the patient's mind and undermine the ongoing patient-counselor relationship.

Most genetic teams consist of several people with differing skills working together for a common goal: to provide information that can be understood and used in decision making. One of the factors necessary for this process is the trust and confidence of the patient in those providing the service. We all realize the importance of consistency towards this end within a team. Contradiction or criticism can easily undermine the patient/counselor relationship, and is clearly out of place and unprofessional.

The guidelines that exist wihin units also apply to the genetics community as a whole. Legitimate differences of opinion concerning diagnosis and/or treatment reflect the complicated nature of the field. The goal, however, remains a shared one.

It is a sad fact that, after working so hard to attain the professional status we have reached, there are still those who do not understand the need for mutual respect, or, lacking respect, for silence. Undermining another counselor's veracity confuses the patient and reflects negatively not only on that individual but on the entire profession. We are not competitors; we are colleagues.

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POSITIONS AVAILABLE

Genetic Counselors: Three positions will be available through the South Carolina Genetic Diseases Program beginning October 1, 1982. These are grant-supported positions. Requirements include a Master's degree in human genetics or genetic counseling or comparable training and clinical experience. Primary responsibilities will include providing outreach genetic services for health department patients through the regional genetic centers and conducting educational presentations for lay and professional groups. Contact: Susan Bergmann, Coordinator, South Carolina Genetic Diseases Program, Office of the Governor, Division of Health and Human Services, 1205 Pendleton Street, Columbia, SC 29201, (803) 758-8016.

Genetic Counselor: Full-time faculty position available at the University of British Columbia, Department of Medical Genetics, Vancouver, British Columbia. Primary responsibilities include: prenatal diagnosis counseling, intake for general genetics patients, community education, teaching nursing and medical students, and doing clinical genetics research. Position available beginning August, 1982. Canadian citizen's and Landed immigrant's applications must be considered first. Please send curriculum vitae to Dr. Judith Hall, Director, Clinical Genetics Services, Clinical Genetics Unit, Grace Hospital, 4490 Oak Street, Vancouver, British Columbia V6H 3V5, Canada.

Clinical Social Worker III—Genetic Counselor: 80-100% time. Salary range $1,926-$2,322 per month. Job duties and responsibilities: screen for appropriate referrals for genetic counseling clinics; request and gather pertinent medical information from outside sources; supervise secretaries in gathering above information; conduct pre-clinic visits—home or office visits to families prior to genetic counseling clinic appointments. The purpose of the visit is to exchange information about the genetics clinic appointment, gather pedigree information, and determine the family's primary concerns prior to the clinic appointment. Clinical responsibilities: coordinate in-house consult; co-counsel with the physician assigned to the family during genetic clinic; conduct primary counseling of families when appropriate; counsel families during or after genetic consult, either while client is in hospital or at home; conduct home or office visits to family to discuss information given during the clinic visit; determine and make referrals to appropriate community agencies; consult with nurses and allied health personnel and community agencies regarding families with genetic disease or birth defects; conduct education of nurses and personnel in related disciplines regarding genetic counseling; teach classes through UCSF School of Nursing, other nursing schools, and community agencies, including public health agencies and regional centers; supervise genetics associate students in absence of student clinical co-coordinator; participate in research projects that involve the contact of genetic counseling clients; coordinate one satellite clinic. Requirements: Master's degree in genetic counseling or equivalent training and at least one year of experience in genetic counseling. Send resume to: University of California San Francisco, Department of Pediatrics, Room 650 Moffitt, San Francisco, CA 94143, Attn: Norene Parkin.

Newborn Screening Program Coordinator: Position available for genetic associate with Master's degree plus minimum of one year's experience, to coordinate nonlaboratory aspects of Washington State's newborn screening program for PKU and congenital hypothyroidism. Duties include: 1) supervising monitoring for completeness of screening of hospital births; 2) coordinating voluntary programs of screening for out-of-hospital births; 3) coordinating follow-up of infants with presumptive positive test results; 4) compiling statistics, preparing and disseminating reports and educational materials; and 5) coordinating state services with management clinics to meet needs of children diagnosed. Competitive salary. For further information, contact Roberta Spiro, M.S., Genetics Program, 1704 N.E. 150th Street, Seattle, WA 98155.

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