PERSPECTIVES IN GENETIC COUNSELING

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.

Volume 6, Number 3, September 1984

THE ROLE OF NURSES AND SOCIAL WORKERS IN THE CARE OF FAMILIES WITH GENETIC DISORDERS

Note: Individuals who have genetic disorders frequently have complex problems requiring care from a variety of health professionals including social workers and nurses. Although there is some overlap of functions, both social workers and nurses have unique expertise that can benefit many clients seen in genetic clinics. An increased awareness of nursing and social work services can improve the quality of care provided by members of the genetic counseling team. Janet K. Williams, chairperson, NSGC Professional Issues Committee.

The Nurse's Role

Irene Forsman

The goal of nursing is to assist individuals, families, or groups, to restore or maintain health, and to encourage and support the development of behaviors that lead to health promotion and disease prevention. Nurses function in this role by collecting and analyzing data about the patient, family, or situation; identifying problems, planning and implementing goal-oriented care; continually evaluating the effects of care and revising the care as indicated. Those activities are accomplished in collaboration with other members of the health care team, even when that team is physically removed from the immediate nurse-patient situation.

Variation within the role is determined by the setting in which the nurse functions, for example, hospital inpatient or outpatient services, private office, or community agency. The level at which a nurse functions is further modified by educational preparation, experience, and the duties and responsibilities of the assigned position. Although the contribution of nurses to the care of families with genetic disorders will differ somewhat according to the situation, some general family needs are commonly addressed regardless of the setting. Among those are information, assistance in planning or implementing a management plan, and identification and use of additional health or community resources.

Family members will commonly ask a nurse for clarification or for additional information about a diagnosis. They may ask about implications of that condition for the individual patient and family, and they may need to know how they might deal with real or potential health problems immediately and on a long-term basis. They may also express concerns that have not been previously articulated. The nurse will provide answers or redirect the questions and concerns to the appropriate member(s) of the health care team. In addition, the nurse follows up to ensure that the patient or family actually got the information, and that it was understood. This process continues during nursing care and occurs in both ambulatory- and acute-care settings.

Nurses in primary health-care settings such as community health may be the major link between a family and a health-care system. They therefore have a broader responsibility for case-finding, referral, and followup of individuals and families who may be at risk. They are expected to recognize unusual physical features, deviations from normal development, or details of family history that indicate a need for further evaluation. Community health nurses are knowledgeable about local resources and are familiar with referral procedures. Prior to initiating a referral, the nurse discusses the reasons for referral with the family and provides them with some understanding of what they might anticipate in terms of process and outcome. Following initial genetic counseling, and in consultation with the genetics team, the same nurse is available to reinforce and clarify the information given the family. This nurse and other community health nurses in remote locations may also be helpful in providing genetic information and referral for extended family members at risk. Because community health nurses are often involved with families over long periods of time, they are especially valuable in contacting families that might benefit from new developments in the field. An example is the current national effort to find young women with PKU who are not under specialized care.

Another need that is commonly addressed by nurses is assistance in planning and implementing care for a family member who is handicapped as a result of a genetic condition. Nurses instruct and supervise family members in special nursing techniques such as tube feeding, suctioning, positioning, or bladder catheterization. Some families need to learn how to obtain and handle laboratory specimens and manage special diets. When a hospitalized patient is to be discharged home and will need special care, instruction is begun in the hospital. Community or public health nurses are contacted to ensure that techniques are properly carried out in the home and to provide continuing support to the family. Most hospitals have formalized procedures for referrals to community health agencies. This is a well established nursing network that supports the smooth transition from hospital to home care. Communication between hospital, primary care provider, and community agency is encouraged to ensure that all professionals caring for the family are informed of progress, problems, or changes in the general management plan. This interaction continues as long as multiple health-care providers are involved with the family.

The nurse who is a member of a tertiary-level genetics team usually functions in four major areas: direct patient care, liason with other community health-care providers and community agencies, teaching, and clinical research. Specific duties and responsibilities will vary with the composition of the team, and there is considerable interdisciplinary overlap. This flexibility allows a family with a particular problem to relate primarily to the professional most skilled in that area, with support from the other team members.

Direct care includes the initial interview with the patient or family, participation in the diagnostic evaluation, counseling, and the development of a management plan. Following genetic counseling, the nurse may see the family at intervals to determine how well family members understand the information that has been given, to answer questions, and to assist the family in caring for an affected family member. Consultation with a community health nurse or other nurse specialists permits long-term family followup. In a tertiary-level medical center, clinical

nurse specialists often function in teams to provide comprehensive care for specific conditions such as cystic fibrosis, spina bifida, or sickle cell anemia. A patient or family would routinely be referred to such a team for long-term management.

Because the needs of families with genetic disorders may be complex, family members frequently need the additional resources of other health and related agencies such as services for the handicapped, special education, or vocational programs. Referrals to such programs can be facilitated by the nurse. In addition to clinical responsibilities, the nurse who is a member of a genetics team will participate in both didactic and clinical educational activities of the team, with particular emphasis on the education of undergraduate and graduate students and on continuing education programs for nurses.

Finally, as a member of genetics team, the nurse has ample opportunity to participate in clinical research. There are few studies in the literature about the models for delivery of genetic services or about the effects of genetic counseling on families. The clinical nurse specialist participates fully in the identification of research problems, design and implementation of protocols, and publication of findings.

In summary, nurses share a body of knowledge and a role that is readily applicable to the care of individuals and families at risk for or affected by genetic disorders.

The Social Worker's Role

Joan O. Weiss

Social workers in all settings must be aware of the need for their services for individuals and families who have or are at risk for transmitting a genetic defect. Social workers are called upon increasingly to identify and work with families where at least one member is affected by a genetic disorder. Families with genetic disorders often need social services over a lifetime, not only at the time of diagnosis. I will discuss the role of the social worker in working with families with genetic disorders, first in settings outside of a genetics clinic, and secondly, within a genetics center. I will touch on service, training, and research.

The goals of social work are to enhance problem-solving capabilities of individuals, to link people with needed community resources and services, to promote use of the most effective resources and services, and to help with the development and improvement of social policy. Social workers are service providers, client advocates, teachers and field instructors, consultants, administrators, policy planners at state and federal levels, health planners, organizers of community groups, and researchers. They have historically been concerned about the problems of the underprivileged, the chronically disabled, and those with emotional needs, both on the individual and family level.

It is traditional in social work that the family, and not just the client or patient, is the focus for ongoing supportive and environmental services. In taking the customary family history, a social worker should be able to detect indications of a hereditary disorder in the family. Every social worker should be able to recognize common genetic disorders, whether he or she is working in a hospital, school system, adoption and foster care agency, institution for children with developmental delay, or public or mental health clinics. The social worker should also be able to refer clients to appropriate genetic centers, evaluate the extent of the emotional and financial burden of the genetic disorder on the family, and offer ongoing supportive services such as respite care and crisis intervention.

Social workers are often in key positions to offer help with family planning decisions and placements such as in adoptive or foster homes, and to locate special educational, financial, and habilitative services for the client and his or her family. The social worker can be extremely helpful in providing to the family of the affected individual services that go beyond the diagnosis and explanation of genetic information. He or she can offer ongoing supportive counseling to each member of the family. Each individual then has an opportunity to express concerns about the possibility of being affected, about having his or her normal routine disrupted, and about feeling neglected or unloved. The social worker can also serve as a coordinator of services for the family.

Within a genetics clinic, the social worker performs an important service in helping people cope with the impact of a genetic diagnosis or with being told they are at risk for a genetic disorder or for passing on a defective gene to their offspring. Other social work services include clarifying misinterpretations about diagnosis and risk, and eliciting fears and anxieties about being labeled, stigmatized, and stereotyped. A social worker's expertise in recognizing the potential damage to one's self esteem when the individual discovers that he or she could transmit a defective gene is crucial to genetic counseling.

The social worker in a genetics center can help couples make realistic reproductive decisions based on the facts shared with them in the genetic counseling session. The social worker in the genetics clinic can often provide marriage counseling to help couples communicate more openly. This helps the couple conduct a careful analysis of alternatives rather than make a random, disruptive choice.

The ability to make a clinical assessment of family dynamics is an integral part of a social worker's training; that facilitates the social worker's understanding of how each member of the family reacts to the genetic diagnosis. Helping the parents of a child with a genetic disorder resolve their disappointments, feelings of guilt and blame, and other major components of the classic grief cycle is one of the social worker's major tasks, and is one that is aided by the social worker's understanding of ego damage. The social worker also helps determine eligibility for medical assistance, disability benefits, and other services.

Patient, parent, and sibling groups—organized, developed, and often led by the social worker—can be a tremendous help to families in combating self pity and feelings of aloneness. Support systems outside of the family, such as experienced parents reaching out to other parents, also can be developed effectively by the social worker in a genetics clinic.

The social worker in a genetics center is often responsible for training and educating other social workers, students, and allied health personnel. Social workers may also be involved in the education of patients, their families, and the lay public with regard to genetic information and greater sensitivity to the impact of a genetic diagnosis on individuals and families.

Another area for social workers involved in genetics is research. Research studies may, for example, determine what services are available to patients and families and evaluate what effect, if any, those services have; identify who is being served, what intervention has taken place, and how successful it has been; and analyze existing social needs and the outcome of existing services. The social worker can also identify those social services that are not available, but should be, and can identify gaps in health-related services within the community, mobilizing local communities to obtain those services. Often,

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the social worker becomes a patient advocate to help populations with genetic disorders voice their needs and educate the public about their problem.

An important part of the social worker's training is the interdisciplinary teamwork. There will always be overlapping services in the helping professions, but a team focus on high standards for coordination of services to clients with a genetic diagnosis will ensure that the clients benefit from those services.

One can obtain directories of accredited, licensed social workers through local chapters of the National Association of Social Workers. The Family Service Association of America has a list of private social service agencies, and Child Welfare of America has a list of child welfare agencies. The Department of Social Services in local communities can often be helpful in identifying local agencies. The Division of Maternal and Child Health (MCH) in Rockville, Maryland can direct you to local MCH social workers or clinics. (The contact person for information about social workers knowledgeable in genetics is: Kathleen Kirk Bishop, Social Worker Program Specialist, Genetic Disease Services Branch, phone: (301) 443-1080).

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RESULTS OF THE SECOND NSGC PROFESSIONAL STATUS SURVEY

Debra L. Collins and Michael L. Begleiter

The second NSGC Professional Status Survey was mailed in the spring of 1983 to 319 members; 190 (59.6%) responded. The second survey was initiated because some of the data from the first survey (*Perspectives* Vol. 3, No. 4, December 1981) were helpful in increasing benefits, salary, and professional status of counselors. The following is a summary of the results.

Demographic Data

Responses about undergraduate and graduate degrees and course work did not differ greatly from the first survey. Approximately 77% of respondents had a master's degree in genetic counseling.

This survey also reflected the preponderance of females (91.9%) in the profession. More than 51% of respondents had been working for fewer than five years. This fact was reflected in the age distribution: 63.2% are less than 34 years old. Most counselors work in university settings (53.7%) rather than in private facilities or outreach clinics. There are 2.7% in private practice settings, with 60.3% in metropolitan areas. Others work in suburban or rural locales, or have statewide responsibilities.

Professional Responsibilities

Genetic counselors are involved in a variety of activities. Most (92.6%) indicated that they are involved specifically with genetic counseling. Other areas included prenatal diagnosis (76.8%), speciality disease counseling (59.3%), teaching (77.8%), clinic coordination (69.1%), research (42.6%), and administration and management (67.7%).

The variety of speciality clinics where genetic counselors work is expanding and reflects the variety of contexts in which genetic counselors can be involved (Table 1).

TABLE 1
Speciality clinics in which respondents work, and the number of respondents working in each

Specialty Clinics	N
craniofacial/cleft palate	29
muscular dystrophy	21
spina bifida	21
hemophilia	19
cystic fibrosis	13
sickle cell	11
Tay-Sachs	10
Down syndrome	8
PKU	5
thalassemia	4
skeletal dysplasia	3
orthopedics	3
cardiac	2
arthrogryposis	1
other	16
N/A	77

Many genetic counselors teach. Instruction includes university students (75.1%), medical students (57.1%), other health professionals (95.8%), and lay groups (94.7%). However, 63.5% have no academic appointment, despite their teaching responsibilities. The 36.5% who listed academic appointments have titles that vary from lecturer (4.2%), to instructor (14.8%), to assistant or associate professor (4.8%); 12.7% listed other titles.

Many counselors assume primary responsibilities for genetic counseling, with 48.1% counseling 151 or more patients by themselves each year. In addition, 24.8% counsel 151 or more families per year as part of a team.

Professional Issues

Most respondents (51.1%) were certified by the American Board of Medical Genetics; 37.4% were eligible for certification.

Salaries have increased over the last few years. The median salary is $23,000 (Table 2). There were no significant differences between regions or locales. Experience was generally reflected in increased salary. When asked what they felt a starting salary should be for genetic counselors, 55.6% felt it should be at least $20,000.

TABLE 2. Salary of respondents as of 1 January 1983

Years of Experience	Mean	Maximum	N
1	$18,500	$23,500	13
2	20,500	30,500	29
3	21,500	28,500	26
4	23,500	40,000+	24
5	24,000	35,000	23
6	23,000	39,500	18
7	26,500	37,000	11
8	24,500	33,500	10
9	26,500	36,000	8
10	26,500	36,500	15
			177

Although many counselors are on "soft" money (37.6% are grant-dependent), 44.8% say that their institution would support them if that funding were discontinued. Another 23.9% think that support probably would be provided.

Although most have job titles of genetic counselor, genetic associate, or clinical coordinator, many job titles are varied and imaginative (Table 3). This probably reflects the newness of the field and the tendency to try to fit this job description into established categories rather than to create a new category for

genetic counselors. Many of those who have other titles prefer the title of genetic counselor or genetic associate to the university description (27%).

TABLE 3. Job titles listed by respondents

Job Title	Percent of Respondents
Genetic Counselor	45.2
Genetic Associate	23.1
Clinical Coordinator	3.8
Director of Genetic Services	2.7
Genetic Services Coordinator	2.7
Other (26 different titles)	22.5

Although most counselors bill for their services under their supervisors' names, 10.3% indicated that they bill in their own names.

After assuming their current jobs, 179 counselors have taken additional course work or training, including a foreign language (10.1%), counseling/therapy (13.4%), sign language (2.8%), and courses toward advanced degress (2.2%).

Most counselors attend regional or national meetings for continuing education; 89.7% have attended one to three regional meetings, 72.3% have attended up to three Birth Defects meetings, and 52.5% have attended up to three meetings of the American Society of Human Genetics (15.9%) have attended six or more).

Sixty-one percent have published in the professional literature including original research (44.5%), abstracts (39.6%), case reports (27.2%), books (2.2%), and chapters (12.2%).

Fringe Benefits

Most counselors receive health and life insurance, retirement benefits, and vacation time according to the standards of their employers. Some counselors also receive additional benefits including full dues (31.2%) or partial dues (12.1%) for memberships in professional societies. Partial (39.7%) or full (34.4%) support is provided for attending professional education meetings. Fifty-six percent indicated that their employers pay for two or more meetings per year. Of those indicating a percentage, 55.7% had 100% of meeting expenses paid. Expenses for certification by the American Board of Medical Genetics were covered for 21.4% and partially covered for 6%.

For counselors who moved to assume new positions, 30.5% were reimbursed for interview/travel expenses and 4.9% received partial compensation. Moving expenses, when appropriate, were reimbursed for 15.6%, while 3.3% received partial reimbursement.

Job Satisfaction

Counselors are generally satisfied with their positions (50.5%), although 33.7% were not sure and 14.7% were not satisfied. When asked whether they planned to leave the field of genetic counseling, 47.8% did not plan to leave, 40.5% possibly would, and 8.4% said that they planned to leave the field.

Respondents felt that areas of professional advancement available to them included expansion of the genetic counseling role (56%) and faculty appointments (8.6%). This category will be explored in more detail in future surveys.

A multiple regression on the data for job satisfaction revealed that the most predictive variables for satisfaction were salary, institutional support for salary, and support for attending professional education meetings, specifically the annual meeting of the American Society of Human Genetics.

When asked to indicate their ideal job title and responsibilities ten years hence, respondents answered that they would like faculty appointments, more involvement with research, and added administrative and supervisory responsibilities. Many would like the same job with more freedom. Some would like to be director of genetic services, while others would like to be in private practice.

Role of NSGC

Most feel that the National Society of Genetic Counselors should be involved with continuing education, third party payments and funding, public relations/community information, increasing salary, role description, and registry of job availability.

The survey questionnaire is currently being revised. NSGC will distribute the survey every few years; some of the questions about demographics will be repeated, while new questions will be added to reflect changing issues in genetic counseling.

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CASE REPORTS IN GENETIC COUNSELING

Case #2

An unusual situation occurred recently when information about the previous pregnancy of a prenatal diagnosis patient came to my attention after her genetic work-up was complete. The question of what to do with the information proved problematic.

A 36-year-old para 1-1-1-1 white female was referred for genetic counseling and amniocentesis for the indication of maternal age. By history, the patient suffered a first trimester miscarriage and a premature delivery induced at six months gestation following maternal toxemia. This fetus did not survive; and the remainder of the pedigree was unremarkable.

The amniocentesis and cytogenetic analysis were uneventful, and normal results were conveyed to the patient within three weeks after the tap. Several weeks after this last patient contact, some loose notes about the previous pregnancy were discovered. An ultrasound study at 25 weeks gestation had detected the presence of a fetal anomaly, off the ventral wall, thought to be an omphalocele or gastroschisis. No information about subsequent management of the pregnancy was available. The sonographer had left this institution. In addition, the patient's former obstetrician was not affiliated with this hospital.

Questions of concern included whether our prenatal studies were sufficient to rule out a recurrence, whether the patient was aware of the anomaly and its possible genetic implications, whether the patient's new obstetrician was aware of this history, and why this information had not been shared in the counseling session.

We felt comfortable that the ultrasound study prior to amniocentesis was of sufficient quality to identify a similar defect without special instructions to the sonographer. An AFP analysis had been obtained in routine screening of the fluid.

The other issues seemed more difficult. We elected to share this information with the patient's new obstetrician, who is a faculty member in fetal/maternal medicine at this hospital. The obstetrician was unaware of this previous history and had been told about the toxemia complications only. She stated that she might raise the question of the sonogram report with the patient later in pregnancy if the circumstances seemed appropriate.

One can construct a number of scenarios around the conflicting stories of the previous pregnancy. I am comfortable about the medical management of this pregnancy and have decided not to initiate further contact with the patient. I do wonder whether a confrontation about the previous records would have

been constructive in any way had the notes come to my attention during the time of the genetic studies. Was my informing the new obstetrician appropriate or justified? If I did not know the woman's new physician personally, could I have shared the information as readily? I feel that the genetics group did what the patient requested, but am confused about the couple's motivation. Most families we see under these circumstances are so concerned about a recurrence of any previous problem that other risks are often over-shadowed.

We welcome comments about this or other, similar situations.

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Response to Case #1 (Vol. 6, No. 2, June 1984)

I read with interest the case report by Dr. Toriello and Ms. Martin concerning the abortion of a fetus of the "unwanted" sex following genetic amniocentesis. We have had a similar case. The couple was referred for maternal age. Both are Chinese and have professional occupations. At the time, they had a healthy three-year-old daughter. The second pregnancy was unplanned. Prenatal diagnosis indicated a normal female karyotype and a normal AFP value. When informed of the results by telephone (our standard procedure), the patient was clearly distressed. However, we perform approximately 25 amniocenteses per week, so we encounter disappointment with the sex of the fetus on a regular basis. Usually, this is a reaction of short duration, and the woman or couple comes to terms with the information, even within the length of the phone call. In this case, the obstetrician's office notified us of the patient's intention to terminate the pregnancy. They requested that we not send the routine follow-up questionnaire. This incident occurred one year ago, and the patient is currently scheduled for an amniocentesis with her third pregnancy.

As Toriello and Martin point out, such a case does raise conflicting feelings for the genetic counselor. In our center, if a patient requests sex selection in the absence of a family history of a sex-linked disorder, I have the option to decline counseling her. This is in part because our staff includes another genetic counselor and a medical geneticist who are willing to do the counseling.

Part of the process of prenatal diagnosis involves an extensive ultrasound, with the woman or couple looking at the screen and receiving both a detailed descrition of what is seen, and polaroid photographs. Many patients speak of the bonding that occurs during this experience. This may partially explain why, in more than 3000 amniocenteses, we know of only this one case where the decision to terminate was based on unwanted fetal sex. Incidentally, only one couple had prenatal diagnosis with the specific intention of aborting a male. They had three boys already, but when faced with the information that the fourth was a chromosomally normal male, elected to continue to term.

When the patient in question returns, I plan to do her counseling review as I would that for any other patient. We tend to assume that if one pregnancy was terminated on the basis of fetal sex, other pregnancies will be also. I am not aware of any supporting data. Circumstances and attitudes change with time. The very experience of a second trimester abortion may dissuade a woman from a similar decision in another pregnancy.

Although I feel strongly that it is unfortunate that some individuals or couples cannot accept a child of a particular sex, two central issues remain. First,a woman must be guaranteed the right to make her own reproductive decisions. Any limitation on that right opens the flood gates for further curtailment of her options. The courts have already heard cases for forced Cesarean sections. A scenario of litigation against one's mother for negligence in pregnancy (taking certain medications known to be teratogenic, for example) has been envisioned in medico-legal articles.

The second issue is that abortion of the "unwanted" sex is but one example of a woman or couple making a decision different from that which the counselor might make. Consider the balanced translocation carrier who refuses prenatal diagnosis even after the birth of one affected child. One might argue that this represents a greater potential harm to a larger number of individuals such as another affected child, the rest of the family, and society. The basic definition of genetic counseling includes the concept of allowing a couple to choose a course of action that seems appropriate to them in view of their risk, their family goals, and their ethical and religious standards, and to act in accordance with that decision.

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CORRESPONDENCE

To the Editor:

I am nudged out of apathy by reading a somewhat uncomplimentary review of *Trisomy 18: A Book for Families,* a booklet written for parents (*Perspectives,* Vol. 6, No. 1, March 1984). I have long felt that our field lacks readable, informative, but humanizing literature written for parents about the specific disorder their child has. How many times have you had a parent ask, "But, isn't there something I can read about this?" Often, the only thing you can offer them is a series of treatises on cases, autopsy findings, mortality and morbidity statistics (if you are lucky), and pathogenesis. In that wealth of professional literature, there is scarcely a glimpse of the human feelings involved in experiencing these events, a pragmatic suggestion for what parents might do in such a situation, a simple statement that they are not alone, a clue as to what they might have done to have caused the disorder (much less reassurance that it was not their actions), or a hint of what the future might hold. It is therefore a great joy to me to come across an article, pamphlet, or book that I can actually suggest to parents in good faith. Granted, some of these attempts have obvious shortcomings, especially with 20-20 hindsight, but at least there is something to fill the tremendous void that is often interpreted as abandonment.

I find the booklet *Trisomy 18* helps fill that void admirably. It offers some straightforward explanations such as the mechanics of chromosomal aberration. Although this section may seem complicated, especially to unsophisticated families, it can and should be supplemented by counseling. I do not feel the book is rendered useless simply because the fairly complicated explanations will confuse some families. At best I find these explanations difficult for any but the most sophisticated families; it is like teaching a whole biology course in one counseling session. If the information is in writing, the family can at least reread and digest it over a longer period of time.

The wonderful comments by families who have contributed to the book make it a very alive and human experience for me. This emphasis does not deny the feelings lurking on the other side of the coin: sadness, periodic despair, and a sense of "why me?" that all families feel as well. It is those who have lived through and learned from these experiences who have chosen the message of hope to pass on to others who will tread the same paths.

Families often tell me that they feel a sense of abandonment in the newborn period. The gap between the diagnosis and the rest of life can be a long and lonely one as families struggle to cope with the real situation, which is so much more bleak than the fantasized one. Kris Holladay, the founder of SOFT (Support Organization for Trisomy 18/13) and one of the authors of

this pamphlet, calls genetic counseling "a soft place between a rock and a hard spot," and I think this pamphlet helps fill that same space. There may be a danger of using this type of tool as a band-aid and not offering the appropriate personal counseling and support that these families need. On the other hand, even when appropriate in-depth counseling has been given, people still wish to have something in print that they can take home. Professionals should certainly encourage a family and its individual members to explore honestly all their feelings surrounding the birth of a child with a poor prognosis. One hopes that our expertise enables us to create a safe environment where parents can accept the reality of their situation, the complex feelings it engenders in them, and the alternatives for dealing with it. *Trisomy 18* is a good tool to help achieve those goals. When I feel a particular publication is too unrealistically positive, as some may feel this one is, I often state these feelings to parents and then let them judge. This may be especially appropriate if the situation is an abnormal prenatal diagnosis.

In summary, there are some very important things we counselors have to offer parents in the newborn period when a diagnosis such as trisomy 18 is made:

1. support—we need to be there;
2. validation of feelings—parents need to know it is normal to feel what they are feeling;
3. information—over a period of time parents need to hear the facts about prognosis and recurrence risk;
4. anticipatory guidance—we can help prepare parents for death and life; both are difficult;
5. practical suggestions—parents need to know what to do on a day-to-day basis, and they need help with separating the syndrome from their child;
6. repetition—parents need to hear answers when they have questions; sometimes this means explaining the same issues many times;
7. help in dealing with guilt—this issue is critical early in counseling; and
8. hope—people cannot live without hope; although the object of hope may seem pitiful to outsiders, it is absolutely essential.

Trisomy 18 offers help on every one of these points, and I applaud the people who cared enough to write it.

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MEETINGS AND ANNOUNCEMENTS

Reviewers for *Perspectives*

The editorial staff of *Perspectives* is soliciting reviewers for manuscripts, books, and resource materials. Interested individuals will be asked to complete a short questionnaire about training, expertise, and areas of interest. Contact J.D. McInerney, *Perspectives,* BSCS, The Colorado College, Colorado Springs, CO 80903.

1985 NSGC Education Conference

The program committee for the 1985 NSGC education conference, "Strategies in Genetic Counseling: Religious, Cultural and Ethnic Influences on the Counseling Process," is soliciting ideas for workshops from the membership. The committee will accept and review abstracts from individuals who would like to lead, coordinate, or initiate relevant workshops. Workshops that include active participation or panel interaction will receive greatest consideration, but all ideas are welcome. Those who submit suggestions for workshops can also submit abstracts for paper presentations. The format for workshop suggestions is as follows:

Title
Format (small group discussion, panel, lecture, or others.)
Coordinator of workshop
Leader of workshop (may be the same as coordinator)
1 - 3 paragraphs presenting the topic (need, discussion ideas, and relevance to program theme)

Please send all suggestions by 28 February 1985 to: Vickie Venne, Genetics - CHHC, 8001 Frost Street, San Diego, CA 92123.

POSITIONS AVAILABLE

Genetic Counselor: The Genetics Counseling Laboratory of the Regional Health Resource Center, Urbana, Illinois, is searching for a full-time genetic counselor. Applicants should be board eligible or board certified. The Genetics Counseling Laboratory is part of a statewide system and serves the east-central, and southeastern sections of Illinois. The genetic counselor will participate in the organization and conduct of regular diagnostic clinics. He or she will establish an outreach counseling/testing system in collaboration with the director and current staff. The latter activities will include making contacts with health professionals and agency personnel in metropolitan areas within the region, conducting and coordinating educational and publicity programs, establishing satellite centers in participating hospitals in these cities, and laying the foundation for a regional outreach/referral system. The counselor will participate in genetic counseling and follow-up activities provided by the Genetics Counseling Laboratory. He or she will also facilitate referrals from the Genetics Counseling Laboratory to other centers within the statewide system (Chicago, Peoria, Rockford, and Springfield, or to centers in Indianapolis, St. Louis, and Louisville, where appropriate). This position provides an excellent opportunity to participate in an established and growing counseling program. Contact: Patrick J. Kovar, President, Regional Health Resource Center, 1408 West University Avenue, Urbana, IL 61801, phone: (217) 367-0076. The Regional Health Resource Center is an equal opportunity employer.

Genetic Associate: Tufts-New England Medical Center, Department of Birth Defect Evaluation and Genetic Counseling, has an opening for a full-time genetic associate. The position involves substantial responsibility for counseling for prenatal diagnosis and amniocentesis. There will be opportunities and duties in general clinical genetics as well. The range for the starting salary is $18,000 to $21,000. Contact: Lewis E. Artoshesky, MD, Center for Genetic Counseling and Birth Defect Evaluation, Tufts-New England Medical Center, 171 Harrison Avenue, Boston, MA 02111, phone: (617) 956-5461.

Genetic Counselor: The Genetics Center of Southwest Biomedical Research Institute in Tempe (Phoenix) has an immediate opening for a full-time genetic counselor. Primary responsibilities include genetic counseling, participation in coordination and administration of clinic, specialty clinics, genetics education for medical and lay communities, and participation in research projects. Applicants must have an appropriate master's degree, for example in human genetics or genetic counseling, and be board eligible or certified as a genetic counselor with the American Board of Medical Genetics. Please submit current curriculum vitae to: Judith Allanson, MB, ChB, MRCP, Associate Director of Clinical Genetics, The Genetics Center of Southwest Biomedical Research Institute, 123 East University Drive, Tempe, AZ 85281.

Genetic Associate: Faculty position available for a full-time genetic associate. Primary responsibilities will include patient care, coordination of regional genetic clinics, participation in specialty and prenatal diagnosis clinics, and education of professional and lay groups. Applicants should be board eligible or certified as a genetic counselor with the American Board of Medical Genetics. Submit curriculum vitae and three references to: Dr. Boris G. Kousseff, Department of Pediatrics-Box 15-G, University of South Florida, College of Medicine, 12901 North 30th Street, Tampa, FL 33612.

Genetic Associate: Genetic associate for hereditary diseases program offering genetic counseling, prenatal diagnosis, chromosome analysis, and newborn screening, with outreach and educational component. Funded positions include three clinical geneticists, one biochemical geneticist, one cytogeneticist, and three genetic associates. Salary range $2,486-$3,099/month. Send curriculum vitae and three references to: Dr. Peter Bowen, Director, Division of Medical Genetics, Department of Pediatrics, University of Alberta, 2C344 Mackenzie Health Science Center, Edmonton, Alberta CANADA T6G2R7. The University of Alberta is an equal opportunity employer, but, in accordance with Canadian immigration requirements, priority will be given to Canadian citizens and permanent residents of Canada.

JOBS HOT-LINE NUMBER
Linda Nicholson: (302) 651-4234

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