PERSPECTIVES IN GENETIC COUNSELING
NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.
Volume 8, Number 2, June 1986

RESULTS OF THE THIRD PROFESSIONAL STATUS SURVEY

Debra L. Collins

The National Society of Genetic Counselors again polled its membership for information about salaries, faculty status, third party reimbursement for services, and other demographic and relevant professional issues. It is important to update that information periodically as our members negotiate for new or improved positions, and increased professional status.

This survey was handed to all members attending the combined annual meeting of the National Society of Genetic Counselors and the American Society of Human Genetics meeting in Salt Lake City, Utah, October 1985. Of those responding, 141 were full members, each of whom answered all the questions addressed in the following summary.

Demographic Data

The survey again reflected the predominance of females (96%) in the profession. Seventy-two percent of the respondents were less than 35 years of age. Most respondents held an MS or MA degree (97%). More than half of the respondents had been working five years or less (57%). Most members were board certified (66%) or eligible (30%). The work setting for 53% of the respondents is a university medical center, but many now work in a private hospital or medical facility (16%), a health maintenance organization (5%), or consider themselves primarily state or federal employees (10%). The remaining counselors work in more than one setting, usually a combination of two of the above, or they combine those with outreach clinics and regional genetic network responsibilities.

Professional Responsibilities

Clinical Responsibilities

The survey showed that each counselor sees an average of 377 patients per year. Eight respondents see between 900 and 1200 patients yearly. On average, counselors see 74% of their patients alone (without a supervisor) to obtain a medical history, 82% of the families to obtain a family pedigree, 64% of the families to provide primary genetic counseling, and 59% of the families to provide follow-up genetic counseling. Respondents allocate their time between genetic counseling (22%), prenatal diagnosis (34%), specialty disease counseling (7%), other patient counseling (5%), and other responsibilities (27%).

Teaching Responsibilities and Faculty Status

Annual educational responsibilities include teaching courses as well as presenting lectures to various students and professionals. Twenty-five percent of the counselors teach at least one course per year; 16 respondents teach between 2 and 7 courses annually. Counselors give lectures to medical students (44%), nurses (70%), house staff (41%), other health professionals (72%), teachers (40%), lay groups (34%), and other groups (29%).

Twenty-five percent stated that they had a faculty appointment (see Table 1). Those positions were primarily in the school of medicine (23%), but also in schools of nursing and education.

TABLE 1
FACULTY STATUS

	N	%
Assistant Professor	3	2
Associate Professor	2	1
Instructor	18	13
Associate	3	2
Assistant	1	1
Lecturer	7	5
Other	1	1
None stated	106	75
TOTAL	141	100

Fifty-five percent of respondents have published at least one article in the professional literature. Of those, nine counselors have published more than eight articles. Forty-one percent of the respondents presented one or more abstracts at a national meeting; four members have presented between 12 and 25 abstracts.

Professional Issues

Billing and Reimbursement for Services

In billing for their services, counselors frequently used their supervisors' names (41%), although many counselors used their names with their supervisors' names (15%). Twenty percent did not bill for their services, and 20% used other methods. Only three percent of those respondents used their own name for billing; few were able to report the percentage of reimbursement.

Salary

The item on the questionnaire that concerns salaries (Table 2) always generates the most interest. Salaries have increased over the last three years ($26,102 is the current mean). We hope that trend will continue with increased professional responsibilities, availability of funding, and awareness of the need for services provided by the genetic counselors.

Table 3 lists the regions in which the respondents are located. Tables of salary by region are available upon request.

The board of NSGC has supported and encouraged these three surveys in response to requests from its membership. The data from these surveys have been helpful in increasing the professional status of NSGC members. We appreciate the assistance of the members who responded to the survey.

TABLE 2
SUMMARY OF SALARIES

YEARS EXPERIENCE	MEDIAN SALARY	MEAN SALARY	MAX-IMUM SALARY	NUMBER RESPON-DENTS
less than 1	20,000	21,375	30,000	8
1	21,500	21,644	28,000	19
2	24,400	24,874	30,000	23
3	24,400	24,727	30,000	11
4	26,500	27,834	35,000	18
5	26,000	27,014	35,000	11
6	29,500	28,807	37,600	15
7	30,000	28,900	33,000	5
8	26,000	26,294	30,000	9
9	24,500	24,500	24,500	1
10+	32,700	31,520	40,000	15
				135

Debra L. Collins, chair of the NSGC professional issues committee, is a genetic counselor at the University of Kansas Medical Center, Kansas City, KS 66103.

Additional Reading

Begleiter ML, Collins DL, and Greendale K: Professional status survey, *Persp. in Genet. Coun.* 3(4):1-2, 1981.

Collins DL and Begleiter ML: Second NSGC professional status survey results, *Persp. in Genet. Coun.* 6(3):3-4, 1984.

CORRESPONDENCE

An Alternate View on the Effectiveness of Counseling

The report by Young, et al. *(Perspectives,* Vol. 7, No. 4) is concerned with "effective" genetic counseling. In their view, effectiveness means success in transmitting information. Their counseling ideology is primarily an educational one; what they have discovered is what we already know, namely, that machines can do as well or outperform humans in transmitting factual material. Because they also want efficiency, their ideology eventually leads to assembly-line methods of counseling. That is what Young, et al. recommend as an antidote to the tediousness that inevitably occurs when insufficient attention and energy are devoted to human interactions and relational aspects of the counseling encounter. In the framework of their model, Young, et al. are correct in arguing for more efficient educational methods. However, there is a well-known price to pay when the human aspects of professional encounters are deemphasized or given secondary focus: we see consumer dissatisfaction, unmet needs, unanswered concerns, professional ennui, and increasing dehumanization with its attendant consequences.

Volume 8, Number 2, June 1986

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Editorial Staff, 1985-1986: editor, Joseph D. McInerney; resources, Melonie Krebs; legislation and funding, Edward M. Kloza; book reviews, Joan FitzGerald; counseling case reports, Carla B. Golden. Manuscripts, correspondence, address changes, and inquiries concerning subscriptions should be sent to *Perspectives,* BSCS, The Colorado College, Colorado Springs, CO 80903. See Volume 7, Number 4 for instructions for contributors.

TABLE 3
EMPLOYMENT BY REGION

REGION	N	%
I: (Includes: CT, MA, ME, NH, RI, VT, Canada: NFLD, NB, NS, PEI)	7	5.0
II: (Includes: DC, DE, MD, NJ, NY, PA, VA, WV, Canada: QUE)	24	17.0
III: (Includes: AL, FL, GA, KY, MS, NC, SC, TN)	12	8.5
IV: (Includes: IA, IL, IN, KS, MI, MN, MO, NE, OH,WI, Canada: ONT)	30	21.3
V: (Includes: AR, CO, LA, MT, ND, NM, OK, SD, TX, UT, WY, Canada: ALTA, MAN, SASK)	21	14.9
VI: (Includes: AK, AZ, CA, HI, ID, NV, OR, WA, Canada: BC, Mexico)	47	33.3
TOTAL	141	100.0

Is that the direction in which we want genetic counseling to evolve? Fortunately, there are many genetic counselors who march to a beat different from that championed by proponents of the educational model. Such counselors view genetic counseling as a *helping* human interaction and are willing to sacrifice a bit of efficiency in order to assist counselees to understand, integrate and use information, reach pertinent decisions, and feel greater control and mastery over their lives. That alternative model argues for greater human involvement—not greater dehumanization—as the path to sustain professional interest, aliveness, and personal growth.

One should note two points about the research conducted by Young, et al. First, because their subjects were not given a choice of counseling formats to begin with, the conclusions regarding preferences for various formats may not be valid. Second, the authors do not address the potential for behavioral control and coercion inherent in their educational techniques and how to reconcile that with such other values as nondirectiveness.

Seymour Kessler
Advanced Seminars in Genetic Counseling
Berkeley, CA 94707

Dr. Kessler's letter was forwarded to Drs. Young, Jorgenson, and Shapiro for reply. Young and Jorgenson provided the following response:

The purpose of our report was to investigate a question that has been raised repeatedly, that is: Which of three formats for presenting genetic information is most effective? The focus on education in this case should not be interpreted to mean that we are interested only in the patient's acquisition of knowledge or that they march to an educational beat. To the contrary, we are vitally interested in patient-counselor interaction during counseling and intended merely to investigate options for certain aspects of counseling. Because the results did not favor one method of presenting key information over another, we made no suggestions to genetic counselors about which method to incorporate in their counseling programs. We acknowledge that

the presentation of information is an important aspect of counseling, and if constant repetition impairs the counselor's effectiveness in this area, then the overall counseling experience suffers.

As Dr. Kessler points out, machines, as well as human beings, can apparently transmit information. We contend that the professional ennui and dehumanization he fears from machine-assisted counseling may come instead from having to repeat information. If the counselor is freed from this task by using an effective method, then he or she will retain the vitality necessary to identify the needs and concerns of the counselee and, with a fresh attitude, help the counselee integrate information and reach personally appropriate decisions.

The issue of patient satisfaction is another aspect of effectiveness; we addressed it superficially in the research. By chance, a marginal majority of patients preferred group counseling—one of the "efficient" methods. We did not personally advocate that method. In designing the experiment, we made a choice about assignment to counseling methods. Good experimental design required that the choice be random. Would assignment by patient choice be better? We don't think so. We realize that a family's statement about preference for one or another format is difficult to judge when only one method was experienced, but repeated experiences would have biased any estimate of the educational advantages of the various methods.

Finally, the issue of behavioral control and coercion must be addressed. Advantages of computer-based interviews, slide-tape programs, and other mechanical methods of acquiring or transmitting knowledge are said to center on a more open and honest response to machines than to human beings, who may raise an eyebrow, frown, or express disagreement through innumerable verbal and nonverbal cues. Given similar informational content, which method is more likely to be directive: the impartial machine or the judgmental human? We hold the values of genetic counseling mentioned by Dr. Kessler sacrosanct; they need not be violated by the method of information delivery (a small part of any counseling session). Those values were not under investigation in the research and were not addressed in our report. Rather, we set out to answer two questions: Does the method of presenting factual information during a counseling session significantly affect learning? Do patients have a preference or dislike for a particular method? We presented the answers to those questions in a nondirective, educational way—in the scientific literature for review by others. Had we advocated one of the methods or described its counseling philosophy, many of Dr. Kessler's comments would be more relevant.

Robert S. Young
Ronald J. Jorgenson
University of Texas
Health Sciences Center
San Antonio, TX 78284

CASE REPORTS IN GENETIC COUNSELING

Response to Case No. 5 (Vol. 8, No. 1, March 1986)

I found Ms. Golden's case report most provocative. The profession of genetic counseling attracts individuals who greatly want to help others. Thus, we often become frustrated by those clients we cannot help or by those who do not want our help. The expression of our need to help is molded by legal and ethical obligations. In Ms. Golden's case, who, if anyone, is responsible if D.P.'s baby is born with hemophilia? If the father of the baby asks "Why was I not informed? Is it not my child also? Will I not suffer great emotional and financial burden?"—does he have legal ground to stand on? If the legal responsibility does not sustain this man's arguments, what about ethical obligations?

The health care professional, some would argue, must be an advocate for those on whom decision making will have an impact yet who, for whatever reason, are unable to voice their opinions. Should Ms. Golden be the advocate for the husband? for the fetus?

Who is the patient? The science of genetics challenges our long-standing assumptions about that question. Genetics means that a patient's constitution is not solely his or her own, but is shared with family members. In a health-care system knowledgeable of genetics, one can state that an individual's health and predisposition to disease are not individual phenomena but familial ones. As our knowledge of genetics evolves, society will have to redefine how we are to determine who the patient is.

In the meantime, given our uncertainty about where our ethical obligations should lie, what should the frustrated genetic counselor do? My response is that we cannot rid the world of its problems. We cannot even rid the world of genetic disease. Our role and goal should be to do our best. There will always be patients who lie; there will always be those who refuse our help. We can only do so much. When we've tried our best with those troublesome patients, why should we carry around a lingering guilt? Why have I, Ms. Golden, and many other counselors, found ourselves saying "Maybe I should have done more"? We do the best we can. We try to help to the best of our abilities, within what we see as our ethical and legal framework. When the day is over and another baby is born with hemophilia, don't walk away saying "I failed." Remember that no matter what we do, there will be many more babies born with genetic disorders, many more patients who lie, and many more patients who refuse help. Walk away saying "I did my best."

Seth Marcus, MS, genetic counselor
Lutheran General Hospital
Park Ridge, IL 60068-1174

Response to Case No. 5 (Vol. 8, No. 1, March 1986)

This case report exemplifies two issues that all of us as genetic counselors must face: how do we define our professional responsibility, and to whom are we responsible? Those two questions force us to make the distinction between professional responsibility and social responsibility. How we make this distinction is determined by whom we see as the patient (client). In this case report the initial contact and agreement (contract) for prenatal diagnosis was made with D.P. The genetic counselor provided information, including the availability and the risk of further testing for hemophilia. The counselor entered into and established a relationship with D.P. only. Because D.P.'s husband was not involved, do we have a professional responsibility to go beyond the wishes of the patient to provide him with that information? By going beyond the patient to other people who might be involved, are we fulfilling our own need to satisfy a societal and/or moral obligation and calling it part of our professional responsibility? Are we also breaching patient confidentiality? For example, suppose D.P. had a sister; would we feel the same obligation to inform her of the risk of having a son affected with hemophilia?

We can see a close comparison to this case in families where one member of the couple is a carrier for a balanced translocation. We discuss with those couples the importance of informing other family members who are also at risk for being carriers, and inform

them that testing is available to determine carrier status. Ethically and morally, can we as genetic counselors make that information available to other family members?

With whom do we stop in providing information? I would hope our colleagues in the legal profession would respond to the question, and I would also be interested in the opinions of other counselors.

Joan S. Hogge, MS, genetic counselor
Genetics Division
University of Virginia
Charlottesville, VA 22908

BOOK REVIEWS

Clinical Genetics in Nursing Practice, by Felissa L. Cohen, Philadelphia, J.B. Lippincott Company, 1984, 403 pages, $19.50 (paperback).

Dr. Cohen states in her preface that "it is time for nurses to 'think genetically' and to integrate genetic concepts and principles into their practice." To that end, Dr. Cohen has used her expertise as a nurse and geneticist to produce a text that directly relates basic and medical genetics to virtually all areas of clinical nursing practice.

The book is composed of 26 chapters. The first three chapters discuss the scope and relevance of genetic disease, basic principles in clinical genetics, and human variation. Cytogenetic disorders are covered in some detail, including an excellent discussion of when chromosome analysis might be appropriate. Such information demonstrates the author's commitment to encouraging nurses to "think genetically" and to include the geneticist in evaluation of patients. Mendelian inheritance patterns are described in the chapter entitled "Inherited Biochemical Disorders." Although the chapter title and content are appropriate, the organization is somewhat confusing. The basic principles of Mendelian inheritance seem to be buried within discussions of specific biochemical disorders and may not be understood easily by a nongeneticist practitioner or student.

The chapter on birth defects includes a good discussion of multifactorial inheritance, with helpful illustrations. The next three chapters present excellent discussions of the detection, diagnosis, counseling, and prevention of genetic disorders. That section also emphasizes the importance of the entire genetic counseling process and not just one facet of the process, such as diagnosis.

The chapter on prenatal diagnosis is well written and contains an excellent table of current indications for genetic amniocentesis. Other methods of prenatal diagnosis are described, although only one paragraph is devoted to chorionic villus biopsy. That may be a reflection of when the book was written; the information should be updated. This chapter includes a discussion of many social, ethical, and legal issues surrounding prenatal diagnosis. My only objection to this chapter is the lack of clarity about the role of the nurse in counseling families considering prenatal diagnosis. Throughout the book, the author states the need for qualified health professionals (i.e., genetic associate, nurse geneticist, medical geneticist) to provide genetic counseling. My impression in reading this chapter was that any health professional could provide prenatal diagnosis counseling; that might undermine the importance of genetic counseling in this area of clinical practice.

The remaining chapters discuss specific entities encountered in clinical genetics—such as genetic and environmental influences on the fetus, twinning, and pharmacogenetics—or the genetic aspects of specific disease entities such as cancer, diabetes mellitus, and coronary heart disease. In addition, there is an excellent chapter on the impact of genetic disorders on the family, which emphasizes life span and the effect of genetic disorders on other family members.

The chapters are liberally illustrated, and contain fairly extensive reference lists; clinical situations are drawn from the author's professional practice. The book also includes a glossary and list of organizations or groups that provide information, products, or services for families in which a genetic disorder is present.

Throughout her presentation, Dr. Cohen integrates nursing implications and clinical applications for the client and his or her family. She continually emphasizes the importance of genetic counseling and how the genetic counseling team can help nurses and their clients in a variety of situations. The only fault here is that in illustrating that concept, Cohen provides too much detail occasionally and may overwhelm or confuse a nongeneticist.

In summary, nursing has long needed a comprehensive textbook that integrates genetic concepts and information into clinical practice. Nurses in any clinical practice area from maternal–fetal health to geriatrics should come away with better insight into the importance of the role genetics plays in the health of their clients. This book is also appropriate for students pursuing careers in genetic counseling or those involved with education in genetics.

Anne L. Matthews
American Embassy
(Casablanca, Morocco)
APO New York 09284

Prevention of Physical and Mental Congenital Defects. Part C: Basic and Medical Science, Education, and Future Strategies. Proceedings of an International Conference held in Strasbourg, France, 10-17 October 1982. Edited by Maurice Marois, New York, Alan R. Liss, Inc., 1985, 435 pages, $96.00.

This publication is the third in a series of three books dealing with the prevention of birth defects. The volume begins with an examination of early embryonic loss. One of the more useful papers in this section, by Dorothy Warburton, discusses the effects of common environmental exposures on spontaneous abortions of fetuses with defined karyotypes. This paper addresses the confusing area of counseling patients for lifetime exposure to radiation, spermaticides, contraceptives, and maternal smoking. Warburton suggests that those environmental factors may increase one's predisposition to spontaneous abortion.

The next section defines minor malformations and their significance in evaluating "normalcy" and teratogenic effects. Minor malformations and changes in the central nervous system that may alter behavior must be better defined to monitor the frequency of disorders and define the variability of the defects. That will allow a better assessment of the effects of questionable environmental hazards on human development. The author uses specific chapters on retinoic acids, epilepsy in pregnancy, and moderate alcohol consumption as examples.

Another section uses limb defects as a model of developmental control and the influence of different factors that may inhibit, interfere with, or alter normal development. The association between limb anomalies and spatial restrictive uterine environments, described by John M. Graham, Jr., is part of this larger discussion, and provides a brief but interesting discussion of amniotic bands, oligohydramnios, and vascular occlusion.

One of the more important sections discusses the proper and improper interpretation of drug and chemical information and presents systems and methods for studying the mechanisms involved in human teratogenicity. That section is probably most useful to the genetic counselor because it provides information about the pitfalls in this area and teaches the practitioner to be more critical in the evaluation of the literature and more cautious of case reports. The author warns about misinformation related to the risks of congenital anomalies, as we are still in the shadows of and are affected by the thalidomide experience. The section describes other suggested teratogens that have since been "proven" safe.

Facial clefting is used as a model to enhance understanding of how teratogens may work by killing cells and affecting adjacent structures and/or terminal differentiation. This piece helps us understand the basis for variability by highlighting the issues of dosage, timing, and individual variability that so complicate this area of counseling.

The volume concludes with a section on public education and strategies for future research into control mechanisms of development and differentiation. The discussion of public education and its relationship to genetic counseling defines the counseling role in the "strategy of preventing birth defects." That role includes educating school children, lay society, and professional groups.

The book is a plan for the future and a careful look at the study and development of birth defects. It will benefit those studying epidemiology, teratology, or basic human development more than it will help the genetic counselor and clinical geneticist. Notwithstanding the book's emphasis on teratology and its many interesting papers, I would not recommend this book for a genetic counselor. Many areas are dealt with in greater depth and are better organized in other resource material. The book provides a critical review of the study and etiology of birth defects. It is a needs assessment rather than a useful reference.

Shari Baldinger
The Perinatal Center
Abbott Northwestern Hospital
Minneapolis, MN 55407

RESOURCES

Little People in America—The Social Dimensions of Dwarfism, by Joan Ablon, New York, Praeger Special Studies, 1984, 194 pages, $10.95 (paper).

"We are a contradiction in packaging, for encased in our small bodies are not small minds, not small needs and desires, not small goals and pleasures, and not small appetites for a full enriching life."

That succinct statement by Julie Rotta, a member of Little People in America (LPA), defines the feelings and frustrations of many little people. Joan Ablon's study identifies and explores many of the social problems facing little people. Although the number of individuals on which the conclusions are based is small, similar life experiences and problems have been heard repeatedly by professionals involved with short-statured people. For example, many of the points discussed in the book arise often in genetic counseling sessions; those issues are well-defined and developed by Ablon.

The first two chapters define dwarfism and review the literature on the social development of short-statured people. Chapter 3 defines the sample and study methods, and explores the issues surrounding the initial diagnosis, the impact, and final acceptance. School and dating experiences are also introduced and amplified. Chapter 4 deals with marriage and children; Chapter 5 examines education, achievement, and employment. Physical logistics are dealt with briefly in Chapter 6. Unfortunately, *The Idea Machine,* a pamphlet developed by Mary O'Donnell, is not mentioned. That important resource provides many good ideas to help little people function more easily in the world of average-statured people.

Although general health issues are mentioned only briefly, other references are provided. Coping with the real-world experiences and the impact of LPA on individuals and families are discussed in later chapters. Selected life histories illustrate points made in the previous chapters. In discussing these topics, the author explores two basic themes: (1) the life experiences of a population whose profound short stature leads to stigmatization and (2) the impact of LPA—the prototype of a self-help group—and its effect on the identity, self-image, and life course of those who join. This book also includes a valuable appendix with information about the national LPA, LPA districts and chapters, and clinics for the short-statured individuals in each district.

Because this work is based on a small sample of LPA members—a self-selected group to begin with—some have argued that the life experiences of the study group may differ from those of most other little people. For example, individuals in LPA may have made a better adjustment to short stature and thus have more satisfying lives. The author acknowledges this problem, but does not claim that the experiences described are applicable to nonmembers.

Despite those minor reservations, this book gives important insight into all social aspects of short stature and brings those issues together in a single volume for the first time. This book is a must for all genetic counselors who work with short-statured individuals and for parents of children with dwarfing conditions. I recommend it to all who wish to understand the profound effect that difference can have on societal acceptance. This book is a well-written, important resource for all involved in genetic counseling.

Jacqueline Hecht
University of Texas Health Science Center
Houston, TX 77004

We Want To Help
We Care . . .
J.K. Rucquoi, MS and Maurice J. Mahoney, MD. This booklet may be obtained by contacting J.K. Rucquoi, Yale University School of Medicine, Department of Human Genetics, 333 Cedar Street, New Haven, CT 06510, phone: (203) 785-2660, 10 pages, $3.00.

This little booklet is the one we all wish we had written. It addresses couples who learn through amniocentesis or ultrasound that their baby has an abnormality. The authors describe the difficulties of making a decision to continue or terminate the pregnancy and discuss how the couple can be helped by others who have gone through the same ordeal, as well as by the members of the genetics staff. There is a brief description of a second trimester prostaglandin abortion for those who choose to terminate the pregnancy. Since some of those details are specific to the protocol at Yale, and may be different from other institutions, the booklet may have to be modified for general use.

The booklet is most valuable as a preparation for the range of emotions a couple may feel in the days, weeks, and months after the diagnosis. The couple is advised that those circumstances can bring stress to their relationship. By knowing this in advance there is a good chance that lasting damage can be prevented. The

authors discuss the many questions and fears that arise when an abnormal baby is conceived. They give specific suggestions for dealing with children, other family members, and friends. The booklet is written in a very clear, concise manner that is suitable for patients regardless of their educational background. It is sympathetic without being overly emotional. It is the kind of book that the parents can refer to again and again as they reach each new stage in the coping process. I would hope that the authors plan to write a similar booklet for patients who receive abnormal results following first trimester diagnosis.

Phyllis C. Klass
The New York Hospital–Cornell Medical Center
New York, NY 10021

5p– (Cri Du Chat) Society

A support group for families with children with Cri du Chat syndrome is now available. The 5p– Society was established in 1985 in Indiana and published its first newsletter in April 1986. The society is planning a conference for families at the Holiday Inn in Elmhurst, Illinois, 12-14 September 1986. The program will include invited speakers, workshops, and time to meet and share experiences with other families. For more information and to be added to the mailing list, contact Kent and Edie Nicholls, 5p– Society, 11609 Oakmont, Overland Park, KS 66210, phone: (913) 469-8900.

ANNOUNCEMENTS

DEBRA Registry

The University of Washington (UW) has received a grant from the Dystrophic Epidermolysis Bullosa Research Association of America (DEBRA), to establish the first centralized international registry of prenatal diagnosis of epidermolysis bullosa and other hereditary skin diseases. The goal of the DEBRA registry is to collect and systematize the results of prenatal diagnosis of epidermolysis bullosa (EB) and other inherited skin disorders.

The UW group will use the findings to establish criteria for diagnosis, to help counsel families who have been affected by hereditary skin diseases, and to publish a newsletter to keep the medical community abreast of new developments in the field. Slides and data will be made available to health professionals who are involved with these patients. An added part of the research effort will be to seek genetic markers of hereditary skin disorders in amniotic fluid cells, which may help researchers avoid using the invasive fetoscopy procedure. For additional information contact: Arlene Pessar, RN, DEBRA Inc., (718) 774-8700 or Wendy Lippmann, University of Washington, (206) 543-3620.

New Resources Editor

The *Perspectives* editorial staff has selected Melonie Krebs to replace Beth Fine as editor for the "Resources" column. Ms. Fine has resigned the position of resources editor to assume the presidency of NSGC in October 1986. We wish to thank Ms. Fine for her many contributions to the quality of information we present to the society. All future submissions should be sent to: Melonie Krebs, Genetics Education Coordinator, Children's Hospital, Medical Center of Akron, 281 Locust Street, Akron, OH 44308.

Annual NSGC Conference to be Held in Philadelphia

The sixth annual NSGC educational conference will be held 30 October–1 November 1986 at the Franklin Plaza Hotel, Philadelphia. The conference theme "Strategies in Genetic Counseling: The Challenge of the Future" will focus on botl traditional and nontraditional roles of genetic counselors and on the development of effective strategies for expanding those roles. The conference has again been scheduled to precede the annual meeting of the American Society of Human Genetics, 2-5 November 1986 at the Franklin Plaza Hotel. The general sessions will include the following topics:

"What's Next for Genetic Counseling:
Opportunities and Obstacles," Regina H. Kenen, PhD
"The Business of Health Care: Practicing in a
Changing Environment," Judith Levy Safran, MS, MBA
"The Challenge of Emergent Public Policy
Issues in Genetic Counseling," Robert Blank, PhD
"Prenatal Diagnosis and Carrier Detection
by DNA Analysis," Corinne D. Boehm, MS
"Stress and Professional Burnout," Thomas E. Muldary, PhD

The conference will include five workshops held twice during the session. Topics are: Interdisciplinary Teamwork, Practical Analysis and Counseling Aspects of DNA Diagnosis, New Directions in Genetic Counseling, Computer Applications in Genetic Counseling, and Giving Bad News to Parents. The poster session and media center will focus on emerging technologies in genetics and career challenges.

The registration fee includes two receptions; a dinner, lunch, and breakfast; refreshment breaks; and all registration materials. Leonard Sawisch, PhD, representing Little People of America, will speak at a reception and dinner at Philadelphia's science museum, the Franklin Institute.

For more information about the conference, please contact Susie Ball (509) 575-8160, Linda Nicholson (302) 651-4234, or Bea Leopold (215) 872-7608. Complete information will be forwarded upon receipt of your registration form and fee.

NSGC Education Conference Registration
30 October – 1 November 1986
Franklin Plaza Hotel, Philadelphia

Name _____

Address _____

_____

_____

Phone (Work) _____ (Home) _____

Registration fee enclosed:

_____ $100 NSGC member _____ $85 Student

_____ $115 Nonmember _____ $35 Dinner guest

_____ $15 Late fee (after 29 August)

_____ Please send hotel information

Send form and check payable to NSGC to: Bea Leopold
233 Canterbury Drive
Wallingford, PA 19086

POSITIONS AVAILABLE

Genetic Associate. A position is available for a genetic associate to coordinate a hospital-based prenatal testing program for alphafetoprotein. Responsibilities include patient counseling, staff education, and data management. All ancillary services including ultrasound, cytogenetics, abortion services, and social service follow-ups are available within the institution. The genetic associate will work in the division of maternal-fetal medicine with support from a clinical geneticist. Send resume to: Department of Human Resources, Women and Infants Hospital, 50 Maude Street, Providence, RI 02908.

Genetic Counselor. Stanford University is looking for a qualified individual to join its genetic counseling team. The counselor will provide amniocentesis, MSAFP, general genetics, and teratogen counseling; obtain family histories and gather medical reports; prepare quarterly reports for prenatal diagnosis for the State Health Department; give presentations to professional and community groups; and work toward eventual computer management of data. The genetic counselor will also be responsible for case follow-ups, computer data manipulation, and clinician and public education for the new state AFP screening program. The position requires an MS, MA, or MPH degree in genetic counseling and eligibility/certification as a genetic counselor with the American Board of Medical Genetics. Experience is strongly desired, but recent graduates will be considered. To apply send resume to: Cindy Soliday, MS, Coordinator, Genetics Counseling Clinic A334, Stanford University Medical Center, Stanford, CA 94305, phone: (415) 723-5198. An equal opportunity/affirmative action employer.

Assistant to the Scientific Director. A position is currently available at an emerging high-technology medical company specializing in the area of medical genetics and genetic laboratory services. The assistant will report to the vice president and scientific director and will be responsible for assisting in the evaluation of family histories, participating in seminars, and providing backup support for the scientific director. The ideal candidate has the potential—based on performance—to play an important role in the long-term growth of the company, which is located in southern California. Major responsibilities include: (1) working with the genetics and medical staff to assist in evaluating the family histories of patients; (2) assisting in the planning of and participation in teaching seminars for the lay public and professional audiences: (3) providing educational assistance to physicians, patients, and administrative individuals, including sales representatives; and (4) assuming other company projects as assigned, including scientific writing. Position requires formal training in human and medical genetics and/or two to five years of experience in genetic counseling; excellent written, verbal, and organizational skills. Computer literacy is desired; candidates with MS or PhD degrees will be given preference. For information call Ruth Hollis at (714) 955-0707 or send resume to: Ruth Hollis, Parillo, Hollis, and Associates, 1600 Dove Street, Suite 330, Newport Beach, CA 92660.

Genetic Counselors: Three positions are available at the Crippled Children's Division, Oregon Health Sciences University: 1) genetic associate for the Prenatal Counseling and Diagnosis Program (available 1 September 1986); 2) genetic associate for the Genetics Diagnostic and Counseling Clinic, with additional responsibilities in specific clinical service projects (available 1 July 1986); 3) genetic associate, half-time with the Genetics Diagnostic and Counseling Clinic and half-time with Diagnosis and Counseling for Fetal/Neonatal Loss Program (available immediately). Salaries for all positions are $22,000-$24,000, depending on experience; board eligible genetic counselor with master's degree required. Please contact or send resume to: Karen Kovak, MS, Child Development and Rehabilitation Center, Oregon Health Sciences University, P.O. Box 574, Portland, OR 97207, phone: (503) 225-8344. The Oregon Health Sciences University is an affirmative action/equal opportunity employer.

Genetic Counselor: The Division of Medical Genetics, Emory University, is seeking a full-time counselor with a master's degree in human genetics, genetic counseling, or a related degree; applicants must be board eligible or certified by the American Board of Medical Genetics. This is a diversified position, including counseling patients for prenatal diagnosis, general genetics and metabolic diseases, and a hospital consultative service. The applicant will join three current full-time counselors. Experience and a strong interest in clinical research is preferred. Salary is commensurate with experience. Applicants should submit their curriculum vitae to Paul M. Fernhoff, MD, Division of Medical Genetics, Department of Pediatrics, Emory University School of Medicine, 2040 Ridgewood Drive, NE, Atlanta, GA 30322.

Genetic Counselor: The California Prenatal Diagnosis Institute has an opening for a full-time genetic associate. The institute provides genetic counseling, genetic ultrasound, and genetic amniocentesis services to patients who have abnormal MSAFP test results. Applicants must be certified or be eligible for certification by the American Board of Medical Genetics. Salary is dependent upon previous experience and is negotiable; reimbursement will be highly competitive with other positions currently available in California. The program has an established retirement plan; all employees receive health and dental benefits plus interoffice travel allowance. For further information, contact: John D. Stephens, MD, Medical Director or Lynne Weintraub, MS, California Prenatal Diagnosis Institute, 1390 South Winchester Boulevard, San José, CA 95128, phone: (408) 866-6266.

Genetic Associate: A position is available immediately at the Genetics Center, Department of Pediatrics, Case Western Reserve University and University Hospitals of Cleveland. This position is diversified and involves counseling patients identified through MSAFP screening as well as general prenatal counseling, and participation in outpatient genetics clinic, and public and professional education. A master's degree in genetic counseling and ABMG certification/eligibility are required. Please contact: Walter E. Johnson, PhD, Genetics Center, 2058 Abington Road, Cleveland, OH 44106, phone: (216) 844-3936.

Genetic Associate: The Children's Hospital of Wisconsin has a position available for a full-time genetic associate in its birth defects center. This position requires a master's degree in medical genetics and ABMG eligibility or certification. Excellent fringe benefits, salary (ranging from $9.13-$12.84/hour) commensurate with the level of experience. Send resume (including salary history and requirements) to: David Berger, Personnel

JOBS HOT-LINE
Linda Nicholson
P. O. Box 269
Wilmington, DE 19899
(302) 651-4234

Specialist, Children's Hospital of Wisconsin, 1700 West Wisconsin Avenue, P.O. Box 1997, Milwaukee, WI 53201, phone: (414) 931-4095.

Genetic Counselor: A position is available in a genetics clinic/prenatal diagnosis center in the San Francisco Bay area. Medical offices/laboratory staff includes five MDs/PhDs. Starting salary $24,000+/year, depending on experience. Contact Jane Congleton, RN, William Conte, MD, or Robin Clark, MD, at (415) 966-8597 for information. Send resume to William Conte, MD, 1580 W. El Camino Real #2, Mountain View, CA 94040.

Genetic Associate: There is an immediate opening for a genetic associate at Central Valley Regional Center, an agency serving developmentally disabled people in Fresno, California. The genetic associate will provide counseling, follow-up, coordination in genetic services, and community education and will assist in the development of genetic services. Requires master's degree and eligibility for certification as a genetic counselor by the American Board of Medical Genetics. Submit curriculum vitae to: Susan Snyder, Central Valley Regional Center, 4747 North 1st Street, Suite #195, Fresno, CA 93726. Central Valley Regional Center is an affirmative action/equal opportunity employer.

Genetic Counselor. A full-time, permanent position is available 1 September 1986 for a genetic counselor in a newly-reorganized prenatal diagnosis program at the University of Texas Health Science Center, Houston. Duties include coordinating prenatal diagnostic studies, routine counseling, and patient education. Board certification or eligibility required; no experience necessary. Salary commensurate with training and experience. Send vitae or call: L. Immken, MD, Department of Pediatrics UTMSH, P.O. Box 20708, Houston, TX 77225, phone: (713) 797-4564. Affirmative action employer.

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC. BOARD OF DIRECTORS, 1985-1986

Officers: President, Deborah L. Eunpu; President-Elect, Beth Fine; Secretary, Joan A. Scott; Treasurer, Anita Anderson Lustenberger; Past President I, Luba Djurdjinovic; Past President II, Ann Walker

Committee Chairpersons: Membership, Naomi D. Kaji Nakata; Social Issues, Edward Kloza; Professional Issues, Debra Collins; Education, Diane Baker; Editor, Joseph D. McInerney

Regional Representatives: I, A. Merrill Henderson; II, Karen Greendale; III, Vickie Hannig; IV, Barbara Bowles Biesecker; V, Rebecca Berry; VI, Beth B. Crawford

---