



PERSPECTIVES IN GENETIC COUNSELING

NATIONAL SOCIETY OF GENETIC COUNSELORS, INC.

Volume 3, Number 1, March 1981

GENETICS EDUCATION WORKSHOP HELD

Roberta Spiro, M.S.

A Workshop on Genetics Education was held September 21-23, 1980 at the Hilton Hotel in Mount Laurel, New Jersey. There were approximately 80 participants, most of whom represented genetics and sickle-cell projects funded in FY 1979 by the National Genetic Diseases Act. The objectives of the workshop were to facilitate exchange of information among health care professionals involved in the delivery of genetics education and informational services and to initiate a broad-based approach for planning future genetics education and informational services. The workshop was organized by the National Genetics Education Work Group, a seven-member advisory committee co-chaired by Dr. Arthur Robinson, National Jewish Hospital, Denver, and Dr. Harvey Bender, University of Notre Dame, and was sponsored by the Genetic Diseases Service Branch of the Office of Maternal and Child Health, Bureau of Community Health Services, Department of Health and Human Services.

A major focus of the workshop was the formal presentation of six different model programs for genetics education. These models highlighted the unique features of various regions and communities, and the critical need for careful regional assessment. For example, provision of genetics education was found to be a particularly pressing problem in large rural, medically underserved areas. In Georgia, this problem is addressed through local nurses who receive training in genetics. The nurses have proved effective in establishing genetics clinics and in providing education for other health care providers and the public. An innovative Alabama program involves the development of "mini-residencies" for local physicians and "mini-internships" for local nurses and allied health professionals. In addition, advocacy by community leaders is accomplished through County Task Forces for Prevention of Birth Defects. These activities successfully promote genetics education at the grass roots level in southern Alabama.

In contrast to states that are grappling with large rural, underserved populations, Connecticut is a state small in area, but rich in genetic resources. Here educational strategy involves a network of cooperation and collaboration among the education providers. In Ohio, health educators on the staffs of regional, associate, and satellite genetic clinics coordinate the broad spectrum of state-wide educational activities. In Wisconsin, a Genetic Contact Network of allied health professionals, including social workers, public health nurses, and developmental disability staff persons, is in operation. Members of the network know whom and how to refer, and are active in organizing community education and service programs.

Finally, the University of Colorado project on human genetics education for secondary schools was presented. With the cooperation of many teachers and students in one pilot school district, the genetics education coordinator developed and field tested curricula for junior and senior high school biology classes. These materials will soon be available for dissemination.

After the formal presentations, the workshop participants divided into small discussion groups. Recommendations for the planning of future genetics education programs were developed and critiqued in animated sessions. Those recommendations were summarized in a final plenary session and submitted to the Genetic

Diseases Service Branch and the National Genetics Education Work Group for study, evaluation, and for possible future program development.

An important point stressed during the discussions was the distinction between training—the preparation of medical geneticists and genetic associates—and education—didactic presentations and/or structured experiences for other health care providers and the public. Program funds authorized under the National Genetic Diseases Act may not be utilized for training purposes, but may be used for education and information, e.g., the distribution of pamphlets and fact sheets, or the development of educational materials and programs.

A recurring theme in the discussions was the recognition of the need for closer ties and better communication among genetics education programs across the country. The consensus was that the wealth of extant materials, ideas, and resources could and should be disseminated and shared through better utilization of the National Clearinghouse for Human Genetic Diseases. The participants recommended that any genetic counselor/associate contemplating development of educational materials check with the Clearinghouse first, to find out what is already available. In addition, anyone who has developed an educational tool is requested to share it by sending a copy to the Clearinghouse. This approach can prevent wasteful duplication of effort.

Overall, the conference underscored the importance of enabling genetics educators to communicate directly with their counterparts from other regions and programs, as numerous points of common concern arise. The Genetics Education Workshop allowed the principals involved in genetics education nationwide to get to know one another and provided a forum for direct exchange of ideas and information. It is likely that there will be another conference, in 1981, designed to continue the development of national cooperation and planning of strategies for genetics education in the 1980s.

The author is Health Services Administrator, Genetics Program, Child Health Section, DSHS-HSD, 1704 N.E. 150th Street, Seattle, WA, 98155, (206) 545-6783.

HOW IS THE NSGC SERVING ITS MEMBERS?

Beverly R. Rollnick, M.S., Ph.D., President, NSGC

In my presidential address I emphasized that professional issues would provide the focus of my year in office. In my opinion, a strong national professional society offers its members a combination of benefits unattainable by most professionals on an individual basis. The purpose of this report is to share with you progress in several important areas.

Education Meetings

The NSGC will sponsor its first national education conference on June 18 and 19 in San Diego, California. The meeting will follow the 1981 Birth Defects Meeting (c.f. *Perspectives*, Vol. 2, No. 4). Carolyn

Bay and Susan Reed, co-chairs of the education committee, and their committee members have planned a stimulating two-day workshop. This session will enable genetic counselors to review the state of the art, to learn new techniques, and to share counseling experiences. We are pleased to report that the meeting will be supported in part by the March of Dimes Birth Defects Foundation. We look forward to your participation.

Continuing Education Criteria

Continuing education is necessary to maintain and advance skills in genetic counseling, and may be required eventually for recertification. Continuing education criteria establish standards for the profession and allow granting of credit for attendance at approved courses. The NSGC has the capability to store members' continuing education units (CEU) in our new computer system.

Most major university medical centers and general universities have continuing education offices that help with planning and program development. In consultation with the Director of Continuing Education Services at the University of Illinois, and with the review of the NSGC Education Committee and Board of Directors, I am developing a proposal for continuing education criteria for the NSGC. This proposal will be reviewed this June in San Diego and presented to the membership.

The National Society of Genetic Counselors, Inc. must assume leadership in systematic planning coordination and in facilitation of continuing professional education for genetic counselors. Toward that end the following guidelines for program development are presented:

An education program qualifies for CEUs if it meets the criteria established by its professional society or other relevant organization and/or plans its continuing education program under the auspices of an accredited institution. The institution is responsible for adhering to established guidelines.

A continuing education service will provide administration support services; develop a budget; coordinate a program; manage registration; keep records; handle logistics, such as conference site, meeting arrangements, lodging, meals, etc.; and meet broad criteria for CEUs.

General criteria for CEUs established by other professions include:

- Needs assessment for continuing education. Minimal criteria include a survey of potential participants. Other criteria could include expert opinion.
- Program objectives stated in a systematic matter.
- Course content that reflects course objectives. Content should be sequential, and follow a logical pattern reflective of course objectives.
- Faculty selection based on demonstrated competency.
- Evaluation. A minimal evaluation process is a participant satisfaction measure.

Funding for continuing education services varies. The fee can be included in the registration fee, provided by the course financial sponsor, or by other mechanisms.

Advantages of continuing education criteria include systematic quality criteria applied to all NSGC continuing education programs and an active role for NSGC in the development of standards.

Professional Status

Any new profession must establish standards for salary, benefits, and opportunities for professional advancement. Data on current and past professional status and experience of genetic counselors is a prerequisite. I have appointed Michael Begleiter to chair the Ad Hoc Committee on Professional Status charged with obtaining and assessing this information. To this end, an instrument has been developed and mailed to all members. Please complete this questionnaire and return it as soon as possible. Remember, we need your help to achieve our mutual professional goals.

Perspectives

The newsletter of the NSGC provides a unique combination of information not available from any other single source. The expanded editorial board established by Deborah Eunpu, Editor, will provide additional features of professional interest. Your contributions are encouraged. We are pleased to report that the March of Dimes Birth Defects Foundation has extended its financial support of *Perspectives* for fiscal year, 1981.

Perspectives, a program for professional advancement, continuing education criteria, continuing education programs, representation on national boards and committees (e.g., the American Board of Medical Genetics), and association with colleagues are some of the benefits provided by the NSGC. Let us all work together to strengthen our Society and to make it work for us. Your membership is an important beginning.

PROGRESS REPORT ON PERSPECTIVES IN GENETIC COUNSELING

Deborah L. Eunpu, M.S., Editor

This year will be one of change and expansion for *Perspectives in Genetic Counseling*. Starting in June 1981, each issue will focus on a central topic, with supporting contributions concerning related legal and/or funding issues, bibliographic material, and listings of pertinent resources. Reviews of new publications that may be of interest to the members of the Society will also be added. *Perspectives* will continue to publish news of the Society and announcements of professional meetings and positions available. Members are encouraged to submit letters to the editor and other contributions for publication in *Perspectives* (see "Instructions for Contributors" elsewhere in this issue).

Publication of *Perspectives*, beginning with this issue, will be accomplished through the Biological Sciences Curriculum Study (BSCS) in Louisville, Colorado. The increased capabilities of the BSCS art and production departments will undoubtedly improve the appearance and quality of *Perspectives*.

The expanded format will be made possible by the newly formed editorial staff. Joseph McInerney, BSCS, has been serving as assistant editor since June 1980. Beth Fine, of Children's Memorial Hospital in Omaha, Nebraska, will serve as the resource compiler. Edward Kloza, AFP Prenatal Screening Project, Foundation for Blood Research, Scarborough, Maine, will be keeping the membership informed of new and significant legislation and funding trends. Melanie Perkins, Children's Orthopedic Hospital and Medical Center, Seattle, Washington, will provide current bibliographic material on selected topics. A book review editor will be appointed in the next few months. Each of these editorial staff members brings with him or her experience in specific areas and interest in improving *Perspectives in Genetic Counseling*.

The board of the National Society of Genetic Counselors, Inc. and the staff of *Perspectives in Genetic Counseling* learned with pleasure of the decision by the March of Dimes Birth Defects Foundation to provide continued support in the amount of \$3,520 for the development, publication, and distribution of *Perspectives in Genetic Counseling* in 1981. This support has been crucial to *Perspectives* in these early years, and I am certain each of you will be glad to learn of the March of Dimes Birth Defects Foundation's generosity in supporting our Society's publication.

Finally, I would enjoy learning of your suggestions for topics to be covered in this publication. *Perspectives* is not the private province of the editorial staff; it is the publication of the National Society of Genetic Counselors, Inc. As such, we hope to make *Perspectives* a publication that reflects the concerns and interests of the Society's entire membership.

COMMITTEE REPORTS

Nominating Committee Seeks Members' Suggestions

The 1980-1981 Nominating Committee of the National Society of Genetic Counselors, Inc. is responsible for preparing a slate of candidates for the following positions: President-Elect, Treasurer, and Regional Representatives for Regions I, III, and V. The committee is anxious to hear from the membership regarding interested candidates or recommendations for candidates. To make a suggestion or announce your interest in running for one of the positions listed above contact any of the following committee members directly:

Diane Baker, 309 North Ingalls, Apt. 1, Ann Arbor, MI 48104

Audrey Heimler, Division of Human Genetics, Long Island Jewish-Hillside Medical Center, New Hyde Park, NY 11042

Evelyn Lilienthal, 34 Duncan Drive, Greenwich, CT 06830

Lucille Poskanzer, Children's Hospital, 51st and Grove Street, Oakland, CA 94609

Julie Shapiro, D-3, 3706 N. Charles Street, Baltimore, MD 21218

**Julie Shapiro, Chairperson
1980-1981 Nominating Committee**

Ad Hoc Committee on Professional Status

By now each of you should have received the questionnaire prepared by the Committee on Professional Status. It is the goal of this questionnaire to learn who we are, what professional responsibilities we are fulfilling, what salaries and fringe benefit packages we have negotiated, and what goals we can look forward to achieving in our careers. We feel that it is important to gather this information in order to define our professional roles and responsibilities and to begin an open discussion of where we go from here. I am certain that if we do not get involved in defining these issues, others will define them for us. If you have not already completed your questionnaire and returned it to us, please use the self-addressed, stamped envelope and do so.

**Michael Begleiter, M.S.
Chairperson, Ad Hoc Committee
on Professional Status**

GENETIC COUNSELING TRAINING PROGRAM, UCLA School of Public Health

A two-year Master of Public Health degree with a specialization in genetic counseling is offered as of the fall quarter, 1981 by the UCLA School of Public Health, Division of Population, Family, and International Health. This Program, funded by the National Foundation March of Dimes, simultaneously provides students with intensive training in genetic counseling skills and with basic public health approaches and methodologies in such areas as epidemiology, health program planning, health education, research, and policy. While the program is centered in the School of Public Health, it draws on course, laboratory, and faculty resources from other parts of the UCLA Center of Health Sciences, and utilizes a number of affiliated community agencies and institutions for the clinical observations and field placements of its students.

The Genetic Counseling Program has been established to respond to the increasing demand for trained counselors in genetic service and research programs. Its primary objective is to prepare students to participate effectively as professional members of a medical genetics team providing direct patient care. Additionally, upon completion of the program, students will have had extensive training in health service organization, planning, and evaluation, enabling them to function in an administrative capacity in both clinical settings and governmental and private sector programs for genetic disease

REGIONAL REPORTS

**Region I Stacey T. Kacoyanis, M.S.
Massachusetts General Hospital
Genetics Unit
Boston, MA 02114
(617) 726-3824**

Our first regional conference was held September 4-5, 1980, in Boston, with approximately 20 Region I members in attendance. Plans are currently underway for our second regional conference, set for September 24-25, 1981, at the University of Connecticut in Farmington. Conference coordinators, Deborah Starkman and Elizabeth Balkeit, both at the University of Connecticut Health Center, are making arrangements for housing and will circulate a planning questionnaire to all Region I members. In the meantime, reserve September 24-25 on your calendar.

Elections will be held this year for the representative of Region I. Those full members of NSGC, Region I, who are interested in serving as region representative should contact me as soon as possible.

At this time there are two positions available for genetic associates in Region I, both of which have been announced in previous newsletters. If any of you would like further information on these job opportunities, I would be glad to put you in contact with the appropriate individuals.

**Region V Jean A. Scott, M.S.
Genetics Unit, B-160
UCHSC
4200 East Ninth Avenue
Denver, CO 80262
(303) 394-8742**

I would like formally to thank Ann C.M. Smith for doing such a good job of organizing our first regional meeting. A pat on the back goes to all who attended for making it a special occasion. Jacqueline Hecht, Vicky Venne, Ellen Marcus, and Christine Gallery will be hosting our next regional meeting this spring in Houston, Texas. Dates and details will be announced soon.

The results of the Region V genetic counselor survey taken last year have been compiled and distributed to Region V members. We now have 29 NSGC members in our region, and there are a number of other potential members. We hope to get as many members as possible so we can continue to be a strong voice in the NSGC.

assessment, treatment and control. The program curriculum has been designed in recognition of requirements for certification as a genetic counselor set forth by the American Board of Medical Genetics.

The two year interdisciplinary curriculum (six quarters) combines courses and seminars in genetics, human reproduction, counseling techniques, psychosocial aspects of disease, epidemiology, demography, bioethics, and health planning with a series of supervised clinical rotations and field placements. In the latter, students will have the opportunity to observe and participate in a broad range of public and voluntary agency programs in maternal and child health care, genetics, family planning, and developmental disabilities.

For more information about the Genetic Counseling Program, contact:

**Maria Hewitt, M.S., M.P.H., Assistant Director
Genetic Counseling Program
Division of Population, Family, and International Health,
Room 36-078A
(213) 825-6855**

POSITIONS AVAILABLE

Coordinator, Prenatal Diagnosis Program: Robert J. Kleberg, Jr. Center for Human Genetics. Call Dr. C. Thomas Caskey, (713) 790-4774, for details. Please submit current curriculum vitae and three references. Room M804, DeBakey Building, Baylor College of Medicine, Texas Medical Center, Houston, TX 77030.

Genetic Counselor: This is a grant-supported, one-year position for a counselor to do outreach genetic counseling and some prenatal diagnosis counseling. The main purpose of this position is to extend genetic services to the underserved. Contact: Personnel Department, Children's Hospital Medical Center, 51st and Grove Streets, Oakland, CA 94609, (415) 428-3000.

Genetic Associate: Rehabilitation Service of North Central Ohio, Inc., announces an opening in the full-time genetic associate position available on or about August 1, 1981. The duties involved in the genetic associate's position include coordination of the genetics clinic, providing genetic counseling for a wide variety of genetic problems, new program initiation and development, and providing educational presentations to interested lay and professional groups. Additionally, the genetic associate serves as the liaison

between the local medical community and university-based geneticists. Requirements for this position include a Master's degree in human gene or genetic counseling, or comparable training and clinical experience. Salary is commensurate with education and experience. Contact: Neil G. Mahon, M.S., Rehabilitation Service of North Central Ohio, Inc., 270 Ste Boulevard, Mansfield, OH 44907, (419) 756-1133.

Genetic Associate: A full-time position available at the University of Connecticut Health Center, Department of Pediatrics, Genetic Counseling Service at Farmington, Connecticut. Primary responsibility is coordination of the three satellite genetics clinics, including education and amniocentesis counseling. Participation in teaching activities for medical students and residents, as well as continuing education for community professionals. Position open as of June 1981. Please send curriculum vitae to Dr. Robert Greenstein, Genetic Counseling Service, University of Connecticut Health Center, Farmington, CT 06032.

Genetic Counselor and Clinic Coordinator: Tulane University School of Medicine and Satellite Clinics, New Orleans, LA 70112. Service sees a full range of genetic disorders, plus a PKU clinic. Beginning salary: \$15,000 and up, with experience. Liberal travel and benefits. Contact: Emmanuel Shapira, M.D., Ph.D., Head, (504) 588-5263.

INSTRUCTIONS FOR CONTRIBUTORS TO PERSPECTIVES IN GENETIC COUNSELING

Types of Contributions Accepted

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

Instructions

All contributions must be typed and **DOUBLESPACED**. Three copies of each article should be submitted. The author's name, preferred title, and address must be included with all contributions. Manuscript for the remaining issues in volume three of *Perspectives* must be submitted according to the following schedule:

Publication Date

June, 1981
(Vol. 3, No. 2)

September, 1981
(Vol. 3, No. 3)

December, 1981
(Vol. 3, No. 4)

Send all contributions to

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

Manuscript Deadline

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July 13, 1981

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