

PERSPECTIVES

IN GENETIC COUNSELING

A NEWSLETTER OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS
Volume 2, Number 1. March 1980.

RESULTS OF THE CONTINUING EDUCATION NEEDS ASSESSMENT QUESTIONNAIRE, Judith Dichter, M.S. and Roberta Sprio, M.S., Co-Chairpersons, Education Committee

A prime goal of the NSGC, Inc. is to further the post-graduate education of genetic counselors. Continuing education programs will increase our exposure to the varied aspects of genetic counseling so that we will be better equipped to meet the needs of the diverse communities we serve. In addition, it is expected that in the future, continuing education courses will be required in order to maintain certification. The NSGC plans to offer courses and programs designed to satisfy both the educational needs of our members and the future certification requirements for Continuing Education. In this context, the Education Committee created a questionnaire designed to assess the Continuing Education needs of our membership. This data will be used for planning local, regional and national continuing education programs for genetic counselors. A summary of the results of this survey is presented here.

In September 1979, the questionnaire was mailed to the approximately 300 individuals who had expressed interest in the formation of the NSGC. Eighty nine questionnaires were returned by December 31, 1979. This represents 59.3% of the approximately 150 individuals who have since joined the National Society of Genetic Counselors.

Responses were received from members in all six Regions. However, several Regions were underrepresented. Three responses were received from members from Region I, 34 from Region II, 6 from Region III, 9 from Region IV, 11 from Region V, and 19 from Region VI. Seven respondents are full time students at recognized graduate programs in Human Genetics.

The First Section of the survey sought to establish a profile of the NSGC membership by defining our educational backgrounds, employment affiliations and job responsibilities. All respondents (other than the students) stated that they hold degrees in Human Genetics or related fields. Seventy-nine percent have MA/MS degrees in Human Genetics, 7% are RN's, 2% have a MSW degree and 4% hold other related degrees. In addition 8% of the respondents have a second graduate degree. The full time students represented 8% of the responses.

The average number of years respondents have been employed in the field of medical genetics is 3.32 years. The range was .5 to 8 years.

Our members work in varied settings, and several respondents work in more than one job setting. The majority (74% of the questionnaire respondents) are employed at a University or Medical Center. Twenty-two percent work in satellite, outreach or regional clinic programs, 6% are employed at State or Federal agencies, and 6% are working in private organizations that provide related medical services.

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FROM THE BOARD OF DIRECTORS

Funds for Newsletter Awarded

It is with gratitude and great pleasure that the Board announces that the grant application of the National Society of Genetic Counselors, Inc. to the March of Dimes Birth Defects Foundation was approved. The funds awarded (\$3000.00) will support publication of the society's newsletter, **Perspectives in Genetic Counseling**. With such funds available, we are now assured that publication of **Perspectives** will continue, and that its scope can be significantly increased.

Social Issues Committee

Last fall, Luba Djurdjinovic resigned from her position as chairperson of the Social Issues Committee. She worked diligently to develop a telephone tree that would permit her committee to discuss selected relevant topics despite separation by long distances. Her efforts to initiate the work of this committee are much appreciated.

Ann Walker has accepted appointment as chairperson of the Social Issues Committee. As a chair of a standing committee, she will also serve on the Board of Directors of the NSGC. We welcome her to these posts, and wish her luck in her work.

Individuals interested in the Social Issues Committee should write to Ann Walker, Division of Clinical Genetics and Developmental Disabilities, Dept. of Pediatrics, Medical Center, 101 City Drive South, Oakland, CA 92668.

By-Laws Committee

On January 14, 1980, the By Laws Committee was officially disbanded and Hody Tannenbaum, chairperson, resigned from the Board of Directors.

Hody made an enormous contribution to the early efforts to establish the NSGC, much of it behind the scenes. It is well known that for two years she skillfully guided the By-laws Committee as it struggled with the challenge of drafting a nationally acceptable document that would reflect the goals and provide the working mechanism of the society. In addition, however, it should be known that she voluntarily assumed and executed with outstanding efficiency countless additional responsibilities.

Although the job for which she was appointed to the Board of Directors is now completed, I was extremely reluctant to accept Hody's resignation. Her valued participation in the work of the Board of Directors will indeed be missed. I am pleased to say that Hody has agreed to serve on the Professional Issues Committee and has recently been appointed to the Nominating Committee.

All of the Directors join me in expressing our appreciation to Hody for her contribution to the efforts to the Board and to the success of the National Society of Genetic Counselors.

— Audrey Heimler, President

Education Needs Assessment, continued

Members who are currently employed have a diverse range of professional responsibilities (all responses that applied were checked off): 82% are doing genetic counseling, 55% are genetics clinic coordinators, 46% perform amniocentesis counseling, 39% provide genetic counseling in specialty clinics, 15% are administrators of statewide or regional programs, 29% are research associates, 5% work in biochemistry and/or cytogenetics laboratories and 13% have responsibilities in related areas (e.g., teaching, research, coordinating NIH study).

During the formation period of the NSGC many discussions took place regarding the choice of a society name that might best reflect the nature of professional responsibilities of the majority of our members. In answer to the question "Which title do you prefer in your work?", 56.6% of the respondents who are employed use the title "Genetic Counselor", 28.9% use "Genetic Associate", 6.6% use both and 7.9% prefer to use other titles ("Coordinator", "Genetic Nurse Instructor", "Instructor", "Genetic Counselor Associate").

The second section of the survey listed potential topics for continuing education that had been suggested at the 1979 Asilomar East Conference by the panel discussing Continuing Education for Genetic Counselors and by several NSGC members who reviewed the questionnaire prior to its distribution. The responses to the questionnaire were tabulated by ranking the educational topic preferences for each region and for the nation as a whole. When the regional and national preferences were compared, very few differences were found. Therefore, the Education Committee feels that the nationwide results can be used by all members who are planning educational programs for genetic counselors.

The educational topic category of greatest interest to the majority of members is to maintain an "Update of New Developments" in the field of Human Genetics. Within this category, the topics of greatest interest are: 1) New developments in amniocentesis, fetoscopy, and ultrasound; 2) Improved knowledge about the biology of common genetic diseases (hemoglobinopathies, muscular dystrophy, neurofibromatosis, etc.); 3) Advances in understanding dysmorphology; 4) Current perceptions of high incidence issues: heart disease, hypertension, allergy, diabetes, etc.

"Counseling Roles and Skills of the Genetic Counselor" is ranked second among the seven categories. Respondents are most interested in the process of self evaluating one's skills and of analyzing and understanding the dynamics of the genetic counseling process so that needs for change and growth can be explored. Within this category the topics of greatest interest are: 1) Ability to critique one's skills, analysis for change; 2) Special factors relating to the diagnosis of fatal disease; 3) Optimal timing of genetic counseling; 4) Follow-up counseling.

"Current Topics in Social and Legal Aspects of Genetic Disease" is ranked third among the categories. "Legal aspects of responsibilities of Genetic Counselors, especially regarding transmission of information about genetic risk" was overwhelmingly chosen as a topic that should be addressed in our Educational Programs. Other top rated topics are: 2) Access of minority and poverty groups to genetic services; 3) Various potential roles of the GC; 4) Confidentiality.

The primary interest within the fourth ranked category "Development of the Genetic Counseling Profession" focuses on the expanding activities of the gene-

tic counselor: on the genetic center team, in rural and outreach settings, in specialty disease services, in the laboratory, in public health administration and in education. Since our survey reveals that we have members involved in each of these areas, our organization has a wealth of information to be tapped and shared.

The three remaining categories and the first ranked topic within that category are listed in decreasing order of their ranking: Category 5) "Understanding of Counselees' Needs in the Amniocentesis Encounter" (Factors which increase vs. alleviate anxiety); Category 6) "Development in the Delivery of Genetic Services in Health Care" (Genetics education for health professionals and the general public); Category 7) "Current Topics in Clinic Coordination" (Obtaining adequate work-ups on malformed stillbirths and neonatal deaths).

The NSGC Education Survey has defined the genetic counseling issues that our members feel are most important to pursue in our Continuing Education Programs. The active participation of all of our members in these Programs is necessary in order to ensure their success and to further the communication effort among genetic counselors. Sharing information about our professional experiences and our individual areas of expertise will help us to broaden our genetic counseling skills, and to define and maintain high professional standards.

The Education Committee wishes to thank all those members who responded to the Questionnaire for their time and effort. A complete copy of the results of this survey is being sent to all Regional Representatives. Any other NSGC member who desires a copy should write to either of the Education Committee Chairpersons:

Roberta Spiro
Health Services Administrator
Genetics Program
1704 NE 150th Street
Seattle, WA 98155

Judith Dichter
32 Clinton Street
Mount Vernon, NY 10552

1980 BIRTH DEFECTS CONFERENCE

The 1980 March of Dimes Birth Defects Conference on the Fetus and the Newborn will meet June 9-11, 1980 at the Sheraton Centre Hotel in New York City. Registration information can be obtained from Arthur D. Bloom, M.D., Columbia University, College of Physicians and Surgeons, 630 West 168 Street, New York, New York 10032.

The National Society of Genetic Counselors, Inc. will hold an open educational meeting during the conference. Our Guest speaker will be Tabitha Powledge, Associate for Biosocial Studies at Hastings Center Institute of Society, Ethics and Life Sciences. The title of her talk is "Moral and Political Dilemmas in Genetic Counseling". The meeting will take place on Tuesday, June 10 from 4-6 p.m. The location will be announced in the Conference Program.

In recognition of the fact that hotel accommodations in New York can be extremely expensive (Sheraton Centre rates start at \$64 per night), Hody Tannenbaum has offered to coordinate a clearing house for rooming arrangements. Individuals who either have a room they can spare for a NSGC member or those who might be interested in staying in the home of a NSGC member should write to Hody Tannenbaum, 17 Ernest Drive, Scarsdale, NY 10583. Be certain to include your full address and phone numbers both at work and home. If you have room for a guest in your home, please specify the number of guests you can accommodate. This service is available only to NSGC members, and further details will be provided after you have indicated an interest in participating.

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NEWS FROM THE REGIONS

As reported in the last issue of **Perspectives in Genetic Counseling**, the regional boundaries have been adjusted to coincide with those used by the Department of Health, Education and Welfare. The amended regional divisions follow.

- I ME, NH, VT, MA, CT, RI, Canadian Maritime Provinces
- II NY, NJ, PA, DE, MD, WV, VA, Quebec, Puerto Rico, Virgin Islands
- III NC, SC, KY, TN, GA, FL, AL, MS
- IV OH, IN, IL, WI, MI, MN, MO, IA, NE, KS, Ontario
- V MT, WY, ND, SD, UT, CO, NM, OK, AR, LA, TX, Manitoba, Saskatchewan, Alberta
- VI WA, OR, ID, NV, CA, AZ, HI, AK, British Columbia

If you have not received mailings from the appropriate Regional Representative, write directly to that individual at the address given with the reports below.

- I Stacey Kacoyanis
Prenatal Diagnosis Laboratory
Genetics Unit, MGH
Boston, MA 02114
617-726-3824

No report.

- II Virginia Corson
Prenatal Diagnosis Center
Women's Clinic, Room 422
Johns Hopkins Hospital
601 N. Broadway
Baltimore, MD 21205
301-955-3091

The second Region II meeting of the NSGC is planned for Saturday, April 19 in Morristown, NJ. The meeting will be arranged on a workshop basis with the members breaking down into small groups for discussion. Topics for dialogue include prenatal diagnosis (new capabilities and new indications), parent groups, roles of the genetic counselor, satellite clinics, legal responsibilities and public policy issues. The focus of our first meeting was on becoming acquainted with each other and our various professional roles. It is hoped that this meeting will again offer an opportunity for personal interaction as well as a forum for discussion of the topics suggested by members and the educational assessments survey.

- III Debra Timmons
Dept. of Peds. and Genetic Counseling Program
University of NC, Chapel Hill
Clinical Science Bldg. 229N
Chapel Hill, NC 27514
919-966-4202

Region III has recently compiled descriptive data on the majority of its members. The data was gathered by a questionnaire and analyzed by use of a computer program, both developed by Steve Shapiro of the University of South Carolina Medical School. In addition to generating some interesting information about our small group, we are hopeful that the use of this type of data collection and analysis could be performed on a much larger scale, perhaps nationally within the NSGC.

The survey was completed by 65% of the known genetic counselors in our district. Ninety percent had undergraduate degrees in biology. One hundred percent had advanced training (i.e., MS degree) with 80% holding MS degrees in genetic counseling. Several of the master degree programs are represented among Region III membership. All members polled were willing to relocate for a genetic counseling position. The majority stated that it was neither easy nor difficult to find a job; the remainder stated that finding a job was easy. Sixty four percent work through a university; 36% have a position in a state program. All members work as part of a team; however, the complexion of the team varied considerably. The supervisors of the teams were listed as: MD (64%), DDS (18%), MSW (9%), and other (9%). The services of most of the genetic counseling units included amniocentesis, biochemical genetics, clinical genetics, and cytogenetics. Dental genetics and immunogenetics were included in 18% (each) of the genetic units. Genetic counselors are primarily involved in amniocentesis (73%), biochemical genetics (91%), clinical genetics (100%) and cytogenetics (73%). Approximately half of those responding are involved in research, 90% are involved in teaching (lay groups to medical-dental students), and 55% have faculty appointments. The salary range was found to be between \$14,200 and \$17,500 (average \$15,337). All members indicated that the attitude towards genetic counselors in their centers when they started was either positive (55%) or neither negative nor positive (45%). Fifty five percent stated that this attitude had improved since they started working.

It is hoped that interest for a regional meeting can be generated. We are tentatively planning a Friday-Saturday meeting in late April or May to be held in Charleston, SC. The exact date has not been set. Please contact Debra Timmons or Steve Shapiro (803-792-2489) for further details.

- IV Beverly Rollnick
Center for Craniofacial Anomalies
University of Ill. Medical Center
P.O. Box 6998
Chicago, IL 60680
312-996-7546

Region IV will hold a two day educational workshop on May 3 and 4 at Barat College, Lake Forest, Illinois. The purpose of this meeting is to provide for continuing professional education of genetic counselors. Small workshop settings will enhance discussion of principles and techniques and exchange of information. The workshops have two focuses:

- 1) Counseling Skills: Interview Techniques and Crisis Intervention

This session will be a practicum applying the principles of interviewing techniques and crisis intervention to actual genetic counseling situations. Discussion will be based on lectures, films and case material submitted by workshop participants. The course objectives are to enable participants to utilize various interview techniques in the genetic counseling setting and to identify the stages of crisis, grief and mourning and apply intervention techniques to families in crisis.

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2) Interdisciplinary Professional Relations,
Outreach and Education

Panelists will describe services in a variety of settings provided by genetic counselors as members of the professional health care team. Factors which influence interdisciplinary professional relations will be discussed. Community contacts for purposes of outreach and education will be identified, and objectives of education programs outlined. Methodologies to integrate the knowledge gained into the individual genetic counseling role to improve interdisciplinary professional relations will be summarized.

This workshop satisfies the requirements for continuing education credits, and can be applied retrospectively. Registrants' material will be stored in a computer for easy retrieval.

This workshop is being conducted in cooperation with the Center for Craniofacial Anomalies, The University of Illinois at the Medical Center, Chicago.

V Ann C. M. Smith
Genetics Unit B121
UCHSC
4200 East 9th Avenue
Denver, CO 80262
303-394-8742

A preliminary meeting to discuss the arrangements for a Region V meeting was held in Denver, Colorado on February 8, 1980. Several individuals (7) from the Denver area have already volunteered to participate in planning the program for this first regional meeting. If any of you would be interested in assisting with this planning, please let me know. The tentative time for the regional meeting is sometime in July, 1980. Joe McInerney (a genetic associate/counselor at the Biological Sciences Curriculum Studies-BSCS-who is involved in the development of educational materials) has offered the facilities at BSCS in Boulder, Colorado (about 30 miles from Denver) for a meeting site.

To minimize expenses, a number of people from the Colorado Genetics Unit have offered their homes to anyone interested. Considering the large territory of Region V, travel costs will probably be the major obstacle for most people. Some may have monies available to cover these expenses from your department. However, we will submit a grant for funds to help defray some expenses (travel and lodging, honorariums for speaker, coffee breaks, etc.). I need to get an idea of how many are interested in coming to this meeting and what monetary requirements you envision so that we can submit a formal grant request.

As an extension of this meeting, I hope that we can develop a regional directory of clinical genetic services to include not only genetic counseling services, but also available lab services. This would be a very beneficial desk reference for each and everyone of us since a number of our families do overlap in this great region.

VI Carolyn Bay
Department of Pediatrics, M-009
University of California
San Diego, CA
714-452-4158

No report.

NOMINATING COMMITTEE SELECTED

The members of the first Nominating Committee of the National Society of Genetic Counselors have been elected by the Board of Directors. This committee will have as its task the preparation of a slate of candidates for the offices of President, Vice President, and Secretary. Candidates will also be nominated for the Regional Representatives of Regions II, IV and VI. The members of the Nominating Committee are listed here.

Dorothy Halperin
Michael Reese Hospital and Medical Center
Chicago, Illinois

Linda Lustig
Children's Hospital Medical Center
Oakland, California

Joseph McInerney
Center for Education in Human and Medical
Genetics
Biological Sciences Curriculum Study
Boulder, Colorado

Cynthia Powell
Children's Hospital National Medical Center
Washington, D.C.

Hody Tannenbaum
Prenatal Diagnosis Laboratory of New York
City
New York, New York

POSITIONS AVAILABLE

Genetic Counselor

Job opportunity available in Department of Pediatrics, Division of Medical Genetics, the core organization for developing and administering Georgia's Comprehensive Genetics System. This position is central to the coordination of the retrieval, diagnosis, management and assessment components of the newborn screening program. Applicant must have a Master's degree and experience in clinical genetics. To apply, call or send resume to Maribeth Ledford or Maggie Joffe, Employment Center, Personnel Department, Emory University, Atlanta, GA 30322, (404) 329-7611.

— An Equal Opportunity/Affirmative Action Employer

Position Available for Genetics Associate (R.N.)

Requirements: B.S. and R.N., extensive experience with genetic counseling and intrauterine diagnosis in an established program of intrauterine diagnosis. Must be able to participate in pregnancy termination.

Duties: Coordinator of a regional prenatal diagnosis program in genetic counseling, outreach educational activities for physicians, nurses, and public health personnel.

Letters of application, curriculum vitae, and three letters of recommendation to:

Edgar L. Makowski, M.D. Chairman
Department of Obstetrics and Gynecology
Univ. of Colorado Health Sciences Center
4200 East Ninth Avenue
Denver, Colorado 80262

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