

FROM WHENCE WE'VE COME: A MESSAGE FROM THE PRESIDENT

In March, 1978 in New York City a small group of genetic counselors met to consider establishing a society of genetic counselors to promote and protect the professional interests of this growing profession. Simultaneously, students at Sarah Lawrence College who were approaching graduation began to discuss the need for a society to provide communication within the profession once they scattered to jobs across the country. It is undoubtedly correct to assume that similar concerns were prevalent among genetic counselors and genetic counseling students nationwide at that time.

This New York based group sought advice from legal counsel and from other professional societies regarding procedures for the establishment of a professional society. In order to establish a national base and to encourage the close and active participation and support of genetic counselors across the nation, it was concluded that the formation of a society must first be discussed with colleagues on a nationwide basis. Three open meetings were held; the first in April in New York City, the second in June in San Francisco and the third in October in Vancouver, B.C. Graduates and students from all genetic counseling programs and all those known to be working as genetic counselors were invited to each meeting.

From April 1978 through February 1979, the Constitution-By-Laws committee met semimonthly to draw up by-laws that would set the tone of the new society in terms of goals and membership and provide a working mechanism to implement them. The committee was charged with the responsibility to consider the diverse training and job descriptions among current genetic counselors while ensuring high professional standards for the future. It recognized that genetic counselors could not reasonably work towards recognition from other professional groups on the basis of standards higher than those they had established for themselves. Also, the committee was determined to develop a society based upon the participation and collaboration of the largest number of active members.

A careful reading of the by-laws will demonstrate an acceptable solution to the above issues. The by-laws specify standing committees and a regional representative network to provide the organizational means for accomplishing the major goals of the Society: "To further the professional interest of genetic counselors, to promote a network of communication within the genetic counseling profession and to deal with issues related to human genetics. The Society shall strive to ensure a high standard for the training of genetic counselors, genetic counseling services and educational programs in genetics".

Several important goals have already been realized. Close to 200 genetic counselors have submitted a fee in support of the Committee to Form the National Society of Genetic Counselors. By-laws have been drafted and submitted to the Society's attorney for final revision. The Society is incorporated as a not-for-profit organization and has applied for tax-exempt status. Regional representatives are working to establish a network of communication and to encourage active participation in each geographic area. The standing committees are actively working despite the distances separating their members. Communication and friendships have developed among genetic counselors across the country. The first newsletter has been published. And all within one year!

I look forward to working with you to build a society that will further our professional interests, stimulate our intellectual appetites and encourage friendships among members. The foundation for the National Society of Genetic Counselors has been provided with sincerity of purpose by the By-Laws Committee, the Board of Directors and all those across the country and in Canada who have participated until now. For the future, it is my hope that genetic counselors everywhere will join in the efforts of the Society to accomplish our goals.

—Audrey Heimler
President

NEWS FROM THE DISTRICTS

"News from the Districts" will appear in each issue of this newsletter. Individuals with regional information for inclusion should submit entries to the regional reporter named with the regional representatives on the insert page.

District I As regional Representative of District I, I'd like to introduce myself to those of you whom I have not met and extend to you and to old friends warm greetings. I would hope that you all share the same sense of eager anticipation that I have with regards to the activities of the National Society of Genetic Counselors. As we move out of the preliminary stages, many important issues that can potentially affect our careers will be worthy of discussion, and representation of our views in the field of genetics will be critical. These matters can, and hopefully, will be addressed by the Society and we as members will determine the ultimate effectiveness of the Society by the degree of our involvement and interest.

As of 1-19-79 there are a total of 112 members of the NSGC in District I distributed as follows: Connecticut, 4; Maine, 1; Massachusetts, 6; New Hampshire, 1; New York, 98; Rhode Island, 2; and Vermont, 0. Plans for future activities include: (1) designating one NSGC member from each state in District I as a key contact person to facilitate communication; (2) a mailing to all members in District I to include the latest news regarding the Society; (3) meetings of District I members, one in New York and one in Boston; (4) Contacting major genetics service providers in New England and New York to make them aware of our existence and to urge them to communicate with us regarding positions available and other relevant information for the newsletter.

A new organization entitled "The New England Regional Genetics Group" is in its formative stages at the present time. The mandate of this group is to address some key issues in preparation for considering regionalization of certain genetic services. Committees have been formed to investigate these basic issues, and interested people in the field are being recruited to assist in this effort. If interested write to the Regional Representative.

District II The response from District II has included 31 individuals expressing an interest in the NSGC with an additional 20 prospective members in the area. A geographic breakdown includes 21 applicants from New Jersey, 2 from Pennsylvania, 4 from Maryland, 3 from Virginia and 1 from Delaware. A questionnaire is being sent to regional members for identification of specific needs, areas of interest, occupational roles, and opinions concerning incorporation issues. The efficacy of regional

THE PROFESSIONAL ISSUES COMMITTEE: A REPORT

meetings will be examined. It is hoped that a mode of communication best suited to the membership can be identified and that contacts at various institutions will be established.

District III Individuals who have expressed interest in the NSGC have been sent a letter from the regional representative. The letter has included some discussion and an update on incorporation and accreditation. The letter has also requested that information about the Society be passed on to interested genetic counselors not presently on the mailing list.

Membership (\$10 interest fee) stands at 12 for the southeast. This includes: three each from South Carolina, Florida and Georgia; two from North Carolina; one from the West Indies. States not currently represented include Tennessee, Alabama, Mississippi, Louisiana and Arkansas. A method by which genetic counselors in these states can be informed about our Society is being investigated. At present no regional meeting is planned.

District IV Methods of communication within the region are still being developed. If members can advise us of major regional meetings, job openings, and so forth, this information will be included in future editions of the newsletter.

The Birth Defects meeting and The American Society of Human Genetics meeting will both be held in District IV this year. Arrangements have been made for general meetings of the NSGC to be held in conjunction with each of these national meetings. Chicago area genetic counselors met to discuss hosting these sessions. In addition to the general meetings of the NSGC, District IV members plan to meet to discuss methods of regional communication and other matters of interest.

District V Several residents in District V met in mid-February to discuss the by-laws of the NSGC. The consensus of this group was that the objectives of the NSGC should be broad enough to include the interests of genetic counselors doing varied types of work (e.g., research or teaching as well as counseling). In addition, a majority of those present felt that MD's should also be admitted to full membership, and that membership should be open to a broad range of professionals. A letter describing the conclusions reached and questions formulated by this group has been submitted to the Board of Directors.

District VII A questionnaire was sent to the 65 members listed as residing within District VI. Results are based on 40 responses, and indicate that 62.5% hold a MS degree, 27% are RN's, 2.5 hold a bachelor's degree, 2.5% hold a MSW degree, and 2.5% are PhD's. The distribution of responses were as follows: California, 29; Washington, 5; Oregon, 3; Nevada, Alaska, Hawaii and Mexico, 0. The remaining 3 responses were from individuals residing in District V. Eighty four additional names were submitted by the responders as individuals interested in the NSGC.

A meeting of District VI members will be held in San Francisco on May 19-20, 1979. Information will be sent to those already on the Mailing list, and others interested in attending should address enquiries to the District VI representative.

Our first important professional issue arose while our Society was still in its formative stages. As is well known by now, the ASHG formed a Council on Accreditation to formulate guidelines for the training and accreditation of genetic service health professionals. The Council comprises ten individuals elected by the membership of the ASHG; two additional individuals were added later. The Council established four task forces to deal with the issues as they related to each of the following: clinical geneticists, genetic counselors, clinical laboratory geneticists and procedures. To our dismay, the genetic counselor task force had not a single representative of non-doctoral genetic counselors.

I wrote to the Council, in the name of our Society, urging that this omission be corrected but this request was politely refused. A second, stronger request was eventually granted and I was asked to join the group. It is clear that the reality of our own professional organization was an important factor in our acceptance.

The Task Force met in Vancouver prior to the general meeting to prepare a draft document for the Council, as did each of the other Task Forces. Since Vancouver, the Council has met to consider the four proposals and to prepare a single report which was issued on November 30th to all members of the ASHG. Substantial changes were made, one of which has major significance for genetic counselors. The Council has proposed that in addition to accrediting Clinical Geneticists (generally physicians and dentists), they would have a new category of "Ph.D. Medical Geneticists" who would be individuals who hold the Ph. D. degree in genetics or a related field and who would be admitted to the qualifying examination upon completion of supervised experience in genetic counseling and presentation of a case log book. In contrast, genetic counselors (who may hold a Master's Degree in Genetics, Social Work, Public Health, Nursing or a doctoral degree) must fulfill certain prescribed coursework in genetics, clinical medicine and the behavioral sciences along with their supervised experience in genetic counseling and log book before being admitted to the examination. Curiously, the Council outlines a job description for the "Ph.D. Medical Geneticist" and for the genetic counselor which are virtually identical yet only the genetic counselor need demonstrate the coursework. This inequity becomes even stranger when it is proposed that the genetic counselor must work under the direct supervision of a clinical geneticist or Ph. D. Medical geneticist. I have written to the Council and to the Task Force outlining these concerns.

I was pleased to have 14 genetic counselors from across the country volunteer for the Professional Issues Committee. Their encouragement and suggestions have been most useful and I look forward to their continued participation.

—Phyllis Klass
Chair, Professional Issues Committee

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Chair, Professional Issues Committee

OHIO MEETING OF GENETICS PROFESSIONALS

On July 23, 1978, a group of genetic counselors and genetic health educators met at Children's Hospital, Columbus to address common concerns and share resources. Present at this meeting were 13 individuals from 10 different hospitals or health agencies. One topic discussed at length was the movement to form the National Society of Genetic Counselors. The group felt that the formation of this type of professional group could be of benefit and hoped that the following goals were addressed:

- 1) Strive to ensure that the quality of genetic counseling services and the provision of genetic education is maintained at a consistently high level.
- 2) Provide a format for improved communication among genetic counselors and genetic health educators.
- 3) Establishment of a means for the representation of the interests of genetic counselors and health educators to other professional organizations and groups, including the American Society of Human Genetics.

Furthermore, the group unanimously agreed on the following points:

- 1) Limitation of membership should be avoided. We feel that individuals working in genetics counseling and education come from a wide variety of backgrounds and that such diversity is both appropriate and beneficial.
- 2) Accreditation for individuals working in genetics counseling and genetic education is desirable. As a group, we feel this should not be a function of the National Society of Genetics Counselors. We do feel that it would be desirable to have a national group, such as National Society of Genetic Counselors, represent our interests and add input to the American Society of Human Genetics and/or any other group or board, setting credentials for genetics counselors and educators.

It should be noted that the meeting on July 23, 1978 was an informal meeting and those attending do not represent any formalized or structured group. However, many of the genetic counselors and genetic health educators working in the state of Ohio were present at the meeting and we, therefore, feel that these views represent valid regional input from the state of Ohio.

—Arthur Vaughn

MEETINGS, LECTURES, AND SYMPOSIA

Genetics and the Law, May 1979. For information write to Aubrey Milunsky, M.D., Eunice Kennedy Shriver Center, 200 Trapelo Road, Waltham, Mass. 02154.

*Birth Defects, co-sponsored by the National Foundation-March of Dimes and Northwestern University, June 25-27, 1979, Chicago, Ill.

*American Society of Human Genetics, Annual Meeting, October, 1979, Minneapolis, Minnesota.

*Denotes meetings during which a general session of the National Society of Genetic Counselors will be held concurrently.

POSITIONS AVAILABLE

University of Kansas Medical School at Kansas City. A position for a trained genetic counselor to coordinate genetics unit activities and assist in development of satellite program. Write to: R. Neil Schimke, M.D., Division Director, Metabolism, Endocrinology and Genetics, University of Kansas Medical Center, College of Health Sciences and Hospital, Kansas City, Kansas 66103.

Northern Coast Regional Center. Write to: Northern Coast Center, Attention Marion Slauback, 1213 5th Street, Eureka, California 95501.

University of Texas, Southwestern Medical School at Dallas. A position for a genetic associate interested in neurological disorders. Write to: Roger Rosenberg, M.D., Department of Neurology, University of Texas, Southwestern Medical School at Dallas, Dallas, Texas 75235.

Birth Defects Center. A position in the Tay Sachs program. Write to: Jaime L. Frias, M.D., Birth Defects Center, J. Hillis Miller Health Center, Gainesville, Florida 32610.

RECENT NEWS FROM THE BOARD OF DIRECTORS

- The by-laws are undergoing their final revision by the Society's attorney. The purpose of this rewriting is not to alter the content proposed by the By-Laws Committee, but rather to tighten the language thus eliminating ambiguities and resulting in an acceptable legal statement of our society's goals and workings. This task should be completed by the time this newsletter reaches members. After final revision, the by-laws will be made available upon request to members.
- Application forms are being revised and prepared for a general mailing to all on the current mailing list.
- The NSGC will hold a general meeting concurrent with the Birth Defects Conference on June 25, 5:30—7:30 PM. Beverly Rollnick, who has agreed to speak at the meeting, will discuss the National Genetic Diseases Act.

**CERTIFICATE OF INCORPORATION
OF
NATIONAL SOCIETY OF GENETIC COUNSELORS,
INC.***

**pursuant to Section 402 of the Not-for-Profit
Corporation Law of the State of New York**

The undersigned, being of full age, for the purpose of forming a corporation pursuant to the Not-for-Profit Corporation Law of the State of New York, hereby certifies as follows:

FIRST: The name of the corporation shall be NATIONAL SOCIETY OF GENETIC COUNSELORS, INC. (hereinafter referred to as the "Society").

SECOND: The Society is a corporation as defined in subsection (a) (5) of Section 102, and is a Type A corporation as defined in Section 201, of the Not-for-Profit Corporation Law of the State of New York.

THIRD: The purposes for which the Society is formed are:

To aid and encourage the development and growth of the profession of genetic counseling; to unite the genetic counseling community and those interested in genetic counseling; to foster and promote communication within the genetic counseling profession; to disseminate information to its members and the general public pertaining to genetic counseling and human genetics; to represent and further the professional interests of genetic counselors; generally to be responsive to issues related to the field of human genetics; to do any other act or thing incidental to or connected with the foregoing purposes or in advancement thereof, but not for the pecuniary profit or financial gain of its members, directors or officers, except as permitted under Article 5 of the Not-for-Profit Corporation Law.

*Excerpted from Complete Certificate of Incorporation.

Deborah L. Eunpu, NSGC
Clinical Genetics Center
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, Pennsylvania 19104

EDITORS NOTE

This, the publication of the first newsletter of the NSGC, is by no means a minor event. The contributors span the country and have much to say that demonstrates how very far we have come in one short year. From a scattered group of professionals whose endeavors were dictated by the meetings of other societies, we have emerged as a separate affiliation that plans to meet and share in its own right.

This issue of the newsletter is the first of many tangible signs of our commonly shared goals and interests. It is hoped that the newsletter will become our primary means of communication, and that through this medium we can make our interests and concerns known to the genetics community at large.

Of course, the effectiveness of our communication depends on the willingness of members to share their experiences and ideas. While this issue deals primarily with basic information (dates, places, and a brief history

of from whence we have come), I hope to publish articles of topical interest in future issues, perhaps devoting each issue to a specific area of discussion. The Newsletter will be published quarterly: March, June, September, and December. If you plan to submit material for publication, it should be received no later than the 15th of the month preceding publication. It is preferable that articles be typed.

I encourage each of you to contribute to the newsletter as you see best: a letter concerning issues of the Society, an article on a subject in which you are particularly knowledgeable and/or interested, a suggestion for a title of the newsletter or particular subjects you would like to see discussed. Communication is indeed a two-way process, and I will need your assistance to make this the best representation of the Membership's concerns and interests. I look forward to hearing from you, and hope to serve you well as the editor of our newsletter.

—Deborah L. Eunpu
Editor

REGIONAL REPRESENTATIVES AND REPORTERS

I (CT,ME,MA,NH,NY,RI)

Representative: Stacey Kacoyanis
Genetics Unit
Mass. General Hospital
Boston, Ma. 02114

Reporter: Kathy Cote
Genetics Unit
Mass. General Hospital
Boston, Ma. 02114

II (Del,KY,MD,NJ,PA,VA,WVA,Wash DC)

Representative: Virginia Corson
Dept. of Peds., Genetics Unit
Johns Hopkins Hospital, CMSC 1004
601 N. Broadway
Baltimore, Md. 21205

Reporter: Not designated

III (Ala,Ark,FLA,GA,LA,MISS,NCA,SCA,TENN)

Representative: Debra Timmons
Dept of Pediatrics
Univ. of N. Carolina Med. Ctr.
Chapel Hill, NC 27514

Reporter: Steven Shapiro
Medical Univ. of S. Carolina
BSB-351,EXT 2489
Clinical Genetics
171 Ashley Avenue
Charleston, SC 29403

IV (Canada,ILL,Iowa,Mich,Minn,MO,Ohio, WI)

Representative: Beverly Rollnick
470/DMP, The Univ. of Illinois
808 South Wood
Chicago, Ill, 60680

Reporter: Michael Begleiter
Genetic Counseling Center
The Children's Mercy Hospital
Kansas City, Mo. 64108

V (AZ,Col,Ida,KA,Mont,Neb,NDak,NMex,Okla,SDak,Tex,Utah, WY)

Representative: Ann Smith
Regional Genetic Counseling Program
Dept. of Biophysics and Genetics
Univ. of Colorado Med. Ctr.
Denver, Col. 80262

Reporter: Not designated

VI (Alaska,Ca,HA,Mexico,Nev,Ore,Wash)

Representative: Carolyn Bay
7064 Vista Del Mar
La Jolla, Cal. 92037

Reporter: Michael Bailey
658 Eighth Avenue
San Francisco, Cal. 94118

and Mary Danca
2210 SW 204 Avenue
Aloha, Ore. 97005

A.B. If you are in either District II or V and are interested in serving as the reporter, please notify both the Regional Representative and the Editor. Reporters are responsible for collecting information of the District and writing reports for publication in "News from the Districts".

BOARD OF DIRECTORS

Officers:

resident Audrey Heimler
Div. of Human Genetics
Long Island Jewish Health Medical Center
New Hyde Park, NY 11040

Vice President

Lorraine Suslak
Dept. of Genetics 8 CHC
Brookdale Hospital Medical Center
Linden Blvd. at Brookdale Plaza
Brooklyn, NY 11212

Secretary

Sylvia Rubin
Columbia-Presbyterian Medical Center OB/GYN
William Black Building
630 W. 168th Street
NYC, NY 10032

Treasurer

Niecee Singer
Medical Genetics Unit
Westchester County Medical Center
Valhalla, NY 10594

Committee Chairpersons:

y-Laws

Hodie Tanenbaum
Dept. OB/GYN, Box 24
Downstate Medical Center
450 Clarkson Avenue
Brooklyn, NY 11203

Education

(co-chairs) Judith Dichter
32 Clinton Street
Mount Vernon, NY 10552

Membership

Evelyn Lilienthal
Dept. of Peds. and Genetics
M.R. Institute of NY Medical College
Valhalla, NY 10595

Roberta Spiro
Health Program Specialist
Birth Defect Study and
Counseling Program
1704 NE 150th Street
Seattle, Wash. 98155

Social Issues

Luba Djurdjinovic
Planned Parenthood of Broome County
710 O'Neil Building
Binghamton, NY 13901

Editor

Deborah Eunpu
Clinical Genetics Center
Children's Hospital of Phila.
34th and Civic Center Blvd.
Philadelphia, Pa. 19104

Professional Issues

Phylliss Klass
Dept. of Genetics
Cornell University Medical College
1300 York Avenue
NYC, NY 10021

Regional Representatives are also members of the Board of Directors, and are listed on the reverse side of this page.